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TELLING THE STORY:

What can be learned from parents' experience of the professional response following the sudden, unexpected death of a child.

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Doctor of Philosophy

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September 2013

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signed.....

Date.....

UNIVERSITY OF SUSSEX

DENISE MARY TURNER- PhD SOCIAL WORK AND SOCIAL CARE

**TELLING THE STORY: WHAT CAN BE LEARNED FROM PARENTS' EXPERIENCE
OF THE PROFESSIONAL RESPONSE, FOLLOWING THE SUDDEN, UNEXPECTED
DEATH OF A CHILD.**

SUMMARY

My research takes a psychosocial approach to exploring parents' experiences of professional intervention in the aftermath of sudden, unexpected child death. In the UK all deaths of this nature are immediately subject to a Rapid Response, which includes forensic investigation, followed by a series of subsequent meetings and the obligation on professionals is to treat parents as guilty whilst also maintaining their innocence. These requirements were part of a number of recommendations arising from the Report, 'Sudden, Unexpected Death in Childhood' (2004) known colloquially as the Kennedy Report, which was a response to the release on Appeal of three mothers, all wrongfully imprisoned for killing their children.

One of the explicit purposes of the Kennedy Report is to avoid similar cases and it therefore attempts to address the complexity of balancing every parent's right to have their child's death properly investigated with the requirement to protect children who may be at risk. As a part of achieving this, the Report identifies a need for appropriate training to assist professionals in becoming sensitised to emotions being experienced by parents, in order that culpability or otherwise may be easier to discern. Despite this, the Working Party for the Kennedy Report did not include parents and this lack of direct access to their experiences is reflected in the wider field. Parents are not allowed to participate in any of the multidisciplinary meetings which follow sudden, unexpected, child death and their narratives are largely absent from literature and training material.

This makes achieving the form of emotional understanding between parents and professionals advocated by the Kennedy Report difficult and thereby increases the risk of potential errors of professional judgement.

This study aims to restore the voices of parents to the field of sudden unexpected child death, by engaging directly with the emotional complexity and trauma of the experience and thereby improving practice. The research is based on eight in-depth interviews with parents who have experienced the sudden, unexpected death of their child, together with investigation, but no accompanying charges.

The research was prompted both by my previous role as a social worker, but primarily by my experience of investigation following the sudden unexpected death of my son Joe. My account of his death and the experiences which led me to undertake this research are offered within Chapter One and thereafter run as a thread throughout.

Drawing on Hollway (2009) I have used a psychosocial approach within this thesis, to combine both the workings of the psyche and the social without diminishing or conflating either. This has enabled me to locate my experience and that of the parents within the thesis, as part of a wider exploration of how parents may be positioned and perceived following a sudden, unexpected child death.

The research uses a narrative, interpretive methodology which draws from the Biographic Narrative Interpretive Method (Wengraf, 2011) and the Listening Guide (Doucet & Mauthner, 2008). Data analysis panels were used as part of the interpretive process and they are discussed and critiqued. The unexpected results produced by the panels forms a significant contribution to knowledge which is also identified.

The thesis concludes that current cultural debates around ‘good death’, together with heightened anxieties about safeguarding children, may lead to the construction of

sudden unexpected child death as dangerous knowledge (Cooper & Lousada, 2005).

Returning to the emotional understanding advocated by the Kennedy Report, I make a number of recommendations including changing the language of investigation and developing opportunities for open dialogue between professionals and parents. I also identify several original contributions made by this work, both methodologically and more substantively, which are partly evidenced by the attention it has already received within academic and wider audiences. Amongst these, the research has formed the basis of a number of Conferences presentations, a journal paper, national newspaper article and a guest appearance on BBC Radio 4.

As a conclusion to the thesis I identify a need for additional in-depth research in this area, together with a re-visiting of the recommendations arising from the Kennedy Report, aimed at further policy change and improving the experiences of all those involved with sudden, unexpected child deaths.

Acknowledgements.

Like the popular saying about the raising of children, it has taken an entire village to raise this thesis and consequently I have many people to thank.

Firstly Barry Luckock, who helped the study through its baby steps and who has remained a great support. Michelle Lefevre, who has patiently borne with me throughout the highs and lows and Rachel Thomson, who undoubtedly brought the project through adolescence and into completion.

Many friends have helped me along the way, amongst them Columba Quigley, a constant friend, who has regularly held me up when I have stumbled. Tish Marrable too has remained an enduring support and her spirit runs throughout this thesis.

Claire Bennett's friendship enriched my University life and has brought great joy to my family, whilst Danielle Kerris and her beautiful son, Clay, have helped me believe in my writing and myself.

Profound thanks to the fairy godmother, Liz Thackray for her help with proof-reading and much more. Michelle Browning has also provided continuous practical and emotional help.

Gratitude is also due to Diana Uprichard and Emma Carlow without whom I simply could not have managed the practicalities of single parenthood, child care and carrying out this research.

The wise witch, Christine Bell, whose generosity and magic transformed my understanding of what research could look like, has also been a constant inspiration.

For all those people who generously agreed to share their stories with me – my gratitude to you is unbounded and I hope that I have done some justice both to you and to the memories of your children.

Thank you seems inadequate for the many friends and colleagues who gave their time to participate in the panels and to those organisations who so kindly helped me to find participants. Particular thanks are due to the Scottish Cot Death Trust, The Child Death Helpline and Child Bereavement UK for their help and support. I also owe a debt of gratitude to Funds for Women Graduates (FFWG) for financial assistance in my final year.

Lastly, but most importantly of all, my deepest love and thanks to my two children, Amy and Dan, who have sustained me through the bleakest of times and whose lives light up my own.

Thank you all.



For Joseph Michael Toby Turner

(Joe)

13 August 2003 – 14 March 2005

From the 'Eskimo Legend of the Stars':

'Perhaps they are not stars, but rather openings in Heaven where the love of our lost ones pours through and shines down upon us to let us know they are happy.'

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Introduction

'Appropriate training was a recurring theme ...
 - for police officers, for doctors, for nurses,
 for social workers and for Coroners' officers.
 Good communication between ...professionals
 and parents is vital but professionals should
 also be sensitised to emotions being experienced
 by parents'
 ('The Kennedy Report', 2004,p.12).

The sudden, unexpected death of a child is now an unusual event in the Western world. Improved housing, sanitation and medicine, together with more effective child protection procedures, have all contributed to a gradual decline in such deaths from 1,226 in 1914 (Ferguson, 2011, p. 27) to 600 in 2004 (RCPath & RCPCH, 2004, p. 3).

Despite this reduction, as I write this the radio news maintains a background stream of stories about child abductions, gang rape, ritual abuse and other potential threats to the continuing welfare of children. Although they may actually be safer than ever (Madge, M & Barker, J, 2007, p. 57) contemporary concerns for the safety of children often seem correspondingly greater.

Amongst the high profile news stories of 2003 were the cases of three mothers each wrongfully convicted for causing fatal harm to their children, filtering this culture of anxiety through a different lens. The repercussions of these cases were widespread and provide much of the cultural context which underpins this thesis.

Sally Clark, Angela Cannings and Trupti Patel had all experienced the unexplained death of more than one child and each had their conviction declared unsafe by the Court of Appeal during 2003.

The Police evidence in the trials, in the absence of any first hand witnesses to harm, had depended heavily on the role of medical experts particularly paediatricians and pathologists. At Sally Clark's trial, the verdict hinged upon the evidence of paediatrician Dr Roy Meadows who assessed that the likelihood of two sudden infant deaths occurring in one family was 1:73 million. A later Court of Appeal hearing found that the evidence 'misled the jury' (Lexis Nexis Butterworth, 2003), whilst a vital microbiology report showing that Harry Clark died from natural causes was found to have been concealed. Similarly, in the trial of Trupti Patel, the original conviction rested around expert medical evidence that cot death does not run in families, but murder does (Holt, 2004).

Following the release of Sally Clark, Angela Cannings and Trupti Patel, the Royal College of Pathologists and the Royal College of Paediatricians and Child Health immediately established a Working Party in order to investigate concerns about 'the role of expert witnesses in the Court, about the standard of proof and the quality of evidence, and about the procedures adopted for the investigation of sudden, unexpected deaths of children' (RCPath & RCPCH, 2004, p. 1).

The findings of the Working Party were published as the report 'Sudden, Unexpected Death in Infancy: a multi-agency protocol for care and investigation', which rapidly became known as the Kennedy Report, after its chair, Baroness Helena Kennedy.

The overriding concern of the 'Kennedy Report' was with taking the steps necessary to 'prevent miscarriages of justice while protecting the interests and safety of children' (2004, p.1). The Report therefore places great emphasis on the complexity of balancing every parent's 'right' to have their child's death 'properly investigated' with the requirement to protect infants and children who may be 'at risk.' (p. v).

In order to try and assist this process, the Kennedy Report made a number of recommendations in respect to investigating and evaluating sudden, unexpected child deaths and these became part of a national protocol in April 2008.

Key amongst these recommendations was the formalisation of a professional Rapid Response. This includes immediate investigation by the police, in order to gather 'crucial evidence before it can be lost or contaminated' and is colloquially referred to as the 'golden hour' (RCPath & RCPCH, 2004, p. 13). Police are required to treat sudden, unexpected child deaths as a 'potential crime' (ACPO Guidance 2005) and although the Kennedy Report notes that 'very few of these deaths will be cause for suspicion' (p. 13), it also acknowledges that there will be some deaths that are. Thus the Report recognizes the 'almighty challenge' for the police and other professionals in attempting to meet the requirement that 'the family should be at the centre of procedures and every process should be sensitive to the family's needs' (p. 3) whilst also meeting the legal requirements for evidence gathering and investigation.

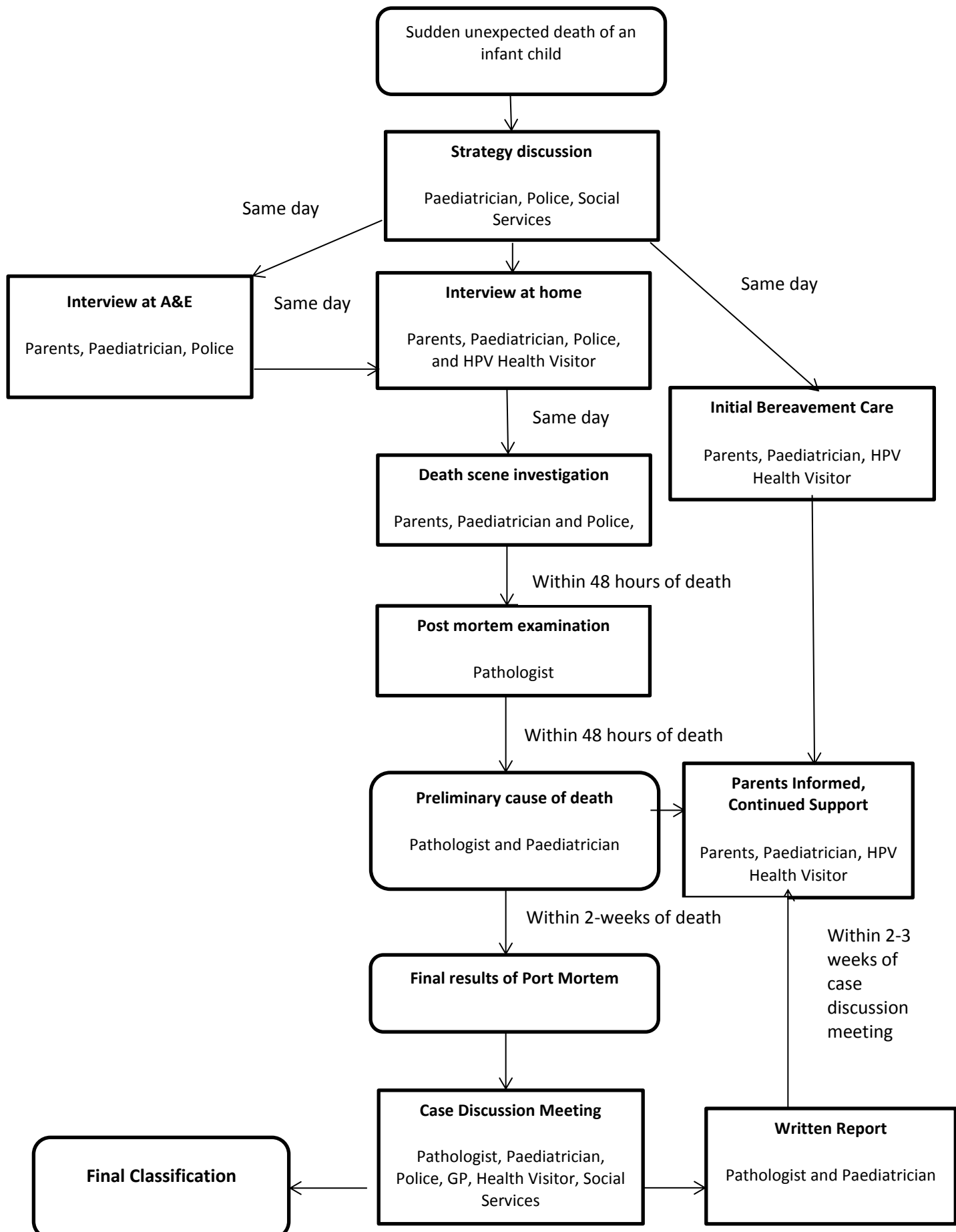
The new protocol devised by the Kennedy Report recommended that the initial police investigation should be followed by examination in A & E and a later home visit, within 24 hours if possible. This home visit should be carried out, ideally, by a 'trained and experienced health professional', usually a paediatrician, 'who will have the confidence of the family and authority with the police' (RCPath & RCPCH, 2004, p. 2).

Once full information about the family and the death is available the Report also advocated for a multi professional meeting to discuss the family and the death and provide a ...report for the Coroner (RCPath & RCPCH, 2004). This is likely to be the first of several meetings, with the aim of considering 'how procedures at the time of the death and afterwards were managed' (FSID, 2011, p. 6) and these meetings will usually culminate in a Case Review.

The conclusions reached from this Case Review also lead to a report which is sent to the Child Death Overview Panel (CDOP), formed in turn from groups of professionals who meet several times a year to discuss child deaths within their area and produce feedback on lessons learnt. CDOP's also produces information and reports for Local Safeguarding Children's Boards.

The chart overleaf is included in the Kennedy Report and helps to summarise the Rapid Response and its aftermath:

Figure 1 The Avon multi-agency approach to sudden unexpected deaths in infancy and childhood



In addition to defining the standards for investigation the Kennedy Report also places great emphasis on the need to support families, stating that ‘parents suffering a terrible tragedy need sensitive support to help deal with their loss’ (RCPa & RCPCH, 2004, p. 1). Arguing for a compassionate approach to investigation, the Report identifies a strong need for ‘appropriate training’ which will both enhance ‘good communication between professionals and between professionals and parents’ (RCPa & RCPCH, 2004, p.12). Furthermore the Report advocates that ‘professionals should be sensitised to emotions being experienced by parents’ and whilst some of this ‘comes instinctively’ training is also vital in achieving emotional understanding (RCPa and RCPCH, 2004, p.12).

Despite this pervasive commitment to effecting better understanding and thereby helping to prevent cases similar to those of Clark, Cannings and Patel, the Kennedy Report is nevertheless characterised by a number of significant omissions.

Firstly, the claim to involve as many interested parties as possible in the Working Party actually translates into including only professionals. Amongst those represented were ‘paediatricians and pathologists...Government departments, a Director of Social Services, a Coroner, two very senior police officers and a member of the Foundation for the Study of Infant deaths’ (RCPa & RCPCH, 2004, p.1–2).

Despite the stress on good communication between professionals and parents, no parents actually participated directly in the Working Party and their perspectives are represented instead as an Appendix to the Report. This contains the results of a postal survey, submitted by the Foundation for the Study of Infant Deaths (FSID), which contains the views of parents from the FSID database ‘on specific points’ identified by them. Of the 3,200 contacted 893 replied (RCPa & RCPCH, 2004, p.54) and these are represented in quantitative form with no direct narrative or opportunity for discussion.

The same pattern is present in the series of multi-professional meetings which follow sudden, unexpected child death. Although the Kennedy Report emphasis is on improving dialogue and understanding between professionals and parents the latter are not invited to participate in any of these meetings.

Recent guidance from the FSID advises parents that following the Case Review meeting ‘someone from the team should meet with you to discuss the conclusions reached and to answer questions you might have’ (FSID, 2011, p. 6). Similarly in the case of the Child Death Overview Panel (CDOP) and the reports for Local Safeguarding Children’s Boards ‘parents are not invited to be a part of this panel’ but ‘may be invited to contribute comments’ (FSID, 2011, p. 6).

Therefore in most of the significant meetings which follow sudden, unexpected child death, parents are not included and this is reflected in the Working Party for the Kennedy Report itself. The continuing references to support, sensitivity and appropriate care in the Report are not grounded in the direct experiences of parents, thus leaving a potential gap in the Report’s rationale of preventing future miscarriages of justice similar to those of Sally Clark, Angela Cannings and Trupti Patel. The Kennedy Report itself concedes this, stating that ‘given the nature and sensitivity of the subject, some contentious issues remain’ and inviting ‘feedback’ (RCPATH & RCPCH, 2004, p.ii).

This research study began, in part, as a response to this invitation, with the intention of filling some of the gaps with parental narratives, which could help ‘sensitise’ professionals to the ‘emotions experienced by parents’ (RCPATH & RCPCH, 2004, p.12). The main impetus of the study was however a personal one – the sudden, unexpected death of my own son, Joe, in 2005. His death, combined with my previous experience as a social worker, led me to research sudden, unexpected child death with the aim of improving future investigations for all those involved.

Chapter One of the thesis describes Joe's death and the questions it raised, thus setting the research study in a personal context. In Chapter Two I offer my 'reading about the subject' (Pelias, 2004, p.7), as a broader context, together with a discussion of the psychosocial approach which now underpins my understanding. Chapter Three focuses on my meandering attempts to develop a methodology suitable for this difficult and often painful subject and in Chapter Four I have collated the experiences of five of the research participants, to form a collective story. Chapters Five and Six extend the threads drawn in Chapter Four, containing the unabridged, in-depth narrative accounts of two other participants.

Chapter Seven offers the panel chunks (Wengraf, 2011) which were used for analysis, thereby offering an opportunity to extend methodological understanding. In the final Chapter, I discuss my findings and the understanding I have reached from my experience of conducting this research, both as a professional and a parent who has experienced sudden, unexpected child death.

Part of this understanding has been a deepening awareness of how difficult many people find it to engage with this subject. Therefore, as I submit this thesis I am all too conscious that it is hard to read in places and I am frequently on the brink of an apology for this. However, I remain in close agreement with Cooper (2009) in his assertion that researchers should maintain the courage to engage with difficult and painful aspects of life, no matter how unwelcome. Whilst the thesis I am now submitting is not what I had originally anticipated, much of the original intention remains. I hope the research can play a useful role in helping professionals to engage fearlessly, as Cooper describes, with some of the most potentially distressing aspects of their work, thus building on the Kennedy Report by providing a channel for communication and in this way genuinely help to 'square the circle of maintaining high standards in the interest of justice for parents whilst also safeguarding the young' (RCPATH & RCPCH, 2004, p. 15).

Chapter 1

1:1: 'Like String Full of Knots'

'Of course that is not the whole story, but that is the way with stories; we make them what we will...some people say there are true things to be found, some people say all kinds of things can be proved. I don't believe them. The only thing for certain is how complicated it all is, like string full of knots, it's there but hard to find the beginning and impossible to fathom the end. The best you can do is admire the cat's cradle and maybe knot it up a bit more.'

(Winterson, 1985, p. 91)

I have chosen to begin with this metaphor of the cat's cradle which I have found lingeringly valuable in writing this thesis, returning to it repeatedly in my attempts to unravel the multiplicity of knots created by sudden, unexpected child death. At first, I had viewed the process of conducting this research as similar to following a simple line of thread - from its origin in the Kennedy Report's recommendations that professionals be sensitized to the emotions experienced by parents through to eliciting narratives which had the potential to assist with this, thus helping to square the circle as the Kennedy Report describes.

However, as the research process progressed I began to encounter knots - legal, social, personal and political - which at times made it hard to keep hold of any one thread for long and which forced me to look deeper than my original intention had allowed. Only one thing remained consistent - at the centre of these tangles was always another absence - the child who had died and their parent's experience of this. It is the personal accounts of eight of these parents which form the heart of this study, whilst the experience of researching it, reflecting upon it and encountering the reactions of others to it have formed the background to my developing understanding of 'how complicated

it all is' (Winterson, 1985, p.91).

Following Winterson's suggestion, to knot it up a bit more involves acknowledging that the original impetus for the study sprang from my professional experience as a social worker and my personal experience of sudden, unexpected child death, following the death of my son, Joe, in 2005. This thesis then, and the research that underpins it, also began with a loss or as Lott (1996, p.82) describes it a 'disappearance.' As my work has progressed I have become less preoccupied with following the threads of the 'cats cradle' (Winterson, 1985, p.91) and more interested in the spaces between, which seem to form a story of their own.

As I described in the Introduction, much of the Kennedy Report is characterized by what is not there as much as by what is, and these absences have become a repeating metaphor in my experience of conducting this research. Parental narratives and representation are absent from the Kennedy Report and, after Joe died, when I sought stories of experience similar to my own I found only more absence, leading to my decision to begin the research.

Much of this thesis then is concerned with bringing meaning and understanding to loss and absence. I do not, as Winterson (1985, p.91) suggests, offer what I have found as the 'whole story' but simply as another thread for the reader to 'make of' what they will.

I have chosen to begin this first Chapter where it all began for me - with the life and subsequent death of my son Joe, one March night in 2005.

1.2: 'Joe's Story.'

Joe was born in August 2003, during the hottest summer ever recorded at that time. He was the oldest, by a minute, of twin boys delivered by emergency caesarean section at 32 weeks. It had been a difficult pregnancy and despite the trauma of the birth there was also an immediate relief in losing the debilitating edema that I had suffered throughout. However, the delivery of the twin boys, Joe and Dan, precipitated more upset. Dan weighed only 2 pounds 13, yet Joe at a heavier 3 pounds 11 ounces faced a series of crises and stayed in intensive care for several weeks. For days after his birth he was attached to so much machinery it made it impossible for me to see his face. He just appeared as a tiny scrap of flesh divided from the world by the glass of his incubator, struggling to maintain his tenuous hold on life.

Dan's tiny form seemed to strengthen daily and he sped through the hierarchy of the Baby Unit, from intensive to fairly low support Special Care. Joe however, failed to thrive and he was diagnosed variously with deafness, necrotizing enterocolitis and other infections, for which he was given powerful doses of antibiotic. In a scene that seemed drawn directly from hospital drama, he suffered a collapsed lung and I was unceremoniously thrust out of the room whilst medical personnel fought for his life. Joe recovered but it was days before a brain scan confirmed that he had not in fact suffered the brain damage that doctors had feared.

Gradually, Joe was allowed to spend time outside of his incubator. As I could not yet drive I had to rely on friends to help me make the twelve mile return journey required twice daily to establish breast feeding. At night I expressed milk for the boys and the days were busy with hospital visits and caring for my daughter, Amy, aged 4, who had just started primary school.

On 22nd September 2003, my birthday, Joe and Dan were discharged from hospital and I began the long task of adjustment to having two babies, as well as a new schoolgirl in the home. Gradually a routine established itself and the boys grew from tiny scraps to more robust toddlers. Joe, always the larger of the two, was a chubby boy who by his first birthday could walk and say quite a few words. By nature he was a stoic child with a sense of humour and infectious chuckle. He made few demands and I viewed him as a real treasure, a kind of miracle child who had triumphed over the odds. As Speedy (2008) suggests, we tell all sorts of stories to give reference to our lives and this formed one of mine.

Physically Joe was very inclined to colds and chest infections. Disturbed by this I made several trips to the GP where they told me Joe was simply a 'Happy Wheezer' and not to be concerned.

By March 2005, Joe and Dan were 19 months old and my daughter Amy, now 6 had settled well at school. I had reinvented myself as a contemporary middle –class mother of three, with as Rose (1989, p.199) suggests 'everything... so organized, programmed, sequenced and monitored' as to 'achieve maximum success' in ensuring my three children's safe passage from harm.

One Sunday night in March 2005 Joe seemed a bit snuffly. I took his temperature, which was normal, checked for signs of a rash and reassured put him to bed as usual. He drank a good bottle of bedtime milk. Colds were very common and because I had been told Joe was a 'Happy Wheezer', I was not unduly concerned.

In the morning, Amy came into bed with me before I went downstairs to get the boys their milk and she went in to say good morning to them. When I walked into the room a few moments later, she was sitting in Dan's cot reading to him. Joe was lying face down in his own cot. "Joe's still asleep Mummy" she said. I took one look at him. He was

cold, stone coloured, like marble. I knew immediately that he had been dead for hours. The moment is frozen in my mind like a still from a film. It is one of those moments that perhaps most parents rehearse in their heads, hoping it will never happen and wondering what they will do if it does? What I did was to get Amy and Dan out of the room. Joe was dead. There was nothing I could do for him. My instinct, in that second was for my two living children. "Yes," I said, "Joe's still asleep. Let's not disturb him" And I settled them downstairs.

Mechanically, in a kind of haze, I woke the children's father with the stark words "Joe's dead". He immediately started to cry and then reached for the phone to call an ambulance, whilst in my haze I remained utterly calm and detached. I remember being almost curious at his tears and not wanting him to call an ambulance, which I now think may have been a form of denial (Hindmarch, 1993, p.16). Frozen in that time, there were still the five of us but the second the ambulance arrived I knew Joe's death would become a reality and that our story would change forever. I would no longer be the mother of twins; we would no longer be a family of five and Joe would no longer be the miracle boy who triumphed over everything. Instead the ambulance would confirm that he was dead and would wake me from my attempts to keep the world and reality at bay.

The ambulance arrived in seconds. The paramedics crashed through the house, into Joe's room and seconds later crashed out again, ashen faced saying there was nothing they could do. It all seemed slightly farcical to me, in my detached state, because Joe had obviously been dead for hours. A paramedic took Amy into her room, whilst downstairs my husband wept on the sofa. The paramedic told him to 'pull himself together', that he should be "putting his arm around his wife".

Our marriage, since ended, was already tenuous and thus I did not want to sit and be comforted but rather to prioritise taking care of Amy. She didn't yet know Joe was dead

and I didn't want her to know that he had died in the night at home, and further that she had been sitting in the room with her dead brother thinking he was asleep. It was still only about quarter past 8 in the morning and I wanted to take her to school and then tell her later that Joe had died in hospital, thus protecting her from everything that was taking place in her home.

I announced my intention to the paramedic, thinking that he would affirm my courage and clear headedness. Instead he looked aghast, telling me firmly that I was to stay at home and mourn Joe and further that we should all spend the day grieving Joe as a family. He added, almost as an aside, that we weren't allowed to leave the house. I reacted badly to this, insisting on my right to take Amy to school and he advised me again not to try and leave. The argument became heated and voices were raised, with the paramedic attempting to control a situation that was simply uncontrollable. I threw a coat over my pyjamas and left the house with Amy. My ex-husband stayed at home with Dan as a sort of hostage to ensure I did not simply 'do a runner.'

At the school, I broke down for the first time, telling the Headteacher, in a confused stream of words, that Joe was dead and Amy still did not know. The Headteacher stayed calm and capable though visibly shocked. We will look after Amy she said. You look after yourself.

When I returned home after taking Amy to school, it was clear that a Rapid Response investigation had begun, for a marked Police car was outside my house, whilst a uniformed police officer seemed to fill the small hallway. As I walked into the front room I found it crammed with professionals who all seemed to know me, like some ghoulis form of cocktail party.

Following procedure, police officers interviewed me and my ex-husband separately, whilst in the boys' room cameras flashed. The interviewing police officer asked what

the children had for tea the night before. It had been tuna and pasta which led him to speculate that Joe had choked on a fish bone. During the questioning, other investigating officers made sorties from Joe's room carrying his last nappy, his cot sheet and the grow bags which both boys had slept in. These had been a gift I was very pleased with. Now the policeman brought the grow bag in with a concerned look enquiring "Whether these were the only bedding Joe had been given."

By the end of the police interview I was convinced that Joe had died by choking on a fish bone, or of hypothermia or simply of my negligent mothering. Part of me anticipated the moment of my arrest and the removal of my two surviving children. Like Davies (2010, p. 7) I felt 'undermined, disbelieved and threatened', propelled by random tragedy into a world of police investigation and forensic evidence where I was a suspect in my own home, only minutes after finding my son dead in his cot.

Shortly after the interview as I was still confined to one room in the house, a female police officer told me that there "may be social workers on the way." I remember replying that "I was a social worker" in the hope that this information may help to ameliorate my earlier belligerent display with the paramedic. In fact this knowledge seemed to confound the policewoman, who, faced with me there in my pyjamas, retorted "Really, I thought you were the mother." This has remained a powerful memory and one to which I will return throughout this thesis.

However, despite the police officer's suggestion that social workers may be on the way they never arrived and I was grateful to be spared more potentially distressing and humiliating interventions. What did surprise me, however, was that hardly anyone came. The G.P called briefly that night to check on Dan. After the tidal wave of professionals who filled our home that morning had dispersed, we were left in the weeks that followed to cope with our two surviving children, the shock of Joe's death

and the surrounding events, as well as the countless tasks that follow a death, with almost no support.

When a child dies, their body becomes the property of the Coroner (Sidebotham & Fleming, 2007, pp. 129 & 147) and is still referred to in the early investigation as the 'crime scene.' When Joe died, the Coroner's officer, one of the many officials who occupied my home that morning, told us that his body would be taken to London where a paediatric pathologist would carry out the post mortem. Joe was taken away in a body bag according to her instructions and it was over three weeks before we had any news of him.

One afternoon during this time, the Coroner phoned and barked at me that I had not registered the death. Impatiently she explained that I was holding up the process at her end and therefore requested that I go and complete this task immediately. I felt foolish and compromised as I had not realized I would have to do this. Dutifully, I set off with Dan in the buggy, to the Registrar's Office. The same registrar who registered Joe's birth only a year and a half before now registered his death in perfect penmanship without uttering a word, leaving in this hushed space where birth and death crossed each other so intimately no hint of humanity.

When the post mortem results arrived they showed that Joe had died from a very sudden form of meningitis, brought on from having a lowered immunity due to the circumstances of his birth, together with some chronic and undiagnosed chest problems attributable to the collapsed lung. It seemed then that Joe was not such a 'Happy Wheezer' after all. But despite this I still blamed myself.

Before the Coroner would release the body for a funeral we were told we would have to pay a £100 charge to bring Joe back from London. We disputed this because the Coroner had taken over legal jurisdiction of Joe's body at the point of death. The

Coroner told us that the charge was the fault of the undertaker whose job it was to transport the body. However, the undertaker told us it was the responsibility of the Coroner. Both told us to complain to the other but as we simply wanted to hold a funeral for our son, we paid the fee.

Years later, at a conference I asked the Coroner responsible for my District whether such a charge was ever levied on parents. She seemed appalled to be asked and told me in no uncertain terms that it did not. During the coffee break, several professionals working with bereaved families told me of various incidences where their clients had been made to pay similar charges. None of them had the confidence to say it to the Coroner and had all waited until the coffee break when they could tell me privately. I was left wondering about this silence and the possible consequences of this.

A while after Joe's death our health visitor, who had been on leave at the time, phoned me in tears. She told me how terrible it was and that it shouldn't have happened, leaving me somehow with the impression that it had happened to her. Responding to her offer of practical help, however, I asked her to contact the Council about a memorial bench we had decided to place in a local park. Six weeks later she telephoned to say actually she was very busy and asked me if I would be able to do this. One of her colleagues later stopped me when I was in the park with my daughter and told me how difficult it had been for my health visitor to cope with Joe's death. She was, her colleague told me, having a terrible time.

That remains one of my lasting impressions of Joe's death. That most of the professionals involved were having a terrible time. No one seemed genuinely able to cope. The horror of the situation, the fear of being held culpable and the sheer randomness of the death seemed to immobilize people's basic humanity at this most human of times.

Hindmarch (1993, p. 100) suggests that ‘whatever their role, any visitor to the home of a bereaved family is likely to feel apprehensive’ or even ‘terrified’. This was certainly my experience following Joe’s death and its effect left me struggling with shock whilst trying to maintain routine and normality for Amy and Dan. However, whilst I was surprised and disappointed by the derisory quality of the interventions we received, as a former social worker myself, I could also empathise with the professionals involved. Ferguson (2011, p. 168) writes lucidly of an experience familiar to many social workers upon discovering a family are not at home, when ‘suddenly the world seems like a better place again, all because you don’t have to struggle through yet another tortuous session.’ This was certainly recognizable to me from my own practice and I found myself dwelling on this and wondering if I had appeared as indifferent to people, as many of the professionals now seemed to me.

There were professionals who remain in my memory as points of light. The Headteacher at Amy’s school was one. Once she learned of Joe’s death, Amy refused to have any evidence of him out on display. She wanted all his photos and possessions to be placed and contained within a box. On her return to school, Amy insisted on taking this box with her and the Headteacher took both box and Amy with her into class, using it to tell the other children what had happened to Joe. She showed them the contents, amongst other things Joe’s toothbrush, his shoes and his favourite toys. That day they kept the box in the school library and Amy was allowed to visit as often as she wanted and to keep it there if she liked. At the end of that day, however, Amy said it was all right to take it home. I felt that it had done what it needed to do. She had brought her dead brother to school and made him and the events of his death real. And she had done all this with the support and humanity of her Headteacher.

1:3 Being a 'Bereaved Parent.'

In the immediate seconds after finding Joe dead my instincts had been for Amy and Dan, my two surviving children. My drive to both protect and navigate them through this time did not diminish as the weeks passed. The funeral came and went and so did the professionals involved with the death. My health visitor telephoned several times with the numbers of counsellors or family therapists she advised I should contact although I did not choose to follow these up. I was still shocked and focused on keeping things normal for Amy and Dan and I did not want counselling, but rather practical support. I felt then, as Hindmarch (1993, p. 99) suggests, that referrals to counselling are 'often made by ... professionals who feel out of their depth and lacking the competency required'. I consequently experienced the health visitor's attempts at support as cursory.

The one helping professional I did speak to was a psychologist who offered his advice via a short 'phone conversation about Amy's refusal to have any evidence of Joe in the house and her request to put all his things in a box. The psychologist was practical and helpful, advising me that Amy's behavior was "normal" and as long as I was "all right" then Amy would be too.

Dent and Stewart (2004, p. 61) suggest that 'the effect of a sudden, unexpected family death means that siblings are bereaved and are living amidst the grief of their parents. I was determined my two children would not live amidst my grief and thus the psychologist's telephone edict that I should "be all right" became the magnetic north I followed in trying to protect them from the aftermath of Joe's death.

The difficulty I experienced was in finding useful advice on how to be all right

following a sudden, unexpected child death. In the small, largely prosperous town in which I live the twins, in their double buggy, had been a focus of attention and Joe's death consequently caused shockwaves. People often struggled with what to say and would do the clichéd thing of crossing the road to avoid me. Other people simply did not mention the awkward social fact that one of my children had completely disappeared and others still seemed to feel I was not grieving as I should. One man, the partner of a friend, illustrated this with his query, "I mean haven't you even broken down yet?" Several more people questioned whether the death "had hit me" and I lost count of those who told me "I would never get over it." At playgroup with Dan someone told me I would "always be known in the town as the woman whose twin boy had died", whilst out on a brief shopping trip with the children, another woman I barely knew, simply stood in the street in front of us and sobbed uncontrollably.

At first this behavior was tiring and sometimes upsetting and I explained it to myself by how difficult it must feel for people to know what to say to me. Additionally, my own guilt was enormous and I therefore found myself avoiding the well-meaning ministrations of those who repeatedly told me '*not* to feel guilty,' thus unwittingly increasing the feeling (Harman, 1981, p. 36).

Another social phenomenon which occurred around this time was people told me, often in whispers, their own stories of pain and loss, most of them kept secret for years. I suddenly learned of miscarriages, still births, generations of lost babies and struggling marriages. Shisler (2006) too, identified this tendency after her own son's death, suggesting that the experience opened her eyes to this 'invisible land' (p. 201). This 'invisibility' is also explored by J. K. Rowling (2003, p.760) in one of the 'Harry Potter' novels through her description of the 'thestrals' - mysterious winged creatures that can only be seen by people who've seen death, but who are also largely avoided because they are a bit 'different.'

In the aftermath of Joe's death it was as if I was suddenly able to see the 'thestrals' and I remember being startled by them and curious that Joe's death had rendered me witness in this way. Since carrying out this research, however, I see these experiences as part of what Frank (1995, p. 39) describes as the 'great permission' provided by confrontations with death and thus view the telling of these stories as attempts at healing and cohesion. These are themes which I will return to repeatedly as the thesis progresses.

In my own quest to follow the psychologist's advice to be all right, following Joe's death I faced an uncomfortable social message which suggested I should instead be breaking down or letting the experience hit me. I began to search for connection in other people's accounts of experience. This search was at first totally indiscriminating and I read anything that contained a child death of any nature. Later I discovered books more relevant to my experience, but I was disappointed to find that these were usually written by professionals for other professionals. This genre also commonly interspersed Chapters on 'Supporting Families' with others on 'Fatal Child Maltreatment' (Sidebotham & Fleming, 2007) and I became accustomed to keeping literary company with people who had harmed or murdered their children, with the boundaries often seeming to blur in front of my eyes.

Whilst my own narrative of Joe's death included an element of accepting it as a random tragedy, I remained enduringly disturbed by the experience - particularly by the Rapid Response investigation - and I found both my memories and my dreams invaded by images of policemen, intrusive flash photography, seizure, accusation and humiliation.

Davies (2010, p. 201) in a personal account of a child protection investigation discusses the 'secondary victimization' suffered by parents and poses the question 'We suffered twice. Was this inevitable?' My own training and experience as a social worker told me

that people sometimes harmed their children and yet the response we had experienced after Joe's death seemed to me altogether inadequate, disjointed and lacking in humanity. I began to question whether the 'tricky business' of 'weighing up who is at risk and those who pose a risk' (Davies, 2010, p. 203) was indeed so complex it too often resulted in heavy-handed and inept interventions, which at best served a lowest common denominator and at worst caused as much harm as they attempted to prevent.

Part of this potential harm centered around surviving siblings, who simply do not appear either in the Kennedy Report or in the literature on Rapid Response. Even one of the most comprehensive and creditable books I discovered in my early forays into the literature mentions investigation on only 4 of its 200 pages, with the longest reference saying simply that 'the requirements for many sudden deaths to be investigated by the police can cause families further distress' (Dent & Stewart, 2004, p. 35). The work does not expand further on what specifically causes this distress; what its long term consequences may be and how this distress could be ameliorated and I could find no other work that did.

The other common depiction within the literature was of the death as 'unacceptable' (Judd, 1989, cited in Bridgeman, 2009, p. 255) and the 'bereaved parent' as almost a thing apart, a special kind of species rather than simply a fully rounded human being who had experienced an unexpected and arbitrary tragedy. The 'bereaved parent' was generally spoken of in 'hushed tones' as 'crushed' (Chalmers, 2007, p. 3) or as a person that never 'feels o.k really ever' (Dent & Stewart, 2004, p. 174). This portrayal is echoed in training material like the DVD 'Why Jason Died' (2008) produced by the Department for Education as a key training resource for a range of professional audiences, where the bereaved mother is played by an actress, with all other parts played by professionals themselves. The mother is thin, frail and rarely speaks. She is supported through a variety of scenes in which she passes ghostlike, shedding the

occasional tear and trembling slightly, but shows no emotional range other than passive despair.

Whilst some of the literature did acknowledge the ‘intensity and range of feelings’ which ‘bereaved parents’ may experience, this defaulted to describing these as ‘a roller coaster of shock, disbelief, anger, guilt, blame, sadness, weariness and hopelessness’ (Dent & Stewart, 2004, p. 174). The last word ‘hopelessness’ is particularly significant as, alongside ‘unnatural’ (Wheeler, 2001, p.53) much of the literature within the field endorses the observation that ‘the sudden death of a child is the most shocking and devastating event anyone must face’ (Simons, 2004, cited in Dent & Stewart, 2004, p. x).

Doka, (1989, p. 132) suggests that it is a common experience following bereavement, to search, as I did, for ‘books in which people shared their experiences and told what helped.’ However what I had sought for did not seem accessible. Rather than ‘books...that helped’, I found a great many which reinforced my uncomfortable feeling that I had not behaved as a proper bereaved parent should. I did not view Joe’s death as ‘unnatural’ nor as ‘the most shocking and devastating event anyone must face’ (Simons, 2004, cited in Dent & Stewart, 2004, p. x). Furthermore I had been belligerent to the paramedic and subsequently had not properly broken down in front of people. It seemed to me then that not only had I allowed Joe to die, but also that I didn’t even seem to be able to mourn him as it seemed I should. I had failed as Speedy (2008, p. 148) suggests ‘to shape up to normalizing judgments about bereavement processes.’

What would have helped me at this time were ‘narratives of survival’ (Ellis, 1993, p. 711). Clinging fast to the psychologist’s advice to be all right for Amy and Dan, yet threatened by the swirling waters of hopelessness and the most shocking and devastating event that can ever happen to anyone (Dent and Stewart, 2004), I simply

wanted someone to tell me that ‘there are survivors’ (Ellis, 1993). At this time, as Nicholson suggests ‘it would have helped me to know that someone else out there had gone through this experience and survived to see the light again’ (2005, p. 8).

1:4: ‘What survives the storm’

In an insightful piece on the individuality of bereavement experiences Chalmers (2007, p. 4) suggests that ‘parents ability to survive emotionally will be impacted by what has gone before in their lives, by their own childhood experience of parenting and by what they have invested in their relationship with this child.’ Thus rather than homogenizing sudden unexpected child death into dramatic and generic descriptions she offers an approach which personalizes the experience and frames it as a life event. Frank carries this idea forward in his description of death and fatal illness occurring ‘in a life that already has a story’ (Frank, 1995, p. 54), which can then begin the ‘repair ... by taking stock of what survives the storm.’ Whilst what Frank describes as ‘the old map’ may now ‘be less than useful...it has hardly been carbonized ‘and traces will remain which point towards new directions and ways of navigating out of a place of hopelessness.

This was certainly my experience following Joe’s death when I was able to draw from previous life experience, together with the time I had spent with Joe and the continuing lives of Amy and Dan, who kept me very firmly on the map. Additionally the circumstances of becoming pregnant and having children at all formed part of the taking stock and the previous life experience described by both Frank and Chalmers. I had never taken it for granted that I would have children and when I did become pregnant, it was reasonably late in life. This carried an increased element of risk, which manifested in the prematurity of all my children and the twin pregnancy itself, which medical staff advised was age related. I had therefore always felt very grateful for the lives of my children which were actually unnatural – the living products of incubators, breathing

apparatus and the power of modern technology, without which they would almost certainly not have survived.

Thus the births and continuing lives of my children, particularly the circumstances of Joe's early weeks, had left me with an unshakable sense of the fragility and also the preciousness of life. Although I am not a religious person the lines 'The Lord giveth and the Lord taketh away' from the Bible (Job 1: 21) seemed best to sum up my enduring narrative about Joe's death. He had so nearly died in the womb, had so nearly died several times in hospital, that despite my feelings of devastation, guilt fear and failure, there was also a 'felt sense' (Gendlin, 1996, p. 19) flickering below all these feelings. This whispered to me that his short life, so precariously given, had actually been a miracle in itself and that we had been fortunate to share the 19 months he had lived.

'What survived the storm' (Frank, 1995, p. 54) of his death was my continuing role as a parent. Yet in the literature I accessed, as well as the Kennedy Report, there is little or no consideration given to the fact that many bereaved parents may still be parents, and that this, as in my case, may still be what defines them. The attention given to siblings also often focuses around the death as an event which may affect these children as adults, influencing their capacity to manage changes like 'going to a new school, leaving home, and getting married' (Dent & Stewart, 2004, p. 177). I could find little that echoed the phone advice I had been given with regard to Amy, that if I was all right then she probably would be too. I continued to navigate by this, as most of the available literature seemed to reinforce the widespread social message that none of us would ever get over it.

Hindmarch (1993, p. 99) suggests that following a sudden child death 'there is usually a need for practical support...parents in extreme shock may find themselves unable to care adequately for their other children.' Following Joe's death I was surprised by the

lack of support we were given in caring for Amy and Dan, although I never felt I could not care adequately for them. Where I did completely fail in confidence, however, was over any matters that affected their physical health. When I put Joe to bed the night he died he was just a tiny bit sniffly and so, particularly in the immediate aftermath, I was terrified of something similar occurring whenever Amy or Dan became ill. With Joe's death I crossed a threshold into a world where death is a reality and where, particularly at first, there seemed little middle ground between a child being ill and a child being dead. The type of practical advice identified by Hindmarch (1993) would have been invaluable to me in ameliorating these anxieties.

1:5: 'A Place for Experience'

In his work on 'emotional life' and contemporary welfare, Hoggett (2000, p. 84) writes passionately of the need for 'a place for experience' within contemporary social science, which resonates with my early forays into the literature. Looking back on these, I now see myself seeking such a place – somewhere to locate my own experience where it could find shelter in those of others. However, as I have described I was dismayed at how little literature on this experience was available, even within the Kennedy Report which places such importance on it.

Davies (2010, p. 209) calls for 'more research to study the impact on the families' following investigation 'particularly when the outcome is no action.' As the years passed after Joe's death, I too began to wonder about the need for this and whether my experience could usefully become part of such research. Ultimately then, this thesis has become my 'place for experience,' whilst researching and writing it have provided me with the capacity to 'contain' the experience by 'being able to think about it' (Hoggett, 2000, p.84). Drawing from Bion, Hoggett (2000, p. 41), suggests that this capacity for containing experience through thought is one of the 'essential tasks of life' and this in

turn complements the work of many modern grief theorists who locate ‘meaning reconstruction in response to loss’ as ‘the central process in grieving’ (Neimeyer, 1999, p. 11).

However Hoggett (2000, p. 85) also criticizes contemporary social science for having ‘little space for experience’ arguing further that even when space is made available ‘academics tend to write in a style which is impersonal, distanced and ultimately boring’ (Hoggett, 2000, p.85). He calls for work that is able to ‘cross boundaries’ and in shaping this thesis. I have attempted to respond to this call both by combining my personal experience with the narratives it contains and by returning to this as a thread which runs throughout.

Crossing boundaries has also required a way of viewing the experience of sudden, unexpected child death as both a uniquely personal event and one which occurs within a social and cultural environment. As I have documented, my own responses to Joe’s death were often deeply affected by the behaviour of those around me and also by what they expected from me in terms of ‘normalizing judgments about bereavement processes’ (Speedy, 2008, p. 148). Therefore, whilst my original intention of adding parental narratives to the field had remained, the experience of carrying out the research has necessitated not just the crossing of boundaries but the excavation of these both at a superficial and a much deeper level. I have been assisted in this by the use of a psychosocial approach, by which I mean one which uses ‘psychoanalytic concepts and principles to illuminate core issues’ (Hoggett, 2000, p. 1). This borrowing of psychoanalytic ideas has allowed me to unite several of the aims of this research with the often intractable reactions I have encountered in conducting it. Beginning with ‘the emotions experienced by parents’ which are both fundamental to and yet absent from the Kennedy Report, my goal has been to fill the gap but further to understand why these emotions are not accounted for.

Cooper and Lousada (2005) share a similar purpose in their own ‘psychoanalytic study of welfare’ (p. 1) in which they too ‘explore what can be learned from [their] own experience and the experience of those with whom [they] work.’ They argue forcibly for the need to link ‘disciplined thought with feeling’ in the creation of effective policy and lament the increasing absence of ‘the emotional sources necessary for good, rational decision making’ within contemporary welfare policy’.

I have found a psychosocial approach invaluable in allowing me to research beneath the surface, (Clark & Hoggett 2009), utilising psychoanalytic concepts so that the absences are not merely noted but are explored in a deeper way which allows for ‘the unconscious communication, dynamics and defences that exist,’ at the personal, group and institutional level. Use of a psychosocial approach has helped me to frame my own place for experience within the narratives contained in this thesis, as well as in a wider cultural context.

However, in a piece of research so underpinned by the miscarriages of justice which occurred through the contested evidence of experts, I have remained aware of the debates which also exist between authorities in the field of psychosocial studies and how these may risk diverting from the research itself. These debates have influenced my own position which is one of utilizing psychosocial approaches to explain experience rather than becoming mired in discussion about the precise application of these.

Key amongst the debates which have helped to influence my approach are the papers of Frosh and Baraitser (2008), Hollway (2008) and Baraitser (2008). In the first of these Frosh and Baraitser debate the use of psychoanalytic concepts within the field of psychosocial studies, arguing that the collapsing of one into another is not always helpful and may indeed be rather dangerous in any claims made for finding the ‘deep truths of human nature’ (2008, p. 346). The paper contrasts Kleinian approaches to

psychosocial studies with a more deconstructive approach represented by Lacan. As a part of this discussion the paper critiques the work of Wendy Hollway, leading to fierce debate in the field and Hollway's own swift response in an article entitled 'Doing intellectual disagreement differently?' (2008). In this article, Hollway describes feeling wounded by the accusations of Frosh and Baraitser. This evoked a further paper by Baraitser entitled 'On Giving and Taking Offence' (2008).

In considering my own position within such academic debates, I have been reminded of the quotation which began this Chapter: 'some people say there are true things to be found' whilst others 'say all kinds of things can be proved' (Winterson, 1985, p.91). Like Winterson, 'I don't believe them', remaining certain only of 'how complicated it all is' (1985, p. 91). Thus I have tried to allow for 'an interplay of perspectives, while privileging none' (Cooper & Lousada, 2005, p. 202).

I discovered psychosocial approaches very late in the research process, when I reached for something deeper than the narrative method which I had been using and found that I had been working in this way all along. However my tardy ownership of these principles means that my interplay of perspectives, is not always as rich as further time might have allowed. Perhaps however, this is simply inevitable, leaving me with one of the 'essential attributes...of the psychosocial researcher' - a space of 'being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason' (Keats cited in Clarke & Hoggett, 2009, p. 16). This place of uncertainty creates the conditions of a space for emergence - an ideal location for a research study so deeply immersed in loss and concerned with exploring the further absences and liminal spaces created by this.

1:6: Conclusion

In this Chapter, I have introduced many of the main threads which will run throughout

this thesis, visualizing these as intersecting strands which make up the cats cradle and additionally highlighting the spaces between strands, which in turn evoke the many absences inherent in the field of sudden, unexpected child death. My own experience of Joe's death is given as both context and impetus for the research itself, as well to set the scene for much of what follows in the subsequent Chapters. The discussions of how to be a bereaved parent and to survive child death, within a contemporary cultural setting that commonly depicts it as 'the most shocking and devastating event anyone must face' (Simons, 2004, cited in Dent & Stewart, 2004, p. x) are other strands which will repeatedly recur in the thesis, alongside a deeper exploration of the emotions experienced by parents.

My use of the psychoanalytically derived concepts inherent in a psychosocial approach has helped me to explain both the prevailing absence of parental narrative and experience from the field, together with the challenges I have faced in conducting the research and I therefore want to conclude by borrowing another psychosocial idea.

In the Frosh and Baraitser article (2008), which became the source of so much academic debate they offer an original use for the metaphorical knots with which I began this Chapter. I had initially viewed these as glitches within the research process itself or as points where different ideas or concepts become intractably entwined. However, Frosh and Baraitser (2008) draw on Lacan to suggest that knots can also tie things together and this seems the ideal image with which to connect all the threads introduced within this Chapter. I have already started to tie together Joe's death with the place for experience which has come from it, together with my position of looking from 'multiple viewpoints' (Ellingson, 1998, p. 500) - as a researcher, a parent who has experienced the sudden, unexpected death of my child and a qualified social worker, experienced in child protection.

Whilst Joe's death was the impetus for the research, my role as a social worker has left me with a powerful drive to improve communication and understanding between professionals and parents and my years as a researcher have increased my own knowledge of the multiple complexities of this role. A psychosocial approach has enabled me to knot together all these strands, whilst ensuring that no one of them ever totally eclipses the other. Thus I hope to go some way towards augmenting the original aims of the Kennedy Report by enhancing understanding between all those involved in a sudden, unexpected child death, thereby improving the experience and ultimately helping to alleviate further miscarriages of justice.

In the next Chapter I will return to the Kennedy Report, locating it within a wider context of child death inquiries as well as exploring the broader setting in which sudden, unexpected child deaths are situated.

Chapter 2

2:1: 'Reading about this subject'

'I had been reading about this subject
For a long time now...
I realized that I might classify it
Into several categories....
After doing that I saw that
There were still several questions unanswered'

(Pelias, 2004, p.7)

In reading about this particular subject, I am returned once again to the theme of absence. Whilst there is a vast and widespread literature on both death and safeguarding, little exists on sudden and unexpected child death, and there are almost no direct parental accounts of this experience, particularly of the investigation and its potential consequences. Therefore, my task in this Chapter appears initially simple. I could, as Pelias suggests, classify it into categories and then identify the unanswered questions. However, in considering this, I find myself revisiting the metaphor of the cat's cradle as a means of framing the threads that intersect at the point of the sudden and unexpected death of a child. The huge and varied literature on death forms one long strand, whilst the equally great body of work on risk and safeguarding creates another, which transects the first. Just as in the cat's cradle, there is a space created between these two threads. It is into this liminal space, connected perhaps by a much shorter thread of its own, that work on sudden and unexpected child death seems to sit, leaving, as Pelias submits, 'several questions unanswered.'

Early sorties into the literature, chiefly via the databases Scopus and Assia (see Appendix 1) showed an almost total absence of parental accounts of sudden, unexpected child death. The terms child*, death, parent, sudden and/or unexpected were used in

different combinations, alongside ‘Rapid and Response,’ within a ten year time frame, beginning in 1997 (see Appendix 1). During repeated searching, several author names recurred, most notably Peter Sidebotham and Peter Fleming, from the UK and Kari Dyregrov, from Scandinavia and their work is used extensively in this Chapter. Snowballing techniques were used to gather further references from the work of Sidebotham, Fleming, Dyregrov and other authors identified in the literature searching. Whilst the searches failed to access work specifically focussed on parental accounts of sudden, unexpected child death, the search terms utilised did uncover widespread work on death studies, together with parental experiences of more generic child loss and of safeguarding investigations. In the absence of a rich store of work specifically on sudden and unexpected child death then, I have focused not just on ‘reading about’ the subject (Pelias, 2004, p.7) but also on reading around it. Although parental narratives of sudden and unexpected child death are largely absent, there are similar accounts of investigation within the safeguarding literature. I have therefore included some of these, both to highlight aspects of the experience and to set the scene for the parental accounts which appear later in this thesis. I have also continued my exploration below the surface in a bid to understand why personal accounts of sudden and unexpected deaths are so scarce. As part of this, I have included a discussion of child death inquiries, both as a means of locating the Kennedy Report and of illustrating how responses to child deaths have developed both historically and culturally.

A discussion of the historical and cultural influences on attitudes to death within the UK has also helped to locate the specific sudden and unexpected deaths of children within a broader domain. What has made the choices complex is that safeguarding and death are both extensive areas in their own right. Therefore, I have had to concentrate on work that, in my judgement, helps to explicate my particular purpose.

Much of the literature that I have used as underpinning for this Chapter is not specifically concerned with death, children or safeguarding, but rather with exploring the absences I have already identified in the Kennedy Report, between emotional experience and social policy. Hoggett (2000), Cooper and Lousada (2005) and Clarke and Hoggett (2009) all excavate the breakdown of the connection between the two, and I have found each of them invaluable in providing a bedrock for this Chapter.

2:2: 'The age of the inquiry': failure, blame and defensive practice.

The 'Kennedy Report', 'Sudden Unexpected Death in Infancy' (2004), remains the most recent and substantive contribution to the literature on sudden and unexpected death in childhood. Prompted partly by the deaths of children, the Kennedy Report is located, albeit tangentially, alongside numerous investigations and inquiries within the period designated by Stanley and Manthorpe (2004, p.2) as the 'age of the inquiry.' During this time, the public inquiry, alongside inspection and audit, has become the key manner in which health and social care services are called to account (Stanley & Manthorpe, 2004). Therefore to reach a deeper understanding of the context for the Kennedy Report, it is worthwhile considering the inquiry as part of a genre (Cooper & Lousada, 2005).

Reder, Duncan and Gray (1993) systematically analysed all known reports of child deaths from non-accidental abuse or neglect from the first, that of Graham Bagnall in 1973, through to that of Doreen Aston in 1989. Their rationale centred on the notion that, far from improving practice, the 'accusatory styles' of inquiries 'grounded in the adversarial framework of the legal system' (1993, p. 3) too readily apportioned blame, and thereby increased professional defensiveness, creating a vicious circle, which dehumanised both staff and service users in favour of bureaucratic process.

Reder, Duncan and Gray (1993) hoped that their own systematic analysis of each death and subsequent review might delve deeper, thereby helping to identify some of the 'psychological processes which had influenced events' (p. 3), so that lessons could be learned without scapegoating. Like the Kennedy Report, they produced a number of recommendations, which included a call for improved training and research, but which hinged on the necessity of understanding the 'complex, fluctuating, emotive and stressful' nature of child protection work which may then be exacerbated by criticism and blaming, leading to many workers practising from a 'defensive posture' (Reder, Duncan & Gray, 1993, p. 122).

Munro (2004) also charts the growth of the public inquiry into child abuse and neglect, from Graham Bagnall's death in 1973 to the inquiry into the death of Victoria Climbié in 2003. Her account provides valuable insights into how the wrongful imprisonments of Clark, Cannings and Patel occurred within the culture produced by these inquiries. Munro, for example, suggests that the inquiry into the death of Jasmine Beckford (1985) caused a shift in the emphasis of child protection work from a 'rule of optimism', where professionals attempted to work with families and were slow to intervene, to a more intrusive stance which primarily protected children and placed the 'rights of parents' in second place' (2004, p. 77). As Munro notes, there was a highly noteworthy shift in emphasis from the very first inquiry into the death of Graham Bagnall, which saw parents and children as equally in need of 'assessment and help' (2004, p. 78). Following the Beckford Report in 1985, the numbers of children placed on child protection registers rose from 11,844 in 1978 to reach 45,300 by 1991 (Munro, 2004, p. 78).

In 1987, two newly appointed paediatricians in Cleveland diagnosed sexual abuse in 121 children from 57 families, all within a five-month period (Munro, 2004, p. 78). The public reaction to this, fuelled by often hysterical media coverage, constituted a

backlash against professionals who were seen as becoming too powerful and unnecessarily breaking up families. The Cleveland report of 1988 echoed this public outcry, criticising the professionals involved and recommending much greater co-operation between professionals and families (Munro, 2004).

However, despite the Childrens Act (1989), which pre-empted the recommendations of the Kennedy Report in advocating a better balance between the need to protect children and the need to enable parents, later studies showed that this balance had been difficult to achieve. Munro (2004, p.78) quotes a Department of Health summary of research published in 1995, which highlighted the fact that social work interventions were still ‘too often characterised as investigations’.

In 1991, the first of a series of ‘Working Together’ documents (Department of Health, 1991) acted as an attempt to stem what had now become a flood of inquiries by placing responsibility for the new Part 8 inquiries (later to be known as Serious Case Reviews) at a local rather than a national level. Despite this, Munro argues that ‘the threat of a public inquiry has remained a major influence on professional action, encouraging a defensive style of work’ (Munro, 2004, p. 74), and accordingly making a culture of ‘balance very difficult in practice.’ Paradoxically, this defensiveness has arisen at a time when for most social workers and related professionals ‘actual direct experience of death is very limited’ (Ferguson, 2011, p. 34), thus making the death of a child perhaps truly the ‘most shocking and devastating event’ professionals may face (Simons, 2004, cited in Dent & Stewart, 2004, p. x).

Reder and Duncan (2004) chart the history of fatal child abuse inquiries from Colwell to Climbié, and suggest that these have at least four purposes: learning, disciplining, catharsis and reassurance (p. 107). All four purposes can be identified within the Kennedy Report, which, despite its central concern with investigating miscarriages of

justice rather than the fatal abuse or neglect of children, is permeated by child abuse and death, declaring ‘child protection is a responsibility all of us must bear because of the special vulnerability of the youngest amongst us, who have no voice’ (RCPath & RCPCH, 2004, p. 15). The exclusion of parents from the Working Party for the Report, however, also leaves parents with ‘no voice’, and thus the learning focus of the Report is diminished.

Reder and Duncan (2004) suggest that generally such learning has been one of the most successful outcomes of public inquiries in terms of heightening public awareness of child abuse and neglect. Ironically, however, it is this very success that may have led to the wrongful convictions of Sally Clark, Angela Cannings and Trupti Patel. The bureaucratic rather than the human focus adopted by inquiries leads, as in the Kennedy Report, to protocol and to procedure rather than to a close listening to the voices of those involved.

This exclusion of humanity can lead to a closed and defensive style of work (Munro, 2004), focused only on apportioning failure or blame, and in this climate it becomes understandable that professionals cannot allow for the fact that babies die from natural causes. The convictions of Sally Clark, Angela Cannings and Trupti Patel can be viewed as the direct result of the ‘conveyor belt practice,’ spawned by inquiries that cannot risk looking at other possibilities, within a general culture of blame (Stanley & Manthorpe, 2004, p. 10).

The Munro Review of Child Protection initiated in 2010 by the Secretary of State for Education is acutely critical of this culture of blame. Munro calls for a renewed emphasis on relationship building between professionals and families, instead of the narrow focus on ‘forms and procedures’, which she holds to account for increasingly defended practice:

A one-size-fits-all approach is not the right way for child protection services to operate. Top down government targets and too many forms and procedures are preventing professionals from being able to give children the help they need and assess whether that help has made a difference (Munro, 2011, p.168).

Assessing what help has made a difference with respect to sudden and unexpected child death is extremely difficult when, as I have described, parents are excluded from all meetings that follow, including the case review, thus stemming the potential flow of feedback.

Excluding parents in this way can be viewed psychosocially as a form of splitting. Drawing on the work of Klein and the tradition of psychoanalysis which succeeded her, Cooper and Lousada (2005, p. 30) describe how splitting can occur at an early developmental stage as a response to pain and other frustrations. These potentially dangerous and uncontrollable feelings are projected into another, thus stemming the immediate threat to the self and creating a split. This can occur as a psychological event or within external processes involving individuals and organisations. This is a concept that I will revisit throughout this thesis.

Hoggett (2000, p. 39) also draws on Klein and her successors to locate another of her key concepts within the welfare field. Projective identification occurs at a very early stage of child development and 'is the first form of communication available to us', a means by which we express experiences 'that we cannot adequately give words to'. Hoggett suggests that this constantly occurs too within social groups and organisations when 'the more the individual or group feels itself to be endangered...the more violent will be the processes of projective identification into the other' (2000, p. 40).

Viewed through this lens, the exclusion of parents from the public opportunity to give any form of feedback following sudden and unexpected child death could be seen as

splitting their experience, which may be too painful or threatening to hear. Correspondingly, the reason that is often offered for this - that the meetings would be too upsetting for parents - can be seen as a form of projective identification in which parents are seen as a threat to the organisation, which is struggling to contain the experience.

The same forces can be detected within the inquiry system where 'the controlling fantasies of ... audit' serve the function of precluding 'true engagement with suffering, deprivation and loss' (Cooper & Lousada, 2005, p. 81). However, Reder and Duncan (2004, p.107) provide a different lens, suggesting that public inquiries into child abuse and neglect offer a form of public 'catharsis', a way of purging the horror of the events and remembering the child who has died. Furthering this argument, they suggest that inquiries may therefore perform a ritual function in which the unthinkable can be thought about and contained, with the accompanying promise that such events can be prevented from ever happening again.

Within this ritual function, as Stanley and Manthorpe (2004, p. 2) argue, each report 'tells a story' of its own, providing a 'narrative account replete with human drama and action...heroes, villains and victims' in which form plays a significant part. This can be clearly identified in the Kennedy Report, which demonstrates a highly charged emotional tone throughout, declaiming, for example:

When we no longer feel rage at injustice, we will have lost our humanity and our claims at living in a civilised society' (RCPath & RCPCH, 2004, p. 15).

The purpose of the Report in sensitising professionals to the emotions experienced by parents also demonstrates an overtly emotional intent, which is then lost in another form of splitting by the complete exclusion of any emotional accounts. In a profound analysis of the Climbié report, Cooper and Lousada identify a similar 'breakdown of linkage

between ... emotional and evidential sources', which they locate within a wider discussion of the problem of achieving 'emotionally intelligent' policy within a culture that has 'great difficulty in maintaining contact with painful emotional realities' (2005, p. 147).

Munro (2004, p. 85) also discusses the Climbié report, which she describes as 'in a class of its own, describing a level of practice that was frighteningly bad'. Detailing much of this bad practice, from social workers through to housing workers, police and healthcare workers, Munro builds a picture of 'a set of professionals trying to avoid taking responsibility for Victoria's welfare by minimising their interpretation of their own role as much as possible and relying on someone else to do the necessary work' (Munro, 2004, p.85). The report into Victoria's death was thus able to detail twelve separate incidents during a nine month period, where professionals failed to carry through the thorough investigation needed (Munro, 2004). Munro echoes Cooper and Lousada in suggesting that the 'bureaucratic solutions' produced by child death inquiries, like that of Victoria Climbié, have a very limited value in prevention, and argues for 'the importance of understanding the psychological dimension of practice' (2004, p. 88).

In the 1950s, Menzies Lyth conducted a now definitive study of organisational defences within a London hospital, which demonstrates that the professional avoidance highlighted within the Climbié and other inquiry reports is by no means new (1960). Her work describes a culture of scapegoating, where both staff and patients were de-personalised, emotionally detached from each other and lacking in effective care and support. Amongst staff, this produced both poor morale and a high resignation rate, particularly within the cohort of student nurses deemed to be the most emotionally intelligent, thus echoing the picture of social work painted by Munro (2011).

In a long discussion of 'From Menzies Lyth to Munro', Lees, Meyer and Rafferty offer a critique of the 'managerialism' that has developed as 'an attempt to defend against the uncertainties of cases, fears of making the wrong decision and...public criticism' (2013, p. 542). Comparing many of the findings of the Munro Review of Child Protection with those of Menzies Lyth decades earlier, Lees et al. uncover many parallels. Notable amongst these are the ways in which rules and procedures may be adopted as a means of creating a boundary between professionals, and the often distressing life experiences of service users.

Menzies Lyth suggested that such attempts to protect against primary anxiety created further secondary anxieties, which echo the contemporary experience of child protection workers and are also highly relevant to those involved with sudden and unexpected child deaths. According to Menzies Lyth, secondary anxieties were experienced as the impending 'threat of crisis and operational breakdown', whereby workers felt overwhelmed by their tasks, leading to emotional detachment and a consequent inability to deploy professional judgement (Lees, Meyer & Rafferty, 2013, p.543).

Lees et al. suggest that both primary and secondary anxieties are at play in contemporary social work, which they also link to the culture of public inquiry. Whilst supportive of Munro's recommendation that professionals should be helped to overcome defensive use of boundaries, they also stress the need for appropriate containment and support in helping professionals to achieve this.

Hoggett's work on linking emotional life with welfare and social policy offers some similarly valuable linkage between the 'contemporary rationalism' of the inquiry genre and the concurrent 'devaluing of emotion' (2000, p.12). Hoggett focuses on 'the power of what is unthought and unthinkable in our lives' (2000, p.12), which helps explain why professionals avoided the necessary investigation into Victoria Climbié's injuries.

Cooper and Lousada, (2005, p. 146) dub this ‘turning a blind eye’, and I have followed their example in drawing on Rustin (2005) to help explain this. Similar to the Kennedy Report, the Working Party seem to have forgotten to include parents or to elicit narratives that would help with the underlying task of improving emotional understanding between professionals and parents. Rustin suggests that those involved with Victoria ‘seem to have been convinced that they could escape having to think about Victoria and her aunt’ (2005, p. 12). This in turn begs the question of why they convinced themselves of this, and by way of answer, Rustin suggests that ‘failing to see what is before one’s eyes’ is caused by an avoidance of the ‘psychic disturbance’ that admitting it to consciousness may cause (2005, p. 12). In other words, we avoid what is too threatening or frightening for us to think about, unless we are well supported to do so.

This is profoundly important for the study of sudden and unexpected child death, which, within a culture of inspection and control, has become one of the most overpoweringly unthinkable events. This helps to explain some of the apparently avoidant, negligent or cold-blooded behaviour of the professionals described within inquiry reports and within this thesis. The general ‘disappearance of child death in child protection practice’ (Ferguson, 2011, p. 26), created by improved health and conditions together with safeguarding practices, has created a culture in which random child death is now thought of as unnatural, and yet at the same time, the media interest in inquiries and the blame attributed by these has led to a paradoxical fear that child death is lurking around every corner. In these circumstances, any form of knowledge that reflects a real child death, can rapidly become unthinkable, leading to the suppression of personal narratives as a way of helping to explain and link events that are otherwise inaccessible to thought (Cooper & Lousada, 2005).

2:3: ‘Systematic investigation’ and a ‘sensitive, caring approach’: professional perspectives.

Aside from the Kennedy Report, and despite the paucity of literature on sudden and unexpected child death, there are nevertheless leading professional contributors to the field. Notable amongst these are Peter Fleming and Peter Sidebotham, both Consultant paediatricians, with the former serving as a member of the Kennedy Report Working Party and the latter as a trustee of FSID, whose Director also sat on the Working Party. Fleming and Sidebotham’s book ‘Unexpected Death in Childhood’ (2007) was a response to the Kennedy Report, and attempts to explore and review the guidelines that arose as a result, whilst advising professionals on the ‘skills needed to respond to unexpected childhood deaths in a systematic yet sensitive manner’(p.98). The book is intended as a Handbook for Practitioners and yet, once again, despite the recommendation in the Kennedy Report that professionals be ‘sensitised to emotions being experienced by parents’ (RCPath & RCPCH, 2004, p. 12), there are no direct parental accounts contained within it.

Additionally, the book contains Chapters both on ‘A Family’s Journey’ and ‘Fatal Child Maltreatment’ within the first seventy-five pages, leading to a rather uncomfortable tension at times, particularly for any innocent parents who may turn to it for information. Within this apparent tension, the authors try to avoid overt splitting by stating that their work is:

Underpinned by two important principles: a thorough systematic investigation of the circumstances of death based on the best available evidence and a sensitive, caring approach to supporting the family (Sidebotham and Fleming, 2007, p. 98)

Whilst they clearly state that ‘that the two are not mutually exclusive’ (Sidebotham & Fleming, 2007, p. 98), this is somewhat undermined by the detail given to the circumstances of investigation, as opposed to the lack of direct parental testimony, and

the brevity given to the potential effects of the Rapid Response on parents. The Chapter ‘A Family’s Journey’, written by a professional with great sensitivity and insight, says of the Rapid Response, that ‘the system which swings into action when a sudden death occurs can leave parents feeling powerless, with everything out of their control’ (Chalmers cited in Sidebotham & Fleming, 2007, p. 6). This goes only a small way to further the detailed understanding between parents and professionals advocated by the Kennedy Report.

Sidebotham and Fleming also neglect an opportunity to explore this further in an article evaluating the response to sudden and unexpected death in one English region (Sidebotham et al., 2010). Here these two authors combine with others to conclude that ‘with appropriate protocols and support, the joint agency approach to the investigation of unexpected infant deaths can be successfully implemented’ (p. 291). However, successful implementation seems to have little connection with parents, whose experiences are described thus:

Although we have not been able to formally evaluate the parents’ experiences throughout the 4 years of the study we were not aware of any complaints in respect of the joint agency approach (Sidebotham et al., 2010, p. 294).

A four-year study which focuses entirely on the joint agency response to sudden and unexpected child death and declares this successful without including parents, seems to illustrate my earlier discussion of avoidance, both at a personal and organisational level. Cooper and Lousada (2005, p. 158) utilise the concept of ‘untold stories’ at the heart of the Climbié Report, which also seems relevant to the above study. Whilst Cooper and Lousada concentrate their analysis on professional avoidance of the suffering of the child, it seems possible that Sidebotham, Fleming and their colleagues may be avoiding the suffering of the parents, whose emotional narratives may have interfered with the successful implementation of their study.

Similar omissions of parental testimony occur in ‘Sudden Death in Childhood: Support for the Bereaved Family’ (Dent, A & Stewart, A, 2004), another noteworthy book within the field. This aims at providing a ‘sensitive and thought provoking practical study of how health professionals can help a family cope with the unexpected death of a child (p.ix).’ Unlike the work of Sidebotham and Fleming, it does not attempt to encompass fatal child maltreatment or the more legal and professional aftermath of child deaths, but rather aims at guiding health professionals through the various stages and aspects of sudden and unexpected child death.

The book is significant for its attempt to include many often marginalised aspects of grief and those who share the mourning process, but in over 220 pages it makes four single sentence references to police investigation and the Rapid Response. Such limited analysis within a work of this scope once again does not go far towards building a comprehensive picture of the lived experience of investigation and professional intervention following sudden and unexpected child death. The absence appears to be based on a tacit understanding that the catharsis of the Kennedy Report was sufficient to lay the cases of Clark, Cannings and Patel to rest, and that there is therefore no further need to focus on the unthinkable.

This pattern is reflected in most works within the broader field of child loss, where parents’ experiences are largely depicted by professionals, and investigation is either omitted altogether or summed up in a sentence. Raphael’s highly influential work, ‘Anatomy of Bereavement’ is indicative of this, stating simply that ‘the legal requirements are a further terrifying factor, for some kind of investigation is usually required’ (Raphael, 1984, p. 256). Rando, in her book ‘Parental Loss of a Child’ lists the ‘legal system’s involvement’ as the fifth ‘unique feature’ of a sudden and unexpected child death’ (1986, p. 165). In one paragraph, she briefly states:

There is all too often an insinuation that the death was caused by some act of commission or omission on the part of the family and this places an undue additional burden of guilt and pain on them (1986, p. 166).

Ironically, it is the detailed description of the police response to sudden and unexpected child death that points to how intrusive this may feel for parents, and consequently to what support may be helpful. Fox (2007, p. 141) provides a flow chart of decision making for police in possible homicides, which demonstrates clearly how the police investigation is focused. Despite employing the generic cliché of providing ‘support to the family’ (Fox, 2007, p. 146), he describes how ‘the body itself is always designated as a [crime] scene’, and that the police often refer to the immediate period after death as ‘the golden hour.’ This is based on the principle that ‘...effective early action can result in securing significant material that would otherwise be lost to the investigation’ (Fox, 2007, p. 150). Consequently, Fox describes how the ‘scene’ (normally the child’s room or family home) is either guarded by a police officer or ‘locked and sealed until a proper investigation can be carried out with crime-scene investigators’ (Fox, 2007, p. 148). However, he does not contextualise this or discuss the potential impact or consequences for other children living within the area of the ‘crime-scene.’

Fox also quotes from the ACPO guidelines (2002), which state that ‘healthy children are not meant to die’, a phrase that puts an uncomfortable tension on the notions of balance and fairness emphasised by the Kennedy Report. As the stories in this thesis show, apparently healthy children *do* die and it is consequently vital that investigating officers during the ‘golden hour’ are firmly aware of this possibility.

Fox also adds his voice to the Kennedy Report’s call for training as a means of increasing empathy and understanding between parents and professionals, stating:

Good training will help senior investigators become confident about what they can and cannot allow and this should lead to less over-reaction and inflexibility (2007, p. 146).

Good training, however, mainly appears to take place without parental involvement. The major training course for professionals within the UK, established following the Kennedy Report, is run by Warwick Medical School, and uses actors to play parents rather than inviting parents themselves to participate. Whilst there may be an argument for maintaining training that does not involve parents directly, when this occurs routinely, as a rule rather than as an exception, it does seem to point towards the avoidance already discussed.

The DVD ‘Why Jason Died’ (Department for Education, 2008) also uses professionals to play themselves, with only family members played by actors. Again, there is a convincing argument for this. However, the consequences of increasing emotional understanding are demonstrated when Peter Fleming addresses the camera directly. He states authoritatively that, whilst professionals often worry that they will do or say something that will make the situation worse, he is able to reassure them that they cannot possibly make it any worse, a statement which contrasts strikingly with the accounts given in the literature and within this thesis.

The Warwick Medical School training for professionals involved with sudden and unexpected child death is convened by Peter Sidebotham, Fleming’s colleague, and is endorsed by both the FSID and the British Association for the Study and Prevention of Child Abuse and Neglect. Thus, as with their work ‘Unexpected Death in Childhood’ (2007), there is an inescapable association between child death and child harm. Perhaps as a result of this link, in all the work and training material discussed thus far, the ‘systematic investigation’ is covered in intricate detail, yet the ‘sensitive, caring approach’ required to balance this, remains another liminal space, with mostly generic, rather than detailed description. (Sidebotham and Fleming, 2007, p.98). Significantly too, as I have now repeatedly discussed, the accounts of what constitutes a ‘sensitive, caring approach’ are almost always made by professionals on behalf of parents rather

than by parents themselves. The Fleming example in the DVD discussed above demonstrates clearly the pitfalls of this in increasing understanding.

The most frequently occurring advice to professionals intervening with families immediately after death is to allow them to 'spend time with their dead child' (Sidebotham & Fleming, 2007, p. 279), and to offer mementoes, including handprints and locks of hair (Dent & Stewart, 2004, p. 142; Sidebotham & Fleming, 2007, p. 279). However, without a profound understanding of the emotions parents may be experiencing, these offers can seem mechanical, or even worse, they may be a gross intrusion into the parent child relationship at a traumatic and significant juncture. Parents who have begun the day freely able to care for their children, end it with their child the property of the Coroner, often not even knowing where their child's body is, and invited by professionals to visit their child or gather mementoes. This is another conflict of practice with the professional literature, which advises that 'parents need time to assimilate information' and should be offered this 'over the following few days' (Dent & Stewart, 2004, p. 139-40).

Unusually within the literature on sudden and unexpected child death, Rando makes some of the avoidance and denial around the topic explicit, referring to it as a 'morass' (1986, p. 163). She describes researching for her book and being advised by a national consultant for SIDS (Sudden Infant Death Syndrome) to 'stay away from it', which is what so much of the literature in the field seems to do. The emphasis within this literature is nearly always on preventing deaths, rather than offering intelligent and user led support when a death does occur. A significant exception to this can be found in the work of Dyregrov, (2004a) whose focus on parental perspectives of loss, whilst not specific to sudden and unexpected child death, is nevertheless often relevant to this research.

In a study of professional assistance after traumatic death, Dyregrov suggests that professionals often disempower bereaved populations, telling them ‘how they should understand, regulate, and experience their bodies’ and ‘increasingly amassing power and influence by controlling more and more of the life world of human beings’ (2004a, p. 182). Dyregrov suggests that, as an antidote to this, people should be empowered to have ‘more control over their lives, to have greater voice in institutions, services and situations which affect them’ (2004a, p. 182).

A different study (Dyregrov, 2004b) similarly showed that parents bereaved by the sudden and unexpected death of a child frequently report feeling disempowered. They may also have contact with a multitude of health professionals, in what can be strained relationships following a death of this nature. This study also found that it is common for parents to withdraw following the death of a child, and thus the ‘sensitive, caring approach’ as cited by Sidebotham and Fleming (2007, p.98) may be of real value here. However, Dyregrov’s findings demonstrate a similar breakdown in linkage to the ones I have described, leading her to comment:

In view of prevailing laws and the comprehensive health concept, the lack of professional help to traumatic bereaved groups in our society is rather surprising. (2004b, p. 187).

When linked to my earlier discussion of the defensive practice that has grown up partly as a result of the age of inquiry, Dyregrov’s observation is perhaps not so surprising and indeed recalls Munro’s description of those involved with Victoria Climbié, who tried ‘to avoid taking responsibility for Victoria’s welfare by minimising their interpretation of their own role as much as possible and relying on someone else to do the necessary work’ (2004b, p. 85). Raphael also found that following the death of a child more than 50% of doctors found themselves ‘unable to handle parents’, whilst ‘reports from other workers are similar’ (1984, p. 261). The climate of fear which surrounds the death of a child has led to professionals distancing themselves from it, as they did with Victoria

Climbié, leading to Dyregrov's observation about the lack of 'professional help to traumatic bereaved groups' (2004b, p.187). In these circumstances, Sidebotham and Fleming's confident assertion, that 'systematic investigation' and a 'sensitive, caring approach' are 'not mutually exclusive' (Sidebotham & Fleming, 2007, p. 98), indicates a need for further research.

2:4: 'Like a surrealist play': parental perspectives

Whilst the literature on sudden and unexpected child death contains few direct parental accounts of the experience of professional intervention following the event, two short articles by Stead (1997) and Harman (1981) offer valuable insights into the emotions experienced by parents, and how professional interventions both helped and hindered. Despite the age of the articles, they resonate profoundly with both my own experience and those offered in Chapters 4-7 of this thesis, demonstrating how consistent many parental reactions remain, regardless of changes to procedure.

Harman's article 'Death of my baby' (1981) describes an experience uncomfortably close to the more recent accounts of Andy, Cathy and Laurie, presented in Chapters 4, 5 and 7, and raises the question of how, despite the work of Sidebotham and Fleming and the recommendations of the Kennedy Report, so much has remained unchanged. Harman divides her article, following an initial preamble, into two sections, 'what helps' and 'what hinders'. Within the former, she places sleeping pills and keeping busy together with the birth of a subsequent child. There is little direct help linked to professional intervention, although she does mention being prescribed medication to stop lactation, echoing Julia's story (Chapter 6). Harman also mentions support organisations, although she states clearly that she did not 'personally make use of this facility' (1981, p.34). In her 'what hinders' section, Harman describes her sense of public humiliation in the hospital following her son's death, where she was left waiting

for two hours to be stared at by ‘bemused strangers’ (1981, p. 35). This description again has uncomfortable resonances with many of the narratives in this thesis, together with her description of being utterly horrified by the intervention of the police, for which she was totally unprepared.

Harman describes the experience of professional involvement, particularly that of the registrar, as ‘like a surrealist play’ (p. 36), a portrayal that vividly resonates with my own experience of Joe’s death and with many of the other accounts within this thesis. Similarly, Harman provides a rich emotional account, both of her own guilt and of the stigma of ‘maternal negligence’ (1981, p.35), coupled with the taboos, which accompany the death of a baby, and which have altered little since her experience.

Stead’s article (1997) describes the sudden and unexpected death of her son Dominic, and echoes Harman’s example of the ‘surrealist play’ with a similar description of the ‘disorganization’ that can follow traumatic death, often accompanied by ‘erratic and illogical behaviour’ (p. 25). This is particularly significant when placed in the context of the police ‘golden hour’, as discussed earlier. However, Stead’s account is perhaps most helpful in the details that helped her at the point of her son’s death, for example the way his clothes were taken care of:

The one thing that struck me as being one of the most caring acts of all, was the fact that someone had folded all Dominic’s clothes up neatly and had placed his little play boots in the bottom of the trolley. They hadn’t been dumped into a hospital property bag as they so often are. It was something so small that meant so much (Stead, 1997, p. 26).

This caring act contrasts sharply with Ellie’s account of trying to get her daughter’s clothes back (see Chapter 4), whilst Stead’s description of photographs, which were taken by the nurse arriving at her house a month later, is also reflected negatively in a similar account given by Cathy (see Chapter 5).

As a nurse herself, Stead determines to show the same ‘empathy, understanding and compassion’ (1997, p.26) in her own continuing practice that she was shown herself, and, in contrast to Fleming’s assertion in the training DVD discussed earlier, she draws on a 1995 RCN Report to demonstrate that ‘the quality of the initial care provided has a major impact on the relative’s bereavement’ (Stead, 1997, p. 27).

Aside from these personal accounts, most of the parental perspectives I have found come from the safeguarding field. However, these are useful in casting light on the experience of professional intervention following sudden and unexpected child death, which itself is underpinned by a safeguarding rationale. I have therefore included some of these within this Chapter.

In their account of parents’ experiences of safeguarding investigations, Cleaver and Freeman (1995, p. 64) introduce the notion of victims and suspects, which is highly relevant to parents’ experience of sudden and unexpected child death. They also pose the related question ‘What does it feel like to be suspected of abuse?’ Whilst arguably a suspicion of abuse or neglect is not as grave as being suspected of murder, the parents in Cleaver and Freeman’s study report very similar reactions to those in presented in Chapters 4-7 of this thesis. Notably, parents felt ‘frightened, ashamed, guilty or powerless’ (Cleaver and Freeman, 1995, p. 70), whilst the ‘enduring psychological reaction to investigation was guilt and self-blame’ (p. 71). The notion of ‘justice’ also appeared in parent’s responses, as it does within the Kennedy Report, with most parents reporting ‘feeling guilty until proven innocent’ (Cleaver and Freeman, 1995, p. 82), which is an oft-repeated theme within Chapters 4 -7 .

Cleaver and Freeman’s research is concerned with child abuse rather than child death, yet it also highlights the potential difficulties of the police ‘golden hour’ earlier described, during which parental interviews form part of evidence gathering:

The impact of an investigation is very considerable. Parents feel angry, resentful and violated...it is difficult in these early stages to distinguish the anxiety and anguish of the innocent from the fear and remorse of the guilty (1995, p. 89).

The difficulty in distinguishing the innocent from the guilty endorses the case for making direct parental testimony a part of the professional training that is promoted so widely. By listening to parents themselves, professionals could be helped to understand the very real emotions highlighted by Cleaver and Freeman, and this in turn may improve investigations and help reduce the miscarriages of justice which prompted the Kennedy Report.

Cleaver and Freeman's research into investigation is also useful in identifying some of the potential family consequences of investigation:

There is much to suggest that an investigation can irretrievably damage family dynamics...the quality of relationship between parents and children, as well as between siblings is all too frequently damaged (1995, p. 117).

The impact of Rapid Response on children features both within 'Joe's story' (Chapter 1) and particularly within 'Laurie's story', which forms Chapter 7, as well as manifesting within Chapter 4. Yet, this remains another powerful absence within the specific literature on sudden and unexpected child death. Where the possible effects of investigation and Rapid Response are discussed at all, it is almost always as part of the literature on child abuse rather than on sudden and unexpected child death.

A more recent piece of research in the safeguarding area, highly relevant to my own research, focuses on parents' experiences of situations where concerns of non-accidental injury were raised. This was carried out as part of a series commissioned by the Department for Children, Schools and Families and the Department of Health, in order to improve the evidence base on recognition and effective intervention in child abuse (Komulainen & Haines, 2009). This study shares with mine the aims of describing how participants remembered and reflected on their experiences and of increasing

professional awareness as to what is perceived as helpful and less helpful practice from the parents' perspective (Komulainen & Haines, 2009).

Although the research focuses on reports of non-accidental injury rather than sudden and unexpected child death, the study participants also reported many factors similar to those identified by my interview participants and by the parents in Cleaver and Freeman's work. Significantly, parents felt they were not listened to and that staff treated them with suspicion. They also requested clear communication (preferably in writing) that their case was closed. Some parents, even years later, expressed uncertainty over whether they were still being monitored, and this was conflated with a general feeling that the investigation left them distressed, with a long lasting effect on the whole family as well as disappointment with what they dubbed the system ((Komulainen & Haines, 2009). The study authors conclude that further work should be carried out to establish a constructive dialogue between parents and child protection teams, regardless of whether concerns of non-accidental injury are substantiated (Komulainen & Haines, 2009).

A similar study by Peter Dale looking at 'Parents perceptions of child protection services' endorses this need for further work by recommending additional 'research focused on family perceptions of services' (2004, p. 137). Dale found 'the views of many parents can extend beyond the biases of their particular personal experiences and consequently offer sophisticated and insightful contributions that are of much value' (2004, p. 138). This finding highlights powerfully the worth of listening to parents' stories rather than constructing their experiences for them, as so often occurs within the literature and training material within this field. Far from remaining in a victim role, many parents are able to achieve significant insights, as Dale suggests, and these could successfully be utilised by professionals.

Ghaffar, Manby and Race (2012) explored the experience of forty-two families subject to child protection plans within the north of England, and found that parents welcomed the ‘opportunity to talk about, and reflect on, their experience...hoping that their experience could improve practice for others’ (p. 901), which is another theme raised by parents within this study. Similarly, they found that ‘the investment in working with parents and responding to the needs of the whole family can produce positive results’ (p. 902), a lesson that is directly translatable to professional intervention following sudden and unexpected child death.

Although the literature on sudden and unexpected child death yielded few personal and reflective accounts, I have found two notable contributions within the safeguarding field, both of which elaborate on issues salient to the professional response following child death. The most recent of these is a very intimate account of being investigated for the potential abuse of her son by Pamela Davies (2010). As an academic, working within the social sciences at a UK university, Davies has both the language and the resources to describe this experience and garner an audience. These are opportunities unavailable to most parents in these circumstances.

Davies describes the investigation that followed an unexplained swelling on the head of her five year old child Frederick, caused, she speculates, by his rolling off a sofa. Although she is careful to note that ‘proper professional procedures were followed’ by a worker who was ‘fair, open, respectful and reliable’ (2010, p. 1), she nevertheless found the experience ‘devastating’. Her conclusions once again echo those of other research into child protection investigations, noting ‘poor communication’ (2010, p. 8) and suggesting that ‘practitioners might be more consciously reflexive about balancing power with compassion’ (2010, p.8).

Davies describes the emotional impact on herself and her family of a system which seemed 'indifferent to her 'pain' and which wielded the 'crushing force' inherent in accusing a parent of harming their child. The theme of 'justice' so forcibly urged by the Kennedy Report also appears in Davies' description of feeling 'guilty until proven innocent', which is another consistent thread within this study (2010, p.4).

Davies (2010, p.201) uses her own experience to suggest that the 'system' is potentially responsible for 'victimizing' parents, and she evokes the concept of 'secondary victimization' to support this. 'Such 'secondary victimization' could also apply to the parents themselves, and more significantly to their other children. Like Dale, Komulainen and Haines, Davies calls for further research to explore the harm that investigations of this nature can cause in the service of protecting the vulnerable.

This notion of 'professional abuse' is picked up in Richardson's article on the personal impact on her and her daughter of a child protection investigation (2003, p. 123). Richardson is also an academic, and has the voice to write about her experiences. Her article charts the information sharing process following an allegation of indecent assault against her husband, although these later proved unfounded. Her, account, like Davies', shares much in common with my own and with those presented in Chapters 4-7.

Richardson reports both feeling 'on trial, without representation' (2003, p. 127), and wanting to be considered 'innocent until proven guilty' (p. 128). To support this, she evokes the Human Rights Act (2000), which affords everyone this basic human right, and thus, as Richardson suggests, should have 'considerable implications for child protection practice' (2003, p. 128).

Most significant in Richardson's article is her focus on wanting to protect her nine year old daughter from the effects of the investigation, a topic which, as I have noted, is entirely absent from most of the literature on sudden and unexpected child death.

In a passage which echoes my own experience with my daughter on the morning of Joe's death, Richardson describes:

Insufficient consideration was given to the difficulties of informing me of the allegations while my daughter was in the house...In my opinion the initial investigation demonstrated a lack of planning and co-ordination, and the failure of the professional to allow me to protect my daughter from this traumatic situation constituted professional abuse' (2003, p. 125).

The desire to protect children from professional intrusion forms a major part of 'Laurie's Story' (Chapter 7), whilst the hope of accessing professional support to help them to cope with their children during and after investigation is described lucidly in Chapters 4 – 7, as well as within Richardson's account:

I desperately needed encouragement, constructive help and support and felt the role of the professional should have been to support me to plan and develop effective strategies to provide my daughter with appropriate information to protect her from the impact of the investigation. It was after all a potentially damaging and abusive situation but many aspects of this were outside my control and all I could do was attempt to limit the damage' (2003, p. 126).

Richardson also identifies another apparent inconsistency within safeguarding practices, which manifests within the response to sudden and unexpected child death and which I have described in Chapter 1. Once the initial investigation was over, but before any conclusive results could be proven, we were left as a family with almost no professional support to care for two young children, whilst under suspicion for murdering their brother. 'Cathy's Story' (Chapter 5) makes this point forcibly, as does Richardson, following the allegations made against her husband:

As a nine-year old child she was potentially exposed to the very real threat of danger and yet nobody offered us any protection or expressed any concern for her welfare' (2003, p.126).

This is a theme that is picked up by Dale (2004) in his research into parents' perceptions of child protection services where one parent states:

I could have murdered them and they would have been none the wiser because nobody was ever here. There was nobody to talk to, no back-up (2004, p. 147)

The description of the black hole given by parents in Dale's study conjures the 'morass' of sudden and unexpected child death evoked by Rando (1986, p. 163). It is highly significant too, that the majority of parental perspectives are drawn from safeguarding investigations, where the death of a child can perhaps be made thinkable by the apportioning of blame and the promise of prevention within the culture created by the 'age of inquiry'.

In exploring some of the relevant literature relating to sudden and unexpected child death and then seeking to bridge the significant gaps with parental accounts drawn from the safeguarding field, I have attempted to show how the professional rhetoric of the Kennedy Report and its associated experts does not consistently match those of parents themselves. This study attempts to bridge the space between the two by offering parental narratives within Chapters 5-7. However, attempting to account for the widespread absence of similar stories within the field requires following yet another thread and exploring, albeit briefly, the contemporary landscape of death and dying.

2:5: 'Knowing the right moment': managing death.

Death is of course at the heart of this study, and thus forms a central thread for discussion. My challenge in effecting this has been where to concentrate, for death studies constitute a vast and expanding field with a wealth of literature. It is therefore impossible to offer a comprehensive historical and cultural overview. Instead, I have decided to focus on those aspects that in my view directly influence the professional and wider cultural responses to sudden and unexpected child death.

In his excellent account of the evolution of child protection practices, Ferguson (2011, p. 27) highlights how improvements in diet, sanitation, housing and medical advances have all led to a fall in NSPCC child death cases within the early years of the twentieth century from 1,226 in 1914 to 277 in 1936. Even in the late 1940s, 'child protection

workers could still expect to have, on average, one child death on their caseload every year', whereas prior to this, in the early days of practice, 'the deaths of children in child protection cases were commonplace' (Ferguson, 2011,p.27).

The common expectation of today's parents 'that their children will survive them' (Chalmers 2007, p. 3) is therefore a relatively contemporary phenomenon, prefaced by a period when 'most death including that of children was a domestic event and a normal part of communal life' (Yates, 2000, p. 221).

Giddens' now classic work on the sequestration of death locates this within the 'professionalisation of medicine' (1991, p. 161), which moved death from the communal sphere, as described by Yates, into hospitals where sickness and death became gradually concealed from the general view. Giddens argues that death has become a largely mediated experience, facilitated either by experts or through 'fictional realism' devices such as soap opera and popular writing (p. 169). The media fascination with high profile deaths like that of Diana, Princess of Wales, provides an example of Giddens' argument, mediating her shocking death in a car crash into a 'fairy-tale' ending where a nation in mourning was depicted as 'willing to wait for hours to sign books' and 'to sleep out overnight in order to glimpse the passing of a coffin.' (Clark, 1998, p. 393). Giddens argues that this 'mediated experience' further sequesters the reality of death, encouraging people to 'live outside the self', conducting fantasy intimacies rather than facing the often uncomfortable realities of their own experience (Giddens,1991, p. 560).

Crucial to Giddens' argument about sequestration is the notion of control. Locating death within his broader discussion of 'fateful moments', Giddens describes it as 'nothing other than the incipient loss of control: death is unintelligible because it is the point zero at which control collapses' (1991, p. 203).

Kellehear (2009) argues that within prosperous countries an attempt is maintained to retain control of death via the concept of 'managed dying' (p. 62), central to which is timing. For Kellehear, 'shameful' deaths are distinguished from 'successful' deaths by 'knowing the right moment' to die and doing so, thus maintaining power and control (p. 61). Kellehear locates this desire for control in what he describes as 'the tiresome cosmopolitan tendency to focus on health, along with wealth, youth and beauty', which he suggests 'continues to threaten the social reciprocity at the core of the dying experience' (p. 65). His argument, that elderly people who linger past their time are therefore stigmatised and viewed as failures, equally extends to the sudden and unexpected deaths of children, which as Chalmers (2007, p. 3) describes are deaths 'out of time', leading to their depiction as 'unnatural' (Wheeler 2001, p. 530).

Sudden and unexpected child deaths thus represent the very antithesis of control and timing, symbolising instead what Giddens (1991, p.560) describes as a 'point zero', and thereby providing a shocking reminder of how uncontrollable and random life can be. To borrow from Giddens, however, they are mediated by the Rapid Response, which can be seen as providing a bridge between the random death itself and a bureaucratic attempt to control the circumstances.

Hoggett explores this further in his discussion of the professional 'psychological investment' at play in 'maintaining a reality which, while it may be unfair '...is at least orderly and predictable' (2000, p. 57). He argues that 'such forms of routinisation provide workers with a way of not thinking or feeling too much', a claim further supported by Cooper and Lousada, who quote a social worker who, during a project into European child protection practices, asked 'How would we manage without the child protection procedures?' (2005, p. 181), a question that highlights the way in which routine can provide a means of 'containing anxiety and other negative emotions aroused by working with ...the dying' (Hoggett, 2000, p. 57).

In providing this function, the Rapid Response can also be compared to historical forms of ritual practice that mediated death, via ‘ritual actions which contain[ed] death by making it open, public but subject to religious and social control’ (Mellor & Shilling, 1993, p. 414).

Leader (2008), in his work on contemporary experiences of loss and depression, also cites ritual practices that can be seen to have an echo in Rapid Response. Describing primitive cultural rituals in which ‘guilt is assumed from the start’, Leader explains that, ‘when a loved one dies, the mourner is treated as guilty without any trial. The community behaves as if that person is guilty, so pre-empting their own unconscious guilt’ (p. 122). In this way, Leader suggests that the ‘mourner is recognized as guilty’, whilst the ‘grief is inscribed into the social structure’ (2008, p. 123).

Mellor and Shilling conclude that death is alarming in contemporary societies because the grief is not, as Leader describes it, inscribed by ritual into the social structure, but rather because modernity has deprived most people of this ‘overarchingly existentially meaningful ritual structure’ (Mellor & Shilling, 1993, p. 427). Thus, the ‘banding together’ that characterised ritual mourning in past societies has been replaced in ‘high modernity’ by ‘people standing alone in the face of death’ (Mellor and Shilling, 1993, p. 427).

In considering this need for banding together together with the descriptions of Leader, I am reminded once again of the ‘systematic investigation’ of Sidebotham and Fleming (2007, p.98) and the Kennedy Report’s emphasis on ‘creating rules and procedures’ (RCPath & RCPCH, 2004, p. 15). Whilst these undoubtedly have a role, the lack of balance evokes a sense of banding together in response to a collective threat – the death of a healthy child that should not happen, that is unnatural and out of time. Crucially here too, as in Leader’s description, this banding together occurs in a context where the

‘mourner is recognized as guilty’ (2008, p.123) , thus inscribing the grief into a social structure where child harm is more culturally intelligible than random child death.

Although there is a very real and proven need to safeguard children, the rules and procedures created by Rapid Response and its aftermath could also be seen as an attempt to restore meaning and structure to the event, whilst excluding direct parental testimony that risks re-introducing both chaos and the threat of meaninglessness. The ‘rage at injustice’ to which the Kennedy Report refers (2004, p.15) , can be viewed very differently in this context, as a rage against the random deaths and ensuing miscarriages of justice, which have potentially ‘lost our humanity and our claims at living in a civilised society’ (RCPATH & RCPCH, 2004). To truly ‘square the circle’ means ‘taking into account parental perspectives’ and ‘surrendering a degree of control to the powerless’ (Cleaver & Freeman, 1995, p. 19), as well as surrendering our attempts at rigid ontological security to the fact that no matter how we construct or deny it, death is still the one absolute certainty in our lives.

2:6: A good death

Much of Kellehear’s critique of finding the right time to die (2009) arises from the now popular concept of a good death, which in its turn arose from the pioneering work of the hospice movement. Beginning as a reformist faction, with the goal of mitigating the increased institutionalisation of death and offering an alternative model of care (Corner & Dunlop, 1997), the hospice movement has been responsible for a contemporary national campaign to increase overt discussion of death, ‘Dying Matters’ run by the National Council for Palliative Care, as well as for much of the current debate about assisted dying, end of life care, living wills and a good death (Kellehear, 2009; Corner & Dunlop, 1997).

Despite the undoubtedly positive contributions of the hospice movement, in relation to sudden and unexpected child death, the consequences of its widespread influence are complex. The good death concept as Kellehear describes, has taken on additional 'moral' attributes, concerned with dying at a 'good' time, together with other 'redemptive social practices' (2009, p. 61) and a 'romantic obsession with heroic storylines of people dying of cancer...fighting for the right to die with 'dignity and choice' (p. 65).

Additionally, as Corner and Dunlop describe, the good death concept itself has been assimilated into the very institutionalization it originally hoped to oppose. They quote a study within a hospice nursing unit, which found that 'certain features of the 'good death' ideal had become routinised, so that such deaths were 'required' by staff in the interest of what might be considered socially acceptable', and where 'nurses were at risk, over time, of developing a rigidity in their views over what constituted a good death, so that those patients who did not conform to this ideal...were seen to have problems' (1997, p. 289).

These attitudes can be seen to be extremely problematic when linked to the sudden and unexpected deaths of children whose deaths are neither good nor planned at a good time, but are random and tragic. In addition, the very success of the hospice and associated palliative care movement has led to a broad association in the public consciousness between death and cancer, when in fact approximately only a quarter of deaths occur in this way. There is evidence that the model of care used for cancer patients cannot be transferred easily to other groups, and the dominance of palliative care with cancer patients has led to accusations of exclusivity and exclusion (Corner & Dunlop, 1997).

This exclusivity can also be recognised within the prevailing influence of the Kubler-Ross stage model (1969), which was developed in relation to patients dying of cancer. This charts five stages following a death, beginning with Denial and Isolation, moving through Anger, Bargaining and Depression, before culminating with Acceptance. The Kubler-Ross stage theory was further amended by Worden (1991) into a series of tasks, beginning with orientation to the reality of the loss and moving to the achievement of a new relationship through withdrawing from the old one.

Stage theories have gained widespread popular acceptance and are taught as fundamental within many professional training courses. Seale suggests that their enduring popularity lies both in their 'classificatory system' for 'organising 'disturbing experiences' and in their link to modernity, in which the 'tasks', properly followed, make death and mourning almost a 'progression or an achievement' (1998, p. 106–7), and therefore good. Thus stage models lend professionals a sense of purpose as well as a job to do in the face of threats to basic security' (Seale, 1998, p. 107). In this way, they echo many of the procedural outcomes of the inquiries and much of the literature already discussed.

Despite their enduring popularity, stage theories have also been widely critiqued for potentially anthologising those who fail to fit into accepted models and for developing the good death model as a paradigm that also separates the 'normal from the pathological' (Seale, 1998, p. 107). With respect to Rapid Response and the 'golden hour', this can create particular difficulties when any departure from normal forms of grief behaviour may be viewed in parents as evidence of their potential guilt. As an example of this, Angela Cannings was criticised for immediately removing her baby's cot (Cannings, 2006, p. 8), whilst Sally Clark's attempts to keep from breaking down led to accusations that she was 'callous' and 'detached' (Batt, 2005, p. 154).

2:7: 'Speaking outside the language of survival'

Most of the literature on sudden, unexpected child death discussed in this Chapter is concerned with the finality of death and with seeking accountability for the cause. However, with every ending there is also a beginning and, as I discussed in Chapter 1, deaths happen 'in a life that already has a story', which afterwards retains fragments of 'the old map' (Frank, 1995, p. 54) that can be pieced together to form a new way forward.

Contemporary grief theorists, amongst them Klass (1996), Neimeyer (2000) and Stroebe and Schut (1994), have embraced this notion of continuity and moved away from stage models towards models that embrace the infinite nature of bereavement and loss. Klass (1996) shows that acceptance is never fully achieved, but rather becomes part of the continuing bond between the bereaved and the deceased. Other leading figures in the contemporary landscape of death studies (Neimeyer, 2000; Bonanno & Kaltmann, 1999; Stroebe & Schut 2001) emphasise 'meaning-making' as the 'central process in grieving' (Neimeyer, 1998, p. 110), which they agree is essential for any kind of 'adjustment or healing', although they offer no prescriptive format for achieving this.

Frank (1995) advocates that meaning making following trauma is wrought through 'transforming fate into experience' via the telling of stories. For Frank 'all those who suffer, can also be healers'...with the trauma itself becoming 'the source of the potency of their stories' (1995, p. *xii*). Recalling themes already discussed, Frank argues that western culture is now dominated by a 'restitution narrative' that is afraid to 'speak outside the language of survival' (1995, p. 115). Where restitution is not possible, illness is incurable or death occurs, and Frank suggests that a 'chaos narrative' takes over, in which the 'voice of the teller' is 'lost as a result of the chaos' (1995, p. 115). This chaos narrative has much in common with that presented to parents facing sudden

and unexpected child loss, whose own experiences are so frequently labelled by others in cataclysmic terms, offering little hope or meaning.

Frank sees the task of those who have suffered as ‘bringing home ‘the boon’’, which he understands to be the gift the teller has been given by the experience, ‘usually some insight that must be passed onto others’. In the case of fatal illness and death, Frank proposes that ‘the boon’ is an acceptance of ‘mortality as common’ with a consequent absence of fear’ (1995, p. 121).

Not only can this be helpful for parents, but it also contains a potentially important function for professionals, who, as Doka (1989, p. 2) describes, may become ‘disenfranchised’ in their own meaning-making by the grieving norms already discussed. Doka argues that these norms belong to socially recognized and sanctioned roles, and thus professionals who do not form part of the immediate kinship group may find their own feelings socially unsupported or even unacknowledged. In addition, many professionals are cast in the role of support to bereaved parents before they have processed their own feelings, leading to the potential errors and appearance of indifference described in both my own experience (Chapter 1), and in the narratives within this thesis (Chapters 4-7).

Shulman (1991) examined the impact of traumatic events like child death on social workers and found that avoidance strategies prevailed, whilst managers, instead of lending support, both apportioned and attempted to avoid blame. Additionally, most of the Rapid Response team members, including paramedics, may never see the family again, and due to the latter’s exclusion from the meetings that follow, the opportunity to remember the dead child, to share experiences and to learn lessons is lost.

Parents then may have a potentially important meaning making role in supporting professionals by integrating them into the experience rather than allowing them to

remain split off and potentially isolated. The metaphorical knots evoked in Chapter 1 can assist Cooper and Lousada's (2005) notion of linkage here by tying together parents and professionals in a way that bridges life and death and permits speaking outside the language of survival. As the stories that form Chapters 4-7 illustrate, many parents are able to access this language because their lived experience has taken place outside of this sphere, and thus they are able to offer 'boons' and things to be learned. In this, they echo Klein's 'depressive position', where both good and bad can be contained in the same object or experience (Hollway & Jefferson, 2000), thereby demonstrating that 'nothing is of itself entirely terrible' (Lott, 1996 p. 258).

2:8: Conclusion

In this Chapter, I have offered a way of 'reading about this subject' (Pelias, 2004, p. 7) by weaving together different strands drawn from significant work within the field itself, combined with literature around safeguarding, loss and bereavement. I have explored how the intentions of the Kennedy Report to avoid further miscarriages of justice via 'simple practical training' and sensitising professionals to 'the emotions being experienced by parents' (RCPath & RCPCH, 2004, p. 12), may have been hampered by a lack of opportunity to learn directly from parents themselves.

Having identified a lack of research with parents who have experienced sudden and unexpected child death, I have used work from the safeguarding field that focuses on parent's experience of investigation. A safeguarding rationale underpins the Rapid Response following sudden and unexpected child death, and whilst I am clear that child abuse and neglect must be prevented, I identify several gaps in this Response and in its aftermath. These gaps are most significant around the welfare of surviving children and in validating parents continuing ability to care for them. Many of those studied in the safeguarding literature share similar feelings to those highlighted by parents in Chapters

4-7 of this thesis, particularly around being judged guilty until proven innocent and in on-going concern for other children.

I have explored how the lack of both parental accounts and opportunities to participate in training around sudden and unexpected child death may reflect a more general ‘sequestration’ of death and a corresponding decline in meaningful public ritual. To illustrate this, I have discussed both stage theories and other significant contributions to the field of death and bereavement.

Many of the themes introduced here recur in the next Chapter, where I chart the development of a methodology capable both of evoking the complexity of loss and of ‘experiencing the experience’ (Ellis & Bochner 1992, cited in Ellis, 1993, p. 726), thus helping others to be ‘sensitised to the emotions being experienced by parents (RCPath & RCPCH, 2004, p. 12).

Chapter 3

3:1: Meandering methodologies

'We stumbled...across a meandering method that we were not looking for... and we have kept writing... into these lacunae; these gaps, cracks, fissures and extended silences.'
(Speedy et al, 2010,p.899).

A 'meandering method'... I 'was not looking for' fittingly describes the process of carrying out this study, which began with the explicit purpose of adding parental narratives to the field and through the research process became something other, an exploration not just of loss, but of the 'gaps, cracks' and 'fissures', which border sudden and unexpected child death.

In this Chapter, I aim to capture the meanderings that have led to this final thesis in a way that links 'what I did' (Dunne, Pryor & Yates, 2010, p. 1) with the emotional process of researching and writing. I have found this a challenge that has returned me to the task faced by the authors of inquiry reports discussed in the previous Chapter, one that again requires 'linkage' between ...emotional and evidential sources' (Cooper & Lousada, 2005, p. 147). I can explain my methods in a way that would chart reasonably accurately the processes I undertook within the research. However, like the evidential sources Cooper and Lousada describe, this would achieve little in terms of portraying the meanderings and 'extended silences', together with the emotional choices that I have faced in writing this thesis.

The psychosocial concept of researching beneath the surface (Clarke & Hoggett, 2009) has been helpful in writing this Chapter, as it encompasses both the surface of what I did and the emotional and unconscious processes which underpinned the work.

Crucially too, a psychosocial approach has given me a means of knotting together my multiple positions as a researcher, parent and professional, and undertaking research involving other parents and professionals whose experiences so closely mirror many of my own. The psychosocial emphasis on reflexivity, with the concomitant stress on the researcher constantly reflecting back on themselves and remaining forever suspicious of the source of their own knowledge (Frosh & Baraitser, 2008) captures my own reflexive and often tortuous position as I have tried to simultaneously peer both inwardly and outwardly.

Attempting to sustain this composite perspective has not provided absolutes, but rather a way of adding depth (Hollway, 2008) and integrity to a research process that is now a prolonged distance from my original aim of being the ‘expert...the intellectual, the detached and the objective’ (Lerum, 2001, p. 471). The meanderings that led from my original desire to occupy this role to one that reflects my complex positioning and offers a ‘space for emergence’ (Clarke & Hoggett, 2009, p. 16) is charted in the next section.

3:2: ‘Getting personal.’

Writing of their collective experience within a writing group, Speedy et al. (2010, p.441) describe a process of ‘getting personal, getting political, getting up close and moving back and forth’, which echoes my own meanderings in conducting this research.

Despite my initial clarity of purpose, as I began the research process I found myself rapidly stepping back from the ‘getting personal,’ which I substituted for ‘trying on research’, as if becoming a researcher were ‘analogous to learning a role in a play’ (Dunne, Pryor & Yates, 2010, p.1). As a new researcher, I had entered a world that was unfamiliar, and I was unsure of my part in it. To protect against this, Lerum (2001, p. 467) suggests that academics often wear ‘academic armour’. This was certainly my

costume at this time, whilst my first drafts made a corresponding case for excluding my own experience, both from the study and from research participants.

With hindsight, I locate these early decisions within Hollway and Jefferson's concept of the 'defended subject' (2000, p. 19), which draws on Klein's theory of splitting as a means of protecting against anxiety. Hollway and Jefferson suggest that 'conflict, suffering and threats to self, operate on the psyche in ways that affect people's positioning', causing them to polarise or split parts of themselves, the world, or others, into good or bad.

In my own case, during the early stages of research I saw the good as lying within a certain limited model of research influenced by scientific positivism, which I was yet unable to attain, and which therefore made me feel an imposter in the academic world. Hoggett and Clarke's (2009, p. 12) notion of the 'defended researcher' describes vividly my own ensuing attempts to remove myself from the research in order to mask my lack of expertise, together with the greater worry that my personal biography would render my research 'underrated, dismissed and trivialized' (Vickers, 2002, p. 611). The 'power' inherent in 'the act of disappearing' (Lerum, 2001, p. 474) allowed me to justify removing my personal experience, whilst simultaneously maintaining me in the role of expert, ironically mirroring the precise processes I was attempting to critique.

Vickers (2002, p.612) suggests that bringing the personal into academic research is analogous to 'writing on the edge and without a safety net'. My own corresponding leap from defended researcher was facilitated by discovering psychosocial methods that allow for the deep exploration of personal experience within a social context, alongside the work of other writers who had either had the courage to jump themselves or have helped others to do so (Bochner, 1997; Ellis, 1993; Richardson, 1995; Speedy, 2008) .

In keeping with the meandering methodology I have described (Speedy, 2010) my

discovery of the psychosocial, alongside the writers who have provided the greatest inspiration for this thesis, occurred mostly via a ‘quiet , fluid meandering from place to place’ (Speedy,et al, 2010, p.895) rather than a purposeful quest. Psychosocial methods have been steadily gaining interest during the many years of this research study and there is still considerable disagreement over their exact constitution (Frosh and Baraitser 2008; Hollway, 2008). As I have previously described I also began the research process somewhat academically armoured and with the aim of adopting only narrative principles throughout. It was after I had completed my field work interviews that both the experience of the data analysis panels (see Chapters 5 -7) and disseminating the work revealed a need to look beyond and below the narratives, in order to understand the reactions they commonly provoked. I had begun this process of researching beneath the surface (Clarke and Hoggett, 2009) informally before my supervisors were able to direct me to psychosocial methods as a more explicit practice for accomplishing what I had already begun.

This occasionally stumbling progress as a means of discovering new methods and ways of knowing, reflects Speedy et al’s description of ‘not ‘Getting Lost’ exactly , and certainly not ‘Getting Smart’ (see Lather, 1991, 2007)’ but rather a ‘meandering, lived in, ongoing everyday...kind of methodology’ (2010, p.896). In Speedy et al’s account (2010, p.895) this methodology leads to several inadvertent encounters with what they dub ‘Gerald’ – the element created by allowing for ‘deep hanging out’ and the consequent creation of new spaces for knowing . My discovery of the psychosocial was in turn a product of the ‘deep hanging out’ afforded me by being a part- time Doctoral student. Whilst having several years in which to complete a research study can have its detriments, in my case it created sufficient space for experiences and knowledge to marinate slowly, instead of being pressured into existence. Amongst these experiences were several chance yet deeply meaningful encounters with people who

changed the course of my research.

Jung (1964) described such happenstances as synchronicity, by which he meant a collision of both inner and outer events which were not themselves causally connected. Two such synchronistic episodes occurred during my research process, when struggling for ways of bringing personal meaning to the study, I was signposted by chance conversation to both Cooper's work (2005; 2009) and to that of Laurel Richardson (1997). The latter encounter occurred by way of a fleeting meeting at a conference lunch where another delegate shared her own work with me (Bell, 2012) and subsequently became a great support throughout the later stages of my doctorate.

The work of Laurel Richardson (1997) has since been particularly influential on my own work. Although not avowedly psychosocial, Richardson situates the narratives and experiences of people's lives 'within the context of larger social and historical forces' (1997, p. 19). She is also a passionate advocate of accounts that tie together the 'knower and the known' (p. 18), thus championing reflexivity within her work, both for herself and for others. In one paragraph, which illustrates my own passage from 'expert' to a more open and ambiguous position, Richardson argues that:

Separating the researcher's story from the people's story implies that the researcher's voice is the authoritative one, a voice that stands *above* the rest...by objectifying ourselves out of existence, we void our own experiences. We separate our humanity from our work. We create the conditions of our own alienation (1997, p. 18).

Richardson's account recalls Cooper and Lousada's description of the Climbié and other inquiry reports where 'the enormity and complexity of achieving a coherent analysis that might contribute to constructive change' results finally in a 'terse lifeless, abstract series of recommendations' (2005, p. 155), thus voiding the experience.

The enormity and complexity involved in my own task led initially to a similar position, one where I was crossing the research road in order to avoid myself, as people had

actually crossed the road following Joe's death, thus creating the conditions of my own alienation. This alienation was not just personal, but professional as well. As a former social worker, I was able to understand why sometimes 'professionals respond in the way they do' (Parton, 1997, p. 232), and particularly how very real organisational constraints combine with personal anxiety to create a 'defended community' of practice (Hoggett, 2000, p. 92). Remembering the police woman on the morning of Joe's death who, in that situation, could not reconcile my being both Joe's mother and a social worker, I hoped to use my personal and professional experience to create a dialogue between the two rather than splitting them as the police woman had done (see Chapter 1).

Finlay (2003, p. 106) describes the reflexive journey as moving 'through the looking glass' to accomplish being 'both subject and object' within the research. Having attempted this, I now view my position as one which has shifted radically from defended researcher to reflexive researcher, and as one who, according to Hoggett and Clarke, endeavours to be 'engaged in sustained self-reflection on our methods and practice, on our emotional involvement in the research and on the affective relationship between ourselves and the researched' (2009, p. 2–3).

However, as the debates that took place in 2008 between Baraitser, Frosh and Hollway demonstrate (see Chapter 1), there are continuing disagreements and risks, even within the general agreement on reflexivity as central to a psychosocial approach. Frosh and Baraitser, for example, focus on the difficulty of 'what account can in fact be given of the investment of the researcher in the knowledge making process' (2008, p. 359), and argue that what the researcher declares about the process can only ever be partial.

Hoggett offers a similar caveat, suggesting that 'our capacity to be reflexive is constantly hemmed in by our own fear ...some ideas are just too dangerous to

entertain...because they pose too much of a threat to one's own conception of self' (2000, p. 109). Hoggett suggests that 'much of the vitality, tragedy and mystery of everyday life unfolds in a way that few, if any, of the participants are fully conscious of', a passage that resonates vibrantly with my experience of writing this thesis. Despite my attempts to remain as reflexive as possible, I am lingeringly aware of the spaces in-between what I have said and what I have missed, a place which Gendlin describes as a 'felt sense', an 'awareness of the border zone' between the conscious and the unconscious' (1996, p. 16).

My efforts to remain reflexive can therefore only ever be partial, as there will always be spaces that I cannot reach. However, I have tried as far as possible to allow for these, and to look both further and deeper rather than using reflexivity simply as 'an excuse – a cover story – which allowed me to look at my reflection' (Finlay, 2003, p. 112).

Another cost of working reflexively is, where the research is difficult for others to hear, the danger of losing an expert role may result in the work being dismissed as a self-indulgent form of 'victim art or confessional' (Bochner cited in Giorgio, 2009, p. 149). This form of ready dismissal can be seen as another cultural form of splitting in order to defend against exposure to painful experience, the risk for the researcher lying in being correspondingly dismissed as a victim by their very sharing of experience.

Richardson summarises this problem, posing the question of 'how to discover and write about yourself without 'essentialising' yourself by the very categories you have constructed to talk about yourself and without 'valorizing' yourself because you are talking about yourself' (1997, p. 107).

In trying to locate myself inside these debates and to find a 'place for experience' (Hoggett, 2000, p. 84) within this thesis, I have been guided by Hollway's responses in the debate between herself and Frosh and Baraitser. Hollway writes, that:

Psychosocial interpretations are useful at helping us to understand experiences. They illustrate the limitations of a single approach...they don't fix and they add depth (2008, p. 3).

I find Hollway's interpretation useful in navigating the complex terrain of reflexivity and research, as it helps both to strike 'some balance between self-awareness and undue navel-gazing' (Finlay, 2003, p. 116), as well as assisting with my task of occupying 'a space not fully one or the other, but with elements of each and the perspective of an outsider' (Ellingson, 1998, p. 501).

Hollway's suggestion that psychosocial interpretations 'don't fix' also returns me to the expert testimony, which became so discredited following the successful appeals of Clark, Cannings and Patel. I have remained mindful of the potential dangers of fixing within this thesis. Rather than such fixing, I have tried to maintain my methodology as one that assists with both the 'intensity and epistemological uncertainties that arise from...research encounters' (Cooper, 2009, p. 432), and perhaps most of all, one that provides linkage between disparate elements and bridges across absences.

3:3: 'The space that connects'

As the discussion of my reflexive journey from anxious expert to a more open and unknowing position has shown, much of the purpose and the work of this thesis lies in linking often contrasting components, amongst them meaning and experience; voice and action; personal and political; and reason and emotion (Hoggett, 2000; Cooper & Lousada, 2005). Essential to the methodology, therefore, has been maintaining what Hoggett describes as a 'space that connects' (2000, p.125), where distinct and often contrasting elements can be brought together in the service of creating a more holistic understanding of sudden and unexpected child death.

Central to this connection is the capacity to feel as well as to think, as the Kennedy Report itself guides in its directive that 'professionals should...be sensitised to emotions

being experienced by parents' (RCPaH & RCPCH, 2004, p. 12). This was a defining force in my decision to undertake this research, and it has also fuelled it ever since. However, as I have discussed in Chapter 2, the pressures of an audit and inquiry culture have created a climate of blame and fear, where random and tragic deaths of children have become almost 'unthinkable' (Hoggett, 2000, p. 20). In the service of creating a methodology capable of connecting this previously unthinkable event with the experiences contained within this thesis, I have chosen to explore further what factors may combine to create unthinkability (Cooper & Lousada, 2005).

The audit and inquiry culture certainly creates, as Cooper and Lousada suggest, a societal structure for containing and ordering 'evidence of unwelcome and disturbing aspects of social life' (2005, p. 59), which I have discussed in the previous Chapter. However, this accounts only for what Clarke and Hoggett (2009) would describe as the surface of the discussion and not for the deeper causes. Hoggett locates these causes through the work of Klein and others in the object relations tradition, and particularly within the concept of the 'paranoid-schizoid' position (2000, p. 68). This is the term Klein used to describe a primitive or early stage of development, where terror of the unknown is kept at bay via the defence of 'splitting' described earlier. Within this split, objects and events become either universally good or universally bad. Crucially however, this position is underpinned by terror and the creation of mechanisms to avoid feeling this (Hoggett, 2000; Cooper & Lousada, 2005). Amongst these is the construction of otherness, whereby the other becomes the container for all the nameless terrors that the individual or the group repress or deny within themselves (Hoggett, 2000).

Hoggett argues that, at both group and individual levels, these split off terrors render actual failure, such as sudden and unexpected child death, to be 'experienced as catastrophic' (2000, p. 67), leading perhaps to their popular depiction in cataclysmic

terms and offering no model for survival (see Chapter 1). Death is particularly significant here, for Klein argued that one of the most basic of human terrors is the fear of annihilation present in both the idea and the ultimate reality of death, which is then also split off into others who become containers for these bad experiences (Hoggett, 2000, p. 145). This may offer an explanation for why parents are not included within any of the meetings that follow sudden and unexpected child death – they are split off and kept unthinkable.

At a group level, structures like audit and inquiry offer what Hoggett describes as a ‘protection racket’, offering ‘good’ citizens security from their nameless terrors, as long as they do not suffer misfortune that ‘others’ them or ‘the police come knocking at the door’ (2000, p. 68). Within both my methodology and the finished thesis, I have attempted to take on the challenge of offering a different form of protection by offering a ‘space that connects’ (Hoggett, 2000, p. 125), thought with emotion and thinkability with unthinkability, thereby reducing the terror of sudden and unexpected child death through ‘fearless engagement with it and recognition of its nature’ (Cooper, 2009, p. 441).

3:4: ‘A methodology of the heart’

At the core of this study lies the body, or rather the loss and continuing absence of a unique and special body with which all the accounts, including my own, begin. This loss is felt physiologically by the survivors, who are also in a body with their lived experience primarily filtered not through words or text but ‘through the five senses’ (Richardson, 1997, p. 66). Therefore loss inevitably creates pain, together with an ‘emptiness’ that may in turn lead to frustration and rage (Cooper & Lousada, 2005, p.70). At the heart of Klein’s notion of terror is the fear of our own emptiness with the concomitant dread of annihilation, and the emptiness of loss may threaten us with the

reality of this.

Frank also suggests that much of the terror that death holds for contemporary society is located in the ‘conditions of embodiment that most of us would rather forget our own vulnerability to’ (1995, p. 25). Within a ‘contemporary culture’, which ‘treats health as the normal condition that people ought to have restored’ (Frank, 1995, p. 77) death is mostly suppressed or denied, or in Kleinian terms ‘split off.’ It is not just our own vulnerability either, but also that of our loved ones that we may choose to ignore. Frank describes reading some of the professional literature after having cancer and finding ‘the language too distant from the immediacy of embodied suffering’ (1995, p. 25) that he had so recently experienced.

To counter this, Pelias (2004) calls for a ‘methodology of the heart’, which he depicts as not one of ‘Valentine’s Day with its lace trimming and perfect symmetrical shape, but rather one exposed, raw...irregular, almost vulgar as it pounds and pounds insisting upon its presence’ (2004, p. 2). Although Pelias, similar to Richardson, is not avowedly psychosocial, he shares much in common with the approach in his desire to drive a ‘scholarship that fosters connections’ and ‘opens spaces for dialogue’ (2004, p. 2). However, I have found his idea of the ‘methodology of the heart’ particularly significant for its visceral description, which locates all research firmly within the body. This links Pelias’ work to Cooper’s discussion (2009) of practice-near research, which forms another significant influence within my methodology.

Cooper argues that practice-near research is essential in social work and other disciplines if knowledge that is helpful in the real world of practice is to be created. Whilst recognizing the difficulty of the task he identifies, he suggests that ‘we can only hope to generate new knowledge in so far as we are open to the possibility of discovering something new’ (2009, p. 431). What prevents this from happening,

according to Cooper, are many of the difficulties I have already identified bound up with defences against ugly or ‘inconvenient facts of life’ (2009, p.431).

As part of his exploration of ‘what happens when we get *close*, emotionally or physically to people’, Cooper identifies four main criteria, many of which speak to Pelias’ notion of a ‘raw...irregular’ and ‘vulgar’ methodology of the heart (2004, p.2). Cooper classifies these as ‘the smell of the real’, which brings us close to people in ‘a visceral, bodily and therefore live emotional way’; the risk of ‘losing our minds’ by becoming ‘psychically mixed up’ with others; the inevitability of personal change from the encounter; and the ‘discovery of complex particulars’, which substitutes for the more ‘positivist world view’ of ‘generalisability’ (2009, p.431). Instead, Cooper suggests that ‘the closer one comes to a single case, the more its uniqueness and particularity demands to be understood’ (2009, p. 432).

The definition of ‘practice-near research’ offered by Cooper, with these four criteria, accompanies a vision of ‘passionate research about passions, in which the boundaries of the researchers self are likely to become fluid and uncertain’ (2009, p. 432). This helps to connect the mission of my research, which is to improve practice following sudden and unexpected child death with the decision to offer my personal experience as part of this. His eloquent account of practice-near research has therefore been particularly valuable in helping me connect many of the disparate parts of my methodology, whilst his notion of passion complements the vibrant embodied methodology of the heart and leads me to an exploration of textual descriptions capable of expressing this.

3:5: Writing as a ‘method of inquiry’

One of my challenges in devising a methodology that both engages and connects, has been to find a language suitable for maintaining the quality of experience contained within the narratives themselves and which depicts my own process of discovery during

the research process. Hoggett (2000, p. 85) describes much academic writing as ‘impersonal, distanced and ultimately boring’, which echoes Cooper and Lousada’s description of the Climbié Report where the ‘enormity and complexity of what had been exposed’, translated during the ‘writing up’ into a ‘terse, lifeless, abstract series of recommendations’ (2005, p. 155).

Hoggett (2000) calls instead for a way of writing within a language that crosses boundaries. However, responding to this plea presents a challenge, for as Richardson argues, how we write about and ‘theorize about *lived experience* and how we experience *lived experience* are at odds...leaving us only ever therefore able to write ‘accounts’ (1997, p. 66–67, original emphasis).

The same has been true for me during the process of writing this thesis, in the choices I have made about including my own lived experience and in the way that I have written about this and also included fragments and snippets of fiction and literature, where these have helped to animate the text. Similarly, I have selected to retain the narratives contained in Chapters 5 and 6 as complete accounts in order to capture as closely as possible the lived experience as described by the teller.

Retaining the original language, rather than choosing to fracture the text, connects with Speedy’s concept of ‘the talk that sings’ (2008, p. 62). This is an approach to language that speaks to the psychosocial in aiming to represent what lies beneath and between inner and outer worlds in a way that brings us closer both to lived experience and to feeling what someone else felt. In thinking about my methodology, I have tried to embrace language that is both relational and accessible, rather than the dry forms, which Hoggett describes and which caused Richardson to ‘yawn her way ... through academic research for years’ (2005, p. 959).

Using language in this way, as a means of expressing and exploring emotion, fits with

Richardson's concept of writing as a 'method of inquiry' (2005, p.959), which has had a significant influence on my own writing process. Richardson argues against the traditional 'mechanistic scientism' which taught her 'not to write until I knew what I wanted to say' (2000, p.959), offering instead a way of writing that fits with the psychosocial emphasis on surface and depth, urging writers to understand themselves reflectively. Writing as inquiry, Richardson contends, also frees writers from 'trying to write a single text in which everything is said to everyone' (2000, p.960). In direct contrast to my early position as defended researcher, Richardson advocates using writing as a means of releasing the 'conscious hold of 'science writing' to foster a place where 'writing is validated as a method of knowing'' (2005, p. 962).

Describing her own writing practice as 'nomadic inquiry', St Pierre echoes Richardson, with her related perception that much 'thought happened in the writing. As I wrote I watched word after word appears on the computer screen - ideas, theories I had not thought before I wrote them' (2005, p. 970).

This is a method of writing that certainly resonates with my own, in remaining more of a continuing exploration than the 'mopping up process at the end of an otherwise...completed study', which Speedy describes in her own consideration of writing as inquiry (2008, p. 138). As such, this method of writing has reflected the psychosocial emphasis of this study, containing the space for experience and allowing ideas to emerge and intertwine rather than 'fixing' it in the way Hollway describes (2008, p. 3).

3:6: 'Pinning a butterfly to a mat'

Alongside all the important yet often nebulous choices that I have described during the course of the research process, there were also others that did have to be more fixed, methodological decisions, which Pelias (2004, p. 9) describes as 'like pinning a

butterfly to a mat.’ This pinning process was not, however, achieved in one single swipe, and in attempting to describe it here, I am faced with the same problem discussed earlier of only ever being able to write accounts rather than to adequately represent my meandering process. The sampling approach was one such meandering, with many twists and turns in my supervision sessions over how I would access participants. With hindsight it seems to me now that we were all uncomfortably constrained by the ethical questions which arose later in the process and which are discussed fully in section 3:9, below. My final sample of eight participants was derived mainly from advertising through the websites of relevant charities, with two other people gained from personal contact and connection. This is discussed more fully in section 3:10, below.

There were, however, some practical decisions that flowed from the early stages of the research process and have remained consistent since. Amongst these were the criteria for inclusion in the study, particularly in relation to the age of the child and the time since the death. The recommendations of the Kennedy Report are applicable chiefly to babies and very young children, although there is much within that also applies to the death of an older child, with the case for extending this until 18 years made within the Report itself (RCPath & RCPCH, 2004, p. 14). The Government document ‘Working Together to Safeguard Children’ (2006, p. 132) defines a child as a young person between 0 and 18 years, and I therefore chose to use this definition within my study. Similarly, I adopted the ‘Working Together’ definition of sudden and unexpected death as one that was ‘not anticipated as a significant possibility 24 hours before’ (2006, p.132).

In early supervision sessions, we also discussed inclusion criteria with regard to the death itself and any ensuing charges. Eventually it was decided that the sample should not include parents where charges were brought, as this would confuse analysis and comparison, as well as raising potential difficulties for researcher objectivity. As the

study's explicit purpose was to discover what can be learned from parents' experience of professional intervention, it was important to study parents who had all shared a common experience and also one which compared to Joe's death, which in turn formed a foundation for the research. Additionally, interviewing only parents where no charges were brought helped to bring into sharper focus the often hostile and defensive reactions to their stories which I later encountered (see Chapter 8). If there had been charges in respect of any of the deaths, the consequent risk of dismissing the parents as guilty may have justified even the most grotesque of procedures and thereby detracted from the research questions and focus of the study.

The length of time since the death was also a criterion that exercised me greatly in the early days. Initially, I was anxious about including experiences where the death was very recent, or conversely where the death had occurred years, or even decades, prior to participation. Some of the literature I read during these initial stages was useful in helping me reach a decision about this. Riches and Dawson's study, for example, of marital breakdown following child death comments on 'the powerful and sustained attention which parents gave to their child's life, death and continuing importance *regardless* of the time which had elapsed. It was as strong in parents whose children died over 12 years ago, as in parents with more recent losses' (1996, p. 359).

From this, and deliberating further on Joe's death and my own experience, I decided that neither historical accuracy nor even contemporary relevance were the key lessons in what can be learned from parents' experiences. I was more interested in the way that parents remember the story, the sequence and those parts that take on the greatest significance. In my proposed sample, therefore, I decided not to ring fence the time of the death and rather to aim for experiences that reflected different time periods and different memories, whilst also heeding Mason's advice that sampling is a 'dynamic and ongoing practice' (2004, p. 135).

Of the eight interviews I eventually conducted, the time since the death varied from over two decades to less than a year. Two of these accounts form Chapters 5-6, where they testify to Riches and Dawson's findings that all the 'interviews regardless of time present as recurrent themes of irrevocable change... expressed in strong and emotional ways' (1996, p. 359).

Early in the study, I also established some generic research questions, which have guided my process since. From my 'initial area of interest', which Richards and Morse (2007, p. 14) advocate as the best starting point for formulating questions, I went through countless different variations of the same question, eventually opting for 'what can be learned from parents' experiences of the professional response following the sudden and unexpected death of a child', which later became the second half of my thesis title. The 'what can be learned' part of this question was especially significant for me as I did not want to close the topic or decide anything on the basis either of my own experience or on my initial forays into the field, but rather to retain a genuine spirit of enquiry.

Eventually, after many more departures from and around similar themes, I devised some further research questions, which were as follows:

- How do parents recall the professional intervention that occurred following the sudden and unexpected death of their child?
- When parents recount the incidents surrounding their child's sudden and unexpected death, are there common factors that emerge as helpful or unhelpful, both in their general experience and in the specific professional intervention they received?
- How can parental accounts of sudden and unexpected child death be best utilized

to extend understanding between parents and professionals and to provide the simple practical training as advocated by the Kennedy Report?

Whilst these questions have guided my research process, I have always been mindful of keeping the process as open as possible. Therefore, it has been the generic ‘what can be learned’ in my title rather than a search for precise answers to the questions, which has underpinned my enquiry throughout.

3:7: ‘Telling the story’

The main title, ‘Telling the story’, emerged from my early incursions into the literature, together with my initial focus on adding direct parental accounts.

Neimeyer (1998) and other contemporary grief theorists whose work I described in Chapter 2, (Bonanno & Kaltmann 1999; Stroebe & Schut 2001) emphasise ‘meaning-making’ as the ‘central process in grieving’ (Neimeyer, 1998, p. 110), which they agree is essential for any kind of adjustment or healing, and whilst they offer no direct formula for achieving this, Frank (1995) champions the telling of stories.

This theme of ‘telling the story’ is echoed powerfully in myriad works on the topic of bereavement and child loss. Amongst these works is a thorough literature review on bereavement and bereavement care conducted by Aberdeen University in 2006, which found that ‘the importance of individuals being able to tell their story is mentioned frequently’ (Wimpenny et al., 2006, p. 113). Another study of bereaved parents’ participation in research reports that, for the 75% who scored the experience as positive, the major positive was ‘telling the story’ (Dyregrov, 2004a, p. 300). Watson (1981) similarly reports that 80% of respondents in her study found the telling of their story therapeutic, whilst Riches and Dawson describe giving the respondents the ‘opportunity to tell the story from beginning to end’ as ‘amongst the most important findings in the project’ (1996, p. 363).

In exploring a subject where these stories are largely untold or even unthinkable (Cooper & Lousada, 2005), ‘giving voice to people to tell their stories in their own words’ can be seen as both ‘cathartic and therapeutic’ (Grafanaki, 1996 p. 336), and contrasts powerfully with what Cottle, in his paper on narrative, describes as ‘the myth of vulnerability’ (2002, p. 536). This refers to the widespread notion that ‘people of certain groups or those having had certain experiences are so damaged that they cannot speak for themselves’, and seems perhaps to underlie much of the popular depiction of bereaved parents as vessels of ‘weariness and hopelessness’ (Dent & Stewart, 2004, p. 174).

Cottle argues for the power of narratives in providing a meeting point between self and other where the teller has the potential to transform the listener in their mutual sharing of the story, a purpose that meets so many of the profound aims of this research. I therefore chose ‘Telling the story’ to be the main title of this thesis in recognition of the literature where this has been so widely reported as useful. The title also provides my own spark of resistance to counter the untold parental accounts of sudden and unexpected child death, providing the wider potential to respond in a ‘humanly worthwhile way’ (Frosh, 1991, p.19).

However, despite the affirmations of story-telling within the literature, there are also many fierce objectors engaged in debate, which echoes that of Frosh, Baraitser and Hollway in the psychosocial field. Amongst these, Atkinson is at the forefront, questioning the usefulness of narrative alongside his concern over the ‘multiplication of narrative methods’ (2005, p. 334). Similarly, there is also ‘considerable disagreement about the precise definition’ of narrative (Riessman, 1993, p. 17). Several key writers, including Riessman, attempt to solve this by offering templates for narrative studies, whilst others (Polkinghorne, 1988; Lieblich et al., 1998) divide narrative research more broadly into studies that use narratives simply as alternatives to more traditional forms

of quantitative analysis (charts, numbers, graphs etc.), and those that use stories to bring meaning to events and experiences.

Amongst most of the significant writers on narrative (Riessman, 1993; Clandinin & Connelly, 2000; Sarbin, 1986), there seems to be a general consensus that endorses Polkinghorne's definition of narrative as 'the primary form by which human experience is made meaningful' (1998, p. 1). This initially attracted me to using the narrative form within my research, as this meaning-making function seemed to fit with the similar meaning-making imperative postulated within contemporary theories of grief (Neimeyer, 2000).

However, writers within the psychosocial field, notably Hollway and Jefferson (2000) and Wengraf (2001), have criticized the tendency for research to take narratives at face value, suggesting that meaning needs to be found in the encounter. They argue, therefore, that the stories themselves are not sufficient for understanding these meanings without a similar reflexive process on the part of the researcher, together with placing both in a historical and cultural context (Hollway & Jefferson, 2000, p. 32). Whilst Hollway & Jefferson use narrative within their method, they make a distinction between 'traditional narrative analysis', 'preoccupation with coherence' in the form of structure, and their own focus on 'free association narrative interviewing', which uses psychoanalytic concepts to explore 'contradictions, elisions' and 'avoidances' (p. 37).

Hollway and Jefferson's free association narrative interviewing technique has its origins in the German 'biographical-interpretative method', which also inspired Wengraf's 'Biographic Narrative Interpretive Method' or BNIM) (2011) that is extensively discussed in the following section. The two approaches, both avowedly psychosocial, share a common commitment to avoiding closed questions, eliciting story rather than simply a pre-determined answer to a query, avoiding the use of 'why' questions which

can lead to explanation rather than story, and keeping the same sequence of events and form that the research participant has used, thus honouring the often unconscious meaning in this order (Hollway & Jefferson, 2002). The Biographic Narrative Interpretive Method (Wengraf, 2011) also makes extensive use of data analysis panels as a means of opening up the researcher's subjective interpretations. As I discuss fully in section 3:8, these panels were both extremely challenging and highly valuable to me in excavating my relationship to the stories.

By use of techniques like avoiding closed questions and keeping to the same sequence as the interviewee, Hollway and Jefferson argue that their method of free association narrative interviewing resonates with psychoanalysis in eliciting narratives that 'are not structured according to conscious logic', thereby offering pathways 'defined by emotional motivations rather than rational intentions' (2002, p.37).

The promise of excavating meaning defined by emotional motivations rendered these approaches very attractive to me in achieving my aim of exploring parental emotions following sudden and unexpected child death. However, still within the early stages of my research, I was correspondingly lacking in confidence and to a large extent covered in the academic armour previously discussed. This made the choice of a method that I could almost select 'off the peg and follow ... to the letter' (Mason, 2002, p. 32) very appealing in holding out the promise of keeping my research 'sufficiently focused and usable' (Gray, 2004, p. 71). I therefore opted to follow BNIM within the first stages of my research, where it was genuinely effective, until my later difficulties in working with it led me towards a form of 'methodological bricolage' (Kincheloe & McLaren, 2005, p. 305).

3:8: The Biographic Narrative Interpretive Method

The Biographic Narrative Interpretive Method, or BNIM, evolved from the work of

German sociologists producing accounts of the experiences of holocaust survivors (Hollway and Jefferson, 2000, p. 34). It also shares with Hollway and Jefferson's model a psychosocial emphasis, which involves both eliciting unstructured and uninterrupted narrative flow together with a focus on understanding both the teller, the way in which they tell and the context for this. BNIM describes this as 'facilitating understanding both of the 'inner' and 'outer' worlds of historically-evolving-persons-in-historically-evolving situations', and particularly the interactivity of such inner and outer world dynamics' (Wengraf, 2001, p. 30).

Unlike other biographic narrative methods however, BNIM also offers a very structured set of approaches to both interview and analysis, advocating the use of panels to encourage greater researcher objectivity. Part of this structured approach lies in BNIM's distinction between verifiable life events, which it deems 'the lived through past/living of the lived life' (Wengraf, 2001, p. 234) and the 'structuring principles of the story as told/the telling of the told story', which represents the way the teller chooses to tell his or her story within the interview. For BNIM purposes, 'the living of the lived life' can concern any episode described in an interview, which for this study were the events surrounding sudden and unexpected child death.

Initially BNIM seemed well suited to my exploration of sudden and unexpected child death, where the requirements of the outer world could impact so greatly on the inner world of parents at such a traumatic time. Additionally, BNIM's location within the recent 'innovations to psychosocial methodology', as described by Clarke and Hoggett (2009, p. 8), made it a potentially exciting means of achieving the connections between my aims and my methods.

During the initial interview stage of my research, BNIM was highly effective. I had formulated a 'SQUIN' (Single Question aimed at Inducing Narrative) using an advisory

template (Wengraf, 2001, p. 111) that aims at eliciting open narrative, rather than utilising structured or semi-structured questions. I used my SQUIN at the start of all my research interviews, staying as close as possible to these words on every occasion:

“Please tell me the story of.....’s death...all the events and experiences that have been important to you personally. Begin wherever you like. I’ll just listen, I won’t interrupt. I will just take some notes for afterwards.”

The open invitation provided by the SQUIN was invaluable in allowing parents to frame their own stories and to tell these freely ‘from beginning to end’ (Riches & Dawson, 1996, p. 363). Despite my initial concern about the limited scope for prompting, or my own interventions, in practice this seemed to enable parents to enter a narrative space where they were almost unconscious of my presence. If, on occasion, I did interrupt or make my presence known, this invariably distracted them and altered the course of their narrative flow.

Following the efficacy of BNIM as a method during the interview stage, I embarked on the next task, which was to produce two tracks from the verbatim transcripts of the interview. These tracks were informed by both the ‘living of the lived life’ and ‘the telling of the told story’, with the eventual purpose of producing a ‘working document’ (Wengraf, 2011, p.239) for each of approximately ten pages and containing ‘transcript chunks’ condensed from the interviews. This document was then presented for microanalysis at a BNIM kick start panel (Wengraf, 2011). These panels are used within BNIM to both ‘kick start’ the interpretive procedure and challenge ‘researcher autism’ (Wengraf, 2011, p. 104), with members ideally being ‘non-specialists’ capable of bringing diverse viewpoints to the process.

Prior to the panels, whilst working on the twin track analysis (Wengraf, 2011) I began to encounter problems with the methodology, which manifested practically as well as personally. Firstly, I struggled with remembering and applying the multitude of

acronyms involved within the process. A flavour of these is given by the production of the first track, which is a chronology known as a BDC (Biographical Data Chronology), leading to the production of a BDA (or Biographical Data Analysis). This is an analysis of the chronology of experiences of the lived through past, characterised by dates, times and other verifiable events, and constructed as objectively as possible without subjective content. This is followed by work on the second track, which is a thematic field analysis aimed at constructing the telling of the told story (Wengraf, 2011) as the person has chosen to tell it in this context. This results in a TSS (Text Structure Sequentialization) on the basis of which a TFA (Telling Flow Analysis) is created.

Despite trying to follow BNIM ‘to the letter’ (Mason, 2002, p. 32), I was bewildered by the number of acronyms and became so immersed in trying to master these that I lost sight of the interviews themselves. Returning to Cooper’s earlier depiction of practice-near research, which brings researchers close to the ‘smell of the real’ and to ‘people in a visceral, bodily and therefore live emotional way’ (2009, p. 432), I felt that I had lost touch, becoming instead a pale imitation of a ‘good social scientist’ who elicited data and coded it into thematic categories’ (Riessman, 1990, p. vi). The consequent risk at this stage echoed Cooper’s description of ‘Losing our Minds’ (2009, p. 432), rather than through becoming entangled with people, my own threat of insanity was through ‘entangling’ myself within a structure that I struggled to understand. Rather than discovering ‘complex particulars’ (Cooper, 2009, p. 432), I felt further and further removed from the people in my research.

Another practical difficulty lay in the production of a BDC, which the BNIM Guide suggests is ‘relatively unproblematic as it corresponds with our normal way of thinking’ and ‘provides no conceptual difficulties’ (Wengraf, 2011, p. 239). However, after I had produced one for my first interview, I found that the verifiable fact and hard data it produced were mostly reiterated within the TFA panel, and thus it did not lend itself

easily to two separate panels covering such similar material (Wengraf, 2011, p.294). Where this occurs, the BNIM guide advises ‘where there is not much ‘hard biographical data’ for a chronology (and hence for a BDA) then there is not much point in spending too much time in acting as if there were’ (Wengraf, 2011, p.294). I therefore decided to convene panels solely on the TFA.

The BNIM kick start panels formed from three or four people known to the researcher, but ideally not as specialists in the subject, are presented with chunks of the transcript, which help to form a ‘special sort of contents page’ or ‘working document’ (Wengraf, 2011, p.104). This was a task I also struggled with, as it seemed to me that what I chose to both include and exclude within the ‘transcript chunks’ would have a significant effect on enacting the reality that the panel then observed. Finding it almost impossible to resolve this issue, I eventually chose to depart from the advice given and presented large chunks of the transcript to the kick start panels I convened.

Wengraf advises that the panel process is ‘for all concerned – as a personal and professional learning experience [is] both insightful and often funny’ (Wengraf, 2011, p. 104). When setting up my own panels, I was advised by this as well as by the advice to try, as far as possible, to create diversity within the panel structure. Every panel consisted of three members, drawn from friends, colleagues and others who were recruited through professional contacts and each had one member who was, or had been a social worker, as I found this useful in representing the views of the child protection practitioner in the panel process.

Prior to each panel, I sent out an Information Sheet for prospective members (see Appendix 5), which detailed the potential sensitivity of the material and encouraged people to think about this before deciding to commit. Alongside this, the Information Sheet also suggested areas for the panel members to focus on, drawn from BNIM

guidance. The suggestions were 'what might the interviewee have been feeling and thinking (experiencing) at the time of a particular event' and 'what does the way the interviewee is now talking at this point in the logic of sequence suggest about their later perspectives and current perspectives on that same event as originally experienced?' (Wengraf, 2011, p. 413).

Additionally, the BNIM guide advises panel members to consider that the interviews commence with a SQUIN, which sets no conditions other than a simple opening question, thus leaving both form and content open to the interviewee. This, therefore, poses the further question of 'how did the interviewee experience the interviewer and his interventions and non-interventions?' (Wengraf, 2011, p. 413), which panel members are also asked to consider.

In my Information Sheet I also detailed the concept of future blindness (Wengraf, 2011) which aims to mirror the experience of the interviewee as the actual events unfold. Everyone agreeing to participate in a panel for my research knew that the transcripts concern child death. Due to the nature of the material, I believe this was ethically responsible. However, no other detailed knowledge was disclosed to panel members prior to the panels themselves.

Selecting which interviews to bring to the panels also caused me ethical and moral difficulties as BNIM guidance simply suggests that researchers identify 'gold star' interviews (Wengraf, 2011, p.413), raising again questions of selection akin to the chunks. Whilst it was not practical for me to convene panels on all the interviews due to the level of work involved, I was aware in choosing some as 'gold star' versions that I was demonstrating the 'asymmetries of power and divisions of interest' (Giddens, 1999 cited in Shaw & Gould, 2001, p. 19) that I was trying to uncover. This also represented an ethical concern as each of the interviews had been offered in the same

way, with the same understanding. Thus, by highlighting some rather than others, I felt as if I were reneging on my ‘moral stance of caring for the Other’ (Bauman, 1993, cited in Kellner, 2002, p. 30). I ultimately solved this practically by running panels for five of my eight interviews based on their value in offering a breadth of experience and meeting my research purpose. On a personal level, however, I still struggle with this notion of selection.

Before convening a panel for the first time, I was sceptical about the usefulness of the process. Although I did find them valuable in practice, this was not necessarily for the intended reasons but rather for the window they opened onto the complex feelings that sudden and unexpected death can engender at both conscious and unconscious levels. I will offer a fuller discussion of this in Chapters 5-7 and in the discussion of ethics that follows.

3:9: ‘Walking the tightrope’

Van Den Hoonaard (2002) compares the process of gaining ethical approval to ‘walking the tightrope’, and although I had initially viewed it essentially as a ‘procedural or practical issue’ (Dunne, Pryor & Yates, 2010, p. 1), there were times when, in practice, it did feel like trying to cross a high-wire whilst concomitantly deepening my awareness of different perspectives on sudden and unexpected child death.

One of my first ethical decisions was where and how to seek participants. Raphael’s discussion of professional reactions to child death was valuable here, persuading me not to seek participants through the NHS or other statutory bodies, where:

Doctors ...often wish to avoid any discussion of the dead baby and display general discomfort and ignorance about such deaths’ (1984, p. 261).

This resonated with my own experience at the time of Joe’s death, and it is a perspective further supported by Dyregrov’s study of parent’s participation in research where she

notes that ‘it is well documented that research proposals in this field are more likely to be rejected by Institutional Review Boards’ (2004, p. 5). I therefore decided to concentrate on seeking participants via specialist charities operating in the area of child death and bereavement.

This decision spared me from having to gain NHS ethical approval, yet I was still required to obtain permission via the university’s own ethical review process. It was here that my walking the tightrope began. My original submission for ethical clearance, submitted at the beginning of my third year, was rejected on the grounds that the Committee was not yet satisfied of the ethical case made. Whilst some of the comments reflected my status as a ‘novice researcher’ (Gray, 2004, p. 16), there were others that were particularly significant to my work, which left me with an enduring sense of unease. Amongst these were the repeated descriptions of my research as ethically sensitive and the participants as vulnerable, both of which troubled me as they seemed to uncritically endorse the ‘myth of vulnerability’ (Cottle, 2002, p. 536), and thus to construct both the research and the participants in a particular way before I had even embarked on fieldwork.

Whilst assumptions like this are commonly made and ‘research on vulnerable populations’ habitually considered ‘unethical because it may rip open old wounds’ (Dyregrov, 2004a, p. 8), a growing body of evidence has shown that ‘instead of causing distress, research may be educational, enriching, therapeutic or empowering for vulnerable populations’ (Dyregrov, 2004a, p. 6). I was consequently troubled by the tone of the ethical decisions. Whilst I completely acknowledged the need for safeguards, I pondered whether those categories of people labelled as ‘vulnerable’ may in practice be those who make others feel vulnerable, for as Henderson et al. argue, ‘vulnerability is by definition, relational’ leaving ‘one ... always vulnerable *to* someone’s or something’s *influence*’ (2010, p. 50).

Henderson et al. further suggest that in research contexts, ‘applying vulnerability to only one party’ may contribute to conceptual confusion’ as the latent vulnerability of ethics committee members can be masked by their authority’ (2010, p.50). The potential consequences of this undisclosed vulnerability for what is researched then lies in less overtly sensitive studies being privileged over that which may make professionals feel uncomfortable, but which nevertheless is hugely valuable in researching traditionally uncharted areas.

Following my own ethical review and recalling the breakdown of linkage between emotion and procedure in the inquiry reports discussed in Chapter 2, I was left wondering whether a similar process occurs within ethics procedures, where the procedure and protocol eliminates a deeper understanding of the research populace to be studied. To counter this possibility, Van Den Hooanard suggests that ethics could be made more ‘ethical’ by including ‘the perspectives of the populations being studied’ (2002, p. 183).

However, despite the focus of the ethical review procedure on some aspects of my research, it was the panels, which were not highlighted at all, which proved to be the most ethically challenging in practice. I had also understood the panels initially at a fairly superficial level, advised by the BNIM Guide’s description of them as both ‘insightful and often funny’ (Wengraf, 2011, p. 104), which contributed to my under-estimation of the potential effects of the chunks on the panel members. Whilst I had advised them both in person and within the Information Sheet that the nature of the material was sometimes highly emotive and challenging, for three panels in particular these ethical concerns were demonstrated by the acute emotional responses produced, with members describing feelings of being chronically polluted by the process of picking over people’s words, together with a general sense of unease. The feelings reported by panel members recall my earlier discussion of the nameless terror which

Klein posited was inside all of us, leading threats to the social fabric, such as that represented by sudden and unexpected child death, to bring about the 'experience of catastrophic anxiety' (Hoggett, 2000, p. 67), or, in the experience of panel members, a feeling of chronic pollution.

Andy's interview, which focuses on the death of his young son, particularly resulted in significant distress for one panel member, who was reminded painfully of experiences in her own past. She was clear that this was not the narrative she had expected to hear and was hugely discomfited by the version of society that Andy's narrative portrayed. Describing this as a 'living nightmare', she reported feeling the need to try and find some good in this, something, in her words, to hang onto. Similarly, the panels for both Julia's and Cathy's interviews (see Chapters 5 and 6) provoked emotional reactions ranging from distress to anger. In retrospect, I find it hard to believe that neither I, nor the ethics procedure, considered this possibility, focusing instead on the parent participants.

I also saw this as a potential methodological difficulty within BNIM and accordingly discussed this, via email, with Tom Wengraf, leading him to place a caveat in the part of the BNIM Guide (2011) concerned with panels. This now suggests that panels are 'not always funny...sometimes, the panel may be unexpectedly distressing' and advises 'counselling back-up for the interviewees...but also for those who sit on panels' (Wengraf, 2011, p.104). Whilst this is a useful addition, it remains relatively superficial. I would therefore advocate for further work on panels, drawing on the work of Morgenroth (2010), which explores in a purposeful yet profound manner the conflicts, and emotional and embodied responses that may arise in data interpretation panels, alongside the causes and possible consequences of these. This is explored more fully in Chapters 5-7.

Despite my continuing concerns about some of the ethical aspects of my work and of the ethical review procedure, I was granted approval following my second application. This enabled me to begin the search for participants.

3:10: 'Real humans'

Richardson makes a distinction between the methods and means by which researchers plan their work, and that which then occurs as we 'bring real humans into our stories' (1995, p. 115). In my own research, the process of turning the lengthy and often rather lifeless procedure of design and recruitment into such 'real humans' willing to take part in my study appeared almost as a form of research alchemy. Beedell describes this vividly in her account of working as a researcher, where 'the most exciting moments of my working days have consisted of that still, quiet interval between knocking on someone's door and the response these strangers offer upon their opening of that door' (2009, p. 104).

Before I could actually knock on any doors, however, I had to begin the long process of recruitment based on the criteria I had previously agreed in my ethics application. Accordingly, I wrote to over twenty organizations with an interest in the field, finally gaining permission to place an advert on the website of two national charities, with a third agreeing to recruit on my behalf.

In accordance with the requirements of ethical clearance, I completed an Information for Participants sheet (Appendix 4), which was sent out to anyone who expressed an interest in participation. The Information Sheet explained that the interviews would be recorded and transcribed, together with procedures for disposing of the recorded material in the aftermath of transcription. Many people did not contact me again after receiving the Information Sheet, whilst some women replied that their male partners did not wish them to participate. I can only speculate at the reasons why people did not

return contact. Van Den Hoonaard (2002, p. 185) suggests that some of the commonly used terminology within ethical clearance applications, alongside consent and other forms, may ‘instill fear in research participants about projects that actually carry minimal risk’, and therefore Information for Participants sheets need very careful phrasing if they are not to deter people from taking part. Nevertheless, ‘real humans’ did contact me and sustain this contact, and I remained both delighted and astonished every time that they did, particularly so when we came through the initial emails and later a telephone conversation to reach the interview stage.

I finally interviewed eight people, seven women and one man, transformed from names on a computer screen to real people, and each with an important story to tell. They are identified by pseudonyms throughout this study. Cathy and Andy are married and contacted me initially via an advert which they had seen on the website of a leading UK Charity. Ellie, Hafsa and Laurie were all approached by a charity with whom they were involved and which contacted them on my behalf. I met Chrissie at a different charity open day and later followed up the contact via email. Julia and Terri both came forward via mutual acquaintances and I contacted them both via email and telephone prior to their agreement to participate.

Importantly for me, given my initial struggles to locate myself within the research, several of the interview participants told me that they had only responded to my request because it stated that I had experienced the death of a child, thus endorsing both my decision and Dyregrov’s finding that ‘parents claimed it had been especially important that the researcher clearly understood our situation’ (2004a, p. 20). Most of the parents in my study seemed content with knowing that I was a researcher who clearly understood, and they did not pursue information regarding my own experience. However, two parents, Cathy and Laurie, were specifically interested in me as ‘one of us’ (Ellingson, 1998, p. 499), and this interest required careful consideration ethically

(see Chapters 5 and 7).

All interviews were conducted in the person's home or, if this was not possible, a secure and uninterrupted space, mostly chosen by them, and each interview was audio recorded. The interviews were prompted by a SQUIN, which was highly effective in eliciting their largely uninterrupted flow of speech.

Despite the emphasis of the ethics committee on their vulnerability as participants, the interviews were all 'quite trouble-free' (Van Den Hoonaard, 2002, p. 12). Some of the participants were tearful, although this was not so much a reflection of great pain, but rather indicated Klass's concept of the continuing bonds (1996) and their hope that 'their research participation might help other people in their situation' (Dyregrov, 2004a, p. 5). After the interview, once home, I thanked each participant by email and their feedback about the experience was generally warm and thoughtful.

Once the transcripts had been completed, all participants received a copy, apart from Ellie, who had previously asked not be sent one. Her choice casts some further light on the ethical review process, where so much is decided in advance, for whilst she was happy to give the interview, Ellie experienced the transcripts as something other and did not wish to be presented with her words set in stone.

Several participants did not wish to be anonymised as they specifically wanted their story to be heard and to make a difference, which proved a genuine lived dilemma for me within the field. We did, however, easily agree on their being anonymised within the work, according to my previous ethical undertaking, and they understood that their story would help to make a difference regardless of the name used.

The previously agreed consent forms also felt 'obtrusive and established an atmosphere of formality and mistrust' (Van den Hoonaard, 2002, p. 10). Although this was quickly dispelled during the interview, I was left reflecting on Richardson's notion of trying to

decide so much in advance on behalf of the ‘real humans’ who will eventually form the participants in our carefully planned research.

3:11: ‘The Listening Guide.’

As I have documented, BNIM was highly effective at the interview stage, whilst the multiple perspectives of the different panels helped me to guard against ‘wild analysis’, which Clarke & Hoggett posit as a potential risk of psychosocial methods (2009, p. 18). This was particularly important given some of the possible parallels between my personal experience and those of research participants. As Clarke and Hoggett discuss, data analysis does not ‘come later’, but stems initially from the ‘judgements and interpretations’ made by the researcher during the time with participants, no matter how rigorously they may try to avoid this’ (2009, p. 18). This was certainly the case for me, and the panels helped me face my own preconceptions more clearly, whilst also attempting to find meaning in their own, as I will explore more fully in Chapters 5-7.

However, if the panels opened windows on the worlds of the participants and the different ways their stories could be viewed, the processes involved in the BNIM stages that followed the panels seemed to slam this window shut again. I struggled greatly with the acronyms and prescriptive approach, and was left feeling that I had become ‘distant from the lives of participants’ (Van Den Hoonaard, 2002, p. 182). Whilst I had set out to produce research that listens and hears untold stories, making them audible to others, along the way I had somehow become so immersed in following the method precisely that I had could no longer hear the stories themselves. To reclaim this, I sought a new method that would help me in thinking ‘with’ the stories, and not just ‘about’ them (Frank, 1995, p. 25), thus offering a means of truly listening, a task Frank dubs ‘one of our most difficult duties as human beings.’

I was initially drawn to the ‘Listening Guide’ (Doucet & Mauthner, 2008), partly

because it introduced itself as just such, a listening method. Although that appears, as I write it, rather trite, it recalls my earlier discussions of the way that language is used both in academia and in the inquiry reports described in Chapter 2. As Stanley and Manthorpe (2004, p. 2) say of these inquiry reports, ‘form is also relevant’, and thus the words used can have a powerful effect on controlling our response to them. In contrast to the acronyms of BNIM, the ‘Listening Guide’ seemed to invite me from the outset to do just that, to ‘listen’. ‘The Listening Guide’ (Doucet & Mauthner, 2008) proposes a flexible structure, based around four main readings, which may be altered ‘depending upon the nature of the topic under investigation’ (Doucet & Mauthner, 2008, p. 405). The suggested readings are firstly for accomplishing the work of ‘doing reflexivity’, and secondly for focusing on tracing ‘the particular subject...and how this person speaks about herself and the parameters of their social world.’ The third reading is suggested as one ‘for social networks, and close and intimate relations’ (p. 406), with the fourth concentrating on ‘power relations and dominant ideologies that frame narratives’ (p. 406).

I found this structure of multiple readings useful, not only in helping to further my view of the story teller in a holistic way, but also in encouraging me to metaphorically move around the transcripts in a manner that reflected my own compound positioning as researcher, parent and social worker. Braun and Clarke (2006, p.16) suggest that the first stage of data analysis should be one of ‘familiarising yourself with your data’ by ‘repeated reading’ and ‘reading the data in an active way – searching for meaning, patterns and so on.’ I followed this advice in my multiple readings via the Listening Guide, searching for patterns within individual narratives and then comparing these across the entire ‘data set’ which included all the interviews and transcripts of the panel reactions (Braun and Clarke, 2006, p.6). Within the active process recommended by Braun and Clarke, I became my own one-woman panel, bringing all the different

perspectives I had gleaned to the multiple readings. I also added the panel interpretations as an extra column to those advocated in the Listening Guide's worksheet technique, as it was useful to see this visually mapped alongside the interviewee's words and the researcher's reactions and interpretations' which lay adjacent to this.

Braun and Clarke's (2006) guide to thematic analysis also states that total immersion in the data is vital. Where I had initially been immersed via the transcription phase, I had become temporarily detached from the data during the post panel stage of BNIM and the Listening Guide therefore allowed for total re- immersion.

What was enduringly problematic however was the difference, as highlighted by Hoggett and Clarke, between single case analysis and cross-case analysis. Hollway and Jefferson (2000, p. 70) stress 'the importance of keeping the whole in mind', a purpose narrative theorists like Riessman endorse:

Precisely because they are essential meaning-making structures, narratives must be preserved, not fractured by investigators who must respect respondents ways of constructing meaning and analyze how it is accomplished (1993, p. 4).

This meaning-making function was vital to my research purpose, and I therefore tried to stay as close as possible to the individual stories with the four-reading structure of the Listening Guide helping me to achieve this. Additionally, I share with Cooper (2009, p. 440) a 'special aversion to qualitative research in which lots of people are interviewed, and then the research is written up in loosely themed groupings of quotations from the research subjects.'

Nevertheless, the practical considerations of this thesis made it impossible to retain all the narratives in their entirety and this has consequently been the most difficult of all my methodological decisions. I eventually tried to solve it by drawing out threads from all the stories in Chapter 4, which, when woven together with the complete stories in

Chapters 5 and 6 and the chunks of Chapter 7, offer a holistic structure of both surface and depth, which after Richardson (1997, p.33) I have dubbed a ‘collective story’ .

The stories I have chosen to leave as un-fractured in Chapters 5 and 6 and the panel chunks within Chapter 7, are those that I felt most diversely addressed my research question and purpose, as well as illustrating the extreme reactions which may occur amongst analysis panels (Morgenroth, 2010).

The remaining five stories were analysed over time in a manner appropriate to my meandering methodology, which allowed for the experience of transcription, the panels, the Listening Guide and the draft writing which also took place over a period of years. Braun and Clarke (2006, p.16) endorse this process of data marination stating that ‘analysis is not a linear process where you simply move from one phase to the next. Instead it is a more recursive process, where you move back and forth, as needed, throughout the phases. It is also a process that develops over time and should not be rushed’. In keeping with this process I finally came to address the inevitable task of data reduction at a point where I was steeped in the stories themselves (Braun and Clarke, 2010) via a series of stages, culminating in the Listening Guide. The disadvantage of this familiarity with the stories however, was that I initially saw the themes as emerging from the data independently, forgetting as Braun and Clarke counsel that my active role as researcher was actually the major influence in this (2006, p.7).

Floersch et al (2010, p.408) suggest that a theme is not simply identified because of its frequency, but rather its ‘substantive significance ‘, which relates to how consistently it occurs across and within study participants. Rather than emerging independently then, the threads which I explore fully in the next Chapter were those which, on repeated readings of the stories, occurred regularly (Floersch et al, 2010) , which best answered my research questions and which explicated some of the deeper meanings inherent

within the stories themselves and in the panel reactions (Braun and Clarke, 2006). For example, I first identified the thread of temporality (see Chapter 4) as one which often occurred within the surface of the narratives. Parents frequently referred variously to actual times of day, intervals, delays and lengths of time and in exploring these references more deeply I began to understand the importance of temporality for containing anxiety (Giddens, 1991). At a deeper level still, lay the symbolic fracturing of time caused by a child death, which can be conceived as a 'death out of time' (Chalmers, 2007, p.3). Following this process with each of the threads therefore involved a progress from description, in which I simply noted the frequency of any given topic across the data set, to interpretation where I attempted to theorise the significance of the patterns, particularly with reference to the panel data and my own reactions (Braun and Clarke, 2006; Floersch, et al, 2010).

In identifying the wide threads of emotion and professional intervention (see Chapter 4) I initially noted every time a professional or an emotion was identified in each of the narratives. These were assigned different colours using felt tip pens (Braun and Clarke, 2006) so that I attained several transcripts with, for example, red for anger and purple for guilt. When I compared these across the stories I was able to see that emotional reactions were common to the narratives and therefore important for answering my research questions. Similarly, I colour coded for professionals with a different pen for each occupation, finally assigning them to a common thread.

This process follows Braun and Clarke's 'step by step guide' to doing thematic analysis (2006, p.15) in which codes are first identified (and in my work highlighted in felt tip pen), sorted into potential themes and then combined to form overarching themes. In my work these 'overarching themes' (Braun and Clarke, 2006, p.19) became the six threads identified in Chapter 4 which were formed from the process of conflating smaller sub themes. In creating the latter, Braun and Clarke (2006, p.20) advise staying mindful of

whether themes ‘cohere together meaningfully’ even if they seem disparate and the thread of ‘chaos and meaning making’ provides an example of this (see Chapter 4).

The themes which became the threads were initially identified by close attention to each individual interview, highlighting each part of the narrative as it evolved. I found the interviews followed a common pattern beginning with some form of temporal description, moving to the death and subsequently discussion of professionals. There were also differences in the narratives, for example only a few parents specifically mentioned Funeral Directors, where all mentioned medical personnel and the police. However as one of my research questions specifically focusses on common factors which emerge as helpful or unhelpful in the aftermath of child death, my analysis emphasized these, generating initial codes from individual narratives and then identifying repeated patterns across the data set (Braun and Clarke, 2006, Floersch, et al , 2010).

Due to my experiences with the panels ,where I had become aware of my own bias towards particular parents and their stories, when searching for patterns I tried to remain mindful of maintaining the element of surprise in an open approach that is recognisably psychosocial (Hoggett & Clarke, 2009). This openness also reflects my previous discussion of writing as a method of inquiry (Richardson, 1997), in which even the writing up itself is seen as a form of ‘data collection’ with different nuances appearing during the process (St Pierre, 2005, p. 970). Braun and Clarke echo this in their guide to thematic analysis, suggesting that ‘writing is an integral part of analysis, not something that takes place at the end, as it does with statistical analysis (2006, p.15).

Kincheloe (2005, p.317) describes embracing the surprises that arise during the research process and incorporating these into the methodology as ‘bricolage’. He urges researchers to:

Actively construct our research methods from the tools at hand rather than passively receiving the ‘correct’ universally applicable methodologies.

Although I was initially concerned about leaving BNIM behind, I now view this as consistent with the connection that has been one of the underlying purposes of my research. By tying the two together in a form of ‘methodological bricolage’, which is also fused with the panel perspectives, I have tried to break down the walls of the ‘defended community’, reinforcing this with the ‘team work’ so central to a psychosocial approach (Hoggett & Clarke, 2009, p. 21). Inevitably, however, there will be gaps, missing pieces and places into which I simply cannot see.

Speedy (2008, p. 138) suggests that one of the most fundamental of these spaces is that between the author and the reader, and thus advocates for writing which provides a link between the two, capturing the ‘readers’ attention’ and engaging them ‘in conversation’ rather than allowing the researcher’s view to be absolute. This resonates with my own aim of building dialogue and crossing boundaries, and thus I hope that I have created text that uses accessible language and that demonstrates my workings out, thereby inviting the readership as far inside as possible. As Pelias advocates, this is text that ‘asks for your consideration’ and is ‘listening for your answer’ (2004, p. 11).

3:12: Conclusion

This Chapter has been a tour around a meandering methodology, which is underpinned by three fundamental principles, the ‘psychosocial notion of both ‘surface and depth’ (Cooper & Lousada, 2005, p. 145), together with a commitment to building bridges between these, and perhaps most vitally, between thought and feeling.

I have described my initial anxieties as I began the research process and how these contributed to the defended practices implicit in the audit and inquiry culture I was critically appraising. Notable amongst these was my early position as ‘defended

researcher' (Hoggett and Clark, 2009, p.12), attempting to remove the personal both from my research and from my writing. The discovery of writers who advocated the use of self within research, together with the gradual emergence of a psychosocial understanding in relation to my own, helped me make the journey from defended researcher to reflexive researcher, and has altered the whole nature of the project.

This Chapter also discusses the concept of practice-near research (Cooper, 2009), which has provided another fundamental link, this time between the research itself and the way it may influence future interventions with parents experiencing sudden and unexpected child death. All participants in my study reported wanting to make a difference, and I have argued that confronting the 'myth of vulnerability' (Cottle, 2002, p. 536) furthers this by allowing parents to speak and others to listen.

This ability to listen has also been a theme within my methodology. I have charted my struggles with BNIM, together with my solution in combining it with the 'Listening Guide' in a form of methodological bricolage (Kincheloe, 2005). Bonded to this bricolage too has been the manner in which I have tried to write, and the language I have used. I have attempted to sustain this as a method of inquiry (Richardson, 2005), and one that is also embodied, thereby reflecting both Cooper's call for 'passionate research about passions' (2009, p. 432) and Pelias' pounding 'methodology of the heart' (2004, p. 2).

Finally, whilst I have tried to chart the decisions I have made, amongst them how and where to recruit, and who to include and why, I am also aware that in the end this can only ever be an 'account', and it thereby ironically shares much in common with Cooper and Lousada's description of the Inquiry Report into the death of Victoria Climbié:

The events recounted constitute a story...with many missing dimensions,

connections, lost threads and silences...factually coherent, but also radically incomplete (2005, p. 152).

In the following Chapters, I hope to fill some of these silences both with the narrative threads and complete accounts of sudden and unexpected child death, which form the heart of this research.

Chapter 4

4:1: 'Constructing a collective story'

'By emotionally binding people together
who have had the same experiences,
whether in touch with each other or not,
the collective story overcomes some of
the isolation and alienation of contemporary life'
(Richardson, 1997, p.33)

In the previous Chapter, I described the aversion I share with Cooper to 'research written up in loosely themed groupings of quotations' (2009, p. 440), combined with my corresponding struggle over the inevitability of some form of 'data reduction', a 'task which confronts all qualitative investigators' (Riessman & Speedy, 2007, p. 435). This was an undertaking that initially felt impossible to achieve, as it was linked to the intense gratitude and loyalty I felt towards the eight people who had responded to my research request. They had invited me both into their physical spaces and into their emotional ones, trusting me with stories of pain, loss and courage. I was also aware that one of the only times they may previously have shared these details within an interview setting may have been with the police, and this increased my consciousness of how to speak for people who had already been portrayed as either victims or suspects.

Viewing their stories as data or 'material suitable for the 'codification of procedures' (Richardson, 1997, p. 20) did not seem to me sufficiently respectful of these very real people, neither did it adequately account for warnings such as those given by Riessman and Speedy against over-use of 'reductionist techniques' (2007, p.434) in research studies where too often:

Lengthy accounts ...were abstracted from their contexts of production, stripped of language and transformed into brief summaries (2007, p. 434).

Writing of her own desire to co-research ‘unheard of stories’, Speedy refers to ‘the possibilities that lurk beneath the surfaces of the ‘statues’ that have been made of them’ (2008, p. 57). I feared that in fracturing the text into sound bites, I would similarly make ‘statues’ of the words, thereby setting them in stone, devoid both of context and of meaning. This was a process that already seemed to have taken place within so much of the literature in this field, where parents' views were ossified out of existence in favour of professional perspectives. I did not want my research to further re-produce this.

In ‘Fields of Play’ (1997), Richardson describes being similarly ‘frozen by indecision’ when faced with how to represent the people within her research in a way that stayed close to their words and experiences, and furthered a sense of both ‘emotional needs, and spiritual connectedness’ (p. 5). Imagining research as a ‘tapestry composed of threads of many different hues’, Richardson poses this question, so reflective of my own dilemmas:

How do we speak the tapestry...because wherever text is being produced, there is the question of what social, power, and ...relationships of production are being produced. How does our writing, including this writing, reproduce a system of domination and how does it challenge that system?’ (1997, p. 57).

This metaphor of the tapestry recalls Winterson’s image of the cat’s cradle with which I began Chapter 1, together with the symbolic knots that I had often envisaged linking together otherwise disparate elements within my research. When I viewed the themed groupings, each one connecting with the others to form an overall structure, I began to see how I might weave the stories in this thesis together to form a ‘collective story’, (Richardson, 1997, p.33) rather than leaving them as ‘accounts of lives...abstracted from their contexts’ (Riessman & Speedy, 2007, p. 435).

Richardson (1997 p. 33) defines the ‘collective story’ as a means of ‘giving voice to silenced people’ who are ‘socially constructed ...in the context of larger sociocultural and historical forces,’ a description that blends with my aim of giving voice to largely

untold parental narratives of sudden and unexpected child death.

Additionally, when I recalled my own unsuccessful attempts to find accounts of experiences similar to my own following Joe's death, it was the collective story that I had hoped would call to me, 'That's my story. I am not alone' (Richardson, 1997, p. 33). The notion of the collective story combined with the image of threads, which link to form a united structure, allowed me to tackle the inevitability of 'data reduction' (Riessman & Speedy, 2007, p. 435). Although it is not a perfect solution, I have chosen to treat five of the stories as threads within the collective, whilst retaining two as the complete accounts that constitute Chapters 5 and 6. In Chapter 7, I offer Laurie's story in the same chunks that were presented to the panel. My hope is that all eight narratives remain in dialogue with each other as well as with my own experience (see Chapter 1), thus emotionally binding people together, as Richardson suggests, whilst at the same time creating a fuller understanding of parents experiences of sudden and unexpected child death and what may be learned from these.

4:2: 'Threads of many different hues'

I searched for common strands within all the narratives as described in Chapter 3. My experience of the data analysis panels and the literature on sudden and unexpected child death has highlighted the dangers of relying too heavily on researcher explanation or interpretation. Mindful of this, I have used parents' own words wherever possible as a means of 'revelation' assisting towards making these experiences 'thinkable' (Cooper & Lousada, 2005, p. 23). The threads discussed in this Chapter are drawn from five of the narratives and link to those in the complete accounts which form Chapters 5–7. Chapter 8 offers my analysis, which connects the parental narratives and threads to both the literature and to my experience of researching sudden and unexpected child death.

The five speakers in this Chapter are Terri, Hafsa, Andy, Chrissie and Ellie. The latter

four came forward in response to charity links, whilst Terri was reached via a personal source. Andy, in his late twenties, is the husband of Cathy, and her narrative describing the death of their very young son forms Chapter 5. He was the only male willing to participate in the study. Hafsa is in her early thirties and her Muslim religion and lone parent status are very significant within her story. Hafsa's daughter died at only a few weeks old, eighteen months prior to the interview. Hafsa has an older daughter and another young baby, having become pregnant very quickly again following the death. Ellie is in her early thirties and has three surviving children. Her daughter, a second child, died at 71 days, 11 years prior to the interview. Chrissie is in her thirties and her son died, at a few weeks old, less than a year prior to the interview. Chrissie has a stepson by marriage but no other children of her own. Lastly, Terri is in her fifties and describes the death of her son, aged six, twenty one years prior to the interview. He left a surviving sister and Terri had two subsequent children following the death.

As I described in Chapter 3, common threads were surprisingly easy to discern within the five narratives, with comparable events occurring and similar emotions expressed, although I was ever open to the element of surprise, which Hoggett and Clarke (2009) cite as fundamentally psychosocial. Variations did assert themselves in the diverse ways that meaning was constructed from events, and also in the importance that individual narrators placed on different experiences, particularly in the aftermath of the death. All five accounts share a strikingly collective 'beginning-middle-end sequence' (Sarbin, 1986, p. 248), and it is with this and with the notion of time which underlies such structuring that I want to begin my discussion of the threads.

4:3: 'It's all been in pods of time': threads of temporality

Time enacts itself in complex ways within and outside the narratives. They are all narratives of remembering, which were spoken at a fixed point in time within an

interview situation. In telling their stories, the participants are choosing what to remember, and, in so doing, they are ‘giving meaning to the past from the point of view of the present and future’ (Richardson, 1997, p. 30). In the act of recording and writing about the interviews, I too am remembering the remembering, an undertaking which recalls a set of Russian dolls, one contained within the other.

Giddens (1991, p. 48) suggests that ordering activity within the structures provided, both by daily time and the concepts of past, present and future, creates a general sense of ontological security in which ‘the world is as it is because it is as it should be.’ Hoggett echoes this view, suggesting that routine activities, such as work, reinforce ontological security by offering ‘orderly and predictable’ routines, which prevent people from ‘thinking or feeling too much’ (2000, p. 57). Disruptions to this sense of security, such as that presented by sudden and unexpected child death, can therefore be seen to provoke the ‘experience of catastrophic anxiety’ (Hoggett, 2000, p. 67), which I discussed in the previous Chapter.

This catastrophic anxiety stems in part from an unconscious fear of annihilation posed by the threat of death and loss, which serve as a reminder that ‘non-being is part of one’s own being’ (Giddens, 1991, p. 49). Arguing that ‘the unconscious cannot conceive of its own death’, Giddens suggests that primary anxiety therefore develops in relation to the loss of others, notably care-givers, from whose possible absence ‘fears of death and sickness emerge with regard to the self’ (1991, p.49). Defences against this anxiety lead to the splitting described by Klein, which in contemporary attitudes to death manifest in Kellehear’s distinction between shameful deaths and good deaths (see Chapter 2). Kellehear suggests that the moral distinction between the two is provided by ‘knowing the right time to die’ (2009, p. 62), which renders the sudden and unexpected death of a child truly a ‘death out of time’ (Chalmers, 2007, p. 3), and contributes to the incomplete picture of the experience contained both within literature and within training

material.

Amongst the multiplicity of practical and emotional tasks faced by parents then, is a symbolic one of repairing the ‘thread of continuity’ (Hindmarch, 1993, p. 24), which has been so harshly broken by their child’s death. Richardson suggests that narrative accounts can help in this repair, by retrieving the past and reliving it in the present so that a future is made possible (1997, p. 30). This is demonstrated within this research by the parents expressed desire to ‘make a difference’, thereby giving continued purpose to their child’s life, together with a ‘place for experience’ (Hoggett, 2000, p. 84).

More pragmatically within the narratives themselves, time is utilised as an underlying structure via common use of a ‘beginning-middle-end-structure’ (Sarbin, 1986, p. 248), which helps to order the scenes of chaos and trauma, and thus to make them ‘hearable’ (Burr, 2003, p. 191). Beginnings frequently feature the death itself and often the hospital, whilst middles show the parents returning home, disoriented yet trying to accomplish necessary tasks. Ends commonly illustrate a coming to terms or reparative, meaning-making capacity within the narrative telling.

Ellie demonstrates a very clear ‘beginning-middle-end structure’ in her description of the course of events over time:

It’s all been in pods of time if that makes sense...there was the initial event and then a few months later we got all her things back and tried to put life back to some kind of normality. We got on an even keel and then decided to have another baby...

Each of the five narrators begins their story by locating themselves at a point in time. Ellie and Andy begin with the day or time of death, in Andy’s case ‘it was a Saturday morning.’ Chrissie also begins with the specific date of death, whilst Terri locates this in both the past and the present:

Well it’s a long while back; he’s just had his 27th birthday, amazing isn’t it because he was 6 when he died so it’s 21 years now.

Hafsa begins her narrative by locating the death of her baby in the recent past but also seamlessly within the present and the future:

It's only been a short time...well it was last March that I lost her...she died last March and a couple of months later I got pregnant again and in my mind it was like a kind of continuation, which sounds awful in a way but I was just beginning to unleash this love and something else had stopped dead.

The endemic use of time as a means of beginning the stories demonstrates how powerfully it organises life, as Berger and Luckmann suggest:

...In cases where I may be 'disoriented' for one reason or another I feel an almost instinctive urge to 'reorient' myself within the temporal structure of everyday life. I look at my watch and try to recall what day it is. By these acts alone I re-enter the reality of everyday life (Berger & Luckmann, 1966, p. 42).

With an experience as shattering as sudden and unexpected child death, reality is transformed and the consequent disruption to everyday life is also depicted within the stories, as Ellie observes:

It's funny how such a normal day...well we had been out shopping ...to buy a few bits of pieces with gift vouchers in the afternoon and to go from having such a normal afternoon to by 7 o'clock our whole lives had just been decimated.

Andy, in his description of the hospital that forms part of the beginning of most people's narratives, utilises time graphically to illustrate his sense of powerlessness, with repeated phrases such as 'it felt like a lifetime', together with his evocative description of the doctors' prolonged attempts to keep his child alive:

It was just dragging it out. It was quarter past 7 in the morning we found him and it wasn't until half past ten that night they switched off the machine...longest day of my life.

Similarly, Ellie invokes time to illustrate her sense of dispossession:

Within the space of about three quarters of an hour, everything had just been torn apart and I remember sitting there and thinking 'well what do I do now?'

Andy also references unnatural time when he describes the medical staff getting 'a

heartbeat back by giving him drugs', together with his own sense that this was simply 'dragging it out', a phrase he uses often. Andy's sense of impotence in the face of this attempt to raise his child from the dead is vividly portrayed by his joke:

What's the difference between God and a surgeon? God doesn't walk around thinking he's a surgeon.

Many of the other parents use the idea of waiting as a platform to illustrate difficulties with professionals both on the day and in the aftermath of the death. Chrissie describes waiting in the hospital for an 'Inspector from Project Indigo', for whom they 'waited and waited and waited. It must have been at least five or six hours from us arriving at the hospital.' Andy, Hafsa and Ellie all give lengthy accounts of waiting for contact from the Coroner, together with delays with both the post mortem and other procedures, as Hafsa describes it:

I finally got the post-mortem report but only because I'd said look I'm taking this to the Chief Executive because it's ridiculous that it's taken this long...and suddenly as if by magic the report was ready within three days.

As the narratives reach their ends, time is used increasingly as a tool for remembering and building meaning, as well as for expressing regret. Hafsa reflects the latter in looking back on her baby's life:

The time I had with her, well if anyone had told me you've got 70 days with her, make the most of it...but you don't. You do all your normal things like 'Oh my god I've got to do this and remember to do that.'

Ellie, who has had longer since the death than Hafsa, also uses time in her meaning-making:

It would be easy just to say she was never here...to shut it off and just pretend it never happened...but for your own good you can't just back away and we were lucky enough to have her for 71 days, 71 happy days and if people don't get to have that time, maybe if their babies are stillborn or they've been stuck in an incubator for all the life they've had. The whole of her life was a happy time; it was something to properly celebrate.

Within these end sections, descriptions of time shift gear from the past to locating the parents more firmly in the present, with a sense also of looking towards a future, in which participation in the interview itself may form a part. The talk here is of becoming involved in support organisations and other charitable events, as Ellie and Hafsa both describe:

...And about 6 years after she died I got in touch with the Trust then because I wanted to offer some support because I had so much it was unbelievable (Ellie)

And I got to do a walk in memory and that helped and I thought if I'm doing something useful; fundraising whatever to stop me dwelling on it and help other people at the same time as raising awareness (Hafsa)

Ellie effectively expresses her wish to keep her child's memory alive in a culture that is unwilling to allow this:

I've got a friend and she's in remission from cancer but she can talk about that because she's getting better, but when you mention the death of a child, it's like 'gasp...we don't want to hear about that, just shut that away' but I think it's important to keep the whole awareness thing going...

All five narratives explored here blend together 'autobiographical time, mythical time and narrative time' (Speedy, 2008, p. 7), and demonstrate powerfully how these can be used narratively to 'tell one's story...and deeply give meaning to the past in order to give meaning to the present life of the person' (Richardson, 1997, p. 30).

4:4: 'I was a bit annoyed': threads of emotion

One of my primary aims in beginning this study was to help meet the Kennedy Report's recommendation that 'professionals ...be sensitised to emotions being experienced by parents' (RCPATH & RCPCH, 2004, p. 12). Emotion, therefore, is a highly significant thread on which to draw within these narratives.

Guilt is named as an emotion within all five accounts. Terri, for example, describes her circumstances at the time of her son's death when she was a young single parent, and

states, 'this is where the guilt already starts coming up.' Hafsa, a single parent with two young children, was staying with her sister at the time of the death. Her sister offered to look after the baby, giving Hafsa a rare opportunity to go shopping alone. Shortly after she returns, Hafsa finds the baby dead in her cot. She expresses her feeling of guilt poignantly:

My conscience is pricking me and I'm thinking 'why did you not go up and check on her, you're meant to do it every ten minutes or is it every 20 minutes, but I wasn't there and I just wanted to get away from my kids for a bit, you know, I am on my own and if you get an offer to help you take it with both hands.

Hafsa returns to this towards the end of her interview querying whether

She just died in her sleep or did she wake up and call for me and I wasn't there or I just didn't hear her 'cos the telly was on...when you're at home, you have your monitor on but I was at my sisters and I wasn't near the room and I wouldn't have heard her...you know you just go over and over it trying to think why was I not there for her in those last few minutes, I was there for my mum, why couldn't I be there for my baby?

Burr suggests that such feelings link to common cultural assumptions about culpability:

In our culture, we see ourselves as to some degree responsible for catching a cold; we may have gone out without our coat...this moral dimension has implications for the extent to which we can claim sympathy (2003, p. 37).

In cases of sudden and unexpected child death, where a 'suspicion of child abuse profoundly affects people' (Cleaver & Freeman, 1995, p. 83), the feelings of guilt expressed by the narrators are often linked to fear focused on the police response. As Chrissie states:

The fear about being blamed for his death overrode a lot of the initial grief. Instead of thinking 'how will I live without my son?', I was thinking, 'do I need a solicitor?'

Such fear as expressed by Chrissie is often articulated through references to the media high profile cases of child abuse. Dent and Stewart (2004, p. 57) refer to the influence of the media in cases of sudden and unexpected child death, and Hafsa reinforces this,

describing ‘CSI’ and ‘all the things you see on the telly’, whilst Andy states ‘I was aware of the Baby P case.’ Chrissie expresses her fear vividly:

There is a thing in your head which prompts fear when the police want to talk to you and if you’ve ever watched crime drama on the TV you have a perception that they can somehow read you like Derren Brown...

These feelings of fear and guilt, expressed so lucidly through popular media depictions of authority, cast shadows on the ‘Kennedy Report’s’ oft-quoted it ‘is every family’s right to have their death properly investigated’ (RCPath & RCPCH, 2004, p. 1). As Chrissie reflects, the police prompt ‘fear’ in many people and thus it is vital that investigating professionals are aware of this as a common emotion experienced by parents (RCPath & RCPCH, 2004, p.12).

Alongside the guilt, parents often implicitly express anger towards professionals. Dent (2000) found that parents’ anger in cases of sudden and unexpected child death was most often directed at others, whilst guilt caused many parents to search ‘for what they did to cause the death’ (Dent & Stewart, 2004, p. 57). Both these emotions are reflected in the five narratives discussed here.

Ellie, who tries to emphasise positives within her narrative, expresses anger tacitly in a long story of trying to get her dead daughter’s clothes back from the police. She describes enquiring about the clothes and being constantly told ‘we have to hang onto them.’ Four months after her daughter’s death, Ellie enquires once more and is told ‘they weren’t sure where they were’, which puts her into a ‘panic.’ Finally, Ellie contacts the Coroner, who has the clothes in his office and she is told to collect them from the police station, which Ellie describes as follows:

I don’t quite know what I was expecting but I was handed back two big brown cardboard envelopes and they were sealed with a tag...and I just felt that this was really impersonal I mean they could have handed them back to me without the bag...it felt like they were, well they were evidence I suppose.

Ellie also describes her anger with the policeman, during the investigation interview: I felt like he was wasting time...and I wanted him to go and find me an answer from all these questions.. .

Andy is particularly angry with professionals, whom he also identifies as ‘blaming everybody else.’ He apportions much of his own anger to a lack of ‘common courtesy’:

I used to run a garage and we specialised in MOTs...and I think we used to keep people more informed about their cars than they did...it’s just common courtesy...that’s all it needed really...that would have been such a big help.

Andy’s most forceful statement, however, is towards the end of the interview when he declares:

The day itself and how we were treated was worse than actually losing him.

Although anger appears in the narratives, it is frequently hidden behind other emotions. Chrissie, for example, describes being ‘very unhappy’ at being taken home in the back of a police car, when what she seems to be reporting is anger. Ellie also often touches on anger, but then tones this down, as can be seen here in her description of the police interview:

He was asking me all these questions but he kept staring at the baby in this Moses basket and...I was a bit annoyed and I thought actually I shouldn’t be annoyed, you’ve probably never seen a dead body before, let alone a dead baby.

Dent and Stewart account for the frequent suppression of anger, suggesting that it is ‘not necessarily seen as a socially acceptable part of grief’ (2004, p. 172), whilst Batt suggests that ‘the urge to co-operate with authority is compelling; it is irresistible to most ordinary people’ (2005, p. 71), which may also account for the reluctance to express anger. A fuller exploration of this is given in relation to ‘Cathy’s story’, which forms Chapter 5.

Feelings of shock and disbelief also feature alongside guilt, often in relation to professionals, as Terri illustrates:

I do remember when the police showed up thinking they can't possibly think I've done something...do they seriously think I mean do they honestly think that I could've killed him?

Many of the narrators report being 'in shock', particularly during the beginnings of the narratives. This is confirmed by Dent and Stewart (2004, p. 138), who suggest that for many parents 'shock and disbelief may prevent the reality of the situation from being absorbed.' Hafsa evidences this in her description that it all seemed a 'nightmare, or a dream, or a trance', and describes rocking her baby for hours in the hospital, all the time thinking, 'It's time to feed her; if I feed her she'll be fine.' Chrissie sums up the feelings of many parents when she says 'I felt like I was dead as well.'

Recalling Sidebotham and Fleming's emphasis on 'thorough systematic investigation of the circumstances of death ...and a sensitive, caring approach to supporting the family' (2007, p. 98), which they suggest are not 'mutually exclusive', the feelings of dispossession described here point to the intense complexity of achieving this. Hafsa's powerful disassociation and Chrissie's sense of being 'dead as well' both suggest that if the two aims are going to be successfully linked, then professionals will require a profound, rather than a superficial, understanding of the emotions experienced by parents.

As with guilt, feelings of shock and disbelief link to concepts of media and technology. Hafsa vibrantly describes finding her baby dead in a passage that also links to time with technology and the contemporary drive to renew:

I mean in the age that we live in everything's rechargeable isn't it? So my first thought was 'that's ok', I can fix it. Where's my charger. Your camera, your 'phone and everything. You can just re-charge it or get another one- or new batteries...

For Hafsa, the feelings of shock also manifest as 'flashbacks, which you just sort of re-

play,’ whilst for Chrissie the shock is physical and she cannot return to her house where the baby died.

Also reported in the narratives is ‘felt sense’, similar to that which I experienced when Joe died. Gendlin describes ‘felt sense’ as an ‘awareness of the border zone’ between the conscious and the unconscious’ (2007, p. 16), which echoes Winnicott’s notion of ‘transitional’ or ‘potential space’ (cited in Hoggett & Clarke, 2009, p. 16), in which a different form of knowing emerges.

All five narrators briefly reference this sense of ‘knowing’ in relation to their child’s death, as illustrated here by Hafsa:

I knew what had happened straightaway. I thought that’s it...she’s gone.

In his account of terminal illness, Frank (1995, p. 141) also speaks of spaces where ‘embodied knowledge is in excess of speech’, thus reflecting this space of knowing yet not knowing. Whilst such accounts can be reduced to mechanisms for retrospective meaning making, they form a strikingly common thread, which links with my own experience of Joe’s death (see Chapter 1).

These accounts of felt sense or knowing are significant, for they may affect the ways in which parents respond at the point of police interview. Sidebotham and Fleming (2007, p. 99) suggest that, in most cases of sudden and unexpected child death, the parent or carer will immediately seize the child ‘to establish any responsiveness.’ However, this is not what I did myself, and the narratives shown here, together with the accounts of felt sense, show that there is nothing that is done typically as Sidebotham and Fleming suggest, a factor which is crucial within the investigation that follows.

4:5: 'She really did put herself on the line': threads of professional intervention

One vivid thread in all the narratives is the succession of professionals that intervene with the parents during the beginnings, middles and ends of their reported experience, and frequently beyond. These professionals densely inhabit the narratives and are often accompanied by value judgments, which clearly demonstrate the findings of the Royal College of Nursing (1995), as discussed in Chapter 2, that the care provided to relatives at the point of death can greatly affect the subsequent bereavement process.

The police are inextricably woven into every narrative to a greater or larger extent, and appear very near the beginning of each. For Terri, the police do not feature as a key part of the experience, as she reports:

I don't really remember, I just remember the health visitor...I don't think the police stayed terribly long.

However, for other parents the police intervention and their response to it forms a significant part of their narrative and is mostly associated with stigma. This forms a sharp contrast with the Appendix to the Kennedy Report, which, as discussed in the Introduction, reports the surveyed opinions of 893 parents. According to the Report, a number of these parents reported having been 'reassured by the police investigation because when they have come through it they feel they have been formally exonerated of any suspicion of wrongdoing, so that no stigma can remain' (RCPATH & RCPCH, 2004, p. 55). However, for most parents in this study, far from removing stigma, the police investigation directly contributes to it, and when they speak of the police it is often as a symbol of authority and fear.

The dichotomy between the reassurance cited in the Kennedy Report and the different

reports from parents in this research can be located within Hoggett's theme of 'allusion', which forms the link between 'a violence that is embarrassed or ashamed to speak about itself and the everyday life which proceeds in the shadow of this force' (2000, p. 105). Furthermore, he suggests that when this 'violence' is 'alluded' to rather than made explicit, 'it vanishes' ((2000, p. 105).

Hoggett's analysis has uncomfortable resonances with the Kennedy Report's alluding to parental experiences by placing these separately in an Appendix, where the powerful stigma often associated with police investigation is vanished by the emphasis on exoneration and no stigma remaining.

The parents in these five narratives and those which form Chapters 5–7 tell very different stories, which point to Hoggett's discussion of the violence that is always present at the borders of 'everyday life':

So we phoned emergency services and probably naively we imagined it would just be an ambulance that would turn up and help but it was actually a police car (Ellie).

Two uniformed officers arrived...a great big guy with full uniform on (belt etc) and not sure if he was armed, I didn't really look to check (Chrissie).

Well we had armed police, because I saw a Taser and I said 'Is that a Taser gun? And she said 'no it's a real gun' (Andy).

The police shut the bedroom door and we weren't allowed back in...And I remember thinking 'Crime Scene' (Andy).

Hafsa vividly depicts her fear of the police, which is endorsed by Chrissie:

I'm thinking 'bugger, I'm in trouble now, that's it I'm going to get handcuffed and you know what have I done wrong because I hadn't checked her enough and I'm going to get done for that you know (Hafsa).

I don't have any contact with the police, on either side of the fence, including any friends/relatives in the force, we simply don't know any police officersyou have a perception they will decide on the truth and fit a case against you around it... (Chrissie).

These anxieties of having done something wrong are aggravated by the very real language and behaviour used in the Rapid Response:

And then we had two plain clothes turn up, 'The Child Abuse Team' their business cards said, or words to that effect, rather than child protection...so you were sort of guilty until very much proven otherwise (Andy).

I didn't like being in the back of a police car...when we got to our house; several neighbours were outside keeping an eye. There was a uniformed officer outside and a squad car (Chrissie).

These accounts of the police cast further doubts about the efficacy of interviewing parents so soon after the death of their child, when, as Klass reports, the 'initial response to... death is disassociation' (1997, p. 151). This is powerfully evidenced by Chrissie:

I was lying on a gurney...I didn't want to be awake and was considering asking for sedation...and he sat by me and asked me the basics, my name and baby's name and how old...

Andy describes how the police took him away for interview, in the hospital, whilst his son was still being kept alive via life support:

The two coppers interviewed us separately, they took us off whilst they were still trying to resuscitate him...which was a bit much.

Ellie gives a bizarre description of being interviewed in hospital with her dead baby lying in a Moses basket beside her:

My husband was taken away to a separate room in the hospital by a police sergeant and the policeman had a sort of list of questions to run through like what her feeding habits had been, where she slept and basically how her day had been before we realised she wasn't breathing...

The memories of the police evidenced by the parents in this study paint a very different picture to the one depicted in the Kennedy Report, where parents were commonly reassured by the police investigation (2004). This once again highlights the complexity of achieving 'a thorough, systematic investigation of the circumstances of the death

which also integrates ‘a sensitive, caring approach to supporting the family’ (Sidebotham & Fleming, 2007, p. 98).

Hafsa’s account offers yet another prism with which to view this notion of ‘thorough, systematic investigation’, as, far from experiencing investigation, she is left waiting for it:

I was thinking, you know...of all the things you see on the telly...don’t they need to tape off the room and take away bedding and evidence. Well they didn’t do anything. But we left everything as it was just in case they needed to.

This sense of the inconclusivity of police investigations is particularly present at the ends of narratives, as Ellie and Andy both describe:

And as I say they never...we were just kind of left, well we never had any sort of conclusion from the police (Ellie).

So then the police weren’t involved after that but they never sort of rang or got in touch, to say or to tell us anything...we just didn’t hear from them again (Andy).

Ellie and Chrissie also report having to attend the police station months after the death to collect the clothes that their babies had been wearing when they died. Their accounts are a sharp contrast with Stead’s description (1997), referred to in Chapter 2, of someone folding her son’s clothes and shoes and not dumping them into a property bag.

Despite powerful memories and strong feelings towards the police, many of the narrators of these five stories also made a considerable effort to understand the police perspective and to show compassion, thereby avoiding the splitting described by Klein, and helping towards achieving the depressive position of recognising all sides (see Chapter 1).

Chrissie, who describes so powerfully her own fear of the police, also portrays the police officer who was first on the scene as ‘mostly soft spoken and looked terrified’.

Andy, who is most candid with his anger, similarly states that ‘the actual uniformed

officers were pretty good. One of them had a baby the same age so I think he was finding it pretty hard'. Hafsa adds to this, stating 'you do feel like you're in trouble but they have to do it haven't they? It's part of their procedure.'

It is Ellie who 'humanises' the police the most in a powerful anecdote about encountering the police officer who interviewed her several years later whilst waiting for a routine health visitor appointment. Ellie is initially traumatised when she sees him with his own baby:

He had this baby in his arms, this little thing, wrapped up in a pink shawl and I could just see him taking my baby away...I started crying and the health visitor asked what was wrong and I said that was him, that was the policeman...and she says 'oh right, ok, what can I do' and I said 'well nothing its nobody's fault'...it was just a flashback to that night although it was about six years since I'd seen him...but obviously having his own children sort of prompted something inside him and he got in touch with the support organisation I volunteer for and he ran the half marathon and asked if he could mention my baby's name in his 'just giving page' because that was his inspiration for doing the run.

For Ellie, this story helps her to understand the professionals that are involved and the personal effect it has on them. By so doing, she avoids the splitting of us and them, consistent with Klein's paranoid-schizoid position, moving instead towards an understanding of sudden and unexpected child death as an event that has affected everyone involved, and thus locating the bad inside the experience rather than within the participants (Hollway & Jefferson, 2000).

Aside from the police, medical staff also feature as dominant professionals within the narratives, often with similar attempts to unite good and bad. Andy, for example, describes the doctor in the first hospital he has contact with, as 'quite good and kind of honest,' whilst others receive less favourable comments.

For most people following the deaths, paramedics are often the first point of contact and they therefore commonly appear at the beginning of the narratives. Andy describes the paramedic talking him through trying to resuscitate his baby:

I was talking to the guy on the phone and he was telling me what to do to try and resuscitate him...so I was trying and blood was coming out of his mouth and I kept clearing his mouth but nothing was happening...I've never done anything like that before so I didn't really know but the guy on the 'phone was very good.

Hafsa also vividly describes her sense of panic with the emergency services:

So I was saying to the 999 people no you're not listening, you need to send someone now, and then the paramedics came and they tried to give her mouth to mouth resuscitation as well but I said no I'll do it but I just couldn't and I felt her forehead and it was starting to get cold.

In the middle of nearly all the narratives there is a description of waiting in a hospital. It is generally medical personnel who take the narrative baton from the police within the marathons these parents find themselves running on the day of the death. Hospitals are associated with a sense of disassociation and alienating protocols. Hafsa gives a powerful illustration of this as she describes transporting her dead daughter within the hospital:

They put her in this basket and we had to carry her through the hospital and I couldn't understand it but I thought, maybe that's why she's in a basket, so other people won't know she's dead while we're walking past them.

For Andy, whose baby is kept alive on life support within the hospital, the process is described as mostly painful and alienating, similar to his descriptions of the police:

The doctor said he'd come and get us once they had got him settled and we waited. It must've been an hour, an hour and a half or so, it felt like that...Then it turned out they'd forgotten to come and get us.

Andy also describes a language barrier, and, whilst acknowledging that a lot of 'foreign doctors have better English than I have' he states regretfully, 'but this one wasn't particularly good.' He is quick to follow this, however, with 'the nurses they were good', demonstrating his investment in fairness and understanding.

Procedural blunders were a recurrent theme in the narrative. Andy's son is transported between two hospitals, which led to professional delays and errors. He describes this as

follows:

They were blaming everything on the fact we were moved between hospitals and so no-one liaised between the different counties...they were all saying 'well it happened in P hospital', but in this day and age how difficult is it for someone at one hospital just to ring or email the other one? I don't know...we just felt on our own with it really.

Despite his criticisms and obvious anger, Andy continuously demonstrates his attempt to unite good and bad in the balancing comments, which often follow his reproaches, for example, his comment that the 'nurses...were good' and his description of the 'human' nurse who 'lost a baby to cot death herself about twenty years before.'

The Kennedy Report states that 'Coroners play a vital role in cases of sudden unexpected infant death' (RCPATH & RCPCH, 2004, p. 9), and in these narratives, they are the only professional group who receive collective censure. For most parents, the death will be their first experience of contact with a Coroner. All the narrators report distressing and alienating experiences with Coroners, making their vital role both worrying and in need of improvement. Andy describes the Coroner as remote and unaccountable in that 'he just blamed everyone else', whilst Ellie reports having to give permission for a post mortem but being told 'it would happen anyway, whether we signed it or not'. Everyone describes the waiting and procedural delay caused by Coroners, echoing Hafsa's account of waiting:

20 weeks for the post mortem...I had to chase them up...and even then I can't remember half the legal terms, but it was like going into court.

There are professionals however, who are described in the narratives as being of great support, with health visitors depicted most positively. Terri, Andy and Ellie all describe health visitors as helping them cope. Terri encapsulates this as follows:

Thank god for that health visitor, who I don't even know if I had met before, this lovely woman... She was the only thing that was keeping me even vaguely together.

Ellie, whose narrative is filled with particular anecdotes about professionals, tells the

tale of a nurse that powerfully illustrates the difference that they can make to the parent experience, even years after the death. In her story, Ellie, who has just given birth, requests a hospital apnoea monitor but is told she has no reason for one. The new baby is healthy, and Ellie's only reason for wanting a monitor is her enduring fears from the death of her daughter years before. Procedurally, this is not a sufficient reason to issue a monitor. However, emotionally for Ellie, the monitor is vital for her to feel confident enough to take her new baby home, as she describes:

And of course I just immediately burst into tears...So this nurse basically smuggled me out of the hospital with the apnoea monitor...she really did put herself on the line to do that for us. I think she had some idea of what it actually did mean to have that but I just thought it was so insensitive of that doctor to say 'no you can't have it'...

Other professionals are alluded to within the narratives, but none take centre stage as strongly as the police or the medical personnel. Funeral directors, mentioned by both Terri and Hafsa, are seen as helpful. Terri mentions that the Co-op 'do free funerals', thus alleviating an important practical and financial strain. Ellie, Terri, Andy and Hafsa all mention referrals for counselling, which Terri finds invaluable and Ellie conversely describes as being a 'fat lot of good to me.' Hafsa also mentions the 'hospital bereavement team', although she is disparaging about this service:

They had a very sympathetic voice but they didn't really know what I was saying. It was all 'ooh...ah...how are you doing? Well I was 'no as a matter of fact, tell me what's happening, cut the crap, you know she's gone now, I'll deal with that, I need to know...why you are not following the procedures, you know?

Many of the parents spoke about voluntary support organisations, who, in Ellie's words, are 'just brilliant', although initial contact with these is often made at the parents instigation rather than through any formal referral system. Ellie describes 'picking up the 'phone' to her local support organisation after the birth of her youngest child, when 'everybody just assumed that I would be fine.' She telephones the support agency to say 'I'd quite like some support thank you very much' and they send out a befriender. Later,

Ellie undertakes ‘befriending training’ herself, whilst Hafsa and Chrissie also become support agency volunteers following the deaths of their children. These voluntary agencies feature strongly as source of both formal and informal support within the narratives.

Despite the Kennedy Report’s call for improved communication between ‘professionals and between professionals and parents’ (RCPATH & RCPCH, 2004, p. 12), descriptions of professional interventions within these narratives demonstrate that provision of care is still largely influenced by ‘the interest and commitment of individual health professionals’ (Dent & Stewart, 2004, p. 111), whilst the instances of police involvement demonstrate a wide chasm between professional rhetoric and the actual experiences of some parents.

4:6: ‘The point where I was most unlike myself’: threads of parental identity and agency

Hindmarch describes how ‘the loss of one’s child...is often fundamental to one’s sense of self’ (1993, p. 30). This is fully illustrated in the narratives, where personal identity and agency are implicated in sudden and unexplained loss of a child.

Chalmers states that ‘the system which swings into action when a sudden death occurs can leave parents feeling powerless, with everything out of their control’ (2008, p.6). This can be immediately made concrete by the arrival of the police.

Hoggett locates the border between ‘violence’ and ‘everyday life’ in the centrality of privacy as a basic form of social containment (2000,p.99), a place where private identities can be protected, and thus the requirements of Rapid Response can be seen as a violation of this. In these narratives, this is poignantly symbolised by those parents who describe wearing their pyjamas or slippers both as the police enter the house and

even later in the hospital. Their private home identity, represented by intimate domestic apparel, is thus breached and brought under the public gaze, alongside their identities as parents and even their ‘ownership’ of the child who now becomes the ‘property of the Coroner.’

Chrissie illustrates vividly both her personal loss of power and her sense of identity:

When you are at that level of trauma, you don’t trust your own actions, you don’t trust anything...it seemed to me that I was going to be scrutinised at the point where I was most unlike myself and most afraid.

Hafsa also describes strongly her attempts to restore her own sense of self and judgement, whilst professionals intervene around her:

You’re just thinking ‘hang on, I just need to figure out what’s going on’...but you’re not even thinking really...it’s all a bit of a nightmare.

Echoing Chalmers’ description of the system swinging into action, Bridgeman describes the time following death as one when ‘formal processes of investigation prevail to exclude the parents in their attempts to care for and protect their child’ (2009, p. 269). Despite good practice guidelines, which advise that ‘parents need time to assimilate information’ and that this should be offered ‘over the following few days’ (Dent & Stewart, 2004, pp.139–40), the reality of Rapid Response makes this impossible. Instead parents are offered contact with their child, who is no longer their property and which is mediated through professionals. Thus, good practice recommendations in the literature are usually accompanied by a list of ways in which parents can be enabled to ‘spend time with their dead child’, including the offering of handprints and locks of hair (Sidebotham & Fleming, 2007, p. 279).

However, as the earlier discussion of time demonstrated, sudden and unexpected child death occurs on an ordinary day, when only moments before the parents were totally responsible for their own child’s care. The immediate move from this to contact mediated through professionals can therefore be difficult to process, as Hafsa movingly

demonstrates in her description of leaving her dead daughter:

So we had to leave her there and I just thought ‘Is she just going to be in that room, on her own?’...because it was a tiny little room, with dim lighting and a nice little Moses basket and I thought, ‘is this where I’m supposed to leave her? I mean is that it? I’m just expected to go home and go to sleep tonight and be normal?...There could be all sorts of creepy people about and I’m thinking I actually didn’t have a clue what was going on and what was going to happen next.

As Hafsa’s description poignantly shows ‘Death does not extinguish the relationship between parent and child: the child remains the child of the parent, and they continue to feel a sense of responsibility towards their child’ (Bridgeman, 2009, p. 265). Trying to sustain this relationship and responsibility towards the dead child in the face of the systematic investigation provoked by professional intervention can leave parents struggling for respect, agency and a coherent sense of self, as evidenced by Andy in a very affecting passage within his narrative:

We were in a cubicle on a big ward rather than in a private room...I mean it had curtains, but a lot of the time you’re looking over at other kids and parents...and they kept telling us to get out of the way while they did this and that...so they just switched everything off and we had a chance to say our goodbyes, but it would have been nice to go to a private room...they sort of pulled the curtains round but he sort of died in my arms gasping for breath...everyone else could hear, everyone else was around.

For Ellie, Andy and Chrissie also, whilst they are at the hospital the police are at their houses, as Ellie describes:

The police had been to the house, whilst we were still at the hospital and they took away some bottles, her clothing that she was in and some bedding.

For Andy, the sense of violation implied by this unendorsed entry into his home is expressed via his description of the family pet:

The plain clothes officers had come to look around the house and do whatever...I think they were here most of the day because they shut the dog in the garden, poor thing and he was barking...I think one of the neighbours took him out for a walk.

In their seminal work on ‘The Social Construction of Reality’, Berger and Luckmann

state that 'identity is...a key element of subjective reality and like all subjective reality stands in a dialectical relationship with society. Identity is formed by social processes' (1966, p. 194). Hoggett supports this, drawing both from Honneth and Winnicott to suggest that 'being' is a 'fundamentally social' state in which our 'well-being is equivalent to being well with others' (2000, p. 6).

Furthering this, Hoggett (2000, p.6) argues for Honneth's model of three different forms of identity, all linked to recognition. The first of these, individual identity, emerges primarily from consistent loving care and secure attachments in childhood, whilst the other two are particularly significant for parents following sudden and unexpected child death. The struggle for self-respect, which Hoggett links to recognition by the state, expressed in the form of rights, is withdrawn from parents immediately after the death when free access is denied, both to their child and to their home.

Lastly, the 'recognition of one's traits and abilities by the 'communities of value' to which one belongs', which Hoggett (p. 7) argues is essential in achieving the struggle for self-esteem, is also threatened following sudden and unexpected child death. As I have argued elsewhere, contemporary debates around dying have created value judgements, which focus on the concepts of a good death, together with the correct timing of this, in which the random deaths of children are rendered almost 'unthinkable'. Therefore, parents who experience this find that membership of their 'communities of value' may be severely restricted, stripping them of their familiar social identity. Instead, they are faced with a denial of their rights and are viewed simultaneously as both victims and suspects, creating a new and uncomfortable social identity, which they then have to work to overcome.

In this context, agency has to be reasserted and identified anew. In my research, this is demonstrated within the five narratives discussed here, usually towards the ends.

Paradoxically, for Hafsa the funeral arrangements restored some choice and self-confidence, despite her recognition of the irony in this:

I had to go to the funeral director and pick a coffin...and the name plaque and you know it's like picking wallpaper and I'm thinking, I'll have that colour, I like the brass...I was being really kind of matter of fact about it because I was thinking, I'm going to do this myself and I'm going to do it right and I don't want somebody else making those choices.

Other parents assert their agency through written complaints. Andy writes to the Case Review via the health visitor, but is doubtful of the outcome:

They didn't want to hear our criticisms...but they've written to us to say they're trying to put things into practice. Whether they will or not I don't know.

For others, participating in the research interview itself may have formed part of their rebuilding of agency and identity via 'telling their story from beginning to end' (Riches & Dawson, 1996, p. 363), and thereby helping towards the making a difference, which so many parents stressed. Becoming befrienders and support volunteers themselves as previously discussed is another important way in which parents restored their sense of belonging to a community of value, thereby re-building identity following the initial loss.

4:7: 'And my daughter came running in': threads of siblings and subsequent children.

As I have discussed in Chapter 2, bereaved brothers and sisters have been called the 'forgotten mourners' within the literature in this field (Hindmarch, 1995, p. 37). There is therefore a dearth of research literature, especially around the potential effects of Rapid Response (Dent & Stewart, 2004). Amongst the narratives in this Chapter and within my own experience, siblings and subsequent children feature significantly throughout, highlighting their importance and adding to the knowledge in this area.

At the beginnings of the narratives, when the death and the immediate police response

are described, other children are often identified as present, as Terri illustrates:

I screamed and I was trying to give him mouth to mouth and you know I was just hysterical obviously and my daughter came running in and I just told her to go away because everything was such a mess.

Andy also describes his other children, who were ‘all a bit unsettled and didn’t really know what was going on, so I was trying to sort them out’, whilst Chrissie describes her three year old stepson and his father finding her asleep on the sofa with the baby, who is not breathing. All these narratives subsequently describe the act of finding care for these children, whilst simultaneously confronting death and the subsequent response. Terri recalls taking her daughter next door, ‘because she had a little friend next door’, whilst Andy and his partner ‘rang the godmother, who only lives up the road, to see if she’d come. Chrissie’s stepson is driven back to his mother’s house, whilst his father and Chrissie are taken to the hospital.

However, these arrangements are impromptu and thus reflect the lack of any provision for siblings within the protocols for investigating sudden and unexpected child death. This also reflects the common focus on parents as bereaved parents, rather than, as in many cases including my own, as people with other children to care for.

This continuing caring role and the difficulties caused by the death feature prominently within the narratives discussed here. Many of the parents explain their fear of another death occurring, as Hafsa describes in relation to her new baby:

I’m still paranoid and you know I end up checking the baby’s cot all the time, thinking ‘oh my goodness she’s not breathing’ or ‘oh my god, she feels a bit cold’...or I can’t hear her and if she’s a bit snuffly, I watch her like a hawk and I do try not to because she doesn’t know what’s happened. I mean what kind of a weird world have I brought my daughter into?

Like Ellie, Hafsa borrows a monitor for the new baby, which provides her with some reassurance. Chrissie endorses this anxiety, stating ‘it took weeks before I stopped checking everyone in the house as they slept to make sure they hadn’t died in the night’,

whilst Ellie also illustrates the fear connected to other children:

I don't think I slept for probably a good year and a half...I would wake, give a prod and it would be 'oh you're fine' and then back to sleep for a bit.

Ellie also describes her strategies for controlling the overwhelming anxiety that engulfed her after the birth of her youngest child, several years after the death:

When I had him I'd got it into my head that everything had to be done in a set order and if I didn't do it in that order he would die and if I broke the pattern he would die and I did drive myself a bit nuts.

Despite their fears for their surviving children, many of the parents describe also how they gave them a reason for living, as Hafsa illustrates:

In my mind, that night I ended up thinking what's the point of anything, she's gone, so I may as well be gone as well...and as I turned on my side I saw R there with me and I thought actually there is a point, I've got to get on with it, I've got to be there for her.

Terri echoes this, stating, 'I just remember thinking that I have to be there for her,' whilst Ellie recalls 'having to pull our socks up and get on with it for her which was probably a good thing'. Whilst all these extracts demonstrate the positive effect that surviving children may have on parent's well-being, they also point to the potential difficulties for parents who have no other children once the death has occurred. This is therefore a strong thread for professionals to be aware of in their expressed desire to provide 'sensitive support to help deal with their loss' (RCPaH & RCPCH, 2004, p. 1).

Towards the ends of the narratives, many parents describe trying to explain the death and helping their surviving child or children cope with the effects. This is mostly a task they accomplish alone, with no reference to professional input. Given findings that it is not the death itself so much as 'changes and readjustments to the family system' (Dent & Stewart, 2004, p. 85) that may most profoundly affect children after a sibling death, there are opportunities here for professionals to provide the sensitive support so often referred to in ways that could be genuinely beneficial. Ellie explains her struggles with

trying to explain death to her 15 month old daughter, following the death of her sibling:

Obviously you can't explain death to a 15 month old...the whole concept of death and things meant she would just ask where her sister was and it was just like, well, we said she had gone to heaven but she couldn't understand how she wasn't coming back from this place.

Hafsa too discusses how she is attempting to help her young daughter to understand the sudden and unexpected death of her baby sister:

Whenever R wants to talk about her then I say, 'of course, you're free to talk about her' and I say 'what do you think she's doing now? Do you think she's got teeth yet?'...I think I'll just be led by her questions as she gets older, whenever she wants to know and if I think she's ready to know.

Terri also describes her immediate worries for her surviving daughter:

I was really beside myself and of course I was really worried about my daughter, because they were really close and you know, what do you say, what do you do?

These difficult decisions are also reflected in the funeral process, where professional support, apart from that of funeral directors, seems entirely lacking. Terri describes the funeral as 'just awful', although she says she knew her surviving daughter 'needed to go', whilst Hafsa conversely describes her feelings of guilt at not allowing her daughter to attend:

I didn't really want R to go and I think looking back maybe that was unfair of me, but she had seen so much because she was only two at the time.

Towards the ends of the narratives, all five parents describe how their surviving children have helped to orient them towards the future. Hafsa also demonstrates the complexity of this, alongside the enduring effects of the death:

I don't think I would ever take her to the cemetery. Can you imagine trying to explain, 'well I do love her, but I buried her and then I leave her and come home'. I think that's too much, that's disturbing even if you're 16.

Terri also reflects on not ever having spoken to her daughter, who is now an adult, about the death:

I've never. Well you know I've never spoken to her, I can't remember ever speaking to her about what she remembers about that day. I think she said at some point that she remembers a lot of screaming, you know it's not good memories...

Within Ellie's family, the dead child is both narratively and visibly integrated as a part of the family history:

Her pictures will always be on the wall, the boys know who she is, her sister is always going to know who she is...it's just about being as positive about it for them as possible.

Ellie's description has strong echoes with Julia's story, which forms Chapter 6, and both demonstrate the importance of surviving children, both at the point of death but also within the continuing narrative of their families. These strong threads render the absence of surviving siblings within the Rapid Response and in the processes that follow, as a lost opportunity for providing support and increasing understanding.

Sidebotham et al. in their evaluation of the Rapid Response state that processes should be evaluated with respect to 'assessing outcome in terms of...understanding of child death and support for families' (2010, p. 295), thus signposting the need for more comprehensive consideration of other children and endorsing the call for further research in this area (Dent & Stewart, 2004, p. 87).

4:8: 'Is there ever going to be a light at the end of the tunnel?': threads of chaos and meaning-making.

In Chapter 2, I discussed Frank's notion of the chaos narrative, the 'opposite of restitution' in which there is no possibility of life 'getting better' (1995, p. 97), which he counterposes, and it is suggested that this is the pre-dominant cultural form offered to parents following sudden and unexpected child death. Popular depictions of this as

‘abhorrent’ (Raphael, 1984, p. 235), ‘unnatural’ (Wheeler 2001, p. 53), or as ‘one of the most disturbing, shocking, unacceptable events that can occur’ (Bridgeman, 2009, p. 255), encourage a practice of cultural paranoid-schizoid positioning in relation to the experience, which splits it from the possibility of healing and restitution.

However, as the earlier threads demonstrated, parents are often keen to show the good things that emerge from the initial chaos, together with their own ways of managing this and beginning to create meaning. Many of these are located within religious belief or spirituality. Andy, for example, describes trying to get a chaplain at short notice to baptise his son, which, although not being especially religious, felt to him and his wife like a way of managing a process that was largely out of their control. Hafsa, who is a practising Muslim, describes most powerfully the support her faith gave her:

You think ‘am I ever going to get over it? Am I never having children again?’ You know all these things, ‘How will I get on? How will I do it?’ But you just do and I think at a time like that your faith kind of pulls you through...because at a time like that I just thought God gave me the baby, God has taken the baby back.

For Hafsa too, washing the body, a religious ritual, helped her to manage the immediate chaos and to reclaim a sense of agency and responsibility towards her dead child:

How you wash them, it’s like a little vertical table, but there’s like a shower there and we used normal soap and everything and it was really just like giving my baby a bath, but she was asleep.

For other parents, it is those people or professionals around them who help them manage the chaos. Terri’s health visitor was an ‘absolute star’, whilst Chrissie describes the arrival of her father who removed the sofa on which her baby son died. Hafsa also turned to her brother-in-law and family for support, whilst Terri felt the lack of this:

Maybe if I’d had loads of relatives that would’ve come and stepped in ...I don’t know siblings or something. Someone that could’ve come and helped do the organisation...because I had no idea what to do. I mean it’s not something you plan for is it? And you have to face all this stuff, that you never thought you were ever going to be facing, ever.

Facing all this stuff, as Terri describes, whilst avoiding condemnation to a life lived in chaos and ‘never getting better’ (Frank, 1995, p. 97) moves all the narratives towards some form of the meaning-making, which contemporary grief theorists emphasise as vital in moving on from death (Neimeyer, 1998, p. 110). For Hafsa, this process was emotionally demarcated by the funeral:

I couldn’t really relax until she was buried really and once she was buried then you could sort of start getting on.

Establishing a cause of death is also an important boundary for parents. Terri describes this as ‘helpful’, whilst Andy feels cleared of suspicion by being ‘found innocent’ via the post mortem. Hafsa reads through the post mortem with her boss, who is a doctor, and whilst she is initially distressed by the conclusion, she reflects on this:

It came back with ‘cause unknown.’ And I thought ‘Great, I’ll never know, but then I thought, ‘Maybe that’s a good thing because she wasn’t suffering, there was nothing wrong with her and at least she was o.k.

The meaning-making is also demonstrated by looking towards the future and trying to change things for others, either by complaining or by joining support organisations, as Ellie describes:

I’ve supported a lot of families...some of them just come and go, it’s only maybe one ‘phone call’ or whatever, it’s just what everyone needs because sometimes you’re just really having a bad day and you think, ‘Is this normal? Is there ever going to be light at the end of the tunnel? Will I ever smile again?’

For Ellie too, the sense of renewal and meaning is drawn from professionals remembering the death, like the policeman who runs marathons and other professionals for whom her baby’s death had ‘made a huge difference.’

Ellie also describes always telling people that she has four children, which resonates with Julia’s story (see Chapter 6) as another way of ensuring a continuing bond (Klass, 1996):

At work I've got pictures up and people ask 'I thought you had 4? And I say 'Well I have had 4 and then they're like 'Oh I'm really sorry and I'm like, 'well you don't have to be sorry, I didn't have to tell you!

For Terri, there is a profound spiritual dimension to her meaning-making and she draws on dreams and symbols to explicate this. Amongst these is the tale of a fox killing the family pet rabbit, shortly after the death of her son:

And I'm grappling with this death in my garden...and I managed to hide the rabbit from my daughter and to tell her that it had run away or something. I just couldn't cope with telling her about her rabbit dying. But to me it was just like ok I get the point, these things happen. Nature is as cruel as it is kind...we have to face the fact that death is part of life, just as life is part of, well life and death are connected.

Hafsa also describes simply yet richly how 'life and death are connected', demonstrating the ways this experience has changed her own approach to life:

It changes the way you get on with things...life's too short so I started using things I had put away for my daughter, you know 'no I'm going to save that for a good day' and instead I said 'you're going to wear it, because today's a good day, every day's a good day from now on.

Whilst so much of the literature and training material in this field depicts sudden and unexpected child death as apocalyptic, these accounts, shared by so many of the parents in this study, demonstrate instead a powerful drive towards reparation and meaning-making, as Ellie summarises:

I think if you can have a good experience of this situation... then I think we had the best experience we could possibly have.

Similarly, whilst the professional literature often places sudden and unexpected child death at the pinnacle of cataclysmic experience as 'the most shocking and devastating event anyone must face' (Simons, 2004, cited in Dent & Stewart, 2004, p. x), the parental narratives here demonstrate a different perspective. Hafsa, for example, muses:

I thought at least she's not missing because my heart goes out to parents whose kids have gone missing; my god there's no finish line. I think I'd actually go loopy if that happened to me...I knew where she was and she's in a good place and in my heart I believe the angels are taking care of her.

Hoggett's notion of 'communities of value' (2000, p. 7) is also useful for understanding the meaning-making that follows the death, via the unsolicited sharing of previously untold stories of child loss, which are shared with the parents. This echoes my own experience following Joe's death (see Chapter 1) in which, like the thestrals described by Rowling (see Chapter 1), the experience seemed to provide access to new ways of both seeing and hearing. Andy summarises this, stating 'after it happened, the amount of people you find out it's happened to as well', whilst Hafsa similarly describes:

And then people would come out with 'well I lost a child and he'd be 17 or she'd be 30 now' and then there was this one woman who hadn't actually spoken about it at all but she lost a child to cot death as well and all her other kids were grown up.

This sharing of previously untold stories helps all those parents bereaved by child death, no matter how long ago, to form a new community of value in which the death is a 'great permission' (Frank, 1995, p. 39) to finally release this experience. Richardson's concept of the 'collective story', within which this Chapter is embedded, can also be seen as a way of calling 'I am not alone' (1997, p. 33), which Hafsa portrays simply yet profoundly:

It helped them to talk about it and it helped me to hear their stories and to think that I'm not on my own.

It is Hafsa too, who sums up the need to move on and accept the death, when at the end of her interview she says simply:

I think everyone's different and I think that's the end of my story apart from just getting on with life...

4:9: Conclusion

I began this Chapter by describing my struggles to do justice to the stories that had been told to me, whilst facing inevitable choices about what I could realistically include within this thesis. My solution sprang from Richardson's notions of weaving a tapestry composed of 'threads of many different hues' (1997, p. 33), in order to form a 'collective story' (p. 33). Inspired by her ideas, I have conceptualised the five parental narratives within this Chapter as threads weaving together with both my own experience and the accounts, which form Chapters 5–7, to build a more holistic picture of parents experience of sudden and unexpected child death.

Beginning with temporality, I have also drawn upon and discussed threads of emotion, professionals, identity, siblings and meaning-making. All the threads share within themselves common strands of trying both to defend against and to accept chaos, as well as working with this to build meaning.

The 'beginning-middle-end' structure (Sarbin, 1986, p. 248), which the accounts share, acts as a means of ordering the experience in a socially accepted form, thus rendering it thinkable, whilst the common act of looking forward begins to demonstrate the meaning-making that is so powerful within these accounts. The threads of emotion and professional intervention similarly move from anger, fear and dispossession to trying to understand the professionals involved, thereby avoiding splitting.

The loss of identity, which may be triggered by sudden and unexpected child death, is a powerful thread, and I have discussed this in the context of Hoggett's 'three different forms of identity' (2000, p. 6). This demonstrates how police intervention, far from removing stigma, can be destructive in removing parents from their communities of value, where they may now be viewed as both victims and suspects. Nevertheless, there is, as with the previous threads, a vigorous drive towards rebuilding identity by helping to make things better for others. Surviving and subsequent children also help parents to

locate themselves within a future, where the death is integrated into their lives. However, their centrality in many of the narratives renders their absence within the literature on Rapid Response an important area for further research.

Finally, the threads of both managing the initial chaos of the death and of finding meaning portray a radically different picture to that commonly given in the literature. Far from viewing the experience as ‘one of the most disturbing, shocking, unacceptable events that can occur’ (Bridgeman, 2009, p. 255), the parents in these five accounts identify events that would be much worse, alongside their own sharing of untold stories and rebuilding new ‘communities of value’ (Hoggett, 2000, p. 7).

The three Chapters that now follow are an attempt to show how these threads are woven together in accounts that are presented as ‘unashamedly lengthy’ (Riessman & Speedy, 2007, p. 440). My aim in offering these in this manner is to build a fuller understanding and affective sense of the whole experience, by presenting the story from ‘beginning to end’ (Riches & Dawson, 1996, p. 363). However, the threads discussed in this Chapter can be distinguished very visibly distinguished within the following three accounts and should be kept in mind whilst reading them. In Chapter 8, I will weave them all together in my final discussion of the stories themselves and my experience of researching them.

Chapter 5

5:1: Cathy

"There was no framework for society."

In the previous Chapter I focused on the threads that I had drawn from five of the narratives as part of the painful yet inevitable process of distilling the stories to fit within the constraints of this thesis. This Chapter and the two that follow now build on this analysis by offering the accounts, firstly of Cathy, and then of Julia and Laurie.

Whilst the first two are complete accounts of the interviews, I have removed the pauses and breaks, which in the original transcripts did not seem to enhance the text but rather distracted from it. Richardson describes such interruptions to the text as 'like answering the doorbell in the middle of a lively conversation' (1997, p. 167). I have therefore chosen to follow her example and have removed these. By so doing, I hope to capture the spirit of the accounts, which were all offered in a fairly seamless and sometimes urgent manner. Following each of the three accounts, I will discuss the interpretation of the BNIM panels, together with my understandings of these.

Whilst I view these Chapters as forming part of the collective as described in Chapter 4, by offering two in their entirety and the final one in the 'chunks' provided for the panel, I hope to provide greater direct access, thereby helping to reduce the inescapable space between author and reader (Speedy, 2008). My unfaltering purpose of not replicating the expert positions of those who contributed to the wrongful imprisonments of Cannings, Patel and Clark, renders me ever mindful of not 'making statues' (Speedy, 2008, p. 57) of either my own interpretations, those of the panels, or indeed of the participants themselves. By combining the threads from the previous Chapter with the

accounts that follow, in a way that invites the reader to choose their own ‘pathways through the material’ (Morgan, 2000 cited in Speedy, 2008, p. 185), I hope to keep them dynamic and to avoid researcher absolutes.

However, as I discussed in Chapter 3, the nature of the researcher role is that they alone have had personal contact with participants, and this informs all their later judgements and interpretations, no matter how rigorously they may try to avoid this (Clarke & Hoggett, 2009). My other main aim therefore, within this Chapter and the subsequent two, is to focus more closely on my personal understanding of their stories, formed both from our meetings and from working with the transcripts, combined with my own personal experience. Subsequently, I will explicate how these personal understandings were radically and sometimes shockingly challenged during the BNIM panel interpretation processes, in a manner which eventually led me to a much richer understanding of the participants, of myself, and of researching the area of sudden and unexpected child death.

5:2: Context

Cathy is a young, white woman in her mid to late twenties. She is married and lives with her partner, Andy, who is the father of all four of her children, including twin boys. I also interviewed Andy separately from Cathy, and his narrative forms part of the analysis discussed in the preceding Chapter.

Cathy responded by email to a request for participants, which I had placed on a national charity website. The request described the research study and made brief reference to my own experience of sudden and unexpected child death.

Cathy initially requested the ‘Information Sheet for Participants’. Following this, again via email, she stated that she was willing to take part. We had an exchange of emails during which Cathy made some basic enquiries about my own experience,

including Joe's name and age. She referred to her own child and Joe collectively as 'angels', which initially discomfited me and led me to judge her as perhaps mawkish and sentimental, an impression that altered radically during our meeting. Apart from this, Cathy's questions were straightforward and clearly part of her process in assessing whether she was safe with me as a researcher. This impression was supported by a telephone conversation I had with Cathy prior to meeting her. She told me that her experience of sudden and unexpected child death had left her very suspicious of professionals, and that she had only agreed to talk to me because she knew that I had 'been through it', thereby validating my decision to include my experience in the recruitment of participants.

Cathy's interview concerns the death of her youngest child, Dylan, at eight weeks. Dylan was premature and had experienced breathing difficulties, which had necessitated a stay in the hospital's special care baby unit after his birth. His death had taken place approximately ten months prior to the interview.

Cathy was keen to participate in the interview, which took place in her home. She arranged childcare so that we would not be disturbed. She presented as helpful and friendly, although it was clear that the interview represented an important opportunity for her to tell her story.

The interview lasted for over an hour and was prompted by the initial 'SQUIN' (see Chapter 3). My initial impression of Cathy proved entirely wrong in practice, as she presented as quite the opposite. She was articulate and feisty, telling her story in an almost uninterrupted flow of dense speech, barely pausing for breath. The urgency with which she spoke gave me the impression that she had thought a great deal about what she wanted to say, and saw the interview as an opportunity to create some meaning from both Dylan's death and from the experience that had followed:

to ‘change things’, as she herself stated.

Following the interview, I had limited contact with Andy and Cathy. Andy had been ill when I had visited, which Cathy had put down to nerves and ‘man flu’, but she later emailed me to say that he had been taken to hospital the following day with appendicitis.

Once the transcripts were complete, I sent them via email. However, they did not comment on these and I have had no further contact. The transcript was later converted into ‘future-blind chunks’ for presentation to the BNIM interpretation panel. This process was carried out as described in Chapter 3.

The panel for Cathy’s story consisted of three people, all white British females in their early fifties. Within this Chapter, they are identified by pseudonyms to assist confidentiality. Charlotte is a marketing company executive; Susan is a craftsperson and teacher; and Maggie is a Senior Social Work manager. Charlotte and Susan are friends of mine, whilst Maggie answered a generic advert aimed at recruiting interested participants. Charlotte and Susan both have children and Susan is also a grandmother. Maggie did not disclose this information, and so her parental status is unknown. The panel interpretations will be discussed and analysed following Cathy’s story, which is presented in its entirety.

5:3 Cathy’s story

Dylan had been ill when he was born but he had got better and come home and so we just expected him to be o.k.

The night before he died we went to bed about half past six or thereabouts. It’s hard to remember times accurately which I found difficult later when the police were asking all these questions about time, because normal life doesn’t work like that. In

the morning I was feeding Dylan and we both fell asleep again, but then my husband, Andy came into wake me up because the other kids were shouting for me and I knew then that Dylan was dead. I think you just know these things. Andy thought I was joking when I said that Dylan was dead and then I don't remember quite what happened. I remember Andy being on the phone and coming into me and I was saying "I've killed him", because he was in bed with me. I was saying that it was all my fault all along, even when the police came because he was in bed with me and I was bed sharing.

Then the house swarmed with people, people with guns and so many other people. I have no idea who any of them were because I don't remember them introducing themselves. They may have done but I don't remember. I just felt that they were trying to separate me, from Andy and from Dylan.

They took Dylan off into an ambulance, and it was so different from when my other son was ill. He was premature as well, when he was born, and he had some problems and we had to call an ambulance, but he was still alive thankfully so they treated me like his Mum. They were helpful and made sure I came in the ambulance and offered to sort out his brothers. They treated us like we were the parents of a sick child, but this time, with Dylan from the moment that the police came, it felt like Dylan was their child and we were...murderers. Perhaps that's too strong a word to use but I just felt right from that moment that we weren't innocent until proven guilty, we were guilty and we might be found out otherwise.

As a concept that shook me because I've never been in trouble with the police and it meant that so many parts of my life and the cornerstones of society that I believed in, including the idea of justice, I no longer accept or believe in. When I read stories like mine I'm now much more shaken because I felt when Dylan died that they thought

we had shaken him or that we'd done something. Obviously with sudden death there is a bit of blood but I felt it was as if the blood was evidence of my shaking him.

At that point I also felt it was my fault and I told them this because Dylan was in bed with me. I did think that then, although I don't really think it now, because I chose to bed share with all my children. I still think ultimately it is the best option and if I had another child I would still bed share. I did a lot of research before deciding to do it too. I research all my decisions because I'm a very controlled person and then all of a sudden, something like this happens and you are left with no control over your children or anything.

Dylan went in the ambulance and we went in a separate ambulance and no one would tell us anything or at least that was my overwhelming feeling. I was quite hysterical but nevertheless in all other walks of life you get informed and, people talk to you, whereas people here were sort of herding and patronizing me until we got to the hospital.

Once we reached the hospital there was a big difference, because the hospital treated me like a mother and the police thought I was a murderer. It was very stark and very noticeable because the police said we need to interview you, you need to come away. My son was dying; they were working on him, they'd got a heartbeat back and my son's dying and I believed he was actually dead and yet all they wanted to do was separate me from him and from my husband to find out what had happened.

The way I see it is there is a line between police officers that are human and police officers who maybe are hardened by what they're seeing day in and day out. I realize that they do see lots of children that are battered and that those battered children deserve a policeman to stand up for them and bring them some justice and I accept that. However, I don't accept the way in which every family is seen to be the worst

case scenario. When I was actually interviewed, I was interviewed by a policeman called Jack and he was human and he really listened and so talking to him I didn't feel like I was being interrogated. He told me he had to interview me and that he didn't want to and that was honest. He also mentioned briefly that he had a young son himself and that just made it more human. It helped me realize that it was a job that he had to do and of course they have to do their job it's just the manner.

One of the biggest factors that I would like to see changed is national so I doubt it will ever happen but it happened when I had just finished talking to the human policeman. He was helpful and understanding and just doing his job and I was happy with that but I then encountered some plain clothed detectives who gave me a card saying 'Child Abuse Team.' I had just left a policeman who basically wanted to know the story, because at the end of the day, Dylan had come to harm, even if we hadn't harmed him. So straightaway I go to someone giving me a card that says 'Child Abuse Team.' It made me think "Shit...Do they now think I'm guilty?" There was a part of me that felt guilty anyway, as I had failed as a parent because my child was dying so I couldn't fail any more than that. So to then have this feeling that they actually thought that, gave me this fear of being like that solicitor that went to prison and she didn't do it...Sally Clark it was I think and so I knew that it happens and that all of a sudden it's happening to me, although I knew I wasn't guilty.

Before all this happened I knew that people in this country were innocent until proven guilty. Now I know it doesn't work like that and I was guilty until proven innocent so therefore anything else that I held true and believed no longer existed. There was no framework for society at all. I felt I had been very naïve because suddenly the world I'd been brought up in had changed.

In the hospital I wasn't dressed in much more than pyjamas and I had police staring

and standing around me and everyone else in A & E was looking at me. Some of the police were even armed. Part of me just thought that I didn't give a damn what they thought but there was another part of me that thought I was part of a circus and that everything was playing out like a hospital drama and there was no understanding that this was my life and that that this was our world. It was our child, our son, not just another case or not just another thing for someone else to gawp at. I wanted a bit more privacy and maybe a bit more respect and dignity for my son as well.

It felt like from the beginning that we were sidelined and we weren't his parents because, we had very little choice or say in anything. There was one doctor who listened to me and he got Dylan's heart beating.

I was pleased because Dylan was baptized and that meant a lot to me but really I wish he'd just died straightaway because I didn't want a dead child alive. I didn't want him to die, but you can't die and then live and I knew that he was dead, straightaway and I accepted that he was dead. In some ways I found all the rest of it a bit perverse, that they were trying to get a dead body going but then they're doctors and that's their job. I know they did their best and it was hard for them.

After that we were transferred between hospitals and the two hospitals treated us very differently. Perhaps doctors see the good in parents and the police see the bad in parents but I was very surprised by how different the hospitals were. In P hospital, we were parents and I felt like Dylan's mother and then we were transferred by the police, which didn't help, to S hospital. All of a sudden in S hospital I was just another mother and Dylan was just another baby and possibly we were parents who might have harmed him. Obviously the police contacted the hospital first and they did seem to treat us differently.

We were just left in a room there at first. They took Dylan and I kept thinking that

he'd only been alive for eight weeks and he was sort of living because his heart was going. So we were left in this room and no one came, although we were told someone would come and get us but no-one did. I would have gone and asked but I felt like they were looking at me as if I'd murdered him. And I felt I should just be doing as I was told because everything seemed to have snowballed, so if I was told to sit and wait then I would just sit and wait. I also thought Dylan may be dying and I didn't want to stop them getting him settled. I was thinking that perhaps it was just taking them longer to get him settled but those two hours seemed so long. Normally I would have got up and demanded to see someone but I didn't feel strong enough to do anything. Those were an extra two hours we could've been with Dylan and we were just left sitting in a room.

Once the doctor finally had to make the decision about his life support she made it like she had done it hundreds of times before. She probably had, but she just didn't have the courtesy to see that I hadn't done it hundreds of times before. If she'd come to me and said 'I'm going to do tests A, B and C and test C especially is very hard for you to see so maybe you'd like to leave the room while I do this,' then maybe I would've been more accepting. As it was she did not explain anything and it felt like she did this morning, noon and night so why should I be concerned about what was happening? They did these tests by switching Dylan's life support off and back on again. To see him gasping like that and to not know what was happening was awful.

I am someone who likes to have facts, like the MMR, I researched the MMR before it happened and I knew which treatment I wanted because I believe in being proactive and having facts. I don't go into things blindly but this time I just sort of sat whilst everything was taken away from me. I wish that the doctor had been able to talk to me first and that doctors were taught to deal with bereaved parents. You lose all control and you are not who you are so I was really passive and to see Dylan and to

not know if this was the moment he was going to die, was really hard.

When he did actually die it was really bad. They pulled the curtains round and I was thinking that perhaps I watch too much telly because there you're taken off into a room and left in a bit of privacy. When Dylan died there was a baby next to us on a ventilator who we knew was better than Dylan because his arms and legs were moving. Dylan was just a body and then they turn him off and you know that you're watching your son die. And there's a separate self that's watching you watching your son die and therefore that part of me was aware that there were nurses going about their business in the curtain next to me, walking past and then the other part of me is just watching him die and I thought this is his dignity. He is dying in a curtained hospital cubicle.

They took some photos just before Dylan died and I hope they're etched on my mind as they deleted them because they don't understand the whole data protection act. This makes me cross because I do, but they told us they would forward us these pictures. In them Dylan looked like a character from a children's TV programme, the one who wears the little blue hat and a little blue suit. The clearest picture I have of him is when he was in the funeral home but they look a bit weird there. I would have liked to have the photos of him in the hospital because although he's dead he's alive dead; he's not stuffed dead, like in the funeral parlour.

It was just another huge lack of respect that they deleted those photos. He was my son and they deleted him, a dead boy, a dead baby and those pictures can never be taken back. If I'd known he was going to die I'd have taken a camera with me but you don't plan for these things. There is something callous that I still can't quite forgive and it's probably my biggest bugbear about the whole situation, that someone can just delete a dead baby without contemplating what they might be doing. Even worse is the idea

that it might be data protection because that just makes me cross in so many walks of life.

I can see that the doctors in S hospital are doing a hard job and they're fighting for the living and it must be pretty clear cut who's going to die, so a part of me can accept that they have got to focus on the living, I know that money is tight.

Then there was the huge problem of our treatment in-between Dylan actually dying and being cleared of what felt like accusations of murdering him. After he died there was this huge vacuum and we didn't know where to go next. When Dylan was transferred between hospitals there was this big feeling that he might come back well and he might be O.K. but he didn't and he died. So then what? You already know that they think you might be responsible for harming him and then when he died you're obviously the next level up. But when he died there was, nothing but this vacuum.

On the Saturday, we spent the day in hospitals and I was interviewed on and off all day. Then the Sunday comes and there was just nothing, no one comes, no one rings, no one does anything. I kept wondering what I was meant to do and whether I was charged and a suspect. I came home on that Saturday night to Dylan's home and his stuff and his bed and his blood on the floor and I knew the police had been there to take photographs because they think I may have murdered him, I just did not know where to go with it and we didn't have anyone that we felt we could contact so we contacted the hospital. They were friendly but they just told us we had to speak to the Coroner. So we rang the Coroner but he told us he couldn't talk to us because the police would not let him. After that we rang the police, specifically the person that had given us a card that said 'Child Abuse Team'. By this time it was about 6 o'clock on the Sunday and I told them I could not wait any longer without knowing what was happening and they told me a home visit appointment had been made for 5 o'clock on

Monday.

I remember thinking that I had three living children and that I'd been here with them while they had been organising and talking about Dylan and what's going to happen to me and planning it all but none of them had even given me a call or told me that a meeting was arranged for 5 o'clock on the Monday. It was like we weren't in the loop and that there were all these machines that were going on behind us.

If they'd made a 'phone call on the Sunday, if they'd informed us it would have made such a difference. These things didn't have to cost very much money because I know everything is limited resources and we can't expect what we might want. But a 'phone call just to check that you hadn't hung yourself or just a call to check that you were there or whether you needed some sedatives. And also just to check that my other children were all right because there was part of me that thought 'hang on a minute; you think I've killed my son, but you don't actually care where my other children are.' It all seemed a bit weird because if I had killed my son then someone needs to be looking after us or at least asking. We were just there waiting so it would not have been that hard just to ring me up and talk to us about things. If they had done this the whole situation would've been easier.

When the meeting happened the police came with the doctor and you suddenly realize that they're asking you questions about your past and I wasn't sure if it was an interview or if they were trying to find things out. It was weird. It was a meeting but I didn't know what kind of a meeting it was because there was a woman there who I knew was a Child Abuse team Officer and I felt unsure of the situation and of what they were trying to work out.

The police officer was called Deirdre Bailey and she made me feel all along like I'd hurt Dylan. Then again after that meeting on the Monday there was nothing and we

never heard from her again. She never called to say 'Oh by the way, yes, you were right, you didn't hurt him.' I felt it was rude and I was cross. I wanted and want to say 'How dare you come into my house and accuse me of hurting my son and when you realize I'm telling the truth, you can't even have the decency to ring me up and say actually "What happened is every parents' worst nightmare and there's nothing that you could've done." Obviously she would have waited for the post mortem because by then they knew I hadn't battered him.

I wanted to know what time Dylan was going to have the post mortem. I wanted to know what time it was going to start and I wanted to know what time it would finish. And that Tuesday was as bad in many ways as the day he died because I woke up knowing that morning he was going to be cut open and all I could think of and see was him being cut open. We were trying to get hold of the Coroner to find out when it was going to happen so we 'phoned and he said, "Yeah, yeah it should be tomorrow." This was on the Monday and then he rang up the next morning and told us it should be sometime that day. Andy and I said, 'Look we need to know when it finishes, we need to know,' but we didn't hear anything and I was pulling my hair out because I just wanted to know that he was back together. I don't have any religious beliefs about any of this but I just didn't want my son on the scales in bits.

If you have an operation the doctors tell you when you're going to come in. My father-in-law had a big back operation and they told him when he was going to go in and as soon as he came out they rang us and said 'He's out, he's well. He's in recovery.' With Dylan it was like we didn't deserve it or was it because at that point they still thought we had battered him. Maybe until the post-mortem has been done then they still thought that.

It all felt inhumane, that was my biggest feeling. I'd lost my son and I needed some

help getting through the formalities, some human decency, a bit of understanding, that it's not another Coroner case, it's not another body. Dylan is my son and he has a name and he is loved and that funnily enough, as a mother, I'm not a big fan of him being chopped up and weighed. They told me that apparently I'm the only mother who has ever said she wanted to know exactly when the post-mortem ended but I don't believe that. It's probably just that I voiced it clearer because I got cross.

I felt there are ways of telling people things, like ringing time zones because when someone dies you are aware of every second and you cope by the minute, by the second, probably. You're aware of every moment and although I knew they were doing their best, once they had said they were going to phone at 4 then I needed them to phone perhaps at 1 minute to, or at least at 4. Whereas quarter to 5 is three quarters of an hour that I've noticed every millisecond waiting for that 'phone. You can't agree times with the recently bereaved unless you're going to meet them and if you say you're going to ring in two weeks, and then you ring in two weeks and one day then that extra day is more than a day, it feels like a lifetime but there was no understanding of this.

I go on internet forums where other people have mentioned waiting for the Coroner and for the police but I don't think the authorities realize that we are waiting and that we are aware of what they said. It's not that we can't accept that things take longer, what I can't accept is that they can't be bothered to ring me to tell me that it's going to take longer. A 'phone call in the morning to say 'I know you're expecting it today, but it's going to be tomorrow' would've been fine. I still would've been a little bit cross but I was prepared for that and at least I wouldn't have gone through the whole day waiting, waiting and you get to 5 to 5 and you just sort of think 'Are they going to be going home?' and you think they're a Coroner, so maybe not and you think 'Do I ring, do I hassle?' and you feel so separate from it all. You don't want to hassle but

you want to know and that's what I want changed and I want people to realize that.

It's about realizing its people. I did a report for my hospital Child Death Team, although initially no one even told me when the Death Review was. It was my health visitor who realized that the Death Review was going to be on this date and she informed me but the officials, who I'd kept on at, asking them to keep me in the loop, didn't realize that it would be important for me to know when the Death Review was. It's hard for me to see how they could think that because they're talking about my son and my life. How could they not think it was important?

I don't know what they think grief is. I don't know if they think that once you're in the ground that's it, because we did bury Dylan. When the post-mortem report came I was very glad that he had died of something because after the police make you feel guilty, there was a very big part of me that didn't want him just to have died of nothing. To have him die of an illness, made it easier although they still said it was a sort of cot death because they can't explain why it killed him so quickly. It was better than nothing because otherwise I think it would've been harder to deal with perhaps.

Dylan had a 'Sensomat monitor', so if he'd died when he'd been on that it would have alarmed. My previous son slept on his tummy and although I don't believe in things like that really the Health Visitor said if he was sleeping on his tummy, I should have a monitor. So I still wonder if Dylan had been in his Moses basket, would he have died but probably he would've died anyway because he was just poorly.

My very biggest wish is for them to realize that we're parents and I'm a mother and to treat us as if he's our baby, our child and that I'm his mother. That's what I came away with I guess, that Dylan wasn't just a case, that he was a baby, a person and that he matters to a whole world. He's not just a job that they've done a hundred,

thousand times and I just sometimes think they need to realize that. I asked Deirdre Bailey the police officer, 'Look can you not treat us, can you not realize what's happened to us, can you not see,' and she said, 'Oh even if someone has smothered their baby, a lot of them still genuinely regret it and feel grief, so even those people should be treated with compassion.' If that is the case then we can't be treated like someone that has just picked someone else off the street and deliberately murdered them, because that's what I felt like. Like just a criminal. Even if people have hurt their children, then they deserve to be treated as mothers that have snapped or whatever, but not as pre-meditated murderers because that's different. It felt like the police were speaking in code aware of what they said in case it all got on the T.V.

I think it has all left me rather against any sort of professional because all along it felt like they increased your grief by not doing things as they are done in the real world. If you buy things off eBay, you get emails and phone calls all the time about where it's coming and what's happening.

We get surveys about stuff from the Council all the time too which I'm always doing because I enjoy them, but when Dylan died there was no one to hold accountable, there was no one to go to and say this is what's happened and this is how I am feeling. The Coroner and the police were above everything and there was nowhere else to go.

I know this person whose son was killed by a serving police officer who got away with everything when the case went to court. So who does a very grieving, slightly hysterical at times, mother go to because you want to feel that someone is watching out for you but no one's watching and you don't feel you have got anyone to complain to.

I did a report for the Child Death Panel so that I could feel there was something

positive going on but even doing something like that depends what kind of background you've come from. You have to be quite confident about compiling reports that are going to be seen by professionals. I did that whilst I was at university so it doesn't daunt me, but I know other people that said they'd got loads to say but wouldn't know where to begin. I tried to do it as unemotionally as possible and I tried to be just clear. On forums I told people I was going to do this report and they warned me to be careful and that they may just say that I was talking rubbish. I think that fear is one of the many reasons that people don't complain about things like this.

5:4: 'An aggressive story': Cathy's interpretive panel.

In this discussion, I want to focus primarily on the interpretations of the BNIM panel, to demonstrate how these differed radically from my own, and to describe my reflexive struggle with this. However, in order to set the scene, I need to explain my own responses to Cathy and my interpretations of her story, as well as connecting these to the narrative threads previously discussed in Chapter 4.

Throughout the process of transcription, BNIM analysis, transcript chunks, and later through the 'Listening Guide', I re-visited Cathy's narrative repeatedly. Each time I remained struck by the force of her telling, which had also impacted on me at the time of our meeting. As Hollway and Jefferson observe, 'first impressions contain much that eludes our conscious mind' (2000, p. 46), and I had experienced Cathy as being helpful and open. Whilst she was also obviously angry, I could see the pain of her narrative as well as her determination to tell it.

This determination rendered the interview itself as part of her attempt to 'change things'. Both the meaning-making purposes implicit in this, and the other parts of Cathy's narrative, pick up threads present in the other stories and in my own experience of Joe's death. This is particularly significant in view of the 'unconscious dynamics'

(Hollway & Jefferson, 2000) that I now see were present. Like me on the morning of Joe's death (see Chapter 1), Cathy was angry and yet struggling, as I myself was, to change things and to help others. From working with her transcripts and the various interpretations over time, I now see that I identified with Cathy by transferring some of my own feelings onto her, whilst she in turn returned this by categorising me as like her, as 'someone who had been through it' (Hollway & Jefferson, 2000).

These complex and initially unconscious identifications left me very protective of Cathy, who in so many ways reminded me of myself. I understood her story as primarily a 'cry for witness' (Frank, 1995, p. 137), which linked to my research purpose of giving voice to the parents in my study. Hoggett argues that 'finding your voice' is, for silenced and marginalised groups, a task that is linked to audience and therefore not just a matter of being heard, but also of helping this audience 'learn to hear in new ways' (2000, p. 115). I thought of Cathy's story with its powerful and sometimes hard to hear descriptions, such as those of Dylan's death 'and there's a separate self that's watching you watching your son die', as perfectly fitted for this purpose. It was this and my own unconscious relationship to her that I brought with me to the BNIM panel.

With the benefit of hindsight, I can see now that I expected the panel to share my own perceptions of Cathy and, as I explained in Chapter 3, I was not sufficiently prepared for the powerful feelings that would emerge in the panels, nor for the 'not uncommon... differences of opinion', which 'occur amongst research teams particularly where data interpretation is involved' (Morgenroth, 2010, p. 268). I therefore want to focus on these differences of opinion and particularly on the thread of anger, which became so pre-eminent for the BNIM interpretation panel. The challenge of understanding how their analysis differed so brutally from my own has deepened and extended my awareness, both of the stories themselves and of the factors which may influence professionals involved with sudden and unexpected child death.

The panel began the process by speculating on how Cathy would manage the interview, whether she had rehearsed it and if she would be able to talk without crying, showing from an early stage a clear consensus on how Cathy should behave as a bereaved mother. As the process progressed, the panel members became discomforted by the narrative itself, but most significantly by Cathy's style of telling. Whilst I both identified with her experience and felt protective towards her, the panel rapidly became critical of her reporting style, which they termed as 'like a police drama' and only describing 'outrage'. They were particularly uncomfortable with what they characterised as Cathy's 'angry' tone. I had been aware of this, and had identified with it from personal experience on the day of Joe's death. Anger is also an emotion shared by many of the participants discussed in Chapter 4, and I therefore viewed Cathy's anger as a driving force and something that had helped to carry her through the obvious alienation she so forcefully describes. The radically different opinions of Cathy, which the panel was already beginning to form, proved a challenge to my own. At points in the narrative where I had felt outrage like that experienced by Cathy herself, for example at the arrival of 'people with guns', the panel simply dismissed this as 'there must have been a reason for the guns'. Instead, they focused on Cathy's 'mess' of feeling and her intertwining of her own grief with the police response, of which they were sharply critical.

From their initial assessment of Cathy, the panel rapidly began to form the hypothesis that she may have killed Dylan, possibly by 'shaking' him, a fear she herself expresses, whilst Maggie repeatedly postulated that the family may already be 'known' to the police and social services, thus providing a rationale for the guns. In the middle of the narrative, as Cathy describes the scene in the first hospital with Dylan on life support, it seemed to me as facilitator that the panel reached a crisis in their choice of how to interpret this story. They described 'not knowing how to make sense of the events' and

asked ‘Do we question the family?’ or ‘Do we question the police?’ Whilst they feel ‘cross’ that the police take Cathy away for questioning although Dylan is still alive, an event which initially provoked my own feelings of outrage, the panel rapidly question whether this actually happened, suggesting that Cathy has misremembered it. From this crisis point, the panel’s judgment of Cathy concretises and she is made a ‘statue’ (Speedy, 2008, p. 57). Returning to their initial consideration of how Cathy would ‘get through the interview without crying’, the panel now concurs that ‘this is not the story they expected to hear’, that it is an ‘aggressive story’, and that therefore the telling of it is a ‘surprise’. Maggie in particular becomes increasingly angry with Cathy, stating that she is ‘really struggling with ‘this belligerent woman’ who makes her very ‘angry’. The two other panel members, whilst more sympathetic than Maggie, agree that Cathy has a ‘strange way of articulating her needs’.

Maggie remains visibly enraged by Cathy throughout the remainder of the process, demonstrating this by remarking both that Cathy ‘does not behave as a grieving mother should’ and that ‘she has choice in the way that [she] reports her grief’. For Maggie, Cathy has made the wrong choice.

Although the panel recognises that Cathy is ‘trying to show she is ok’, they do not view this, as I had in my interpretive reading, as a means of holding back the tears and trying to achieve some meaning by ‘making things better’, as she herself suggests. Instead, they are sharply critical of her ‘lack of emotion’ and remain ‘angry and troubled’ by this narrative, which they reiterate was not what they had been ‘expecting to hear’.

The panel members ultimately summarise their thoughts, concluding that this was a ‘rehearsed interview’ and describing Cathy as ‘never off the stage’. They dislike what they view as her control and her lack of emotion, and describe her as ‘not altruistic’.

5:5: ‘The story I expected to hear’: exploring meaning in Cathy’s panel

This panel for Cathy's story was the first that I had convened and I was therefore still influenced by the BNIM Guide's description of panels as 'both insightful and often funny' (Wengraf, 2011, p. 104). Whilst eventually the panel did prove to generate insight, it was a while before I was able to gain from these insights, as initially I was shocked by the panel's judgments about Cathy, which in turn produced complicated reactions for me.

During the process and immediately afterwards, I could see that the panel members, and particularly Maggie, were enacting 'feelings of shock, surprise and confusion' (Hollway & Froggett, 2011, p. 2). However, as facilitator, interviewer and a parent with an experience similar to Cathy's, I found that my own 'shock, surprise and confusion' at the panel's characterisation of her initially mirrored their own. I did not recognise Cathy as they depicted her, nor what I then viewed as their failure to identify vital parts of Cathy's narrative. Following the panel process, as I worked with the material, I found myself initially experiencing feelings of guilt at involving people, two of whom were friends, in a process that had upset them. One of them, Susan, later reported feeling 'chronically polluted' by the process of 'picking over' Cathy's words, which increased my own sense of guilt. However, this guilt was later replaced by my own feelings of anger towards the panel members, whose understanding of Cathy differed so radically from my own.

I felt that the panel had displaced the emotional force of Cathy's account, letting themselves be sidetracked by her lack of tears, which they distinguished as her drive to present as 'unemotional as possible.' In my understanding, far from seeming 'belligerent' or 'lacking in emotion', Cathy demonstrates vividly her own vulnerability and lack of agency.

In her exploration of conflict within data interpretation panels, Morgenroth (2010, p.

277) suggests that the ‘emotional and bodily reactions experienced by data interpretation panels can be said to provide valuable insights into the research data’ and the ‘data’s latent meaning’. Gradually, through the process of supervision and writing, I began to see much further into the latent meaning, both of the panel’s responses and of my own, and these insights were to prove fundamental to my entire research project.

Returning to the concept of splitting, which I have discussed in previous Chapters, Cathy’s story represents an eruption of disturbing material from a ‘comparatively sequestered domain’ into the ‘public arena’ (Cooper & Lousada, 2005, p. 10). Thus, as the panel say themselves, it is not the ‘story they expected to hear’ and they felt ‘polluted’ by it. Cathy becomes a bad object – she is not ‘behaving as a grieving mother should’ – and she is making the panel face difficult and almost unbearable emotions. By investing the bad in her, they contain the experience and make it bearable once more.

Hollway and Froggett (2011, p. 5) provide further helpful explication of this form of splitting in their work on ‘scenic understanding’. Drawing on the work of Lorenz, a German psychoanalyst and social theorist, they suggest that when accounts or experiences are understood as ‘surprises’, as in the panel’s statement that this is not ‘the story they expected to hear’, a ‘disjunction’ in world view occurs, which can produce a profound personal sense of ‘irritation and ‘lack of fit’.

For the panel, this ‘lack of fit’ produces a split, evidenced not just by their irritation, but also by their overt anger at certain points within the process. Maggie in particular is almost furious with Cathy and condemns the choices she has made, which for Maggie are not as they should be. Her notion of how a grieving mother should behave recalls both the popular depiction of bereaved parents as hopeless, together with the portrayal of the mother in the DVD ‘Why Jason Died’ (see Chapter 2). The actress who plays the role is thin, vulnerable and barely speaks, she certainly never raises her voice, thus

setting a model for how grieving mothers should behave, which renders Cathy's powerful account almost aberrant. Additionally, Cathy's own battle with meaninglessness, evidenced by statements such as 'there was no framework for society', provides an ever present menace, bringing the account disturbingly close at times to the chaos narratives described by Frank (1995). The lack of fit produced by Cathy's vision of a world where there is 'no framework' for society recalls the Kennedy Report's warnings of 'losing our humanity and our claims at living in a civilized society' (2004, p. 15), which therefore understandably causes the panel to project this onto Cathy herself, thus preserving their own 'capacity for containment' (Cooper & Lousada, 2005, p. 11).

However, as I travelled further into the project of developing my own objectivity through subjectivity (Hollway, 2009), I recognised that my irritation with the panel members echoed their anger with Cathy, and that consequently I was mirroring their own splitting. As I have discussed, I identified with Cathy, whose anger resonated with my own on the morning of Joe's death. I also recognised much of the detail in her narrative, both from my own experience and from other stories I had heard. Consequently, I read Cathy's lack of an overt display of grief as an attempt to be taken seriously and not dismissed as a hysterical mother, whilst also defending herself against the threat of chaos, which is ever present in her narrative. Her anger too did not surprise me, as it seemed to be consistent with the situation she found herself in and with her powerful drive to produce meaning from Dylan's death. Thus, where I had a fit for the situation, the panel had none. However, initially I blamed them, just as they had blamed Cathy, as I could not tolerate their inability to understand her, which in turn resonated with the misunderstood part of myself that I had invested in Cathy.

Additionally, as a researcher involved with a process of education, I had also unconsciously expected the panel members, as intelligent, educated women and, in

Susan and Charlotte's case, personal friends of mine, to respond within a 'feminist process of knowing/telling', which related to and merged Cathy's story with their own (Richardson, 1997, p. 166). Thus, like the panel members themselves, I had very fixed ideas about how women should behave, and when they behaved differently I was shocked and angry in my own response, just as they had been in their reaction to Cathy.

As I revisited the panel procedure, I also realised that the process itself may act as 'a provocation', leading to a potential 'disjuncture' (Hollway & Froggett, 2011, p. 5), which may thus have caused strong reactions. The panel members were offered the transcript chunks in a future blind way (Wengraf, 2011) (see Chapter 2), and therefore as facilitator I was the only person present who knew what was coming next, which vested in me an uncomfortable power imbalance, together with a sense of tantalising the panel members as I revealed the transcript chunks. Although this was an unintentional byproduct of the process, there are possible connections between the panel's outrage as they tried to restore their sense of the world, and Cathy's own outrage on the day of Dylan's death. As the professionals 'swarm' around her house, undermining her own agency, Cathy turns to them for containment but finds they are mostly unable to offer this. Like the panel members, the professionals are depicted as struggling with an event they did not expect, which is unfolding in a future blind way and where they too do not know who to question. Where Maggie becomes outraged, the professionals defend themselves behind guns and the ritualised procedures described in Chapter 2, including interviewing Cathy before Dylan had even died. Cottle (2002, p. 541) describes this powerfully in his discussion of the potential impact of traumatic reports and events:

To reject the gaze or words of another and thereby engage in the act of disaffirmation is an endeavor on my part to preserve the nature of the perception and knowledge I have of the world and myself. It is an attempt to solidify my identity.

For professionals, arriving at the scene of a sudden and unexpected child death,

expected to balance care and support with thorough yet sensitive investigation, a mother who responds, like Cathy, outside of their own unconscious expectations may provoke them to feelings of hostility or anger in the same way that the panel was provoked by Cathy, and I was in turn was provoked by the panel. The ‘rage at injustice’ (RCPath & RCPCH, 2004, p. 15) referred to within the Kennedy Report may rapidly turn to rage against the parents or simply at the lack of fit, which the experience itself evokes.

5:6: Conclusion

In this Chapter, I have presented Cathy’s story in its entirety as an attempt to reduce researcher subjectivity and to allow the reader to make their own ‘pathways through the material’ (Morgan, 2000 cited in Speedy, 2008, p. 185). The panel process was then evoked in order to provide context for a further discussion of the lack of fit between my own view of Cathy and that which the panel formed, one which I felt ‘made a statue’ of her (Speedy, 2008, p. 57). In the final section, I explored the panel’s standpoint that this was not the ‘story they expected to hear’, locating this within the concepts of splitting and defence mechanisms discussed in previous Chapters. Hollway’s concept of achieving ‘objectivity through ‘subjectivity’ (2009) was then illustrated via my struggles to understand the panel’s reactions, which initially made me feel guilty and subsequently angry. Finally, I furthered the ‘linkage’ (Cooper & Lousada, 2005, p. 147) that is at the heart of my research purpose by commencing an exploration of the similarities between the panel members, who are struggling to control what they are hearing and the professionals involved in sudden and unexpected child deaths, who may also be defending themselves from what is happening. These links will be further investigated in the next two Chapters, which, in contrast to Cathy’s ‘angry’ narrative, offer different forms of meaning-making and corresponding difficulties within the panel process.

Chapter 6

6:1: Julia

"We were so blessed."

In the previous two Chapters, I have tried to find ways that 'capture the reader's attention and engage them in conversation' (Speedy, 2008, p. 138), both with myself, as researcher and writer, but also with the parents and panel members who have helped form the final version of this thesis. Whilst Chapter 4 provided common threads, Cathy's story within the previous Chapter is offered in its entirety, together with the panel's view of it as an 'aggressive story' and my own subsequent struggles with this.

In this Chapter I focus on Julia, whose story I also offer in its entirety, following the same format that I used in Chapter 5. I chose Julia's story as one of the three complete narratives, partly because it picks up many of the threads already discussed. However, it does so in a way that is not immediately apparent, and which therefore caused me to dismiss it initially. As the panel in the previous Chapter found with Cathy's narrative, Julia's was not 'the story I expected to hear' and it was only through the processes of transcription and interpretation that I began to recognize its latent power, particularly in terms of my own unconscious processes. Whilst it is a radically different account from Cathy's, recounted in a similarly different style, the panel also responded to Julia's story with 'irritation' (Hollway & Froggett, 2010, p. 5), and their reactions, alongside my own, cast further light on the concept of what is thinkable when responding to sudden and unexpected child death.

6:2: Context

Julia is a professional woman in her early fifties. She lives with her husband, Steve, and they have three sons who are now in early adulthood.

Julia contacted me via a mutual friend who had mentioned my research study to her. Our initial contact was by email. This was followed by a telephone conversation as agreed in the 'Information for Participants' (see Appendix 4). Julia was given the relevant information and signed a consent form.

Julia's story concerns the death of her first child Kitty, a daughter, who died during her first weeks of life, more than 20 years prior to the interview. Julia was keen to be helpful and to participate in the study, although she expressed anxiety that the great length of time since the death may render her story less than valuable. Whilst she was very willing to participate in the interviews, Julia was not interested in seeing the transcripts. Her major concern was that the story would be useful in some manner.

The interview took place in her home and lasted for well over an hour. As with all the interviews, the narrative was prompted by the initial SQUIN (see Chapter 3). Unsurprisingly perhaps, given the length of time since the death, Julia had clearly told the story before and it is notable for its 'scenic' sense (Hollway & Froggett, 2011, p. 1), derived from the location of the death, which features powerfully within the narrative.

During the interview, there were occasional interruptions from a son still living at home, as well as a lengthy tea break in the middle during which Julia chatted openly. She presented as a highly gregarious and hospitable person at the hub of her family.

After the interview, I had some brief email contact with Julia once the transcripts were complete, and also after my appearance on a BBC radio programme. Julia admires the

presenter and was keen to hear about my experience. We therefore exchanged emails. Following this, we have had no further contact.

The transcript was later sectioned into future-blind chunks for presentation to the BNIM interpretive panel. The panel for Julia's story consisted of three people, all white British and friends of mine. Their names have been changed, as in the previous Chapter, to ensure confidentiality. Marcus is in his fifties and is now a specialist social worker, having previously worked in child protection, Belinda is an academic in her forties and Elaine is a graphic designer and craftswoman, also in her forties. All three are parents.

6:3: Julia's story

Kitty was born in spring 1984 and she was beautiful. She was our first child and so it was a lovely special moment. There had been no problems and she had come home as normal.

When she was 6 to 8 weeks old we went on holiday, up to a remote island where we've always gone on holiday since I was a child. We were so excited because we wanted to introduce her to friends and we went via my husband Steve's parents and his grandmother who was very, very old and in a home. She was very excited to see her great grandchild as my husband hasn't got any siblings, so this was all very exciting. We took Kitty to see my sister and my nephew and nieces as well and they were all pleased because it was the first next cousin. It was all lovely.

We got to the island after a good journey and because I'd been going to this place since I was very young, we knew everybody so it was like going home. Everyone was very excited that this new little baby had come and up and I hadn't seen it before, but they crossed her hand with a coin.

We were with friends of ours who'd got a little girl called Helena who was 9 months

older than Kitty. I had been at school with Gill, the Mum, and we'd been bridesmaids together. So they were very good friends and we were having a lovely time.

Half way through the week, I think it was either a Monday or a Tuesday, after we'd had a nice day I fed Kitty and put her to bed as normal. We had Kitty's crib and this and that because we didn't want anything to be different from home as she was just getting used to that routine. I think every parent with their first child takes everything because you don't want to disturb the routine and you still have room in the car. So it wasn't as if she was sleeping in anything different.

I put her to bed about 8 o'clock and Helena had gone to bed too so Gill and Rick and Steve and I were enjoying the evening. About 11 I went up to feed Kitty like I always did and I thought, 'Oh my god, she's stiff.' I can just remember saying to Steve that he must come and that 'I think Kitty's dead, I can't pick her up.' Steve picked her up and said she was dead and should he try and resuscitate her. I can remember we didn't know what to do and so we were going, "Yes, no, yes," because we didn't know how long she'd been dead for and he did try to resuscitate her because there were no phones there, it was completely isolated.

The house is so amazing, I just love the place. On the hill there's some people that I've known forever, Alison and Peter, the local fisherman, who are just lovely. So Gill said, "I'll go and get Alison to call the doctor," and she rushed up the hill and Alison called the doctor.

We were just so blessed, I can't tell you how blessed we were because a doctor came and confirmed what we already knew that Kitty was dead and that she was probably a victim of cot death. The doctor stayed with us and she was just lovely. She was an island doctor – youngish - who said she had young children of her own. She told us that because of the circumstances she would have to call the police. And this is another

reason that we were so blessed because the police on the island are the local farmer and the local fireman and the ambulance man.

In those days the special policeman was Reggie, who I'd known forever and seen him in lots of different outfits, in his kilt and other things. So about half an hour or perhaps an hour later Reggie turned up in his police uniform which was like the dressing up box of a child. He was the most wonderful gorgeous man and I knew he'd had some tragic experiences in his life, because on island life they all have. So Reggie came in and I can remember, he just threw his arms around me and said, "We're all here together." That was all he said but he gave me the biggest hug and I said, "Reggie my boobs are killing me" because of the milk. Everyone was laughing and Steve was still holding Kitty and she was wrapped in this beautiful hand-made blanket that an old lady had knitted. It was a patchwork one that I had wanted and couldn't make myself. Kitty looked so beautiful and serene, just perfect really.

We just had to go through and give a statement to Reggie but it just felt like telling somebody with real empathy what had happened. The doctor was wonderful and told us she would take Kitty back to her house because the surgery was just like a house. Then she explained that Kitty would have to go for a post-mortem, which would be on the mainland and asked if we were ok with that. We just felt that she had to do what she had to do but she told us we could visit Kitty the next day before she was taken off the island. She had such a wonderful balance of empathy for this sudden death and also such empathy with me and my physical needs of being a new first time Mum who was breast feeding. She also had such empathy for our friends who had their own small baby, just 9 months old and for the anxiety that they might be feeling. The doctor and Reggie the policeman took all of us in and nurtured the whole group and of course me and Steve as well. They were phenomenal, absolutely phenomenal and they gave us that time and peace, so we were very blessed.

The doctor had brought some vitamin B and told me I had to take several that day to help with the recovery of my breast feeding. I was so uncomfortable and she had thought of that and so we were really blessed.

Steve managed to phone my Mum and Dad and also my sister and they were all devastated.

A long while after Kitty died we discovered that my husband had siblings on either side of him, who had been stillborn because of the Rhesus factor, but his parents had never shared this with him and he always thought he was an only one. He had always been wary of having children although he did want them but from the moment Kitty was born she was such a Daddy's girl and the bond was huge between them from that first moment.

On the night she died we went to bed in my very favourite place and although we were in shock because we'd been so cherished in that horrendous 2 or 3 hours I can remember saying to Steve, "Gosh, we're just so lucky. We've had what some people never have. We've had the most beautiful daughter who's never done anything wrong, we've never had to tell her off, we've just been able to love her really and explore the joy of parenthood with her. She was a real blessing." I remember Steve saying that he hoped we would have more children but if we couldn't we would always have the lovely daughter that some people never have and can't have. I can also remember him saying that if we did have any others we would never forget that Kitty's our eldest and any other children would always know. He is such a quiet and reserved man but he wanted to ensure that people always knew about Kitty and that we would always tell people about her and that they mustn't be embarrassed. He saw it as our mission.

The next day, two extraordinary things happened. The first was that there was a ferry strike which meant that they couldn't get Kitty off the island and also that my Dad who

had been up all night, couldn't get on the Island. So suddenly that day a helicopter arrived on a nearby patch of grass and all of a sudden I have my Mum, Dad and sister. It was such a parental thing to do.

My Dad just said, "I'm your father, I needed to be here for you, I needed to be here," and I have always remembered it. I never found out how much it had cost him. I was very close to my father and although I have two brothers and a sister, my Dad was special, everyone says so and we were very close. What he did that day was incredible, because I would never have asked him to come. We were all right but we were even better once he had come.

The other good thing about Kitty not being able to leave the island was that she had to wait for the lifeboat to be off duty and to come and pick her up... This all meant we could go to the doctor's house, which was lovely and there was Kitty in her crib, wrapped up in her blanket, looking absolutely rested and serene. My Mum and Dad and my sister and Steve and I all held her and then, and then the doctor told us that we were lucky because the lifeboat was coming straight into the groyne by her house and so we didn't have to go in the ambulance across the island to get the ferry. So again it was the quality of local life which was the blessing and this is why we felt so blessed. When the lifeboat came we all took Kitty on board and the lifeboat men were crofters, so I felt so lucky to be able to hand her over to people who didn't do this day in and day out and who took it so seriously. It was a really emotive, memorable moment to be witnessing. The lifeboat men told me that they would look after her until they handed her over to the ambulance people, who were going to drive the ambulance on the long journey on the mainland.

After that we weren't allowed to leave the island until the results of the post-mortem, which was fine. Kitty's death had to be registered on the island, which was also a

blessing because it gave us time to do things to remember her by in a place which was so unique and special. Our dear friends Gill and Rick stayed as well because they loved the place too and were in no rush to leave. My Mum and Dad and my sister also stayed and the island people were wonderful. One of them, a fisherman, told us that he didn't know what to say but he asked Steve to go lobster fishing with him because he knew Steve loved this.

Once we had registered Kitty's death we had to come home and although it wasn't planned Kitty was brought back on the same flight as my Mum and Dad. When I got back home my Mum told me that the plane had circled the place where I grew up for several minutes before they were given permission to land and things like that were just incredible.

As soon as we got back here it was like entering another world really. In some ways we were still lucky because it was just about at the end of having a family GP. It's all different now because I don't even know who my GP is. Our old family GP was good and he came round and told me that he didn't know what to say but that he was really sorry. He knew me well enough to know that I would see him if I needed to but apart from that he really didn't know what to say, which I remember thinking was open and honest.

After that we had some odd people who came round. I don't know where they came from but they were most odd and they said they were bereavement befrienders. They told me that this should not have happened to me and asked me what Steve and I worked at. I told them we were both teachers and they said as we were both professionals, it really shouldn't have happened to us. I also remember them asking if we smoked and we didn't, so they said it should DEFINITELY not have happened to us. When they learned we were home owners they emphasised that cot death should

simply not happen to professional, non-smokers, who own their own home and for the first time I was really angry.

I told them not to tell me that it shouldn't have happened because it had happened and we had been really blessed to have had the most beautiful, stunning daughter that anyone in the whole world could have. It had happened and it was proof that it could happen, so I asked them to let us enjoy what we had. Then they asked me if I would like to make a regular appointment to talk about the bereavement process, to which I said, "No thank you."

We were absolutely fine by that time and oddly it was only a few weeks later that I became pregnant again. Steve and I had agreed that if we had another baby, we would be happy but not to get fixated on it. When I became pregnant again, I did not see my own GP but a random doctor who told me it was extraordinary because I'd had a birth, a death and now I was pregnant again. I remember thanking him for confirming the pregnancy although I wasn't sure he had handled it in the best way. After that I made sure I saw my own GP.

We were really well supported by the vicar that we'd known for ages who was just phenomenal. We went to church the day we got back and he said, "Gosh, how wonderful to have lived a life of love, she's given love and received love."

He told me and Steve this story about a man of 85 he had just buried. He was a good man, he said, but he had known things other than love, that had made his life perhaps rich, but also sad. Kitty had never known sadness or suffering and we thought how nice it was to look at it that way. Then we had to think about the funeral and there were certain things we wanted and that Steve said we would do. The funeral service was very important but it didn't really feel like a funeral but more a service of thanksgiving. I was young then and I hadn't been to many funerals other than grandparents. I just

wanted people to share in the celebration of Kitty's life and that's what we did. We made it a service of celebration. The vicar helped make it that too and that was really important to all our friends. I couldn't believe how many people came but there were so many friends and colleagues from work and I thought that was great because they're getting a sense of how important it is to do that. Steve was adamant that he was carrying Kitty into church because he had carried her around during her 8 weeks of life and he did not want her carried by an undertaker. I will always remember him walking just as he had held this little thing in life, even in a coffin.

The little things were really important to Steve. As Kitty was a baby they assumed we would want a white coffin but we didn't. Steve said no because we wanted to make our mark on it and I think we did. Things like that were really special. I think we were able to do all of this because of the nurture that we'd had.

I had taken maternity leave with Kitty which in those days was unusual. My plan had always been to go back to work and I know a lot of people really disapproved. The Head was clear with me that it was my right to return as soon or as late as you wanted and I was really touched by that because she was trying to show me there was no pressure. So I knew whatever I decided would be respected and I can remember starting back much earlier than expected. I will always remember one of the young people saying to me, "We're so sad about Kitty, so sad but then we're so glad because it means that you've come back to us sooner." I still remember her name, Claire Richardson she was called and she was such a naughty girl, so it was so touching.

I remember thinking at the time that out of the mouths of children comes the quality conversation because she could acknowledge it. It was so important that she could acknowledge it and say it to me and I knew she could only do that because I had such a very positive relationship with her.

Kitty's life has touched us like nothing else really. Her three brothers are all very clear that they've got an older sister and they're very proud of that older sister who they never knew. A number of times at school, when you have to write about your family or whatever the teachers would ask us if they boys are all right because they didn't realise they had lost a sister. We would always say that the boys would not have mentioned it if they weren't all right about it and people knowing about it. The boys have always talked about Kitty and they still do. They say, "She's the best sister in the world, she's the sister around us but she doesn't need make up or clothes and she doesn't fill up the bathroom with stuff." So we laugh about it and sometimes we talk about family dynamics. The boys realise that if Kitty had survived we would all be different people and we have long conversations about this. Kitty's eldest brother my next one, Tom was born on her birthday, a year, exactly a year after her.

So that was always strange. When he was born no one offered me any support or anything like checking I was all right to take home a baby home after I had experienced a cot death. We had no support at all and nobody would acknowledge it. Of course we acknowledged it and because of the way we were and the beliefs we had we were always very clear that we would treat this baby in exactly the same way that we were going to bring Kitty up.

So if it cried we would let it cry and it wasn't going to sleep next to us as Kitty wasn't going to sleep next to us. We had to support each other hugely in making sure of this but we didn't need a parent's book to tell us how to bring up your children in the first eight weeks because Kitty had written it for us. I know that sounds arrogant, but that's how we handled it. Other than that nobody ever asked or offered us anything other than my befriending friends who couldn't befriend us!

No one ever openly talked about the chances of it happening again but then it happened

to my cousin. Her baby was six years younger than Kitty, the same birth weight and the same gender. It was just extraordinary and even then there was nobody who took an interest even when we had subsequent children. My youngest was only three months after my cousin's daughter died and people knew this but nobody was interested. Of course we didn't want them to be interested, but we were just surprised that nobody talked to us about the likelihood of it happening again and what the chances were. When it happened with my cousin's child I had this fear of there being a second time around and something happening to my youngest two. It was hard to shake the fear...

One of my boys was born in the winter with a heart problem, the sort of thing babies can have I can remember wanting to stamp my foot and say what was all the fuss about but on the other hand to say we had experienced a cot death and could they just help us. I hated the fuss but I can be stubborn and I remember wondering if I was being stubborn or being strong or simply going into denial. I wondered whether I should be noticing and watching everything but I can remember my Dad talking to me about it. My Dad sometimes took the boys to the Doctors when they were young so it was my Dad and my Mum who were often making that decision.

Shortly after my youngest boy was born, cot death became quite high profile. It certainly wasn't so when Kitty died so around that time people would ask me if I was ok and I was fine because these things happen.

Kitty has had such an impact on my life because you know statistics are pointless and that awful befriender woman who told us that statistically it should never have happened to us was meaningless because what happens happens.

I think it's why I can't get excited about children's statistical achievement in school now. Whether they 5A stars, 50% or 40% because in the end it's about people and individuals. I do wonder sometimes about Kitty sleeping on her front but then Ben slept

on his front too. I can't remember when we were supposed to put them on their backs. Who knows?

All I do know is that I wish that everybody could experience the kind of love and real support, caring and quality of time that we had on the island when Kitty died. It was quality time not based on results or outcomes or somebody only being allowed to be with us for ten minutes. I have a friend who was a district nurse and she gave it up because she was told not to spend too much time with vulnerable people. She really listened to people so she was told she shouldn't have a cup of tea with a person she was injecting with insulin for example. She knew she provided the only human contact that person may have had and that human contact is as important as the medical intervention for quality of life. Steve and I had that quality of support because in the situation we found ourselves in, we had people who knew very genuinely how to be empathetic.

We were with people who knew. We still go there, to the island and we still look at the lifeboat. They have all the outings on a board and it goes right back to the lifeboat that took Kitty off the island. It says on this date a body was brought from the island to the mainland and things like that are so important. They are acknowledgement that it was real work and they did it in such an empathetic way.

That's my story really.

6:4: 'A beautiful story': Julia's interpretive panel

Although I had liked Julia and enjoyed our meeting, I found myself initially becoming very irritated by her story, which on further reflection I understood as indicative of the 'lack of fit' (Hollway & Froggett, 2011, p. 5), which was discussed in the previous Chapter. Whilst Cathy's story did not surprise me, Julia's insistence on 'being blessed' did, leading to my initial dismissal of the story as unsuitable for presentation to an interpretive panel. Gradually, and somewhat uncomfortably, however, I began to see that I was mirroring the very processes that I was also critiquing in others. I had split Julia's story from the collective, and my irritation came from defending myself from her 'otherness' (Cooper & Lousada, 2005, p. 86). Whilst I had wanted stories that bound people together, Julia told a different story, one in which she was 'blessed' and contained, and thus I initially did as Cooper and Lousada describe and 'stripped her of her citizenship and right to be included as worthwhile' (2005, p. 86).

In this, I also recognised 'counter-transferences' (Morgenroth, 2010, p. 267) similar to those within the panel response to Cathy's story, and this growing and uncomfortable realisation helped me realise that, far from excluding Julia's story from panel interpretation, I needed the assistance that a panel could provide. As Ogden (2009 cited in Hollway & Froggett, 2011, p.281) suggests, it 'requires two minds to think a person's most disturbing thoughts', and thus, far from being unsuitable for panel interpretation, I understood that it was actually vital for me to introduce another set of voices.

In common with all the other narratives, Julia's commences by locating itself temporally – 'Kitty was born in the Spring of 1984'. However, the threads of emotion and professional involvement contained within Julia's narrative are markedly different from the others, particularly at first examination. Julia's narrative is also unique

amongst all the accounts for its sense of the 'scenic' (Redman, Bereswill & Morgenroth, 2010) with which it is saturated. There is a forceful drive towards the thread of managing chaos and finding meaning, as explored in Chapter 4, which is demonstrated by the repeated use of the word 'blessed'. Whilst in Cathy's story this thread is half-hidden by her powerful and often disturbing description, in Julia's it is predominant, and this is perhaps partly explicable by the 'distance' both of time and of 'the telling' (Frank, 1995, p. 8), a factor that emerged during the discussion of this thread in Chapter 4. Julia shares with Terri a sense of the symbolic within Kitty's death, and whereas for Terri this is expressed through the tale of a fox killing the family pet rabbit, for Julia it is expressed through the almost mythical nature of the island, where 'real work' happens.

Siblings are another common thread within Julia's story. Although Kitty is her first child and only daughter, she is very careful to locate her relationship to the subsequent boys both within the contexts of their lives and within the interview: 'Her 3 brothers are all very clear that they've got an older sister and they're very proud of that older sister'. This has strong parallels with Ellie's description in Chapter 4, where two brothers, also born subsequent to their sister's death, will 'always know who she is'. For Ellie and Julia alike, maintaining this 'thread of continuity' (Hindmarch, 1993, p. 4) seems to form an essential part of their meaning-making.

Julia and Ellie's stories are also linked in their understanding of the professionals that are involved. Whilst Cathy invests much of her outrage towards professionals, both Julie and Ellie describe demonstrations of humanity. In Ellie's story this manifests as the policeman who runs marathons in memory of her child, whilst in Julia's the policeman, Reggie, 'threw his arms around me and said, "We're all here together".' Whilst Julia feels 'blessed', Ellie also believes she has had 'the best experience' possible.

Through multiple readings and interpretations of Julia's story, I began to see that, despite its extraordinary aura, derived from Julia's love and investment in the island and my own initial reaction to this, the story has far more threads in common with the others than I had originally perceived. I approached the panel process intrigued to discover what threads would dominate and what 'counter-transferences' (Morgenroth, 2010, p. 267) of their own the panel might bring to this story, together with how they would interpret these in the wider context of sudden and unexpected child death.

The panel begin by immediately commenting on the 'filmic' quality of the transcript, which they concur is described almost as a 'pilgrimage' to a 'place of great importance'. They are clearly bemused by this, and there are early echoes that it is 'not the story they expected to hear'. At this early stage, the panel shows a degree of consensus in their understanding of Julia and all identify class as being an important aspect of her identity. They view her as locating herself early on as a middle class parent who 'gets things right'.

In common with both Cathy's panel and the collective threads, described in Chapter 4, the concept of blame begins to manifests itself, although not, as with Cathy, as a suspicion of her harming the baby. In this panel, blame is raised by Marcus, who asks, 'Was it a good idea to take such a young baby to somewhere so isolated, where there are no phones?' In a parallel with Maggie within Cathy's panel, Marcus' sense of irritation with Julia becomes rapidly discernible early in the panel process, although he is able to temper this with humour. Marcus feels that Julia's self-narrative has been 'tripped up' by the death of Kitty and that the story she tells is designed to reinstate it.

There is a long discussion within the panel of Julia's repeated use of the term 'blessed', and they question, 'Why was she so blessed when her baby has just died?' Seeking to answer this hypothetical question, the panel members then formulate the twin

hypothesises that the ‘blessed’ may simply be a denial of the death or may actually feel real to Julia because people were nice and there was so little officialdom. The panel agree that there is deep connection shown within the relationships in this story, and that the ‘blessed’ is also invested deeply in the mythical nature of the location. The panel dub the island ‘Balamory’ after a popular children’s television programme, which they agree is fitting for such a ‘fairy tale’ aimed, in their view, at not being ‘judged harshly’ and at ‘being understood’.

In contrast to other panels, this one (despite Marcus’ growing irritation) demonstrates great humour in response to this story, within which they seem to find a sense of the ridiculous. This is the only panel where members frequently laughed and the narrative is derided at times. One example of this is a period where the panel starts speculating on who will make the film of this story and which actors will play the various characters. Despite this, at no point does the panel suggest that ‘this is not the story they expected to hear’, nor query whether it actually happened, as Cathy’s panel did in response to a more distressing narrative. This suggests that, although Julia’s perhaps seems the most implausible of all the narratives, it is not as emotionally demanding as Cathy’s and thus there is less need to defend against it.

However, the panel suggests that Julia herself has defended against a terrible tragedy from which she can’t escape by ‘wrapping herself’ in ‘Balamory’, which becomes the grounding for her attempts to avoid the reality of Kitty’s death. Julia thereby protects both herself and others from being deluged with unbearable feelings by her scenic reconstruction of a magical island where people are ‘blessed.’

The panel also observes the absence of technology in Julia’s story, which both dates it and provides a stark contrast to Cathy’s narrative. Here the attempts to resuscitate Dylan, to make a ‘dead baby alive’ as she describes it, together with the ‘deleting of a

dead baby' in the photographs, all add to the unbearable quality of the account. By comparison, Julia describes Kitty being wrapped in a shawl on an island where 'tragedy happens'. The modern world does not intrude except in ways that are gentle and helpful, such as the doctor providing her with a way of stopping her milk production. The panel comments on this vivid description of Julia as a person with her needs being met, a feature that is entirely absent from Cathy's story.

Interestingly, although Julia does not mention Sally Clark or Angela Cannings as other narratives have, the panel raises these cases as part of the 'absence of the architecture of modern life' within her narrative. There is a long discussion in the panel about how these cases, together with notorious child deaths, inform our cultural understanding of sudden and unexpected child death. They note that, perhaps due to the time of the death, this aspect is totally absent from Julia's narrative.

Marcus' irritation with Julia, which has been increasing throughout the panel process, becomes gradually heightened as the transcript chunks progress, leading him to comment that, 'If I met her at a support group, I would have to leave, because I would be getting angry'. Belinda responds by saying she feels sorry for Julia, whom she feels is 'not feeling the pain of her loss'. This has parallels with the panel for Cathy's narrative, where Maggie's anger was paramount, but equally where all panel members felt they knew what Cathy should be feeling in some way.

In parallel with the crisis I identified in Cathy's panel, in Julia's story the arrival of the helicopter is an influential moment. Elaine, who had previously been quite jovial, began to cry and eventually explains this in terms of wanting 'the man in the helicopter for herself'. Consistent with the mythical quality of the island, it seemed as if 'the man in the helicopter' provides the figure of the 'hero' (Frank, 1995, p. 119), who is able to accompany Julia on her 'journey of suffering' and to help her 'bring back the boon'

(Frank, 1995, p. 119). Not everyone on the panel responded to ‘the man in the helicopter’ in the same way as Elaine did, however, with Marcus once again expressing scorn and describing the scene as both ‘tragi-comic’ and ‘ridiculous’. Despite this, no-one queried, as in Cathy’s panel, whether this actually happened.

The helicopter landing also provides the demarcation between what has happened on the island and the imminent introduction of the outside world. From this point, and as Julia describes leaving the island, the panel members are very divided. Marcus feels that the ‘lovelies’ and the ‘blesseds’ are now being ‘laid on with a trowel’, whereas Belinda and Elaine feel that there is ‘closure’ here and that Julia is telling a ‘beautiful story’ in which she is ‘held.’

The panel members all note a difference between the way Julia reports the island and what they describe as the ‘real world’, which is ‘harsh.’ Julia’s description of her response to the ‘odd’ befrienders – ‘I was really angry’ – is the first time that her emotions have mirrored the thread of anger so strongly present in Cathy’s story and in many of the other narratives. Marcus feels that this is because they have ‘burst Julia’s bubble’, and paraphrases this as ‘I went to a magical place and real life intervened.’

In parallels with the panel’s experience for Cathy’s story, this one closes with a generic feeling of ‘irritation’ towards Julia, whose narrative is finally interpreted by them as one ‘lacking in humility’ where she never explicitly ‘deals with her guilt’. Thus, despite responding to the atmosphere of the story, which Belinda formerly described as beautiful, this panel echoes Cathy’s in expressing what Julia ‘should’ be feeling in these circumstances. There is little allowance within the panel for different emotions or for meaning-making, which forms a strong thread in Chapter 4 and which ultimately drives Julia’s story.

6:5: 'Why is she so blessed when her baby has just died?': exploring meaning within Julia's panel

Whereas in Cathy's panel the radically different understanding of Cathy made me feel an outsider, I initially felt closer to Julia's panel as I had experienced similar irritation in my original response to Julia's story. At first, therefore, the panel process was more collusive than that experienced with Cathy's. However, as it continued I began to feel increasingly protective of Julia and thereby to experience a sense of irritation and 'lack of fit' with the panel themselves (Hollway & Froggett, 2010, p. 5), whose ridiculing of Julia began to feel like a provocation.

Clues to this provocation are provided by Morgenroth (2010, p. 268) in her work on data interpretation panels. She discusses 'excluded elements of the scene', which nevertheless are implicitly present within the data and thus cause the provocation caused by the lack of fit between these. The panel identifies one of the main 'excluded elements' in Julia's story as 'the big issue of mortality' (Frank, 1995, p. 84), which they feel Julia evades, leading them to question 'why is she so blessed when her baby has just died?' Despite the differences between the accounts, Julia, similar to Cathy, is therefore identified by the panel as not 'behaving as a grieving mother should' in turning her account into a 'beautiful story.' The panel mirrors Cathy's too in their implicit judgment that Julia has shown the wrong choice in how she reports her grief, which they view as a means of never explicitly dealing 'with her guilt.'

Thus Julia and Cathy's stories, which in many ways are the antithesis of each other – one spreading 'restitution' (Frank, 1995, p. 83) whilst the other teeters on the edge of chaos – find union within the panels, who both blame the women for not behaving as they expect them to and for challenging them by not 'telling the story [they] expected to

hear’.

My own corresponding provocation led to me to replace my initial irritation with Julia and to transfer this to the panel. In so doing, the excluded elements, which had previously been invisible to me within Julia’s narrative, started to reveal themselves. Rather than evading the ‘big issue of mortality’ as the panel felt she was doing, I began to view Julia’s narrative as an attempt to counter the common depiction of sudden and unexpected child death as ‘the most shocking and devastating event anyone must face’ (Dent & Stewart, 2004, p. x). Thus, like Cathy whose drive to change things steers her away from chaos, Julia’s account, so finely honed over twenty years, leads her from the darkness of Kitty’s death to the light of a new day. This answers the panel’s question ‘why she is so blessed when her baby has died’ for, echoing Ellie in Chapter 4, Julia strives to believe that she has had a ‘good experience’, one that leaves her, like Hafsa, in ‘a good place.’

As the panel suggests, this is not a ‘true’ version of the story, but its truth in ‘factual’ terms is not what is important in coming to understand the meaning of Julia’s narrative. As Hollway and Jefferson discuss within their own application of Kleinian principles, remembering is in ‘continual tension between a truthful acknowledgement of the (emotional) reality of a past event and defensive distortions of that reality in the service of psychological self-protection’ (2000, p. 151). Thus, whilst Julia has certainly defended herself as the panel suggest, her account represents a reworking of events in the light of later meanings (Hollway & Jefferson, 2000), including the birth of her sons and their assimilation of Kitty into the family history. Whilst this challenges the panel who project their own shock and distress into Julia, finding her lacking, the account she gives is actually an ‘example of maintaining depressive positioning functioning rather than resorting to paranoid-schizoid splitting’, which the panel does. (Hollway & Jefferson, 2000, p. 151). My own initial irritation stemmed from a similar splitting; as

the containment Julia describes was so unlike my own experience, I found it harder to hear than Cathy's angry narrative, thus causing me to reject it.

For Julia, this containment is crucial to her remembering and to her integration of the experience, thereby allowing her to move towards a depressive position. As she herself says to the befriender, 'It had happened and it was proof that it could happen so I asked them to let us enjoy what we had.'

6:6: Conclusion

This Chapter focused on Julia's complete account of her baby Kitty's death, which occurred over twenty years ago. Like Cathy's story in Chapter 5, I have presented the entire narrative, together with comments from the panel and with my later understanding of these. Most notable in this Chapter has been my own shift in position from dismissing Julia's account as a superficially beautiful story with little relevance to my research, to a deeper understanding of its importance within the wider context of sudden and unexpected child death. The role of the panel in helping me to achieve this transformation in attitude demonstrates further their potential to act as far more than a simple 'kick start' procedure. It was by observing and intertwining the panel's response to Julia with my own that I was able to empathise with her and to recognise the reasons for my own initial dismissal of her story, which was too hard for me to hear.

Julia's memory of the professionals who supported and believed her, within a context where 'tragedy happens', demonstrates powerfully the crucial role of containment in helping to achieve meaning-making and a move to the depressive position. In this way too, Julia's narrative is surprisingly subversive, disrupting the popular notion that child death is insurmountable, and in so doing, challenging normative preconceptions both of behaviour and of remembering.

Thus Julia's account of Kitty's death, far from being irrelevant as I had initially thought,

actually contains profound lessons for professionals responding to sudden and unexpected child death, whose actions may exert significant influence on parents' meaning-making processes over time.

Chapter 7

7:1 Laurie

"We have just been doing things right."

This Chapter focuses on Laurie and offers an opportunity to access the future-blind chunks, which were presented to the BNIM interpretation panel. I had originally written and presented Laurie's story in the same way as both Julia and Cathy's, including her complete account and the interpretations of the BNIM panel. My rationale for this was that Laurie's story offers some grounding to the two preceding Chapters, as her style of telling and her emphasis on 'doing things right' contrast with the rawness of Cathy's account and the filmic quality of Julia's.

The panel's response to Laurie's story was also very different. Where previous panels had labelled Cathy's story as aggressive and Julia's as lacking in humility, Laurie's measured reporting of her experience seemed to lead to a sense of disengagement within the panel. My two thesis supervisors similarly reported finding it difficult to concentrate on Laurie's story, partly due to its length as well as her determinedly thorough style of telling.

These responses, combined with the practical difficulties of including Laurie's lengthy account within the permitted word count for this thesis, led me to alter my original decision and to include Laurie's complete account as Appendix 7. Within this Chapter, I offer the same chunks that were presented to the data analysis panel, as an opportunity to enhance methodological understanding and to view the account through an alternative lens.

7:2: Context

Laurie is a married woman in her mid- thirties. She lives with her husband Mike and their young son Josh.

Laurie contacted me by email in response to one of the requests for participants that I had placed on the website of a support charity with which Laurie is closely involved. I sent Laurie the Information Sheet (see Appendix 4) and she then agreed to be interviewed. We followed this with two telephone conversations.

Laurie's partner Mike had recently had a kidney transplant at the time of the interview and, as I had a cold, Laurie arranged to meet me at a friend's house due to the possible risk of infection. She had also arranged for her son Josh to be looked after elsewhere so that the interview would be uninterrupted.

Her narrative concerns the death of her two year old son George 19 months prior to the interview. It was prompted by the SQUIN and was the longest of all the interviews in this study, lasting well over two hours. Laurie was often emotional throughout and she showed me photographs of her two sons. Laurie presented as gregarious and sociable with a strong driving force to 'make meaning' from her son's death. It was clear that she saw the interview as part of this process. Laurie remains very active within her local support charity and has featured in several media pieces on the work she has done since the death of her son. She undertakes regular fund raising work and has her own blog.

Following the interview, Laurie has kept in regular contact, describing the experience as 'very powerful'. She has seen the transcript of her interview and offered comments on this, notably corrections to minor details.

The transcript was divided for the panel into numbered future-blind chunks, following the same process that had been used for the other panel sessions. The panel consisted of

three people, all white British and previously known to me as colleagues and friends. This was probably the least diverse of all the panels as each member had formerly been employed as a child protection social worker, a fact that may be significant. All names have been changed, as before, to ensure confidentiality. Stan is in his early sixties and is now retired from a long career within child protection, Jess is also in her early sixties and still works part time as a social worker and Betty is a former social worker in her mid-forties who now works as a person centred counsellor. All three are parents.

7:3: Laurie's story: future-blind chunks.

1. Denise: So basically, yes, I want you to tell me about when George died, any events and experiences that were important to you. Whatever order you feel is right and I will just try and listen and I may write a few things down for after, but I'll try to just let you talk about anything that comes up, that feels or was important for you.
2. Laurie: Well, George had his 2nd birthday on 4 March 2009 and throughout his whole life he had been a very, very, healthy well boy.
3. Sunday, 15 March was the day he died. He was 2 years 11 days old. He'd been in the park with his Dad and his brother, in the car, dozed off, a nap, as he would have any other day. We just thought he was having a longer nap than usual.
4. Mike went to check him, realised that George wasn't breathing. The utmost panic arrived. Mike brought him downstairs we phoned the emergency services. Josh woke up as well. He was quite terrified at the panic that was going on.
5. Mike tried to resuscitate George. We waited for the emergency services. That took something like 15/20 minutes but obviously felt a very long time.
6. The ambulance took him straight to hospital and I went with them. All the way

they continued to try and resuscitate George. At the hospital there was a flurry of people waiting on him. They tried their utmost to revive him but I think I knew in my heart that there wasn't really much they could do.

7. We were led away into a room. The medical team agreed there was nothing further they could do. The paediatrician came into the room and told us George had died.
8. A lot of what happened that day is hazy. I do remember we couldn't donate an organ, because they didn't know why George had died. It was explained that there is a legal requirement for a post-mortem instructed by the Coroner. Not something we could give permission for. We totally understood this.
9. We were taken to the relatives' room to spend some time with George. This was very special. A nurse was there, a minister came in and we were left for a short while ourselves. I would probably have stayed longer but my husband was really keen to get back for our other son.
10. While Mike and I were away the police arrived at our house. My friend Sue, her 7-year-old daughter and my son Josh were still in the house and preparing to go to Sue's. Sue was keen to take Josh to her house and provide him with warmth and love and a safe place until we returned.
11. The police entered and informed Sue that she, her daughter and my son should not leave the house. Sue persuaded them that this was not the right thing to do. She understood that the most important place for Josh to be was around his peers, his friends and comfort. Josh remembers the policeman arriving at our house.
12. Back at the hospital Mike was insisting that we leave. In his words there was

nothing they could do for George, but it was very important that we handle Josh the way we chose to, the way we thought was right.

13. Mike had phoned and told 2 or 3 families. It's a small village so word travelled incredibly fast.
14. As we got back we had no input from the police although we were aware that they were going to be involved but we hadn't been made aware of the actual involvement. When we arrived in our road there was a police car parked in our street and policeman standing on our front door step. We went up to the door and the policeman told we couldn't come in. That it was a crime scene and Mike said that it was our house and what did he mean that we couldn't come in? The policeman said that he'd just been told to come here.
15. He was just following instructions, which I understood. Mike could have happily punched him. The way the policeman handled the situation was not particularly sensitive.
16. Later we were told by one police force that we were in their area, whilst the hospital is in a different area. We should have been met and told what to expect next but there was a mistake and that meeting never took place.
17. We were left having left our dead son at the hospital, to be told our house was a crime scene and to wonder if we are under suspicion of something, which was hideous.
18. I immediately said to Mike, in the scheme of things this doesn't really matter.
19. The ripple effect must have worked as my friend's mum found us and took us to her house. I think she got past the policeman to get jackets for us because we were in shock and had left the house in our slippers.

20. She told us we were in no fit state to speak to Josh. He was obviously our main concern. We wanted to handle it well, to say the right things.
21. I wanted to work out when we could get back into our house, so I could set Josh's expectations as well as our own. Our friend took us back to our own house. The forensics guy was there. He had to take photos, take away bedding, check the scene and make decisions whether it was suspicious or not.
22. I totally understand why they have to do that and I respected it. However the way we were dealt with just didn't seem fitting with the situation.
23. The forensics guy told me he hoped we would be back that night so that was enough for me to go and talk to Josh. I told him that George had died. That his heart had stopped. I used all the language associated with adults because it was instinctive. In hindsight it looks like we'd done all the right things.
24. Josh was distraught. Because of Mike's renal failure we had a lot of dealings with hospitals and he is very familiar with them. George's death was like shattering his illusions that doctors are wonderful but we had to tell him the truth. It was one of the most devastating things I've ever had to do.
25. We took to Josh home to our house. The police had gone. It was just my mum and dad and some friends. The main objective was to get Josh settled but Mike was badly due dialysis so he had to go to hospital as an emergency.
26. Before Mike left, the police returned for a statement. So there's Mike needing dialysis but before he can get this we have to give statements. I guess it was evidence for the police to pass on to the Coroner.
27. Because of the earlier mistake when the police had not met us, I was told I would have to go and identify George. There was no way I was doing this until

Josh was settled which was around 10 o'clock, when I got a lift to the mortuary.

28. It was one of the most spiritual experiences I've ever had. It felt like he was moving to somewhere better but what could be better than being with his mum. I'm very glad I did it. It gave me a sense of hope and belief that he was okay.
29. The police at the hospital were very sensitive. They apologised for their colleagues in the other police area. One of them was playing the role of a Family Liaison Officer.
30. I do understand the logic behind moving children who die but it made me quite angry the night it happened. All the moving around of George really upset me on the day. In hindsight I understand but on the day it just seemed unnecessary stuff.
31. The initial cause of death was unascertained because they were assuming that he died of cot death. It was explained that the full post mortem results would take some time but we could now go ahead and plan a funeral.
32. That was another logical step along a crazy week.
33. When the police came back on the evening of George's death, they said they needed to take away the bedding. George shared a bedroom with Josh and I didn't want him freaked out any more than necessary so I had asked my Mum to run them through the washing machine as they had blood on them. So the police ended up taking them soaking wet out of the washing machine. They obviously needed to tick a box that said bedding collected. That's the way I rationalised it because it seemed ridiculous.
34. The police were back and forward that week. The liaison officer was fantastic. She kept me in the loop. There were lots of things that were very negative about

the police but she sticks out as someone very positive, who made the experience a lot less bad.

35. The evening I was at the hospital identifying George a different police officer put cot death leaflet through my door. I came home to find it. It's left me really confused because we assumed that just babies die of cot death. My husband's brother died of cot death so in my head I was making awful connections about genetics.
36. We organise George's funeral. There seems to be an incredible lack of information on how to explain cremation to a 4-year-old. I sent friends on a mission of finding books and other things. I was lucky that Josh couldn't read because words like coffin are not part of a 4-year-old's vocabulary.
37. The morning after George died I took Josh to nursery so he had his peer group and not just a bunch of sad adults. Mike told me I shouldn't be forcing him to go but I wasn't forcing him. I said I would sit with him for the morning and if he wanted to come home I would let him. The nursery had drafted in extra staff to help with the staff as well as the children.
38. Other parents were very shocked to see us that day but I'm glad I stuck with it because it was the right thing to do for Josh.
39. And that's how it was for the first 6 months. I was so driven by helping Josh that my reaction to the fact that George had died was very much put on hold.
40. Josh was due to start school that year so it was important to me that we maintained a relationship. The fact that my husband lost his brother was also on my mind as he had grown up feeling second-best. It was uppermost in my mind that Josh should not grow up like this and I became almost obsessed, to the point

of reading just about every grief book in the library.

41. It was important to me that Josh understood what was going on. I never doubted taking him to the funeral because the last memory he had of George was of his father trying to resuscitate him, panic in the house and the ambulance arriving.
42. The undertaker was really supportive. I asked for his advice and he told me to follow my instincts. As it happened instincts was the only thing I was flying by because everybody else was pretty much useless.
43. I was kind of left to deal with most of the funeral arrangements. I'd never arranged a funeral before nor seen anyone that had died. One of the undertaker's colleagues was a guy who had been in the year below me at school and it was weird but comforting.
44. We had made the decision that Josh could come and see George if he wanted to so we told him. I think there is nothing that would have stopped him from visiting his brother.
45. We are religious, don't go to church but do have a faith so we explained to Josh that George had gone to heaven. I got a lot of advice from charity. The work they do is immense and I learned that it was important to be honest with children.
46. I had banned black at the funeral. I wanted people to remember George with joy and happiness, as the sparkly little thing he was. I didn't want people feeling morbid all day. I encouraged people to bring children because Josh needed his peers.
47. The majority of people who came have described the funeral to me as beautiful and oddly lovely and that was all I could've wanted.

48. After the funeral we had to think about scattering the ashes. The charity suggested letting Josh choose. Josh said he knew a really good place.
49. The phrase ‘out of the mouths of babes’ seems appropriate to me because children have led me through my grief. Not just Josh but all his little friends. Children’s grief can teach adults a heck of a lot of stuff because adults pussyfoot around it all shockingly. The acts of omission are probably more upsetting than anything that could actually come at children’s mouths.
50. So the scattering of the ashes was very important. We haven’t chosen the last place yet
51. We’ve picked 3 places individually and 3 very different places. From speaking to other people I understand they keep their ashes in the cupboard for years, which is absolutely fine if that’s what’s right for them, but it’s not for us.
52. We have just been doing things right for our individual family.
53. I think I’ve finished now.

7:4: ‘A useful story’: Laurie’s interpretive panel.

My continuing contact with Laurie, discussed in Chapter 2, places my interpretation of both her and her story into a different context from that of all the other parents I interviewed. Where these stories are framed chiefly by the interview meeting and my subsequent work on the transcripts, Laurie’s updates regarding events in her life and how she is ‘using’ the experience of George’s death constantly shift my relationship with the transcript. However, my early impressions have been reinforced rather than radically altered by this continuing relationship, and the very fact of Laurie maintaining contact at all is significant in this. Placing her within Frank’s notion of three narrative purposes (1995), I see Laurie as performing a quest in which her participation in this

research forms a part. Where Cathy's narrative borders on chaos and Julia's on restitution, Laurie's account seems to speak to Frank's question:

How does one rise to the occasion?...by telling not just any story, but a good story. This good story is the measure of...success (1995, p. 62).

This success is very important to Laurie in her drive to make meaning from George's death. She does not want to be dismissed as aggressive or worse, derided. She wants to tell a good story that will change things, although she is not as confronting about this as Cathy, demonstrating it instead by her way of telling and by what she describes.

Managing chaos and making-meaning, a thread described in Chapter 4 and further drawn in both Julia's and Cathy's stories, is at the forefront of Laurie's account, which is dominated by descriptions of going on the internet, contacting organisations, visiting the library and talking to people, all part of her quest to get 'things right'.

The thread of siblings, which also emerges in Chapter 4, is perhaps at its strongest too in Laurie's story, where she makes the powerful statement 'children have led me through my grief'. Laurie is strongly protective of her son Josh, and much of her quest to 'get things right' is motivated by her fears for him. Her descriptions of her efforts to protect Josh resonate both with my own account in Chapter 1 and with Hafsa's statement that 'there is a point, I've got to get on with it, I've got to be there for her', as she describes her continuing relationship with her surviving child.

Professionals also form a strong thread in Laurie's narrative, which at times shares parallels with Cathy's in her description of bungled bureaucracy and seemingly arbitrary acts of authoritarian control. However, although Laurie uses the description 'everybody else was pretty much useless' to describe events, she does not fall into blaming the professionals as Cathy does, but rather mirrors both Julia and many of the parents in Chapter 4 in attempting to understand the professionals involved: 'and that's kind of the way I rationalised that because it seems ridiculous, but it was clearly

necessary’.

‘Rationalised’ is a highly significant word for Laurie to use, as hers is predominantly a rational account. She rarely descends into rage or retribution but rather steadily ploughs through the events in her narrative, omitting few details and ensuring that this is indeed a ‘good’ and ‘useful’ story. I admired Laurie’s stoicism, courage and her sense of humour. My expectations for the panel were that they would feel the same.

The panel respond to the early transcript chunks by commenting on Laurie’s rational stance and her matter of fact reporting style, together with the absence of anger and heightened emotion. Rather than questioning Laurie herself, or the veracity of her account as other panels had, most notably in Cathy’s case, this panel immediately feel that Laurie is a victim and that everything is about the locus of control that belongs to professionals. However, they comment that actually ‘everything is out of control’ and that no one is able to contain this situation. They are very concerned by this, particularly as they have all at one time been child protection professionals themselves. The panel feel that Laurie is the one fighting to take control, and comment that her warmth and love show through the narrative, as she is faced with separation from Josh in order to be with George.

The panel continue to find love and warmth, together with a strong theme of friendship, as the narrative progresses. The panel contrast this friendship, love and warmth against the austere power of the authorities and they become especially angry with the police. Stan asks ‘what the hell are the police doing?’ and queries whether they can legally enforce their actions. This too is in stark contrast to the panel for Cathy’s story where she herself was identified as the problem.

The panel view Laurie as motivated by ‘trying to get it right’, particularly in relation to Josh. They describe ‘her meaning-making as very strong’ and suggest this is how she

manages to keep so calm. Betty questions whether Laurie is 'angry', commenting 'I would be really cross'. This provides another contrast with the panel for Cathy, where her anger caused Maggie in particular so much agitation. The panel speculate as to what Laurie is 'really feeling' under the 'reasonable and understated' veneer of her narrative and wonder whether, as well as feeling cross, she is also frightened and attempting to deal with this by staying calm. They raise, as all the panels have, the themes of guilt and blame, noting that these seem absent from Laurie's narrative. The panel suggest that the emphasis on 'getting it right' is Laurie's way of preventing herself from feeling guilty. Related to this, the panel also speculate as to the impact of the professional intervention on Laurie's determination to get it right. She states at one point that 'instincts was the only thing I was flying by that week because everybody else was pretty much useless', and the panel view her narrative as a 'battle' to get it right against the authorities who are getting it, in the panel's view, so badly wrong. The panel collectively view the professional intervention as 'a mess', with the emphasis on procedure paradoxically causing a complete lack of centre and control. Once again, as in Cathy's panel, the group ask 'can this actually be true?' – a question that was never asked by Julia's panel.

This panel, perhaps because of their previous and current professional roles, become most focused of all the panels on matters of procedure, and there is a long discussion relating to this. Stan asks 'why is no one communicating properly' with reference to the way in which the professionals are interacting with Laurie and Mike. However, the other members counter 'well how do you get an investigation right?' thus identifying one of the key dilemmas at the heart of sudden and unexpected child death. Stan says he would like to see the police protocols.

This panel's unease with protocols, and dismay at the professional 'mess', increase as the transcript chunks progress. When the narrative reaches the description of the police taking the bedding from the washing machine, Stan becomes exasperated saying 'If

there was a case against these parents it would break down' and that it makes 'a nonsense' out of any procedure. In contrast with other panels, once again Laurie is vindicated, and it is the authorities that hold the chaos whilst Laurie herself tries to control it. Compared to Cathy, who saw 'no framework for society' following Dylan's death, Laurie presents to the panel as 'trying to manage the impossible', with an overriding drive to maintain the 'framework' in the way she tells the story. Laurie cannot afford for everything to collapse as she has too much invested in 'getting it right' for Josh, so she 'manages everyone' in order that her relationship with the world is maintained sufficiently for her to do this. She is not prepared, like Cathy, to allow the collapse of the 'framework for society.' The panel concur that this experience is 'horrific', not just because George has died but also because of the process that follows.

As the process continues, the panel are increasingly impressed and 'moved' by Laurie as a person, finding her 'resilient', 'pragmatic', and with a strong gift for meaning-making. They see great thought in Laurie's actions and are continuously impressed by the warmth, love and support of the friends she describes. Jess comments 'this is a woman who has a huge network', which also forms a direct contrast with the manner in which Cathy portrays herself. They identify correctly that Laurie will 'use the story', which she has done in her media and charity work, and that telling a story which is 'useful' is a strong part of her meaning-making process. Betty feels that Laurie also meets this through Josh, and that 'getting it right' with him and seeing the results of this help to reinforce her own identity. Jess comments on the possible pressure this may put on Josh.

As the panel draws to a close, they re-affirm their original sense of Laurie as someone who needs to 'get it right,' commenting that she never descends into anger or uses the kind of powerful language she could have chosen. These are viewed as admirable traits by the panel in contrast with Cathy, who is judged as 'belligerent' and whose own

attempts to ‘control’ are viewed negatively.

This panel’s frustration and anxiety focus not around the narrator, as in Julia and Cathy’s stories, but around the authorities that they see as having failed Laurie. In another reference to technology, Stan reflects that ‘you would hope there would be some support. I mean if you lose your mobile phone you get a counsellor...you lose your kid you get nothing’. Whilst he agreed that the voluntary agencies are very supportive to Laurie, he sees them as not being proactive and so it is left to Laurie to seek support. The panel members agree that this is very disappointing and they are all saddened by it.

7:5: ‘Everything is out of control’: exploring meaning within Laurie’s panel

Laurie’s panel was the penultimate one I convened and in many ways the easiest, lacking ‘explosive’ content, which Morgenroth (2010, p. 268) refers to in her own work with panels and which had manifested on previous occasions. At face value, Laurie’s narrative and particularly her way of telling the story seemed to ensure an adequate ‘fit’ and thus minimised any provocation. In contrast to both Cathy and Julia, Laurie is seen to be ‘behaving as a grieving mother should’, and the panel therefore locate ‘the blame’ and the provocation, not with the story teller as Cathy and Julia’s panels both did, but with the authorities whose interventions are ‘a mess’.

However, during the panel itself and whilst revisiting their account, I was troubled by their apparent lack of engagement with Laurie’s narrative. Whilst the panel members, like Laurie herself, behaved well and tried to get things ‘right’, there was an absence of the embodied expression and emotion that had characterised both Cathy and Julia’s panels. Although Stan became angry at times, this was always appropriately contained and nobody became tearful, as happened in Julia’s panel. This made the panel process much easier, but given the content of the narrative chunks and the panel’s own

description of these as ‘horrific,’ it seemed incongruent. Returning to Morgenroth’s previously helpful suggestion that the reactions of data interpretation panels are often ‘responses to something present in the data and not simply reactions generated by the biographies of individual panel members’ (2010, p. 278), I located the ‘lack of fit’ not within the story itself, but rather in the panel’s reaction to it.

Cathy’s narrative suggests that the chaos she presents becomes enacted by the panel members who blame Cathy for bringing this so uncomfortably close to them, whilst in Julia’s story the panel, faced with the proximity of the death, are unable to achieve the depressive position that Julia has reached during the intervening years. However, in Laurie’s panel, whilst the members acknowledge that ‘everything is out of control’, they seem unable to fully engage with this, let alone contain or find meaning in it, a process Bion identified as crucial for the avoidance of ‘nameless dread’ (cited in Cooper & Lousada, 2005, p. 30). Thus, they end the panel process filled with generic sadness and disappointment. Their inability to fully engage with the ‘horror’ they identify may also be located within their own roles as helping professionals, causing a similar emotional detachment to that identified by Menzies Lyth (see Chapter 2).

The sense of lack of fit also recalls Doka’s work on ‘disenfranchised grief’, as discussed in Chapter 2, in which he suggests that permission to express the emotions surrounding a death is only awarded to those with ‘recognizable kin ties’ (1989), leaving others in the wider network disenfranchised.

My experience of this sense of disenfranchisement, emotional detachment and corresponding lack of fit within Laurie’s panel altered my previous relationship with both Cathy and Julia’s panels. Where I had been critical of their anger and sharp judgments, I began to view these as congruent with Cooper’s argument for engaging with the ‘smell of the real’ (2009, p. 432). The danger here, as Cooper warns, is of

hating or despising people intensely, and some of the ridicule of Julia's panel and the anger of Cathy's demonstrate this vividly. Despite this, both panels attempt to engage with the 'destructive and negative' elements in the stories, even if they are ultimately unsuccessful in containing these (Cooper, 2011, p. 441), whereas in Laurie's panel, emotional engagement with the death and with the unfolding events is kept largely at bay.

This highlights potentially important lessons in answering the Kennedy Report's call for professionals to 'be sensitised to emotions being experienced by parents' (RCPath & RCPCH, 2004, p. 12), as perhaps, without experiencing the 'explosive reactions' evidenced by Cathy and Julia's panel, it may be too easy for professionals to become emotionally detached, hiding behind professional roles and thus avoiding engagement with the reality of sudden and unexpected child death.

7:6: Conclusion

In this Chapter, I have focused on Laurie whose interview was the longest of the eight that I conducted, reflecting her purpose of giving a thorough and complete account containing all the facts, and leaving no stone unturned in her efforts to construct meaning from George's death. The panel seems to understand Laurie's efforts to get things right and they label her story 'useful', commenting correctly that she will use it to help effect change. However, whilst they empathise with Laurie and do not criticise her as the panels for Julia and Cathy had done, they nevertheless demonstrate an emotional detachment, which in turn reflects Laurie's own style of telling.

My thesis supervisors also reported struggling with both the length and the detail of Laurie's complete account, which caused them to become emotionally disengaged. I therefore responded to this by inviting the reader into the process via the chunks that were presented to the BNIM panel, whilst including Laurie's complete account as

Appendix 7.

My own process of trying to understand the responses to Laurie's story altered my initial perceptions of the panels in the previous two Chapters, which I had viewed as harsh and condemnatory. Returning to the nurses discussed in Menzies Lyth's influential study of professional defence mechanisms, I recognised similarities between them and Laurie's panel, whose attempts to manage a story where 'everything is out of control' caused a similar level of detachment. The panels for Julia and Laurie's story conversely attempt the 'fearless engagement' that Cooper recommends (2009, p. 441), but this is largely unsuccessful and they fall prey to the danger of losing parts of themselves in their splitting and their projections onto Cathy and Julia (Cooper, 2009, p. 432).

Laurie's story is the last of the three narratives that I have discussed individually. By offering them in this way and by weaving in strands from the collective threads discussed in Chapter 4, together with details from my own experience and from the panels, I have attempted to achieve several aims. Firstly, I hope that this form of representation moves towards finding a solution to 'the problems of fragmenting qualitative data', which Hollway and Jefferson discuss, whilst also advising on 'the importance of keeping the whole in mind' (2000, p. 68). This form of representation also speaks to psychosocial concerns with ethics by reproducing the stories in the participant's words in the order and sequence in which they were spoken. I have tried to address these ethical concerns too by discussing the panel interpretations and my 'own emotional responses to these encounters', which had such a transformative effect on my understanding of this research area (Clarke & Hoggett, 2009, p. 21). In this Chapter I have also offered the opportunity to view Laurie's narrative via the same chunks that were presented to the panel.

Finally, I hope that by offering the complete narratives, my own responses and analyses of the panel processes, together with the panel chunks in this Chapter, I have managed to invite the ‘ongoing conversation’ that Speedy (2008, p. 145) refers to - conversation which does not end with my interpretations but rather extends an invitation to further discussion and understanding.

In the next and final Chapter I will focus on exploring what can be learned from the stories themselves, together with the various panel reactions and my own experience of conducting the research, finally advocating for some ways in which parents and professionals involved in sudden, unexpected child death can be helped to understand each other.

Chapter 8

8:1: Arriving where I started

'We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time'
(Eliot, 2001, p. 43).

A key thread running throughout this thesis has been anxiety, accompanied by the various mechanisms used to defend against this. As Clarke and Hoggett (2009, p. 21) state, 'we are all anxious', and this was certainly my predominant emotion as I started this final Chapter. The responsibility of making some sense, let alone some meaning, from all that I had experienced during this long research process seemed initially overwhelming. However, one thing that this process had taught me was the necessity of using 'our imaginations to make meaning out of the information at our disposal' (Hollway, 2009, p. 462) and as I approached this Chapter an incident occurred which helped to crystallize my thoughts and provided linkage between the start of the research and this final phase.

A friend had offered to send a piece I had written about Joe's death, much of which forms the first Chapter of this thesis, to an agent who had helped publish her own autobiographical work on early childhood trauma and violent abuse. The agent replied that she was very moved by Joe's story, but that 'deaths of children were too terrible to read about'. Paradoxically, as I read this, a charity advert bearing the script 'Malaria kills one child every second', accompanied by a suitably harrowing image, flashed across my computer screen. I was bemused, although not surprised. As Hoggett points out, 'Academics, literary agents, editors and publishers form part of a broader 'expert

system', which manages access to the publicly written word' (2000, p. 116) and thus they are key players in deciding which experiences are rendered available to thought.

The literary agent's reaction to my experience brought me full circle from the start of the research to my struggles commencing this final Chapter, thereby 'arriving where I started', in a place where the deaths of children 'just down the street' (Cooper, 2009, p. 430) may be 'too terrible to think about'.

In this final Chapter therefore, I want to revisit and re-evaluate many of the ideas and issues that have gone before, and link these to the research process itself, whilst staying mindful of cases such as those which prompted the Kennedy Report. Ultimately, I am aware that this thesis too forms a potential part of the academic expert system as identified by Hoggett (2000) and I therefore hope to honour this by making some suitably practice near (Cooper, 2009) recommendations for further action, research and training in the area of sudden and unexpected child death.

8:2: Dangerous knowledge

In Chapter 2 I charted some of the historical background to sudden and unexpected child death, within both the history of UK safeguarding and the concomitant culture of audit. As deaths of children gradually became less common, the safeguarding agenda shifted towards one of prevention (Ferguson, 2011), and with this shift, previously unthinkable forms of 'dangerous knowledge' about the harm that could be visited on children gradually became accepted by society (Cooper & Lousada, 2005, p.125).

As a consequence of this, however, naturally occurring child deaths become increasingly identified with accountability and blame (Stanley & Manthorpe, 2004), leading to their popular depiction as unnatural, and rendering them a potentially new form of dangerous knowledge.

The consequences of this were powerfully demonstrated by the cases of Sally Clark, Angela Cannings and Trupti Patel, which led to the Kennedy Report. However, despite the Report's recommendations, the culture of fear and blame that surrounded sudden and unexpected child death continues to contribute to wrongful accusation and imprisonment. The death of Jayden Wray in 2009 illustrates this powerfully, and consequently I want to consider it within this final Chapter as a means of demonstrating one of the potential contributions of this research.

Jayden Wray was four months old when he died in July 2009 as a result of rickets that had been caused by a genetic condition passed unknowingly from his mother within her breast milk. His parents had initially taken him to the GP early one morning with concerns about his tongue, which was stuck to the roof of his mouth, causing a consequent inability to feed. The GP referred Jayden to University College Hospital's walk in clinic, for precautionary reasons only. As it was not considered an emergency, Jayden's parents made their way to the hospital by public transport. At the walk in clinic Jayden started to fit, although the paediatrician failed to respond to this. When the fitting continued, the baby was transferred to A & E and referred for intubation. At this point, there followed a series of fatal errors, with an initial 90-minute delay before intubation occurred. When this finally happened, the tube was inserted incorrectly, causing Jayden's lung to collapse, although this was not initially identified. There was then a four-hour delay, during which Jayden's condition seriously deteriorated. During routine tests, Jayden was found to have multiple fractures and, although the radiologist queried whether these may have been caused by severe rickets, this was dismissed by the consultant paediatrician. The discovery of the multiple fractures instead led to concerns that Jayden was a victim of non-accidental injury. He was later transferred, now as an emergency to Great Ormond Street Hospital, where the consultant paediatrician pronounced his condition as 'incompatible with life.' This paediatrician

later acknowledged that the system for transfer of the notes between hospitals was chaotic. At Great Ormond Street, further tests began to confirm the suspicion of non-accidental injury, with the consultant paediatrician specifically rejecting another suggestion of rickets.

Jayden's parents were therefore arrested by his bedside, on suspicion of causing grievous bodily harm, on 23 July 2009. They never saw Jayden again. Although released on police bail, conditions prohibited their return to the hospital where Jayden was baptised and later died on 25th July 2009. No parent or family member was allowed to be present.

Following Jayden's death, the Coroner instructed Dr Scheimberg, a paediatric pathologist, to perform the post-mortem, although this was against the express wishes of the Metropolitan Police. She observed radiological signs of rickets on the Great Ormond Street Hospital x-rays and these were confirmed on her physical examination of Jayden's ribs and skull. On the basis of this, the pathologist initiated requests for Vitamin D testing of both Jayden and his mother. She later faced police criticisms in the criminal trial for this. The tests showed that Chana (Jayden's mother) had severe vitamin D deficiency, which she had passed to Jayden whilst still in the womb, leading to congenital rickets. This condition became more serious after Jayden's birth as Chana's vitamin D deficiency remained undetected and therefore continued to be passed to Jayden through her breast milk. Despite this, the forensic pathologist, Dr Cary, instructed by the Metropolitan Police, determined the cause of death as non-accidental injury, leading to a charge of murder. When the couple's daughter Jayda was born on 17 October 2010, neither the father nor any other family members were allowed to attend, and the baby was removed at birth. Chana was not allowed to see her own baby (Delahunty et al, 2012).

The parents were eventually acquitted of murder by the Old Bailey in December 2011, two years after Jayden's death. The trial judge, Justice Theis, said in her judgment that Jayden had received 'suboptimal care' from both University College and Great Ormond Street hospitals. Baby Jayda was finally returned to her parents by the family Courts in April 2012 (Delahunty et al., 2012).

This case and the missed opportunities, which led a non-emergency visit to the GP to terminate in death and prosecution, is almost, in the words of the agent quoted earlier, 'too terrible to read about'. However, it powerfully exemplifies many of the threads that I have drawn in this thesis, notably that 'within the modern experience of the well-managed life', the sudden and unexpected deaths of young children represent unpalatable information capable of 'threatening the supremacy of both medical control and technology' (Kellehear, 2009, p. 68). The conditions of unthinkability (Cooper & Lousada, 2005) created by this threat are demonstrated by the senior medical personnel treating Jayden, who repeatedly failed to see what was in front of their eyes, even when this was pointed out to them. Paradoxically, it was easier for them to drive forward a diagnosis of non-accidental injury than to accept that the death was caused by a deficiency, which, had it been identified, was easily preventable.

Following the death of Jayden Wray, I wrote an article for the online version of the 'The Guardian' newspaper (Turner, 2012). Many of the comments it received illustrate how difficult it can be for people to process the fact that children do still die from natural causes and that the professional response could be improved.

The first comment, for example, stated that, for parents to be treated sensitively:

Well...it does depend a bit on whether they killed them

A later response suggested that I was not helping with what was described as my 'scaremongering' techniques.

These responses, and some of the others that surrounded Jayden's death, are reminiscent of my own experience following Joe's death (see Chapter 1) and of many of the stories told within Chapters 4–7.

The inefficient transfers between hospitals and subsequent breakdown in protocols recall the details of Cathy's, Andy's and Laurie's stories (see Chapters 4–7). There are similar failures in communication both between professionals themselves and between professionals and parents. The arrest of Jayden's parents at the bedside of their dying son recalls the guarding of Andy and Cathy by armed police and their being interviewed before their son had even died. Seven years after the Kennedy Report and the accompanying recommendations, there is a clearly identifiable 'policy-practice gap' (Lees, Meyer & Rafferty, 2013, p. 551) compromising its aim of squaring 'the circle of maintaining high standards in the interests of justice for parents whilst also safeguarding the young' (RCPATH & RCPCH, 2004, p. 15).

8:3: Defending boundaries

The case of Jayden Wray offers a powerful opportunity to learn from mistakes made, and to thus move towards a more holistic understanding of the fact that, whilst harm is undoubtedly acted upon children, they do also die from natural and preventable causes. However, this learning is only possible in so far as we are 'emotionally and ideologically open to the possibility of discovering something new' (Cooper, 2009, p. 431). Where that something new is simply dangerous to know about, as I discussed in the previous section, it may transgress a boundary beyond which people are simply unable to travel (Cooper & Lousada, 2005).

During the course of this research, I have experienced a number of occasions where different audiences have reacted as if their own boundaries were being transgressed by the content. These experiences helped deepen my own understanding of the

research, and consequently I want to give them some consideration within this final Chapter.

The first of these examples arose in the penultimate year of my PhD study, when I was asked to give a presentation on my personal experience and research to social workers undertaking advanced post-qualifying study. As the students were mostly in management positions within front-line agencies, they were experienced professionals and I therefore did not anticipate any particular complications with my presentation.

However, during the course of the presentation, one of the attendees rose and swiftly left the room in tears. When I enquired later, I was told that Joe's death had stirred difficult emotions connected to a previous life event. The general feedback following the session was that the attendees had found it extremely upsetting and had to support each other informally. It was suggested that if I were to repeat the presentation in the future, it should carry a 'warning' for those who may find the content upsetting.

This response initially evoked feelings of guilt in me, which echoed those I had experienced after Joe's death, and which are further discussed by the parents in Chapter 4. I felt ashamed that I had upset these people with the events of my life, and that I had exposed them to what Cooper (2009, p. 432) dubs 'the smell of the real'. Echoing C. S. Lewis, I wondered once more if it would be better for me to be 'isolated in a special settlement' (Lewis cited in Ellis, 1993). However as time passed, I became indignant and irritable about this, thus echoing some of the splitting that had occurred during the panel sessions.

This was an influential moment for me, both in terms of understanding how difficult experiences like mine are to listen to, but also in terms of my own reactions to this. As time passed and my emotional responses changed from guilt to anger, I began to see

more clearly that these conflicted feelings had transformed the bewildered professionals into persecutors who could not listen or understand me (Hoggett, 2000).

Hoggett locates such emotional defences inside a broader discussion of welfare, which constitutes 'public-sector workers as an enemy within, a fifth column sapping the moral fibre of the British people' and thereby locked into 'conflictual interdependence' with service users (2000, p. 15). To counter this, he advocates for a form of welfare that recognises the fear within all of us, and the corresponding urge to 'distance ourselves from the 'mad, bad, dangerous, and profane and dirty parts of our own subjectivity'. Only by embracing these and viewing 'difference as a source of ...wonderment' Hoggett argues, can a 'benign' welfare be reached in which the 'depressive position' replaces 'splitting' as the dominant form (2000,p.15). However, in terms of my own research progress, this is to jump ahead, for there were several similar encounters before I gradually became able to replace my own splitting with a perspective closer to the one Hoggett advocates.

One of these similar incidents occurred a few months later when I was asked to be part of a presentation focusing on complexities in safeguarding for newly qualified and practising social workers. On this occasion, I did suggest that attendees were given advance notice of my subject material, but this was chiefly to protect me from their reactions. As a response to this, however, it was proposed that attendees who were especially sensitive should be given an option to leave after the other presentations and before mine. As these other presentations focused on child neglect, drugs and domestic violence, I again questioned why my own experience was so particularly painful for people to hear.

My last example occurred during my presentation to a Local Safeguarding Children's Board. Those attending had been invited via a specially selected guest list' and thus

their attendance was largely voluntary, with suitable forewarning as to the content. As I spoke, a row of police personnel sat in the front row with their arms tightly folded and lips pursed. When I had drawn to a close, one of them stood up and asked me ‘what is the point of this research?’ I explained, once more, that as a parent with this experience and as a professional, I hoped to increase mutual understanding and thereby to improve the experience for all. At this point, the man turned on his heel and left the room. One of his colleagues, a female detective, then disputed much of my presentation, especially the details of ‘Cathy’s story’, which she stated could simply not have happened. Her response mirrors the behaviour of Maggie and the panel for Cathy’s story (see Chapter 5), whose own challenges to ‘legitimation’ demonstrate further the limitations of ‘our social capacity and willingness to know about painful and conflictual matters at the level of social discourse’ (Cooper & Lousada, 2005, p. 128). This information was ‘painful’ and ‘conflictual’ to both the panel and to the police, perhaps for different if related reasons. Where some of the panel members felt polluted by the information (see Chapter 5), Maggie, as a social work manager, may, like the detectives, have felt criticised and attacked by Cathy’s story, leading to her anger. The line of detectives with folded arms and pursed lips were similarly defending themselves against Cathy’s own anger and potential criticism of their role.

These responses invoke yet again questions about the role of procedure and audit evidenced by the stories within this thesis. As Lees, Meyer and Rafferty argue (2013, p. 542), the ‘prescriptive and tightly defined risk and performance management techniques’, which have been developed as a consequence of defending against the blame and public criticism emanating from inquiry and audit, have created a culture where procedure, rather than relationship, is paramount. As I have discussed elsewhere, these procedural tasks can perform an almost ritualistic purpose with the promise of warding off failure, and therefore perceived attacks on them, such as those evidenced by

Cathy's story, are commonly met with 'institutional defensiveness... denial, disavowal, repression and splitting' (Cooper & Lousada, 2005, p. 129).

Perhaps the most surprising example of this institutional defensiveness occurred within an organisation as I was attempting to recruit participants. I initially approached several leading charities and some were immediately able to offer support and assistance. However one important organisation in the field did not respond. When I followed my initial query with a later one, they did reply but presented as defensive and mistrustful, querying both the rationale for my research and my authority to conduct it. They asked to meet me in person and to see evidence of my suitability to manage research, together with all the paperwork involved in my ethical clearance. Despite their apparently mistrustful approach, it seemed reasonable that they would want to be cautious in involving me with potential participants and I therefore approached the meeting on this basis. However, during this meeting they were sharply critical of the University for sanctioning the research, telling me that it was 'misguided', and querying whether I actually had ethical approval at all. They also criticised those agencies who had agreed to my putting an advert on their website, suggesting that this represented a significant 'lack of control.' As the meeting progressed, one of the staff grew especially angry, saying that my research was 'disrespectful' as 'whole professional lifetimes had been devoted to this topic'. Throughout the meeting, they referred to parents as 'theirs' and towards the end offered to find me a selection of 'their parents' who may not be too traumatised by my research. This was an offer I later politely declined, as I wanted to find parents able to tell their own stories freely and not those who were 'their' parents, belonging to an institution who hand-picked them as suitable.

This level of defensiveness and even anger on the part of this organisation initially left me bewildered and angry myself. I could not understand why an organisation, which partly existed to support parents who had experienced sudden and unexpected child

death, was so unsupportive of my work. Only later, as my research progressed, did I begin to explain their anger. This charity was in some ways a victim of its own success, helping to achieve the fall in child death rates, and therefore its very survival was underpinned by anxiety. Further, it was staffed by people who had, in their own words, devoted ‘whole professional lifetimes’ to the subject and to ‘their parents’. My own research was therefore perceived as a threat to this.

Returning to the concept of boundaries, Hoggett suggests that ‘these are vital to ...identity’ and examines the accompanying ‘vagaries’ of this when people are ‘besieged by fear’ (2000, p. 8). This seems particularly relevant to my contact with this organisation where, as a bereaved mother, I should perhaps have become one of ‘their parents’ rather than attempting to try on the mantle of researcher. The latter was part of their identity and therefore their description of my work as ‘misguided’ suggests an attempt to ‘maintain their boundary’ (Cooper & Lousada, 2005, p. 188), similar to the detectives and to the professionals who required a ‘warning’ when they felt their own boundaries and identities being transgressed.

8:4: Excluded middles

In Chapter One I drew on Frosh and Baraitser’s idea of knots to act as a means of tying things together (2008, p. 258), which has been one of my key purposes in this research. This constitutes something of a rebellion in the field of sudden and unexpected child death, where so much is depicted through radically opposed binaries - parents and professionals; victims and suspects; guilt and innocence; and natural and unnatural. Frosh and Baraitser propose that such rebellion can be carried out by means of psychosocial approaches that oppose binaries, unite the psychological and the social, and assert ‘you cannot have one without the other, that they are warp and weft and

signifier and so on through the different ways of saying that they are two sides of the same thing' (2008, p. 349).

As I have discussed throughout this thesis, the growth of 'managerialism' (Lees, Meyer & Rafferty, 2013, p. 543) has rendered the field of sudden and unexpected child death a place of absolutes, where every death is subject to Rapid Response and all parents are interviewed within time limits, even if, as in Cathy and Andy's case, the child has not yet died. This makes the uniting of the binaries identified by Frosh and Baraitser, extremely difficult to achieve, creating instead 'an epistemology of excluded middles, of binary logical choice, of reasoned determination of truth and falsity according to the evidence available' (Cooper & Lousada, 2005, p. 140).

Many of these 'excluded middles' are demonstrated vividly in this research in relation to the anxiety surrounding 'struggles around identity' (Hoggett, 2000, p. 6) and the concomitant fear, which Cooper identifies as 'losing our minds' by becoming 'psychically mixed up with others' (2009, p. 432). Both of these anxieties can lead to the 'othering' of the 'bereaved parent' that I discussed in Chapter 1, rendering them as almost a separate species rather than simply ordinary people affected by random tragedy. In this way, they are split apart and the boundaries discussed in the previous section remain unassailable.

During the research process, an example of this othering occurred as a sequel to the presentation where students advocated for future warnings. One of the students present was a service manager in her professional life and I had already met her several times at meetings within a more formal academic context. After my presentation, we both found ourselves at the same meeting and we made some time to discuss the impact my presentation had produced. On reflection, she observed that her sense of shock was not

so much because she was not prepared to hear this sort of story, but more that she ‘had not expected to hear it from me’.

Hearing this, I found myself catapulted backwards to the scene of Joe’s death and the police officer who could not reconcile my being both a social worker and the parent of a child who had died (see Chapter 1). These experiences are reflected in the literature, where mostly professionals speak on behalf of bereaved parents, thus defining the experience both for and about them, whilst parents’ own accounts remain largely unsolicited and therefore unable to bridge the middle. The article, which I have previously discussed (Sidebotham & Fleming, et al., 2010), is a particularly striking example of this, evaluating the response to sudden and unexpected child death with no description of either the parents or of the children who died, nor the circumstances of the deaths. Yet the Rapid Response is declared a ‘success’ within a vacuum that is devoid of any human detail.

The ‘excluded middle’ is also evident in the absence of parental accounts within the literature (see Chapter 2), together with the omission of parents from the Working Party that formed the Kennedy Report and from all the meetings that follow the death of a child, culminating in the Case Review (See Chapter 2). The Child Death Overview Panels, which meet several times a year to discuss child deaths within their area and to ‘report on the lessons learnt’ (FSID, 2011, p. 6), also have no parental representation. Therefore, in the reports produced for local Safeguarding Children’s Boards, there is no direct communication with parents. Despite the Kennedy Report’s emphasis on ‘good communication between professionals and parents’ (RCPPath & RCPCH, 2004, p. 12), there is a clear hierarchy in the systems that surround sudden and unexpected child death, which seem to understand good communication as largely a one way process in which parents are kept informed by professionals rather than playing a more pro-active role. As Cathy summarises in Chapter 5:

We get surveys about stuff from the Council all the time too which I'm always doing because I enjoy them, but when Dylan died there was no one to hold accountable, there was no one to go to and say this is what's happened and this is how I am feeling. The Coroner and the police were above everything and there was nowhere else to go.

Throughout the research, I have become increasingly aware that the popular depiction of professionals as in control and parents as marginalised creates yet another powerful binary, which in itself obscures part of the excluded middle. Despite the requirement to demonstrate professional 'competence to practise' reflected in 'maintaining currency of knowledge and developing skills' (Dent & Stewart, 2002, p. 126), my experience when Joe died was that almost none of the professionals were able to manage this shocking death, which was at the centre of their working lives - the paramedic who tried to control the situation by telling me how I should behave was plainly terrified, the registrar was incapable of common humanity, and the health visitor, as her colleague informed me, was 'having a terrible time.' (See Chapter 1).

This experience is reflected by the defended responses of many of the professionals who were described earlier and by the parents in this study. Chrissie comments that the police officer involved with her baby's death 'looked terrified', whilst Andy too describes the police officer as 'finding it pretty hard'. Ellie particularly demonstrates the impact that child death can have on professionals in her story of the police officer who runs for charity in memory of her baby. (See Chapter 4).

However, these anxieties, like the emotions experienced by parents, are not represented within the literature and the training material. In the DVD 'Why Jason Died', the professionals are all played by themselves and are shown as confident, speaking authoritatively directly to camera as they move seamlessly through a series of protocols, and support the terrified mother. Many of the narratives contained within this thesis demonstrate a different reality, in which it is the parents who take control, as I myself

did by taking Amy to school. As Laurie states, describing her own strong ownership of the situation, ‘instincts was the only thing I was flying by that week because everybody else was pretty much useless’ (see Chapter 7).

Although there is limited discussion of professional’s capacity to cope within the literature on sudden and unexpected child death and Rapid Response, this has some representation in the wider literature on child loss, as Hindmarch states:

For the professional carer there is an overwhelming sense of hopelessness...it can be difficult to allow for these personal feelings within a professional role (1993, p. 41).

My growing sense of this professional hopelessness led me to reflect once more on the language commonly used to describe child death in cataclysmic terms (see Chapter 2). As I have discussed in previous parts of this thesis, the popular use of language that leaves no hope omits the profound sense of meaning that parents often bring to their loss.

Cottle’s description of the ‘myth of vulnerability’, ‘wherein we imagine that people of certain groups or those having had certain experiences are so damaged they cannot speak for themselves’ (2002, p. 536), is linked to this widespread use of cataclysmic language, pointing towards a form of projective identification where those who make others feel vulnerable often get classed as vulnerable themselves. This suggests that the cataclysmic language so often attributed to parents is likely to strongly reflect professional anxieties. For those working at the coalface within a culture of risk management, the sudden and unexpected death of a child really can be viewed as ‘the most shocking and devastating event anyone must face’ (Dent & Stewart, 2004, p. x).

However, whilst parents like those reflected in this study can gradually begin to form meaning from the chaos (see Chapters 4–7), the professional role may exclude workers

from ‘a socially recognized right, role or capacity to grieve’ (Doka, 1989, p. 3). As I discussed in Chapter 2, this may lead professionals in these circumstances to become disenfranchised from their feelings about the death, thus intensifying ‘feelings of anger, guilt or powerlessness’ (Doka, 1989, p. 7), and ultimately leading to deteriorating practice and even tragedy.

These unprocessed and disenfranchised feelings help to explicate some of the more apparently ‘inhuman’ behaviour evidenced within this research. The guns and marked cars described in both Andy’s (Chapter 4) and Cathy’s stories (Chapter 5), together with the ‘uniformed officers’ and the ‘great big guy with full uniform’ described by Chrissie in Chapter 4, become more understandable when viewed as attempts to shore up identity in the face of the ‘catastrophic failure’ (Hoggett, 2000, p. 67) symbolised by sudden and unexpected child death.

What falls into the ‘excluded middle’ is the ‘psychic damage’ (Cooper & Lousada 2005, p. 95) to professionals that the death of a child may invoke. It is therefore possible, as I suggested in Chapter 2, to view Rapid Response as a container for professional anxiety helping to dispel this psychic damage by the rigid following of procedure. As the social worker quoted in Chapter 2 suggests, it is interesting to pause for a moment with this in mind and to reflect on how professionals would manage a sudden and unexpected child death without these procedures (Cooper & Lousada, 2005, p. 181).

Where ritualised performance tasks and audit take the place of relationship and emotion, the gulf that forms the excluded middle becomes a chasm. The very real and worthwhile purpose behind the Kennedy Report is lost as policy consumes relationship and is seen ‘to underpin a deadened and fragmentary state of mind in professionals who cannot enter into live here-and-now relationships with service users and their painful experiences’ (Cooper & Lousada, 2005, p. 40).

This inability to tolerate painful experiences recalls the behaviour of the police at my presentation as described earlier, one of whom simply left the room and the other who queried every detail of Cathy's account, suggesting that it could not have happened. The Coroner described in Chapter 1 is another example of this, telling me emphatically that parents were never charged for the release of their child's body, whilst the health visitors who approached me later to confirm their experience of this were too frightened to speak out at the time.

The DVD 'Why Jason Died' (Department for Education, 2008) provides a similar startling example of this 'fragmentary state of mind' in a section where Peter Fleming, a Professor of Infant Health and international expert in the field of sudden and unexpected child death, addresses the camera directly. He states authoritatively that, whilst professionals often worry that they will do or say something that will make the situation worse, he is able to reassure them that they cannot possibly make it any worse. Fleming's statement in such significant training material, which is widely distributed to social work teams and Local Safeguarding Children's Boards across the UK, contrasts strikingly with many of the accounts given in this thesis, and particularly with Andy's powerful statement (see Chapter 4):

The day itself and how we were treated was worse than actually losing him.

Advice such as that stipulated by Fleming in a highly influential resource acts to re-enforce the excluded middle by giving an expert professional view on behalf of parents, rather than representing their views directly. Some of Munro's recommendations, if implemented effectively, may help to counteract this by promoting practices of relationship, within social work at least, which move away from a culture of blame towards one of learning (Munro, 2011).

The most surprising example of the excluded middle that I have identified within this research lies in the lack of consideration given to surviving siblings within the professional response. In ‘Why Jason Died’, Jason’s siblings are described as staying with relatives and are therefore never seen and only fleetingly mentioned. This mirrors the literature within the field where siblings are never accounted for in both the Rapid Response and in the aftermath of a sudden and unexpected child death. However, my own experience (Chapter 1), and that of many of the parents described within Chapters 4–7, prioritises the welfare of surviving children both as an immediate and as a longer term concern. Terri, Cathy, Andy and Laurie all speak vividly of their surviving children, with Laurie’s account perhaps forming the most powerful (Chapter 7).

Cathy too mentions her children in a typically striking passage, highlighting the anomaly of investigation and the support so often mentioned within the professional literature:

There was part of me that thought ‘hang on a minute; you think I’ve killed my son, but you don’t actually care where my other children are.’ It all seemed a bit weird because if I had killed my son then someone needs to be looking after us or at least asking.

The omission of siblings from the literature on sudden and unexpected death supports the proposition made throughout this thesis that over engagement with procedure, and the related focus on high risk events, is in danger of creating the very situation it is setting out to avoid – the risk of harm to children. Whilst audit replaces relationship and professionals are not supported adequately, there is the ‘impulse to turn a blind eye...creating structures that purport to see but in practice turn away’ (Cooper and Lousada, 2005, p. 113). Siblings therefore fall into the excluded middle, tidily out of view, in a place where they cannot interfere with ‘systematic investigation’ (Sidebotham & Fleming, 2007, p. 98).

In Chapter 2, I quoted Rando, who describes researching for her book and being advised by a national consultant for SIDS (Sudden Infant Death Syndrome) to ‘stay away from it’ (1986, p.163). It is as if the overwhelming anxiety that now surrounds child death, sucks everything down into this morass, leaving only the rigid binaries still standing. The solution to this lies in finding a means to excavate the excluded middle and to answer the question posed by Cooper and Lousada (2005, p. 113):

How do we manage the social task of both addressing toxicity and damage in a contained or safe enough manner without thereby sequestering it, or pushing it so far out of mind that we come to turn a blind eye to its reality?

8:5: Reclaiming the middle

As I have shown throughout this thesis, direct opportunities to hear from parents themselves are mostly regulated within all consultation processes following sudden and unexpected child death, and indeed within the Working Party for the Kennedy Report itself. Thus, where procedure purports to be ‘promoting community interest’, it may actually act as a mechanism for ‘institutional self-preservation’ (Edwards, 2004, p. 50) and a means of controlling the terror of blame and failure, which has arisen under the culture of managerialism (Lees, Meyer & Rafferty, 2013).

Munro’s review of child protection, as discussed in Chapter 2, is clear that these managerialist policies are defensive, creating as many problems as they attempt to solve, and she therefore advocates for new’ ways of working, which are capable of reclaiming the excluded middle via increasingly relationship-based and containing practice cultures (Lees, Meyer & Rafferty, 2013).

My own anxiety about following systems to the letter within this research, and thereby avoiding my failure as a researcher, was demonstrated during my own interpretation

phase (Chapter 3) when my rigid attempts to maintain BNIM processes led me further and further away from the stories themselves. To counter this, I returned to a method that announced itself as a way of listening, which helped me to set aside my own anxieties and to move instead around and within the stories themselves.

However, whilst parents remain excluded from meetings and consultations, professionals do not have access to their stories and are thus unable to listen, even when they are willing to do so. This study has shown that there are many parents eager to engage with professionals in order to bridge this excluded middle, and that what makes them ‘vulnerable’ (Cottle, 2002, p. 236) is largely not the telling of the story, but the lack of opportunity to tell. As Ellie says:

When you mention the death of a child, it’s like ‘gasp...we don’t want to hear about that, just shut that away’ but I think it’s important to keep the whole awareness thing going...’ (Chapter 4).

Cooper suggests that ‘the power of the destructive and the negative is reduced or attenuated through fearless engagement with it’, and in this way listening to parents’ stories can assist professionals with facing their own anxieties and moving towards a place of ‘greater freedom, creativity and even happiness’ (2009, p. 441). This is a place of connection, where the excluded middle can be reclaimed and the sensitive support and balance so much talked about can actually be enacted. Ellie’s story of the policeman who ‘asked if he could use my baby’s name in his ‘Just Giving’ page’ because that was ‘his inspiration for doing the run’, powerfully demonstrates this (Chapter 4). The human connection made here, and the policeman’s ability to turn his own anxieties into a creative act, demonstrates how together they made the ‘unthinkable’ thinkable.

In his story of the death of his first child, Ryan (1989, p. 132) describes his need to make something creative from the death, to personalise his grief. Despite never having done anything like it before, he finds a piece of granite and carves a headstone, an act

which, when completed, helps him to 'reach closure' and to 'rest more easily' with the loss. For many professionals, however, the ability to carry out creative acts like carving the headstone or running marathons is arrested by the constraints of their role, leading to disenfranchisement (Chapter 2). As a professionally qualified social worker myself, as well as the parent of a child who died suddenly and unexpectedly, I am able to inhabit the excluded middle and to look both ways between these roles. Like the carving of the headstone, this thesis represents a creative endeavour, which attempts to bridge the middle and to make meaning from a death.

Although the research is focused on parents' perspectives, this was always as a means of restoring the balance so often cited but so little enacted, and I have discovered that these parental experiences have much to teach professionals, who are often filled with 'fear and unease' (Ferguson, 2011, p. 46). Whilst grief remains an entirely unique event (Ryan, 1989, p. 132) many of the parents in this thesis have 'been all the way to the bottom' and found that 'it is solid' (Frank, 1995, p. 126), thereby reaching a 'depressive position' that bridges the excluded middle (Hollway & Jefferson, 2000, p. 20).

Klein offers an example of this in her case study of Mrs A whose initial reaction to her son's death was of 'feeling numb and closed up', but who moves gradually to a realisation that 'she could, and would, go on living and this meant that she could accept the event of the death free of the entanglements of her own fears and fantasies' (cited in Small, 2009, p. 154). Far from remaining stuck in a pain that 'will never go away' (Dent & Stewart, 2004, p. 58), Mrs A, like so many of the parents in this study, responds from a depressive position where she can go on living, incorporating the death in her continuing life.

The fear and unease that haunts so many professionals, may therefore paradoxically be ameliorated by listening to these parents, whose experiences have given them a singular

form of knowledge. Like the ‘thestrals’ described in Chapter 1, many of these parents are able to see past everyday experience in a manner that can ‘only be seen by people who’ve seen death’ (Rowling, 2003, p. 760). In Chapter 1, I described how following Joe’s death this ability to ‘see’ caused people to tell me their own stories of pain and loss, most of which had been kept circumspect for years, a phenomenon that Shisler (2006) also witnessed after her own son died. Far from being vulnerable then, many parents have a great deal to offer those professionals prepared to enter into ‘fearless engagement’ (Cooper, 2009, p. 441) with their experience.

Within this mutual communication, recommended by the Kennedy Report but largely unimplemented, lies the real bridge over the excluded middle. As a means of accomplishing this, Speedy describes the use of ‘definitional ceremonies’, which give voice to ‘defining aspects of our life stories in the context of a reflecting team or audience of witnesses’ (2008, p. 104). The online forums run by many charities are a form of definitional ceremony, where parents join each other and share stories within a virtual community. However, whilst helpful, they follow the model of parents talking only to parents and not to professionals, who in turn talk to each other. The use of a form of definitional ceremony in bringing both parents and professionals together as witnesses to each other’s stories would be a powerful means of enacting the simple, practical training recommended by the Kennedy Report (2004).

Despite the difficult experience described earlier, during the course of this research I have found examples of organisations capable of facilitating this form of definitional ceremony within their training and education programmes. Amongst these are the Scottish Cot Death Trust, Child Death Helpline and Child Bereavement UK, whose mission to support families and train professionals is led by a commitment to learning directly from parents. These forms of open and appropriately facilitated training are able to bring the ‘professional, the academic and the personal into conversation with each

other' (Bochner, 1997, p. 433), thus offering the opportunity to share experiences and to learn from them, rather than maintaining harsh binaries and shadowy portrayals of actual human experience. Cooper's argument for 'practice-near research' (2009, p. 441) endorses this, making a powerful case for bringing practice and experience into intimate dialogue, thus helping to bridge the excluded middle. I will return to some of these ideas within the penultimate section on what can be learned' from this research study.

Reclaiming the middle also calls for some way of honouring and connecting with the often unthinkable experience of death – the 'still point' (Eliot, 2001). When Joe died, my initial reaction was to stop. It was clear that he had been dead for hours, and initially I did not even want to call an ambulance. Whilst this could be explained by denial, I have always maintained it as something other: as the 'felt sense' of a connection between life and death (Gendlin, 1996, p. 63).

In his poignant description of watching his father die, Lott (2013b) highlights how death is both 'profoundly average yet utterly exceptional', recalling the popular words from the Book of Common Prayer, 'In the midst of life we are in death'. Whilst the death of a child is certainly no longer average, there is nevertheless something in the eventual inevitability of death that momentarily takes breath away, and that calls for stillness and contemplation. Lott (2013b) draws near to this, as he describes his father's last hours:

It took two more days before the end came. That time passed differently from how I had expected. Sad, but also tender and positive and beautiful. Death is so intimate – more intimate than first love. I could hold his hand, gaze into his eyes, stare unhindered at his tender face, stroke his frosty hair.

However, when a child dies suddenly and unexpectedly, there is no opportunity for tenderness and the saying of goodbyes, as Lott describes. As many of the narratives within this thesis demonstrate, from the second the ambulance arrives, the house swarms with people, there is suspicion, investigation, flash photography and

sequestration of the body by the Coroner. Far from the holding of hands and stroking of hair as described by Lott, the best parents may be offered is a lock of hair or brief contact with a child who is now the property of the Coroner – a child who was alive only a few hours beforehand.

I suggested previously that much of this frantic activity may act as a form of ritual response to the enormity of death with which we struggle culturally (see Chapter 2), viewing it as the ‘antithesis’ to life, and therefore as a ‘failure’. (Dent & Stewart, 2004, p. 185).

Many of the narratives contained within this thesis show a humbling acceptance of the naturalness of death, exemplified by Terri’s description of the death in her garden (see Chapter 4), together with the way in which small acts of kindness help to normalise death. Ellie’s description of the nurse who smuggles the apnoea monitor out of the hospital, thereby putting ‘herself on the line’, helps to restore humanity and tenderness to her situation and to bridge the gulf left by death. The Headteacher who, after Joe’s death, was able to talk to the children and to cope with Joe’s box, shows a comparable humanity and an ability to deal directly with the death itself and its immediate consequences (Chapter 1). Similarly, funeral directors, who literally bridge the gulf within their role, are the only professionals consistently described positively by parents (Chapter 4), thus demonstrating the healing capacity of ‘fearless engagement’ with the experience and the magnitude of death itself (Cooper, 2009, p. 441).

Reclaiming the middle calls for a way of repairing the ‘breakdown of linkage’ (Cooper & Lousada, 2005, p. 147), both between life and death and between professionals and parents. Achieving this means exploring the breakdown in open and honest ways that dissolve boundaries and restore credibility to both ‘emotional and evidential sources’ (Cooper & Lousada, 2005, p. 147). As Frosh so powerfully describes:

For tragedy to be possible, for destructiveness to be meaningful and loss appreciated, there has to be something there that can be identified with, something that can love as well as lose, hope as well as be betrayed. In this something, this self, there is enduringly the spark of resistance, a potential to respond in a humanly worthwhile way to the mess that is all around (1991, p. 19).

8:6: What can be learned?

In Chapter 2, I set out three research questions, with the accompanying proviso that whilst these have guided me, it has been the question ‘what can be learned’ in the title that has acted as the foundation for enquiry throughout this research. It is to this ‘what can be learned’ that I now return in the closing sections of this thesis, as I attempt to synthesise some of the findings and ideas from the research process into more substantive recommendations.

After six years of part time study, answering the question ‘what can be learned?’ seems suddenly overwhelming, as I am besieged by memories of the interviews themselves, together with the often difficult process of conducting the research. However, all these experiences and the research questions can be enfolded into one major finding, which appears simple and yet remains challenging to achieve.

When parents, including myself, recall the experiences of the professional investigation following the deaths of their children, they each describe in different ways their deep desire to be listened to and correspondingly heard. As Cathy so memorably summarises:

If you buy things off eBay you get emails and phone calls all the time about when it’s coming and what’s happening... but when Dylan died there was no one to hold accountable, there was no one to go to (Chapter 5).

Whilst it remains a fact that some people murder and harm their children, in the ‘vast majority of cases where babies suddenly die, nothing unlawful has taken place’ (RCPath

& RCPCH, 2004, p. 1). Therefore, to continue to treat each case as if it were child abuse is not just to show insensitivity, but rather to deal a hammer blow at a time of great trauma. In all the stories within this thesis, alongside the traumatic remembering, the tellers also speak of being treated humanely and of being heard, which transform the experience from a nightmare into an event that can be invested with meaning and hope. Terri's account of the health visitor illustrates this vividly (Chapter 4):

Thank god for that health visitor, who I don't even know if I had met before, this lovely woman. She was the only thing that was keeping me vaguely together.

However, as I have documented throughout this thesis, whilst listening may appear simple, it can in reality be hugely challenging for the reasons Lott suggests:

One is brought hard up against the reason for the apparent indifference of the wider world to pain and suffering. Compassion hurts. It means 'suffering with'.... easier in some ways to cut yourself off (2013a).

The psychosocial approach adopted within this research has excavated the surface of sudden, unexpected child death, which commonly depicts parents as the only vulnerable parties, to expose professional vulnerability and the concomitant risk of cutting off that Lott describes.

This approach has also enabled a more holistic picture of parental experience following sudden, unexpected child death, by giving voice to accounts which contain the raw pain and tragedy of the death, whilst simultaneously celebrating the children's lives in a way that creates meaning and embraces the complexity of life.

I believe that the approach taken has enabled one of the major original contributions of this study in a field where surface explanations and process are often unquestioningly accepted and parents' experiences too frequently defined for them. Given the contemporary decline in child mortality rates there is now an opportunity for this work to assist parents and professionals in responding to sudden and unexpected child

deaths in uniquely individual ways, whilst fostering understanding and the sensitivity so often referenced in the Kennedy Report (2004). Additional research which builds on the in-depth, psychosocial approach taken within this study should be commissioned with the aim of further excavating and increasing understanding of the experience of sudden, unexpected child death.

One of the other ways, in which this study has answered the question ‘what can be learned’, lies within the experiences of surviving children involved in sudden and unexpected child death. As I have documented, siblings are absent both from literature on Rapid Response and in the training DVD ‘Why Jason Died’ (Dept. for Education, 2008), and yet were so powerfully present in Joe’s story (Chapter 1) and in those stories that form Chapters 4–7. The capacity to study every case within its own terms (Cooper, 2009) which a declining child mortality rate could create would restore balance by allowing humanity into professional judgements, thereby avoiding some of the inconsistencies involved in parents continuing care of siblings. Professional judgement is highly recommended by Munro who advocates for the ‘replacement of ineffective defensive techniques’ with this more genuinely ‘sensitive’ and person-centred approach (Lees, Meyer & Rafferty, 2013, p. 554).

The need to act on those sections of the Kennedy Report concerned with professional judgments and improved communication has been made even more imperative by a recent Report on Children and Young People’s Health Outcomes (Department of Health, 2012). Whilst Britain’s child mortality rates have declined generally, this report showed that they nevertheless remain too high, with more under 14 year olds dying in England than in the rest of northern or western Europe. Some of these deaths will inevitably be subject to a Rapid Response and other professional interventions, and thus the need to ‘engage openly in debate about how systems and procedures might be improved’ (RCPPath & RCPCH, 2004, pp. 1-2) remains vital.

As I documented at the very beginning of this thesis, the Kennedy Report acknowledges that ‘given the nature and sensitivity of the subject, some contentious issues remain’ and invites feedback (RCPath & RCPCH, 2004, p.ii). In stepping into the space created by that invitation, this study demonstrates powerfully that sibling experience of the Rapid Response is a priority area for further research and improved intervention. The almost total absence of consideration given to surviving children, both in respect of their continuing role with parents and also as siblings of a dead child, is one of the most powerful absences within the field and correspondingly indicative of the reliance on procedure to replace holistic thinking and humanity. I consider this to be another major contribution of this study and one which I hope will influence future research and policy in this area.

The ‘what can be learned’ within my research purpose also points to a number of explicit recommendations which I hope will re-set the agenda for policy in this area. However, as much of this thesis has been critical of rigid structure and the language of experts, I am wary of creating my own set of prescriptive criteria for ‘improving practice and understanding’ (RCPath & RCPCH, 2004, p. 12). I therefore hope that these concerns can become part of a dialogue aimed at revitalising the landscape of sudden, unexpected child death which has ossified in the time since the Kennedy Report and the changes which followed. A decade now since these were implemented the time is now right to re-visit and improve on these, in the light of this new work and the issues it identifies.

One of the key issues identified by parents in this study is the role of language and its latent meanings, which, as Hollway and Jefferson suggest, often express unconscious beliefs and ‘never represent the world neutrally’ (2000, p. 14).

Whilst both the Kennedy Report and the professional literature repeatedly emphasise ‘balance’ and the possibility of combining ‘robust investigation’ with a ‘sensitive approach’ (Sidebotham et al., 2009, p. 294), the designation used when police attend a sudden and unexpected child death is commonly that of ‘Child Abuse Team’. As Cathy, Hafsa and Chrissie so vividly describe in Chapters 4 and 5, this can be terrifying for parents who already feel guilty and under suspicion. If balance was really the desired outcome, the language could easily be altered to help demonstrate this and to achieve greater symmetry.

Another issue that arises from the police response and language used is that of closure. Despite the recommendations in the Kennedy Report that all child deaths are followed by a joint home visit, many parents do not understand this and may view it, as Cathy does, as a further act of suspicion or blame (Chapter 5). What many parents in this research have specifically requested is some form of written document from the police, which informed them that the case was ‘closed’ (Chapter 4). This lack of formal exoneration has been one of parents’ most enduring concerns and this could easily be ameliorated if it were made a formal part of procedure.

As part of creating greater opportunities for ‘communication between professionals and between professionals and parents’ (RCPATH & RCPCH, 2004, p. 12), I would also recommend that parents are at least offered the chance to attend some of the meetings that follow a sudden and unexpected child death. As Cathy says:

There was no one to go to and say this is what’s happened and this is how I am feeling (Chapter 5).

Parents in this study have consistently demonstrated a desire to share their stories in different contexts and correspondingly for lessons to be learned from their experiences. At present, as I have described, parents are not part of any of the meetings following

sudden, unexpected child death, nor where they included in the Kennedy Report Working Group, making the stated intention of auditing ‘how procedures at the time of the death and afterwards were managed’ (FSID, 2011, p. 6) with a view to reporting to CDOP’s on lessons learnt, seem somewhat hollow.

Returning to the definitional ceremonies discussed earlier, Myheroff (1986, cited in Speedy, 2008, p.104) describes these as events capable of dealing:

With the problems of invisibility and marginality; they are strategies for being seen in one’s own terms, garnering witness to one’s worth, vitality and being.

One of the findings of this research has been the impact on both parents and practitioners of potentially alienating procedures which can produce professional disenfranchisement (Doka, 1989) alongside the alienation described so powerfully by parents in Chapters 4 – 7. If lessons are actually to be learned from individual child deaths, as so much of the protocol suggests (FSID, 2011), then rather than endemically barring parents from meetings alternative forms of definitional ceremonies should be developed, which allow for open dialogue and an exchange of views. Many of the parents in this study identify areas for improvement within their experiences, but also recognize numerous ways in which professionals either intervened successfully or needed support themselves. By developing definitional ceremonies, or as Speedy dubs them ‘outsider witness practices’ (2008, p.106) opportunities are provided for genuine, non- judgemental encounters which will help to improve the experience of sudden, unexpected child death and thereby lead to decreased disenfranchisement. Those professionals’ who may have been involved with families for only a brief but nevertheless traumatic time, would gain the opportunity for some closure, whilst parents could feel their experience had contributed positively to outcomes and lessons being truly learned (FSID, 2011). Findings from this study point forcibly towards developing

a practice of this kind in addition to, or maybe instead of, some of the meetings which already follow unexpected child death, but which presently exclude parents.

8:7: What I have learned

This thesis has been a profoundly personal journey, as well as an academic endeavour, and therefore my own learning has inevitably been a blend of both.

I began the research, as I have documented, with the aim of repairing what I perceived to be the split between many parents' lived experience and the professional accounts written on their behalf in influential training and policy documents. I also wanted a place for my own experience, which, like Raymond's carving of the headstone, discussed earlier in this Chapter, made some meaning of both Joe's death and of the events that followed.

I believe I have achieved both of these aims within this study but when I gaze back with the benefit of hindsight across the six years since I began, I realise how naïve I was. Initially, I was pragmatic in my attempts to fill the gaps I had identified, and I had little idea about how painful this process would be, both for myself and for many of those around me. In the course of the research, my supervision team was forced to change, and one of my remaining supervisors generously admitted, towards the close of the process, that she had not herself realised how difficult and painful both conducting and disseminating this research would be.

Completing this thesis, therefore, has taught me much about myself and about those who have both physically and metaphorically crossed the road to avoid me. I have learned mostly to let go of my anger with these people and to understand that often they are simply frightened. I have learned too, that my own resistance to being what one of my supervisors describes as the 'slightly disturbing' candidate can be replaced by

embracing this role and the knowledge that it brings. This is perfectly summarised by bell hooks:

I see how many of the people who are writing about domination and oppression are distanced from the pain, the woundedness, the ugliness. That it's so much of the time just a subject – a 'discourse'...I say remember the pain because I believe true resistance begins with people confronting pain, whether it's theirs or somebody else's, and wanting to do something to change it (cited in Hoggett, 2000, p. 122).

Confronting my own pain has been intrinsic to this research process, and at times attempting to combine this with my efforts at objectivity has been tortuous. I do not claim to have succeeded fully in integrating my own painful experience, should this ever be possible. However, I do believe that I have constructed a reasonable case for challenging accepted ways of knowing about sudden and unexpected child death, within an academic format that commonly drains research of its emotional meaning and dismisses the personal as invalid (Hoggett, 2000). Whilst I find making claims for the thesis and its original contribution as difficult as I have found writing it at times, I do believe that my efforts at turning inside out to view myself as far as possible from all sides, have rendered this a definitively psychosocial piece of work and one which is both innovative and challenging.

I have also learned much academically, and I have many people to thank for this. With the benefit of hindsight, I would have approached the research with a much clearer plan, instead of the sometimes rather tortuous meanderings I described in Chapter 3. As a mature student, returning to education after so long and with other responsibilities, my academic approach often combined these meanderings with sudden surges of energy akin to a moth hitting a light bulb. I believe the result of these processes has lent the final thesis its originality, and I hope its humanity, but there are many factors that I would also have approached differently. The most significant of these is that, in coming

very late to my understanding of the psychosocial, I have not been able to include the work of Bion nor employed the skill and depth I would have preferred. However, I hope that in any future work I will be able to build on my increasing understanding. It is this forward momentum that I want to consider finally.

8:8: 'To make an end is to make a beginning'

I began this Chapter with a quotation from T.S Eliot and have chosen to end in the same way. In 'Four Quartets' (2001, p.42) Eliot suggests that 'to make an end is to make a beginning. The end is where we start from' - a phrase which seems to summarise my feelings at the close of this long research process. I thought I had reached completion, but as I write this final section I see it as only another beginning. As I present and write about this research it still provokes many of the same defensive and aggressive reactions which initially instigated it. Therefore much of my original drive to excavate the contemporary fears surrounding sudden, unexpected child death and thereby to achieve increased understanding and sensitivity between parents and professionals remains unfulfilled.

However, I see this study now only as a beginning and one which has already been the focus of attention from a variety of sources, with the future promise of attracting many more. To date, I have appeared as a guest on a flagship BBC Radio 4 ('Woman's Hour, 2011) and written for the 'The Guardian' online (Turner, 2012) as well as publishing a journal article based on my experience of ethical review (Turner & Webb, 2012).

I have also appeared as a Keynote speaker for Child Bereavement UK and the Coroners' Support Service, as well as an invited guest at Local Safeguarding Childrens' Boards. Additionally, I have given a number of conference presentations, amongst them to the NSPCC 2012, JSWEC (Joint Social Work Education Conference) 2013, Discourse, Power and Education, 2013, and the launch of the International Network of Narrative

Medicine, 2013. I believe the diversity of these presentations demonstrates the potential multi-disciplinary contribution of this work.

The research has also led to an ESRC Knowledge Exchange Partnership Bid with Child Bereavement UK, which, if successful, will provide a mirror to this study by examining the accounts of eight professionals involved in responding to sudden unexpected child death. The proposed project will also further disseminate the findings of this study, via a series of outward facing outputs, including training days and workshops, published educational material and social media activity, all of which will help to break down boundaries and increase understanding, thereby improving practice.

Additionally, the focus on emotions within this study has led to ongoing work, which will help to build psychosocial methodological interest and capacity via a series of events and partnerships. I have already co - convened an initial conference funded by the ESRC Doctoral Student Pathway, which focussed on psychosocial methodology and specifically Hollway's concept of gaining objectivity through subjectivity (2009). This was solely instigated by the findings from and process of conducting this research.

Following this conference I facilitated four supervision groups with doctoral students from different institutions, engaged in particularly sensitive research, which explored the challenges of this both for knowledge creation, as well as for the researchers. The results of this work will form a report to the ESRC and will also be co-presented at the ESRC Annual Research Methods Festival in 2014, via a workshop entitled 'Telling the Untellable', which will specifically address the methodological challenges of psychosocial research in 'sensitive' areas.

This thesis has also directly led to a developing interest in psychosocial methods within my own institution and I have advised several doctoral students both informally and more formally on working in this way, thereby increasing the scope and range of

psychosocial methodologies. Additionally I am now part of a working partnership between my own institution and others, which will seek to extend the knowledge and use of psychosocial methods in teaching and research within Higher Education. As a part of this I will be co- facilitating a workshop on psychosocial data analysis at the Joint Social Work Education Conference (JSEWC) in 2014.

Whilst, as I have already described, there is much that I would have done differently within my own research process, I believe that the outcomes this research has already achieved are all evidence of its original contribution. Much of this originality stems from the power of the psychosocial approach taken and in particular the blending of my personal stance as researcher with the parental accounts, which together help to bridge the gap between the knower and the known in research knowledge. The subject of the research is also one which is little researched or understood and this too adds an extra layer of originality, whilst the direct manner in which often intensely personal and painful experience is conveyed creates both unparalleled depth and meaning. My use of panels to analyse what is frequently distressing data has also contributed to knowledge, countering much of the current theory around group analysis which suggests that groups are mostly containing of data and able to judge it from multiple perspectives (Wengraf, 2011, Elliott et al., 2013). My own experiences with the panels show a much more complex picture in which some elements of the original experience are retained within the text and acted out within the analytical encounter, leading to the angry and distressed reactions of panel members (Thomson, 2012). My work has already contributed to research outputs concerned with group analysis (Elliott et al., 2013) and I believe this will be another important methodological contribution to research knowledge and design in the future.

However, I believe that paramount amongst the many original contributions which the research has produced is that made by the narratives themselves, which challenge

popular notions that parents may be too vulnerable to speak. The parents in this study offer both strong individual and collective voices, which demand to be heard and which demonstrate the triumph of meaning-making over tragedy.

This is a perspective I share, for Joe so nearly died at birth and in his early weeks, and thus I view the time I spent with him as a privilege. His death was an awful shock, but something I had been prepared for by the circumstances of his birth. What made it truly traumatic were the events that followed, which I simply could not comprehend.

I therefore want to close finally by returning to Peter Fleming's confident assertion that professionals cannot make things worse. My experience and those of parents in this thesis contradict this powerfully. But whilst they can undoubtedly make it worse, the narratives also show numerous ways in which professionals can make it better, providing perhaps a simple yet vital answer to the question 'what can be learned from parents' experience of the professional response following the sudden unexpected death of a child.'

I am going to leave the last words to Ellie, whose narrative so vividly demonstrates both the good and the bad in her experience, together with the lingering effects of each. Her simple statement sums up the need for further understanding between parents and professionals and for the development of the training advocated by the Kennedy Report, because, as Ellie says:

After a baby dies things that are said stay with you forever.

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2005 (1)

2003 (1)

Author Name

Brady, J.T. (1)

Brown, D. (1)

Cacciatore, J. (1)

Dyregrov, A. (1)

Dyregrov, K. (1)

Subject Area

Social Sciences (5)

Psychology (1)

Document Type

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Consumer perception of food-borne illness risks before and after the 2006 E. Coli events	Brady, J.T., Li, P., Brown, D.	2009	Family and Consumer Sciences Research Journal	1
Appropriate bereavement practice after the death of a native American child	Cacciatore, J.	2009	Families in Society	7
Sudden and unexpected health situation: From suffering to resilience	Lefebvre, H., Levert, M.J.	2006	Illness Crisis and Loss	4
An exploratory study of post-traumatic stress disorder symptoms among bereaved children	McClatchey, R.S., Vonk, M.E.	2005	Omega: Journal of Death and Dying	8
Predictors of psychosocial distress after suicide, sids and accidents	Dyregrov, K., Nordanger, D., Dyregrov, A.	2003	Death Studies	79

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Year

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- ☐ 2005 (2)
- ☐ 1997 (1)

Author Name

- ☐ Adsheed, G. (1)
- ☐ Ashworth, M. (1)
- ☐ Cartledge, P.H.T. (1)
- ☐ Dunstan, F.D. (1)
- ☐ Epstein, J. (1)

Subject Area

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<input type="checkbox"/> Challenges to implementation of the new Coroners' (Amendment) Rules 2005: Experience from a tertiary paediatric pathology centre	Weber, M.A., Epstein, J., Simons, J., (...), Ashworth, M., Sebire, M.I.	2007	Medicine, Science and the Law	47 (4), pp. 283-288	4 Cited by
<input type="checkbox"/> Differences in risk of mortality under 1 year of age between rural and urban areas: An ecological study	Guildea, Z.E.S., Fone, D.L., Dunstan, F.D., Cartledge, P.H.T.	2005	Public Health		5
<input type="checkbox"/> Evidence-based medicine and medicine-based evidence: The expert witness in cases of factitious disorder by proxy	Adshead, G.	2005	Journal of the American Academy of Psychiatry and the Law		10
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Year

2007 (1)

2002 (1)

Author Name

Afolabi, O. (1)

Daniel, T.D. (1)

Harcourt, D. (1)

Marks, P.J. (1)

Nguyen-Van-Tam, J.S. (1)

Subject Area

Medicine (2)

Neuroscience (1)

Nursing (1)

Document Type

Article (2)

Adjustment to appearance changes resulting from meningococcal septicaemia during adolescence: A qualitative study Wallace, M., Harcourt, D., Rumsey, N. 2007 Developmental Neurorehabilitation 5

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Emergency (999) calls to the ambulance service that do not result in the patient being transported to hospital: An epidemiological study Marks, P.J., Daniel, T.D., Afolabi, O., Spiers, G., Nguyen-Van-Tam, J.S. 2002 Emergency Medicine Journal 38

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2006 (1)

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Bajanowski, T. (3)

Brinkmann, B. (2)

Beike, J. (1)

Findelsen, M. (1)

Furst, P. (1)

Subject Area

Medicine (3)

Social Sciences (3)

Document Type

Article (3)

Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families Vennemann, M.M.T., Rentsch, C., Baja Show author details Jmer, G. 2006 International Journal of Legal Medicine 120 (6), pp. 352-354 4 Cited by

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Year

2010 (7)

2009 (5)

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Author Name

Blair, P.S. (6)

Fleming, P.J. (5)

Platt, M.W. (4)

Smith, I.J. (4)

Fleming, P. (3)

Subject Area

Medicine (69)

Implementation of the American Academy of Pediatrics recommendations to reduce sudden infant death syndrome risk in neonatal intensive care units: An evaluation of nursing knowledge and practice

Grazel, R., Phalen, A.G., Polomano, R.C.

2010 Advances in Neonatal Care 10 (6), pp. 332-342

10 Cited by

Variation and uncertainties in the classification of sudden unexpected infant deaths among paediatric pathologists in the UK: Findings of a National Delphi Study

Gould, S.J., Weber, M.A., Sebire, N.J.

2010 Journal of Clinical Pathology

2

Configurative domains in child health research: Sudden infant death in the Swedish Medical Journal

Brännström, I.

2010 Policy, Politics, and Nursing Practice

2

Peut-on expliquer la mort inattendue du nourrisson ? Réflexions à partir d'une série de 80 cas autopsiés au CHU de Rennes entre 1994 et 2007 [Can we explain the sudden infant death syndrome? About a series of 80 cases with an autopsy in Rennes University Hospital, France in the period 1994-2007]

Saint-Stéban, C., Leray, E., Jouan, H., (...), Venisse, A., Roussey, M.

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English multi-agency approach to the investigation of sudden unexpected deaths in infancy and the care of bereaved families

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2010 Current Pediatric Reviews

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1 Don't knock the experts

Valios, Natalie. Community Care 1511 (Feb 2004): 30-31.

...Meadow and his statement that one cot death is a result of natural causes, two ...Meadow is now the subject of an investigation by the General Medical Council.

Citation/Abstract

2 Epidemiological investigation of Sudden Infant Death Syndrome infants: recommendations for future studies

Blair, P.; Fleming, P. Child: Care, Health and Development 28 (Sep 2002): 49-54.

...the time of death is undermining ...research. To investigate SIDS now means investigating the wider umbrella ...Unexpected Deaths in Infancy

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 McClatchy, Irene Searles; Vonk, M Elizabeth; Palardy, Gregory. *Omega - Journal of Death and Dying* 59.4 (2009): 305-323.
 ...examine the prevalence of **childhood** traumatic grief (CTG)
 ...in parentally bereaved **children** and compare scores between
 ...had lost a parent to a **sudden/violent death** and those who had lost
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16 **The Silent Birth: A Feminist Perspective** Preview
 Cacclatore, Joanne. *Social Work* 54.1 (Jan 2009): 91-95.
 ...frequently than **Sudden Infant Death Syndrome**. Intrauterine **deaths** often happen
 ...who give birth to a stillborn **child** suffer from prolonged depression while
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17 **How does cot death prevention advice influence parents' behaviour** Preview
 Miller, L H; Fraser, A; Moy, R. *Child: Care, Health and Development* 34.5 (Sep 2008): 613-618.
 ...understanding of the recommended cot **death** prevention strategies, and to discuss
 ...and opinions of parents about cot **death** prevention measures. Twelve participants
 ...Parents found that much of the cot **death** prevention advice they were provided
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 Anuntaseree, W; Mo-suwan, L; Vasinanont, P; Kuasirikul, S; Ma-a-lee, A; et al. *Child: Care, Health and Development* 34.4 (Jul 2008): 482-490.

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 Issler, Roberto Mario Silveira; Marostica, Paulo Jose Cauduro; Giugliani, Elsa Regina Justo. *Birth: Issues in Perinatal Care* 36.2 (Jun 2009): 115-121.
 ...**sudden infant death syndrome (SIDS)**, and none has addressed the mother's
 References (39)
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12 **Association of trauma exposure with psychiatric morbidity in military veterans who have served since September 11, 2001** Preview
 Dedert, Eric A; Green, Kimberly T; Calhoun, Patrick S; Yoash-Gantz, Ruth; Taber, Katherine H; et al. *Journal of Psychiatric Research* 43.9 (Jun 2009): 830-836.
 ...covariates and combat exposure, **childhood** physical assault and
 ...physical assault. Medical/**unexpected death** trauma and adult physical assault
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13 **Violent Death: A Qualitative Study of Israeli and Palestinian Families** Preview
 Abbott, Douglas A. *Journal of Loss & Trauma* 14.2 (Mar 2009): 117-128.
 ...to report on how the **unexpected** and violent **death** of a civilian family member in
 ...Palestinian families on how the **death** was perceived, on coping strategies, an
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14 **Embodied Grief: Bereaved Parents' Narratives of Their Suffering Body** Preview
 Gudmundsdottir, Maria. *Omega - Journal of Death and Dying* 59.3 (2009): 253-269.
 ...seven families who lost a **child** to **sudden, unexpected death**, stories of embodied

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3 **Underascertainment of child abuse fatalities in France: Retrospective analysis of judicial data to assess underreporting of infant homicides in mortality statistics** **Child Abuse & Neglect** 34:7 (Jul 2010): 534-544
 ...1/3 of 'accidental' deaths and 1/4 of deaths from unknown cause in mortality ...physicians' inappropriate death certification and underreporting ...for investigating sudden unexpected death in infancy (SUDI). The protocol
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4 **Experiences of widows with children: A qualitative study about spousal death in Iran**
 Khosravi, Shahla; Salehi, Shayesteh; Ahmadi, Fazlollah; Sharif, Farkhondeh; Zamani, Ahmadsheza. **Nursing & Health Sciences** 12:2 (Jun 2010): 205-211
 ...death. The fourth category consisted of two subcategories: 'the unexpected ...helplessness related to spousal death changed the lifestyles of the
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5 **The Long-Term Effects of Prenatal Nicotine Exposure on Neurologic Development**
 Bland, David; Reed, Jane; Rando, Elizabeth. **Journal of Midwifery & Women's Health** 55:2 (Mar 2010): 143-152.
 ...maternal smoking and sudden infant death syndrome (SIDS); however ...prenatally exposed infants and children. This desensitization ...care for pregnant women, children, and families and for
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position: Configurative domains observed in key references

Brannstrom, Inger. **Journal of Neonatal Nursing** 16:1 (Feb 2010): 7-16.
 ...original articles concerning sudden infant death syndrome. In particular ...positions among newborn children, are in focus within ...nursing practices and in child health research. Further
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7 **Attention-deficit/hyperactivity disorder in the offspring following prenatal maternal bereavement: a nationwide follow-up study in Denmark**
 Li, Jiong; Olsen, Jørn; Vestergaard, Mogens; Obel, Carsten. **European Child & Adolescent Psychiatry** 19:10 (2010): 747-753.
 ...the exposed cohort and other children were in the unexposed cohort ...who were bereaved by unexpected death of a child or a spouse, had a 72% ...Boys born to mothers who lost a child or a spouse during 0-6 months
 Cited by (21) References (38)
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8 **Narrating Time: Minimising the Disruption and Discontinuities of Children's Experience of Death**
 Røls, Ul. **Illness, Crisis & Loss** 18:4 (2010): 323-339.
 ...Childhood parental bereavement is a terrible event which ...in the face of the sudden, impending death of her children's father following a ...past which are still 'live' in her children's lives. In holding their future 'in
 References (50)
[Citation/Abstract](#) [Find it @ US](#)

9 **Credibility gap? Parents' beliefs about reducing the risk of cot death**
 Epstein, Joyce; Jolly, Clare. **Community Practitioner** 82:11 (Nov 2009): 21-24.
 ...credibility of risk factors for sudden infant death and adherence to infant ...conducted with 506 mothers of children aged from six months ...reduce the risk of cot death, such as supine sleeping
 Cited by (2) References (14)

ProQuest Applied Social Sciences Index and Abstracts (ASSIA)

Basic Search | Advanced | Figures & Tables | About

Search: child* AND death AND (sudden OR unexpected)

Peer reviewed
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Did you mean: child* AND deaths AND (sudden OR unexpected)

111 Results * Search within | Find related figures & tables

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1 Impediments to DNA Testing and Cascade Screening for Hypertrophic Cardiomyopathy and Long QT syndrome: A Qualitative Study of Patient Experiences
Smart, Andrew. *Journal of Genetic Counseling* 19.6 (Dec 2010): 630-639.
...that place sufferers at risk of **sudden death**. The paper particularly focuses on ...or their relatives (particularly **children**). There was nevertheless evidence of Cited by (2)
Citation/Abstract Find it US

2 Configurative Domains in Child Health Research: Sudden Infant Death in the Swedish Medical Journal
...*Journal of Child Health* 11.3 (Aug 2010): 226-234

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Basic Search | Advanced | Figures & Tables | About

Search: child* AND death* AND invest* AND parents

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Parents & parenting Parents & parenting AND Grief Parents & parenting AND Death
Parents & parenting AND parent-child relationships Parents & parenting AND Child care Parents & parenting AND Child development

55 Results * Search within | Find related figures & tables

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Select 1-20 Brief view | Detailed view

1 Loneliness among men and women -- a five-year follow-up study
Nicolaisen, Magnhild; Thorsen, Kirsten. *Aging & Mental Health* 18.2 (Feb 17, 2014): 194-206.
...the current study **investigates** statuses and transitions
...analyses were used to **investigate** personal characteristics
...Results: Adverse **childhood** events were associated
Citation/Abstract Find it US

2 Symptoms of Post-Traumatic Stress Disorder in Bereaved Children and Adolescents: Factor Structure and Correlates
Boelen, Paul A; Spuij, Mariken. *Journal of Abnormal Child Psychology* 41.7 (Oct 2013): 1097-1108.
...This study **investigated** the factor structure
...symptoms among **children** and adolescents confronted with the **death** of a loved one
...thirty-two bereaved **children** and adolescents

Sort results by:
Publication date (most recent first) Sort

Narrow results by:
Peer reviewed
Source type
Scholarly Journals (57)
Publication title
Subject

Search History.

History Search Terms(TITLE-ABS-KEY(parent*) AND TITLE-ABS-KEY(death) AND TITLE-ABS-KEY(invest*)) AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND PUBYEAR > 1996 AND PUBYEAR < 2011 AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "SOCI"))

944 document results

History Search Links

History Search Identifier32

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996 document results

History Search Links

History Search Identifier31

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10 document results

History Search Links

History Search Identifier30

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16 document results

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TO(DOCTYPE, "ar")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "PSYC") OR LIMIT-TO(SUBJAREA, "SOCI"))

72 document results

History Search Links

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93 document results

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3 document results

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40 document results

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572 document results

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2,837 document results

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3,886 document results

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4,069 document results

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2 document results

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2 document results

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4 document results

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11 document results

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122 document results

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40 document results

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54 document results

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1,196 document results

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2,198 document results

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42,610 document results

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5 document results

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5 document results

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5 document results

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49 document results

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49 document results

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395 document results

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53 document results

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546 document results

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283 document results

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283 document results

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5,979 document results

Appendix 2

The ‘Telling the Story’ Study.**RESEARCH CONSENT FORM**

This form is for you to confirm that you have understood what is involved in the study and that you have received enough information and explanations. If you feel this has not been the case, do get back to me before signing.

Title of Study: “Telling the Story”: What can be learned from parents’ experience of the safeguarding response, following the sudden, unexpected death of a child.

Name of Researcher: Denise Turner

Your Name:

.....

- ✓ I have read the information sheet
- ✓ I understand the purpose and focus of the study
- ✓ I would like to be involved
- ✓ I give my permission for information in my interview to help prepare future training materials, articles, publications, presentations etc, as long as my identity is kept anonymous.
- ✓ I understand that my taking part in this study is completely voluntary and I have a right to withdraw from the study at any point without giving reason or explanation

Signature of Participant;.....

Date.....

Appendix 3

School of Education and Social Work

University of Sussex

Falmer
Brighton
BN1 9RH

11.5.10

Dear Sir/Madam

I am a Doctoral student at the University of Sussex researching what can be learned from parents' experiences of the safeguarding response, following the sudden, unexpected death of a child.

Whilst there has been a great deal of interest in the area of sudden infant death and also on providing support to bereaved parents, there is almost no work focussing specifically on the potential effects of the safeguarding response on parents.

My research aims to look at this and thus add to the knowledge base, so that both parents and professionals may be assisted in dealing with investigation at what is by its very nature a traumatic time.

I have recently gained University ethical approval to begin the interview process and am now seeking to find parents who may be willing to talk to me. My criteria is that they should have lost a child between 0 -18, suddenly and unexpectedly and that this death would have triggered a Police investigation but with no charges being brought. I am using a technique which does not ask questions, but allows people, as far as possible to 'tell their story.' Much previous research has shown that this can be beneficial for parents.

I am therefore writing to enquire whether you have any publications, forums etc in which I may be able to include some brief details about my research work, in the event that people may be interested in learning more and potentially taking part.

I am enclosing an Information Sheet for potential participants, which I hope will provide you with some information about my study. If you would like to discuss it further then do please contact me on 01273 477780 or by email at D.M.Turner@sussex.ac.uk.

I do hope you may be able to assist in what I believe will be a truly valuable study.

Thank you for your consideration of this matter.

Yours sincerely

Denise Turner

Appendix 4

‘Telling the Story:’ What can be learned from parents’ experience of the professional response, following the sudden, unexpected death of a child.

Information Sheet

The Research Study: What is it and how you might help

This research study is called the ‘Telling the Story’ study. I aim to listen and record the experiences of parents who lost a child, aged 0 -18, suddenly and unexpectedly, who were then interviewed by the Police, but without any charges being brought. There is no time limit on the study, so it does not have to be a recent event, although, of course, it can be.

Sudden, unexpected child death is a life event, which involves parents with the Police and other services in an often unprecedented way. All the professional services involved in a death of this nature have procedures to follow, but there is almost no research on how parents experience these and, so, little is known about what has been particularly helpful or unhelpful and what might improve professional practice. This study aims at starting to fill that knowledge gap and to help improve professional practice by inviting parents to ‘tell the story’ of their child’s death.

How you can take part.

Before deciding to take part in the study you and I would have an initial conversation in order to ensure that you understand what the study is about and what taking part involves. This in no way commits you to taking part and is only for you to find out more. After this conversation, you would only contact me again if you wished to take part in the study. If you decided you wanted to help, we would meet together, in an agreed place that is quiet and confidential. This time, I would ask you to tell me the story of your child’s death, in the way that feels right for you, using your own time scale and whatever information feels relevant. It is very important that it is your story and comes out in your own way, so I will not ask any particular questions but will allow you to speak freely. You will be able to talk for as long, or as little as you wish, up to a period of two hours, ending wherever and whenever feels right for you. When you have finished talking, we will have a short break of around 15 minutes to 30 minutes. It is important that we both spend time apart during this break. Afterwards, I will ask you about some of the things you said before the break, and invite you to talk a bit more about these. Again, you can do this in your own time and words.

Following all this, it is possible that I may want to contact you again to ask about some things I may not have fully understood, but this is usually done by ‘phone and only ever with your permission.

What happens to your story after the interview?

What you tell me will be sound recorded, using a small voice recorder. I will then listen to the recording and put it all into writing. Your sound recording will be destroyed once the research study is completed. You will also be given the chance to check the written interviews and to comment on whether you feel they genuinely reflect what you said.

When the study is written up, anything you tell me will have the names, or other details that may identify you, changed to make it anonymous. However, it is worth saying that it can be impossible to guarantee this completely, as events, as well as names, can identify people. I will take every precaution possible to stop this from happening.

The written up interviews, once the names and other details have been changed, will be seen by my Research Supervisors, at the University of Sussex and also by any relevant Examiners for my Doctorate. All these people are bound by the ethical codes of the School of Education and Social Work, University of Sussex. These bind them to keep any information they see confidential. You would be welcome to have a copy of the ethical codes to look through.

Finally, all written information, made anonymous as described above, will be included in my completed research thesis. This will then be destroyed. It is possible that I may want to use some of the information, again suitably anonymised, for the future in training materials, articles, publications, presentations and so on and I would like to get your permission for this now.

What about changing your mind?

Even if you are interested in the beginning you have no obligation to follow this up. In addition, if you do take part and then change your mind, you can withdraw from the study at any time. I will completely respect and support your decision.

What are the possible risks and benefits of helping me with the study?

Previous research studies into infant death have shown that people taking part often felt very positive about their involvement. They had found it personally helpful to tell their own stories and to know that these may be used to benefit other bereaved parents. They were also

pleased to help professionals working in this area learn more about the issues and help develop better practice.

As outlined above, although all the interviews will be made anonymous, it is still possible that some information relating to you, will be recognisable from the description of the events themselves, so you would have to think carefully about how much this mattered to you, just in case it did happen.

Occasionally, people taking part in research studies have found recalling their experiences distressing or stressful. We will discuss your own support networks, when we meet for the first time, and I will also give you details of organisations providing support and advice just in case this should happen to you.

Although confidentiality is of primary importance, there might be very rare occasions when this has to be broken. This would only be if information came to light that either you or someone in your care was at risk in some way. In a case like this, all the relevant circumstances would be considered with care and action would be taken as appropriate. In the unlikely event of this occurring, I would discuss the matter with my Supervisors or appropriate University personnel, in the first instance.

Where can further information be received?

If you are considering helping with this study, you can get further information by email at D. M.Turner@sussex.ac.uk

‘BNIM’ Panels

Information Sheet

1. The Research Study

This research study is concerned with recording parents experience of the professional response following the sudden, unexpected death of a child. In the U.K such deaths are now thankfully rare but there are legal requirements for all the deaths to be investigated by the Police and local authorities also have statutory responsibilities with respect to such deaths. Consequently parents experiencing this event are brought into contact with professionals in an often unprecedented way. However there is almost no research on how parents experience this and therefore what is done effectively as well as what could be improved. This study aims at starting to fill that knowledge gap by inviting parents to tell the story of their child’s death and thus to help inform professional practice. The background to the study was the sudden, unexpected death of my own son and subsequent investigation six years ago.

2.The Method

To gather their stories from parents I have used a method called BNIM (Biographic Narrative Interpretive Method) . As a ‘narrative’ method BNIM allows people to talk, mostly without interruption. It has proved very effective in interviewing people who have experienced sudden, unexpected child death, who often have rarely told their story in detail. The interviews usually last for around 2/3 hours and consist of two halves with a break in the middle. The first half of the interview begins with asking them to tell me the story of their child’s death, in whatever order they please, mentioning any events that were important to them. After the break I ask them to elaborate on some of the issues raised in the first half. All the interviews are recorded and then transcribed as written documents. It is these transcripts we will be working with in the Panels.

3.The Panels

BNIM as a method recognises that cultural and historical factors affect how people experience an event. This is particularly true of sudden, unexpected child death where the requirements for investigation may impact on the family at the same time as the death. Any interviewer also brings to the interview and subsequent interpretation his or her own prejudices and experiences of the world. In my case as a researcher I am influenced by the fact that my own son died suddenly and unexpectedly and that I share this experience with my interview participants.

To assist with widening the scope of interpretation and guarding against a blinkered approach by the researcher, BNIM uses ‘Panels’ consisting of different people who are willing to assist in looking at the interview material.

What does a Panel involve?

If you are willing to be part of a Panel, you will be asked to meet with me and 2/3 other people, probably at the University. We will go through the transcribed interview in 'chunks' and you and the other Panel members will be asked to give your thoughts and opinions on each 'chunk' and what you think may have happened next.

There are no right or wrong answers and it is certainly not a test. Any views you have will be enormously helpful in helping me as researcher to view the interview material differently, particularly as I share a similar experience to the people I interviewed.

All the 'chunks' and your views, thoughts etc will be recorded on a flip chart and these will be stuck on the wall alongside each other to record the progress of the interview as the Panel goes through it 'chunk' by 'chunk.'

The whole process should not take longer than three hours. If you have enjoyed it, you are welcome to join another Panel, if not you need never do so again!!

We will of course stop for breaks/refreshments etc and the whole process will be very informal.

What do you gain from it?

Sadly there's no financial benefits, but I can provide cakes and drinks ! You will also be contributing to research which may help parents with the experience of sudden and unexpected child death in the future. This study has already attracted positive media attention and promises to attract more.

Are there any drawbacks?

Apart from the obvious loss of time involved, anyone agreeing to be a Panel member should be aware that, due to the subject matter, these interviews are at times powerful, emotional and potentially distressing. It is therefore important to be sure that you feel able to listen to these interviews before you agree to take part.

Thank you for your time in reading this. If you feel you would like to help by being on a Panel, or would like to find out more please contact me at D.M.Turner@sussex.ac.uk.

Denise Turner

March 2011

Appendix 6

Some thoughts on panels....

Imagine you are telling your friend Anna a story about something that happened with your mutual friend Emma.....there would naturally be ways that you told this story that would be different to Emma telling it to Anna....you would emphasise different bits of the story, perhaps put yourself in a better or worse light, choose different things to include/exclude.....

You will also in telling the story, be conscious of your relationship with Anna and also of her relationship with Emma. This too will influence the way you tell the story.....we do this unconsciously many times in a day in social interactions in our daily lives.

As we listen to stories, we also anticipate what is coming, sometimes we even finish off people's sentences! We might say 'Oh that's just typical of so and so' as if there were no other way the story could have worked out....

The BNIM method applies some of this everyday interactional material to analysing and interpreting research interviews. At the interviewing stage the researcher says very little but rather invites the interviewee to 'tell the story of what happened...' choosing their own form, order and content.

As a panel, you will be shown summaries of an interview with some quotations. As you look at each 'segment' you're asked to bear these questions in mind:

- 1. How do you think the interviewee experienced the researcher and her interventions/non interventions?**
- 2. What do you think the speaker was experiencing when at a certain point in the interview they decided to change tack?**
- 3. What decisions may have made them choose this topic or this shift of topic?**
- 4. What emotional and moral choices drove the way they constructed everything in the interview?**

So....as in the way we recount stories to friends...we don't use many of the actual words spoken but rather dwell on the events and we choose to order these for our own effect...not always consciously....

In addition to considering how the interviewee may be experiencing the interview (as reflected in the above questions) we will also look at the notion of 'future blindness'....none of us know what is going to happen in the future, even in the next minute so the 'segments' are presented in a 'future-blind' way and where appropriate you are asked to think about what might have happened next. Any suggestions welcome no matter how outrageous!

Our panel on Thursday 3 Nov is an interview with **Mum C** ; relating events concerning **baby: A** and she also talks about **husband L**.

I will remind you of this on the day and thanks for taking part.

Denise

Appendix 7

‘Laurie’s Story’

George had always been a healthy boy, throughout his life. He had celebrated his second birthday on 5th May 2009. Ten days later on Sunday 15th May, he died. He was 2 years, 11 days old.

He'd been in the park with his Dad, Mike, and his brother Josh that day. On the way home in the car George had dozed off so Mike, had come home, taken off his waterproofs and wellies and just put him to bed for a nap, as he would have any other day. Mike and I just thought he was having a longer nap than usual.

When Mike went to check him, because we were busy doing some jobs in the house, he realised that something was really wrong and that George wasn't breathing, so the utmost panic arrived at that point in time. Mike brought him downstairs and we phoned the emergency services.

His brother Josh woke up as well. He'd also been napping and was quite terrified at the panic that was going on. Mike tried to resuscitate George whilst we were waiting for the emergency services to arrive. Being in quite a rural location that took something like 15 to 20 minutes, but it obviously felt like a very, very long time.

Whilst George had been napping, we'd both been in the room at times and not thought anything was amiss, I put the covers over his legs, but I hadn't actually touched his face or anything like that.

Once the ambulance did arrive, they drove him to hospital and I went with them. All the way to the hospital, which is about 25, 20 minutes in an ambulance from here, they continued with my help to try and resuscitate George. At the hospital we were taken over to the A & E department where there was a flurry of people waiting on him and they tried their utmost to revive him. I think I knew in my heart in the ambulance that there wasn't really much they could do. Knowing what little I know about medical stuff – they couldn't find a vessel and there was no output on the monitors so you sort of know. Then we were then led away into a room and I think the medical team agreed that they would stop trying and there was nothing further that they could do. The paediatrician came into the room and told us that George had died.

A lot of what happened that day is quite hazy. I do remember we were asked about a few things like organ donation which is very close to our hearts but we couldn't donate an organ because they didn't really know why George had died. It was explained to us that when a child dies unexpectedly there is a legal requirement for a post mortem and that's something that is instructed by the Coroner, not something we could give our permission for. We totally understood this.

After a while we were then taken to the relative's room to let us spend some time with George which was very special. At that point the nurse was there and then a Minister came in just for a short while and then we were left with him for a short while ourselves. I think I probably would have stayed longer, but my husband was really keen

to get back for our other son Josh. At that time he was 4 and a half.

As I had left in the ambulance with George, Mike had followed in the car and at the same time my friend Sue had come to the house with her seven year old daughter. They had seen the ambulance and thought there was something wrong with my husband and they had met the paramedic leaving the house with George, so they had also taken charge of Josh at that point.. Whilst Mike and I were away the Police had arrived at our house and at that point in time my friend Sue, her daughter and Josh were still in the house and were just preparing to go up to Sue's house. Sue has worked as an ITU nurse for a number of years and had a lot of experience in dealing with families who lose children, luckily or by fate who knows. Sue was keen to take Josh off to her house and provide him with just warmth and love. She didn't know how much he understood about what had happened but she knew it wasn't her place to tell him anything else other than to provide him with a safe place until we returned. When the Police arrived at the door, they entered and they informed Sue that she, her daughter and my son should not leave the house. I think what happened after that is that Sue had finally persuaded them that that was not the right thing to do in the circumstances. I don't know exactly how that conversation went...

Sue's house is in the same village as ours and she understood that the most important place for Josh to be was around his peers, his friends and comfort and not with them, but Josh obviously remembers the Police man arriving at the house.

Back in the hospital. Mike was insisting that we leave quickly in order to come back up the road and tell Josh what had happened because in his words there was nothing else they could do for George, but it was very important that we handled Josh the way we chose to, the way we thought was right and fair. Mike had phoned and told the two or three families that were at Sue's house and it's a small village so word travelled incredibly fast.

As we got back to our village, we pulled in past the house and up to this point we had had no input from the Police at all. We were aware that the Police Force was going to be involved, but we hadn't been made aware then of the actual Police involvement. When we arrived in the road I said to Mike, well, "there's a Police car parked in our street, I wonder why that's there." Then I realised all the windows were open which seemed really strange. As we drew closer to the house we could see the Policemen standing on our front door step and so we pulled in and went up to the door and the Policeman said "you can't come in, this is a crime scene" and Mike said "well, no this is our house, what do you mean we can't come in?". And the Policeman said "No well until my... I've just been told to come here" He was just following instructions, which I understood but Mike could've quite happily punched him into next week as the way in which the Policeman handled the situation wasn't particularly sensitive.

Later on we were told by the T Police that we were in their area whilst the hospital is in the S Police area, so they had radio-ed across to S and been told that someone from the S Police would meet us at the hospital and explain what we should expect next. It was because there was a mistake and that meeting never took place, that we were left with having just left our dead son at the hospital to come home, to be told our house was a crime scene, immediately thinking "Are we under suspicion of something?" which was hideous. However, I immediately said to Mike "do you know what, in the scheme of things, this really doesn't matter."

As I have said ours is a small village and the ripple effect must have been working as

my friend Kay's mum Josie had obviously just heard what had happened because she came walking down the street and found us there and she took us up to her house. I think Josie had got past the Policeman to get jackets for us, because we were in shock and we had left the house in our slippers and all sorts. Josie told us that we were in no fit state to go and speak to Josh and she tried to give us tea and coffee and stuff, but at the time obviously our main concern was Josh. We wanted to handle it well, to say the right things. So we spent a short time at Josie's house and then it was really important that we go and talk to Josh. Before we did this I wanted to work out first when we could get back into our house because if it wasn't going to be that night then I wanted to be able to set Josh's expectations as well as our own, So Josie took us back then to our own house and at that time the forensic guy was there and he was the one that obviously had to take photographs, take away bedding, check the scene and make decisions about whether there was anything suspicious or not.

I can totally understand why they would have to do that and I respected why they would have to do that, because at the end of the day, the Police have to be in some tragic situations and I suppose they have to suspect bad things until they can prove otherwise, However the way we were dealt with just didn't seem fitting with the situation. When we went back to the house, we spoke with the forensics guy who was obviously a little bit more trained at dealing with situations like this or certainly appeared to be unless it was good luck. He told me they would hope that we would be back that night so that was enough for me to go and talk to Josh,

At that point my parents arrived, my brother arrived, a few neighbours arrived, and then Mike and I went off on our own to speak to Josh. Earlier when Mike had been trying to revive George, Josh had been saying, "Mummy, mummy what's he doing" and I said "Your brother's not breathing, your Dad's trying to make George breathe again" and so the first thing that Josh said to me when I saw him was "Did the doctor's manage to make George breathe?" and I said "No sadly, really sadly they didn't." I told him that George had died, that his heart had stopped and I used all the language associated with adults because it was instinctive and in hindsight it looks like we'd done all the right things because he understands that when someone's heart stops beating and they stop breathing they die.

Of course Josh was distraught. Because of Mike's renal failure, we've had a lot of dealings with hospitals and so he was a very well adjusted, 4 1/2 year old. I've done home dialysis with Mike for years and so Josh is very familiar with hospital equipment and all the rest of it. George's death was like shattering Josh's illusions that doctors are wonderful in one fell swoop, but we had to tell him the truth. I think it was important that we told him it as it was and we didn't allude to the fact that George had 'gone to sleep' which I think in a lot of people's situations, can be quite damaging for children. So we explained what had happened and it was one of the most devastating things I've ever had to do. Then we took Josh back down the road to our house. By that time the Police had gone and it was just my mum and my dad and the friends that had brought my mum and dad over to our house, because they live 50 miles away. The main objective for us was to get Josh settled and get him to bed but at the same time Mike was badly due dialysis as he was about to have it when George died and so my brother took him down to hospital to get emergency dialysis.

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So Mike had to go away and spend 5 hours attached to a dialysis machine with far too

much time to think but the hospital staff treated him with the utmost respect and understood the situation, they were amazing.

Before he left the Police returned because they needed a statement from both Mike and I, so there's Mike needing dialysis and before he could leave the Police were in our house and we had to give statements. I can't remember then exactly what they wanted but it was more or less about any illnesses that George had suffered and everything that had happened that day, I guess it was evidence for the Police pass on to the Coroner and the pathology people, to be able to make whatever judgements they make. I guess decisions on the rightness of the situation or the wrongness of the situation.

. After Mike had gone for dialysis we were told by the Police that because the T Police people hadn't met us in S, I would then have to go back that night to the hospital to formally identify George. So my husband's already gone to the hospital, to a different hospital for dialysis and I have to go and do this. I told the Police that there was no way I was doing that until my other son had settled. George had died about half past 3, or at least that's when the ambulance had arrived and it was around 10 o'clock before Josh settled.

Once he had gone to sleep I got a lift down to S Hospital, where I had to go to the mortuary and formally identify George. My mum and my dad came with me and, bizarrely it was one of the most spiritual experiences I've ever, ever had. It just felt like he was moving to somewhere better and that was weird and contradictory all at the same time because what could be better than being with his mum? I am very glad I did it because it just gave me a sense of hope and belief that he was ok and he felt very much at peace.

The Police who met us at the hospital were lovely and very sensitive. They also very understood and apologised for their colleagues in the other police area. I think one of the policewomen was playing the role of a Family Liaison Officer and the other was doing whatever role he did. I think he was part of the forensics team.

George had to have a post mortem and I do understand this and the logic behind why they have to move children who die, but it made me quite angry the night it happened. George had been taken by A&E from here to S Hospital, he was then in the mortuary at S Royal, but because he was under the care of T Police he had to be moved from S Hospital to Police Headquarters which is around an hour's drive away. All that moving about really upset me on the day. It just seemed ridiculous somehow. And then the next day they had to take him from D down to Y Hospital in G which is the only place that does children's post mortems and the driving about at the time made we think why on earth are they having to that. It seemed so disrespectful and unnecessary. In hindsight I understand that's just the way it had to be, but it didn't seem very logical on the day he died. It just seemed unnecessary stuff.

After all that moving around I think the post mortem was late on the Monday or the Tuesday morning although I can't actually remember for certain. After that they released his body and gave an initial cause of death of unascertained pending further investigation, which is quite common because they were assuming at that time that he died of cot death. At that point it was explained to me that it would take some time to get the full post mortem results but now we had a provisional cause of death and we could now go ahead and plan a funeral. That was another logical step along a crazy week.

It's so hard to remember all that happened that week but I do remember that the Police had been to the house before they let us back in and had examined the scene. I think they were happy that there wasn't anything untoward, but when they came back in the evening, after I had identified George's body, they said to us that they really needed to take away the bedding.

George had shared a bedroom with Josh, so I had mentioned to my mum, when we got back down to the house, before Josh came home, that there was blood on his sheets. I told her that I didn't want Josh freaked out any more than necessary and asked her to just run the sheets through the washing machine. And of course clearly you want to protect your other son from seeing things that he doesn't need to see; you know it's a hard enough situation for him. So the Police ended up taking away the bedding, soaking wet out of the washing machine. For what purpose god knows, but they obviously needed to tick a box on a form that said bedding collected.

And that's kind of the way I rationalised that because it seemed ridiculous, but it was clearly necessary and they maybe should have done it when they were there the first time around. There are so many strands of things that went on and the Police were obviously back and forward the week in between the Sunday the day he died, all the way through the rest of that week. The Police Liaison Officer, Ruth was fantastic. She did keep in touch with me and let me know by phone as soon as the post mortem was complete. She really kept me in the loop as far as what was happening, because there were a lot of things that happened that were very negative as far as the Police were concerned, but Ruth in particular sticks out as someone who was very positive and made the experience a lot less bad.

The evening I had been at the hospital with Ruth identifying George, one of the other Police Officers had popped a Cot Death or Sudden Infant Death leaflet through my door at home but at no point had anyone said to me that this potentially could be a cot death. I remember asking the Police Officer that evening whether in these cases hard as it is to generalise, do parents ever get to know what happened?" Whilst George was in A&E they obviously didn't know what had gone wrong. They tested him for meningitis and all sorts of things that may cause this, blood sugars, all sorts of common things and uncommon things to see what could have been wrong. However at no point did anyone say we suspect cot death, because I assumed at that point in time that only babies die of cot death. So I came home from hospital to find this leaflet and I immediately 'phoned Rosie back and said "what are you suggesting here?" I told her that this was the first time cot death had been mentioned to me and I asked if the assumption was then that this was a cot death. Rosie told me that no answer could be given until all of the tests have been done associated with the post mortem, but it that it was possible and even likely because George had died in his cot while he was sleeping. That left me really confused but it all settled to one side because I didn't contact the Cot Death Trust until after the funeral was past. However, it shocked an awful lot of people because we had just assumed that babies die of cot death and also my husband's brother had died of cot death.

So in my head I was making awful connections about the genetics and all kind of things and whether Josh was at any risk. Anyway, we went ahead and organised George's funeral and we decided that the right thing to do was cremate him. I didn't really think too much about what most families do but in hindsight, it looks like most people bury their children, in order that they have a grave. Obviously since George died I have

spoken to many bereaved parents and there seems an incredible lack of information on how to explain cremation to a 4 year old, which hadn't really occurred to me until we were making the decision. There was no one really to advise us so I sent numerous friends on a mission of child bereavement books and other things. I hadn't really gone online since George had died and so the books and information my friends found provided me a whole of information. I was lucky that Josh couldn't read actually, because I read these books and then I had to say to Josh this is a coffin and that sort of thing because words like coffin are not part of a four year olds vocabulary. So every day I was basically just stressing to Josh what was about to happen next.

The morning after George had died, I got up and took Josh to nursery because I thought it was really important he had his peer group and wasn't around a bunch of sad adults because I thought he is going to see enough sadness. Mike told me that I shouldn't be forcing him to go to nursery, but I wasn't forcing him. I told Mike that I would sit with him for the morning and if he wanted to come home I would let him. One of my friends had already told the nursery what had happened and they had drafted in extra staff to help them cope, not just with the parents and the children, but also the staff, because although George had only just started at that nursery the week before, he was well known to the staff. Its' a very small community and George used to come with me to collect his brother. All of the parents there were very shocked to see me that day, but I stuck with it and I'm really glad because it was the right thing to do. I'm just relieved that I had the strength to do it because it was the right thing for Josh, without a shadow of a doubt

And that's how it was really for the first six months really. I was so driven by helping Josh to deal with the situation that my reaction to the fact that George had died was very much put on hold.

Josh was 4 ½ and about to start school that in August which is quite a critical part in a child's education, so it was really important to me that he and I didn't drift apart and that we maintained a relationship. I wanted him to know how much I loved him and I think also the fact that my husband lost his brother was on my mind. My husband was the oldest of the two boys when his brother died he was much younger than Josh was, but he has grown up feeling second best. I know times were different in the 70's when his brother died and there weren't the resources or the support that there are now, however it was utmost in my mind that Josh should not grow up with any sort of resentments or worries that he couldn't talk to me about things. I became almost obsessed to the point of reading just about every grief book in the library.

And once back online I went on numerous websites just looking for information. One charity was fantastically helpful and although they couldn't help practically because I wasn't in their area they spoke with me for over an hour on two different days by phone, about how to explain cremation to a four year old. It was information that I just couldn't find anywhere else. For example the day before the funeral I took Josh for a drive down to the crematorium and I told him that is was where we would be coming tomorrow and that there would be a lot people who cared for us, and cared for him and cared for George. And I also told him that George would be there because it was important to me that Josh understood what was going on.. I never doubted taking Josh to the funeral because the last memory he had of George was of his Mike trying to resuscitate him, panic in the house, all the people trying to resuscitate him and the ambulance arriving, so it was important. The undertaker was really supportive because I asked his advice on whether I would scare Josh for life and he just told me to follow my

instincts. As it happened instincts was the only thing I was flying by that week because everybody else was pretty much useless.

Then Mike's parents came to stay and I don't have a great relationship with them although neither does he. They stayed with us the week between George dying and the funeral and it was hideous. I do have a great relationship with my parents however although I've realised now that my mum is not the emotional rock I thought she was, but my dad is.

As I was kind of left to deal with most of the funeral arrangements it became very clear to me just how important funerals are. I'd never arranged a funeral before nor seen let alone touched anyone that had died. My grandparents had died when I was still a pretty young child and so I wasn't at any of their funerals and nobody in my close circle had died.

Once George's body had been released by the hospital, the undertaker took him back to the small village not far from here where I grew up. The undertaker was so amazing and the job they do is just worth its weight in gold. One of his colleagues was a guy who was in the year below me at school and it just weird but comforting. We had made the decision that Josh would come and see George if he wanted to and I didn't want him to feel this was thrust upon him, but I did want him to have the choice for when I got questioned in later years, like when he's a teenager.

I would want to be able to say to him with my hand on my heart, "Well you had the choice." So both Mike and I sat down and explained to Josh. At that time we were just basically going day to day, so that anything that happened the next day we were trying to prepare him for. So we told him that tomorrow we were going to visit George and if he wanted to he could come. And I actually think there is nothing that would have stopped Josh from visiting his brother.

When you are a mum there are other mums that you're friendly with who are like mums to your own children and I had two friends like this who I'd asked to come with me to see George. It was a lot to ask because it's a good 50 minute drive from here. I'd also asked my closest friend Judy whether her son Ned who is Josh's best friend, would want to come too. From a very selfish perspective, I was thinking that Josh would have a shared experience with one of his peers and someone else will have the memories that he has in years to come. So Judy asked him and although perhaps other parents would have baulked at that idea, Ned had already seen people that had died. His family's half African, so they had been out there a lot and children do die out there sadly. It was maybe just fate or by coincidence or not, but it certainly felt like the right thing to ask Ned and he was more than happy to do it. Josh looked out a few toys and a few other people had written out a few things they wanted us to put in his coffin. We tried to explain to Josh what he'd see when he got there, so in the car on the way, he then suddenly asked if the head would be there as well. We asked him what he meant and he told us that we were always talking about 'George's body' and so he was wondering if the head would be there as well.

So we told Josh that when people die other people often talk about visiting their body but this means the whole body as in their arms, legs, feet, head the lot. Through Josh's 4 year old eyes I could totally see where he was coming from and then the conversation became even more surreal, when we went into the undertakers. Initially just Mike, Josh and I went in to have family time first and then said Ned and Judy and the others joined us. When we got in there Josh was not at all fazed by seeing George. We explained to him that his body would be cold and that he wouldn't breathe. Josh was very much

aware of the discolouration of his lips. We stood with the undertaker behind us and Josh suddenly said "You know if I die I'm gonna have a bigger coffin than that"... and if you die Dad you'd need a bigger coffin and Mummy you'd need an even bigger coffin too" I could see Josh heading for the undertaker too and he turned round quickly, tears streaming down his face and left because it was just such a weird but surreally grounding thing for a child to say given the seriousness of the situation. Children's grief astounds me and at some point in the future I'm definitely going to follow up on it.

I do believe Josh is a very well -adjusted boy for whatever reasons and you know, part of it I think is parenting but part of it is also just how he is. He wasn't at all fazed and he and his friend Ned were both standing over George's coffin having a good chat. It was weirdly lovely and beautiful all at the same time. Then obviously my friends had been in to see George too. It was a very moving day and then Josh suddenly asked when he could go to the park...and you know that you're back in the zone...!

So Josh and Ned went off to the park with my other two friends and Mike and I had some time ourselves with George. That was on a Thursday and then I went back up to see him myself on the Sunday which was Mother's Day and the funeral was the Monday. March will always be a difficult month.

There is such a lack of information on cremation. There are lots of books that skirt around death or use animals but nowhere tells you how to explain what happens in a cremation. The charity I contacted told me that Josh would ask me questions, in his own time and that I should answer them as honestly as I could and at a level which he could understand. I asked them about explaining cremation without giving Josh a constant fear of fire because children at that age are obsessed by fire engines and fire stations and think they're fantastic.

We are religious, we don't go to Church but we do have a faith and we had explained to Josh already that George had gone to heaven. We talked about all kinds of things in the first few days, but a lot of months went by before Josh actually asked me what had happened to George's body. I had been advised by the charity to use the analogy of a glove to describe the body/spirit thing. It was along the lines of if you were to put your head inside a glove you can move the glove around but if your hands not inside the glove, then the glove can't move and it serves no purpose. So if you were to put your hand inside the glove and put both of them in the fire they would get hurt, but if only the glove was on the fire, then there is no pain and there is no hurt. Josh had it sussed before I even got to the end of the story. The work that charity does is immense and what I learned from them was that it was important to be honest with the children, because if you don't answer the questions that they ask, they'll keep asking the questions until they get the answers.

When we left the crematorium we went straight to a hotel and I had banned black although I wear it a lot. I wanted people to remember George with joy and happiness and the sparkly little thing that he was. It was tragic and sad enough, so I didn't want people feeling morbid all day. I encouraged people to bring their children because Josh needed his peers and the children needed to understand at whatever level. I said to all the parents that every family does it differently and they didn't have to bring their children but if they felt it was the right thing for their family then the children would be welcome and that in time they will help all of us. We had put together a big picture board of pictures because when kids are two there's a lot of people who haven't seen

them for a year and a lot happens at that age. We put the picture board out and left lots of crayons and pens and paper so that kids could draw pictures or whatever they chose to do which was beautiful. Someone's husband had described it to them as if people had looked in they might have thought this was a wedding or a christening, certainly not a funeral. The majority of people who came have described the funeral to me as beautiful and oddly lovely and that was all I could have wanted because it did make me realise just how important funerals were and it's important that it was very George which it absolutely was.

After the funeral we had to think about scattering the ashes and I talked with the same charity about it. I had assumed perhaps naively that we would put all the ashes in one place but they suggested to me that this did not necessarily have to be the case. Initially this felt like too much to organise as Mike and I could not agree on one place. However, the charity suggested letting Josh choose somewhere that's special to him and told me I may be surprised by what he comes up with.

When Josh wanted to talk or ask questions it was normally Mike rather than me and he usually left it until just before bedtime when they were having a last cuddle. I had previously explained to him that at a cremation there's a machine called a furnace and the job of the machine is to make bodies into dust and we had left it at that for a long time. The one evening just before bed, Josh asked his Dad "What happened to George's dust?" We then explained that at some point we would pick special places although Mike and I hadn't actually discussed it as a couple, we'd just kind of loosely talked about it. When Mike and Josh got talking about it that it made it more accessible and more real and so Mike told Josh that we would pick special places and we'll scatter George's ashes in those special places that mean a lot to us. Even before Mike asked if he would like to choose somewhere, Josh said that he knew a really good place. He remembered a boat trip we had taken on a previous summer holiday and how much George had loved it there.

The phrase 'out of the mouths of babes' seems so appropriate to me because children have led me through my grief. Not just Josh but all his little friends. I've seen numerous parents squirming at the voices of their children saying things like "George's dead" and replying, "Yes I know and it's really sad and everything" From the ages of 2 – 10, the little ones are just looking for confirmation that that's actually the case, whilst the slightly older ones are beginning to connect with it a little bit more, but their children's grief can teach adults a heck of a lot of stuff because adults pussy foot around it all shockingly. They think that there's things they can do that will upset you, whereas the acts of omission are probably more upsetting than anything that could actually come out of people's mouths. So the scattering of the ashes was very important and we still have some and we haven't chosen the last place yet. We've picked three places individually and three very different places. From speaking to other people I understand that some people keep their ashes in the cupboard for years which is absolutely fine if that's what's right for them, but it's not for us. We have just been doing things right for our individual family.

I think I've finished now.

