

**‘Research you cannot talk about’: A personal account of researching sudden, unexpected child death.**

**A Very Disturbing Field.**

In her autobiography and account of the deaths of both her husband and her eldest daughter Nicholson (2005) describes the following incident at a dinner party:

This woman across the table from me wants to know if I have a husband, a partner? ‘No’, I mumble, ‘I’m a single parent.’ ‘Poor you, what happened, did he run off?’ ‘No’, I mumble again. ‘He’s just not around.’ The conversation becomes general. The woman is sounding off about men who abandon their children. ‘How old was your daughter when he left you?’ she calls across the table. And something snaps inside me. ‘He died,’ I correct her. ‘He died of leukaemia when my eldest child was three...she died too. Six years later...In the utter silence that descends on the dinner table I regret my words...It’s a wonder I’m ever invited anywhere really (p.1).

I recognise Nicholson’s account clearly from my six years as a part-time doctoral researcher, within a UK University, studying parents’ experiences of sudden, unexpected child death. During this time, like Nicholson, I have often faced the challenges of researching a subject which remains almost unmentionable within both academic and social discourse. My own recent experience at a dinner party illustrated this, when the gregarious woman seated opposite me invited me to tell her about my research. During the preceding six years of study I had learned ways of navigating around a topic which often silenced or discomfited people and consequently I attempted to avoid her question. The woman however persisted, suggesting that

I might at least provide a brief synopsis of my field. I hesitated, trying to think of the best way out of this situation and whilst I did so, the talk around me subsided. I could feel my face colour, yet my brain seemed unable to engage with finding a swift and acceptable form of social escape. Unexpectedly, the woman seated next to me, a successful and prestigious academic herself, came to my aid. “Okay”, she said commandingly, “the field is very disturbing, so it is up to you if you want to hear it.”

The woman opposite me looked slightly disconcerted, as a general discussion of my research into sudden, unexpected child death ensued. After what seemed to me like an eternity, the imminent arrival of dessert was announced and as the conversation shifted I found myself able to breathe freely once more. On occasions such as this, as Nicholson describes, I have always felt myself to be the skeleton at the feast and I was therefore surprised when the woman opposite me, once again leant forward and enquired, in a tone of incredulity: “What is it like to do research you cannot talk about?” Her question pierced straight to the centre of my six years of involvement, with what my neighbour had described as this “very disturbing” field.

In this article I aim to provide some answers to the question of what it is like to conduct “research you cannot talk about,” using examples drawn from my time as a doctoral researcher within the Social Work Department of a UK University. I locate these examples within my personal experience of sudden, unexpected child death and a broader discussion of the sequestration of certain forms of death - related research. I conclude by exploring the potential implications of ‘research you cannot talk about’ for what becomes available as knowledge.

### **Experiencing sudden, unexpected child death**

My Doctoral research (, 2014), accomplished over six long years of part-time work, takes a narrative, psychosocial approach to exploring eight parents' experiences of the professional response to sudden, unexpected child death. The impetus for the work came partly from my former training and practice as a UK social worker, but primarily from personal experience of investigation following the sudden, unexpected death of my son Joe, in 2005.

The eldest by a minute of twin boys, born at 32 weeks during the hottest summer ever recorded at that time, Joe had experienced very serious difficulties at birth. Almost a pound heavier than his brother, but still only weighing 3 pounds and 11 ounces, Joe immediately faced a series of crises which necessitated him staying in intensive care for several weeks. For days after his birth he was attached to so much machinery, it was impossible for me to even see his face and 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. Whilst his brother, despite his tiny form, seemed to strengthen daily, Joe failed to thrive and was diagnosed variously with deafness, necrotising 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 feared.

Gradually, Joe was allowed to spend time outside of his incubator and both boys were eventually discharged from hospital, in September, six weeks after their birth. As the months went by, Joe always the larger of the two boys established himself as a stoic child with a sense of humour and infectious chuckle. By his first birthday he could walk and say quite a few

words and he was the only one of my three children who ever learned to sit up properly as a baby. I viewed Joe as a kind of miracle child who always 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 however Joe remained prone to colds and chest infections. Disturbed by this I made several trips to the doctor where they told me that Joe was simply a 'Happy Wheezer' and not to be concerned.

One Sunday night in March 2005, when both boys were 19 months old, 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 that he was a 'Happy Wheezer,' I was not unduly concerned.

In the morning, my daughter then aged six joined me in bed before I went downstairs to get the boys their milk and she went into their room to say good morning to them. When I walked into the room a few moments later she was sitting in her brother's cot reading to him, whilst Joe was lying face down in his own cot. 'Joe's still asleep Mummy' my daughter said and I took one look at him, knowing immediately that he was dead. 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 to them and wondering what they will do if it does. What I did was to get my surviving children out of the room. I knew Joe was dead and there was nothing I could do for him. My instinct in that second was for the living. 'Yes,' I said, 'Joe's still asleep. Let's not disturb him.' And I settled them downstairs.

In the UK all sudden, unexpected child deaths are subject to a Rapid Response, by police and other professionals, which includes contemporaneous forensic investigation of the death scene

and a series of subsequent meetings. These procedures are part of a number of recommendations arising from the Report, 'Sudden, Unexpected Death in Childhood' (2004) which itself was a response to the successful Court of Appeal hearings of three mothers - Sally Clark, Trupti Patel and Angela Cannings, all of whom were imprisoned for killing their children and subsequently freed, in 2004.

When Joe died, I initially became aware that an investigation was about to take place during an argument with one of the paramedics, who were first to arrive on the scene. As my daughter was not yet aware that Joe had died, and further that she had been sitting in the room with her dead brother, I thought it best 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. However, when I announced my intention to the paramedic, thinking that he would affirm my courage and clear headedness, 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 him 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 my daughter 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 my daughter. My ex-husband stayed at home with my surviving son as a sort of hostage to ensure my return.

When I arrived back at the house, after taking my daughter 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 ghoulish 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) I felt "undermined, disbelieved and threatened" (p.7), 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.

Hindmarch (1993) suggests that "whatever their role, any visitor to the home of a bereaved family is likely to feel apprehensive or even terrified (p.100)." Both at the time and in the years following Joe's death, my experience has reinforced these words. The professionals involved in the initial investigation seemed generally ill equipped to cope with the horror of the situation, the fear of being held culpable and perhaps the sheer randomness of the death, which all seemed to immobilise their basic humanity at this most human of times. In the small town in which I live, this behaviour was also echoed by people who struggled with what to say and would often do the cliched thing of crossing the road to avoid me. Others simply did not mention the awkward social fact that one of my children had completely disappeared, whilst there were also those who did not feel I was grieving as I should. One man, the partner of a friend, questioned me forcibly asking 'I mean haven't you even broken down yet?' 'Several

more people queried whether the death ‘had hit me’ and I lost count of those who told me ‘I would never get over it.’ At playgroup with my son 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 and sobbed uncontrollably in front of us.

Finding myself consequently quite isolated, I sought for similar experiences to my own in books and other publications. Doka (1989) suggests that following bereavement, searching for “books in which people shared their experiences and told what helped” (p.132) is very common and acts as a way for people to build meaning. However, my search, following Joe’s death, drew scant reward as works in the field of sudden, unexpected child death were commonly written for professionals, by other professionals, and did not contain direct parental accounts. Furthermore, work within the field was commonly confined to the literature on child safeguarding, where I became accustomed to keeping literary company with people who had harmed or murdered their children. Other texts took a different stance frequently depicting child death as simply “unacceptable” (Judd, 1989, cited in Bridgeman, 2009, p. 255). The books I sought, those which, as Doka describes “told what helped” eluded me and I could find almost nothing which, “would have helped me to know that someone out there had gone through this experience and survived to see the light again” (Nicholson, 2005, p.8).

My doctoral research ( 2014) was driven in part by these experiences of isolation and social segregation in the aftermath of Joe’s death. In my early sorties into the literature I also encountered the Report, ‘Sudden, Unexpected Death in Childhood’ (2004). This Report, later popularly known as the Kennedy Report, after its Chair, Baroness Helena Kennedy, places great emphasis on avoiding future cases similar to those mentioned earlier and 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. The Report also identifies a need for appropriate training to assist professionals in becoming sensitised to emotions being experienced by parents. 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 thus increases the risk of future miscarriages of justice.

The Report's recommendations, together with my personal and professional experience provided the sparks which fuelled my doctoral research (, 2014). I began the process in September 2007, filled with missionary zeal and the desire to produce an original contribution to knowledge which would bridge the gap created by the Kennedy Report and create a resource for both parents and professionals involved in sudden unexpected child death.

I was determined that the research should engage directly with the emotional complexity of the experience and thereby help to improve practice. However, at this early stage I had no idea how difficult this would become.

### **“Getting personal.”**

Accounting for their collective experience within a writing group, Speedy et al (2010) describe a process of “getting personal, getting political, getting up close and moving back and forth” (p.441). Despite my initial zeal and clarity of purpose, I soon found myself on a similarly circuitous route. As a new researcher, I had entered a world that was unfamiliar, and I was unsure of my part in it. Lerum (2001) suggests that this academic insecurity often leads to the

wearing of “academic armour” (p.467), evidenced by an attempt to exclude all traces of the personal from research. During the early phases of my time as a doctoral student, heavily disguised in this academic armour, I spent long hours debating whether to include my personal experience within the work and initially deciding to exclude it. With hindsight this position looks ludicrous and I now view it as synonymous with that of the “defended researcher” (Hoggett and Clarke, 2009, p.12). In my case this defended position protected me from feeling an imposter in the academic world, where I worried that my personal biography would simply render my research “underrated, dismissed and trivialised” (Vickers, 2002, p.611).

Eventually, I realised that achieving authenticity within my work would necessitate owning my own experience. I therefore made it clear to potential research participants that I had experienced sudden, unexpected child death and the events of Joe’s death came to form much of the first chapter of my final thesis. However, this decision to include personal testimony also created obstacles within the research process and helped to render my work as ‘research you cannot talk about.’

At the beginning of the process however I was extremely naive both about the potential problems inherent in owning personal experience within research and also how difficult it would be to study what the academic described earlier, dubbed this “very disturbing field.” As the years passed and I began to disseminate my research I encountered reactions which helped me to understand why parents’ experiences may be so endemically absent from literature and policy in the field of sudden, unexpected child death. However, this raised further questions about the means by which knowledge becomes accessible and in what forms. Both my position as an insider researcher and the ‘very disturbing field’ I was studying seemed to be categories of “dangerous knowledge” (Cooper and Lousada, 2005, p. 125) - those painful and difficult life experiences which may lead to “research you cannot talk about.”

### **'Dangerous Knowledge'**

Much of what renders research into sudden, unexpected child death as “dangerous knowledge” lies within the history of UK safeguarding and the concomitant culture of audit. As the deaths of children have become gradually less common, the safeguarding agenda has shifted towards one of prevention (Ferguson, 2011) and with this shift, other previously unthinkable forms of dangerous knowledge about the harm that could be visited on children have gradually become accepted by society (Cooper and Lousada, 2005). As a consequence of this, however, naturally occurring child deaths have become increasingly identified with accountability and blame (Stanley and Manthorpe, 2004) leading to their popular depiction as unnatural and rendering them a potentially new form of dangerous knowledge.

However, whilst improved housing, sanitation and medicine, together with superior 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 and RCPCH, 2004, p.3) recent research shows that the UK child death rate is still amongst the worst in Western Europe. The Global Burden of Diseases, Injuries and Risk Factors study (2013) found that children in the UK are more likely to die before they reach their fifth birthday than in almost any other Western European country. The study's senior author, Dr Christopher Murray was quoted as saying:

The higher than expected child death rates in the UK are a reminder to all of us that, even as we are seeing child mortality decline worldwide, countries need to examine what they are doing to make sure more children grow into adult hood (Guardian, 2013).

Commenting on the high child death rates, the shadow U.K Public Health Minister Luciana Berger condemned them as a tragedy not befitting a civilised country, echoing the Kennedy Report's statement:

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).

Such powerful statements linking child death to civilisation itself provide further evidence of the difficulty of researching a subject which strikes so forcibly at the heart of society. In his now classic work on the sequestration of death Giddens (1991) provides additional insight into child deaths as 'dangerous knowledge,' citing the "professionalisation of medicine" which moved death from the public and communal to hospitals where it 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 international 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 willing to wait for hours to sign books and to sleep out overnight in order to glimpse the passing of the coffin (Clark, 1998). Giddens argues that this "mediated experience" further sequesters the reality of death, encouraging people to live outside of their own realities, conducting fantasy intimacies rather than facing the dangerous knowledge inherent in real, lived experience (Giddens, 1991).

Kellehear (2009) similarly argues that within prosperous countries death is managed, in order to try and maintain a locus of control. He argues that shameful deaths are distinguished from

successful deaths, by knowing the right moment to die and locates this within the tiresome cosmopolitan tendency to focus on health, along with wealth, youth and beauty. The sudden unexpected deaths of children, according to Kellehear's argument are truly shameful because they are "a death out of time" (Chalmers, 2007, p.3) - the shame, however, is one that is visited both on those intimately connected to the death and on society itself which becomes termed uncivilised.

My decision, following Joe's death, to research other parents' experiences of professional intervention in the aftermath of child death led me unwittingly into this uncivilised terrain, but it was experiences of data analysis and dissemination, rather than fieldwork itself which helped me to understand the dangerous nature of the knowledge I was beginning to construct.

### **Carrying a 'Warning'**

My journey towards understanding that mine may be "research you cannot talk about" began even in the early days after Joe's death, when people so frequently crossed the road to avoid me, or were rendered speechless by my presence. During the fieldwork stage of the research, in the early process of data analysis and during dissemination I also encountered numerous examples of behaviour which demonstrated the difficulty of engaging people openly with sudden, unexpected child death. I offer some of these examples below, in order to help demonstrate this.

During the planning stages of my research work, I attended a local conference for practitioners involved in sudden, unexpected child death. The Coroner responsible for my district was one of the Speakers and gave a flawless account of the support given to parents who have lost a child in this way. When a child dies, their body becomes the property of the Coroner and after Joe's death he was taken to London for a post mortem on the Coroner's instructions. However, after this procedure had been carried out, and a cause of death established, the Coroner refused to release his body for a

funeral, telling us that we would have to pay £100 charge to bring Joe's body back from London. We initially disputed this as the Coroner had taken over legal jurisdiction 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.

During the time made available for questions at the above conference, I asked the Coroner responsible for my district whether she knew of such charges being levied on parents. She seemed appalled to be asked and told me in no uncertain terms that this never happened. 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 all had waited until the coffee break when they told me privately. I was very perplexed by what seemed to me to be to the keeping of secrets and I was concerned as to the possible effects of this.

The initial data analysis phase of my research, following fieldwork, also produced some unexpected reactions, which furthered my own understanding of the complexity of this work.

During the first few years of research design and methodology, I was following the Biographic Narrative Interpretive Method (Wengraf, 2011) which advocates for the use of data analysis panels to "kick start" the interpretive procedure and challenge "researcher autism" (Wengraf, 2011, p. 104). The BNIM Guide advises that members recruited for panels should ideally be non-specialists who are capable of bringing diverse viewpoints to the process. The panels are presented with "chunks" of the transcript, which help to form a "special sort of contents page" or "working document." (Wengraf, 2011, p.104).

In recruiting for my own panels I was initially advised by the BNIM Guide (Wengraf, 2011, p.104) which suggests that the process is “for all concerned-as a personal and professional learning experience both insightful and often funny.” However, whilst the panels I convened certainly provided rich learning, they were not “funny”, but often rather traumatic at times.

An example of this comes from the first panel I organised, where one member in particular became extremely angry with the interview participant, ‘Cathy’, a woman whom I had viewed with great compassion, believing that others would feel the same. Cathy’s baby son, Dylan had died at eight weeks and her story, whilst demonstrating her anger with some of the professional intervention, was often deeply touching and unsettling, as the following extract demonstrates:

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.

The panel however, viewed Cathy’s story simply as “aggressive”, concurring that she was not “behaving as a bereaved mother should” and questioning whether her obvious anger indicated that she had actually killed her son. Perhaps most significantly they concurred that hers was “not the story they expected to hear” suggesting that there is a more acceptable narrative for

mother's to follow – one that perhaps can be talked about. Following this panel one of the members reported to me that she felt “chronically polluted with herself” for “picking over” Cathy's words.

My experience of the panels demonstrated to me that this was a subject likely to cause heightened and often unpredictable reactions. Similarly, my early attempts at disseminating the work to various audiences helped me to understand further the potential untellability (2014.) of my research material. A particularly influential example of this arose in the penultimate year of my research, when I was asked to give a presentation on my personal experience of Joe's death, 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 did not therefore anticipate any particular complications with my presentation. However, during the course of this one of the students rose and swiftly left the room in tears. When I enquired later, I was told that Joe's death had stirred difficult emotions for her. The general feedback following the session was that those present 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’ or 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. 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) dubs the “smell of the real.” Echoing C.S. Lewis, I wondered whether it would be better for me to be “isolated in a special settlement” (Lewis cited in Ellis, 1993) rather than allowed to undertake research in such an obviously upsetting area. However as time passed, I found myself becoming irritated by their reaction and thus increasingly defended (Hoggett, 2000) against the anxiety the reaction had provoked.

I later experienced a similar form of defensiveness to my own, amongst professionals at a different presentation I gave 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 a suitable warning as to the contents. 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 former professional myself, 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, particularly the parental accounts, which she said could simply not have happened.

These experiences and others which occurred during the course of my research began to make me question how new knowledge may be advanced, where that knowledge is so obviously deeply troubling to so many people. Cooper (2009) suggests that new knowledge can only be created in so far as people are "emotionally and ideologically open to the possibility of discovering something new (p.431)." However this can become a vicious circle for those researching such new forms of knowledge, as where audiences remain both 'emotionally and ideologically' closed, rather than open, the researcher may encounter hostility which like the messengers of old, puts them, metaphorically at least, at risk of being shot. It may take considerable persistence and reflexivity on the part of researchers to bring that "possibility of discovering something new" into existence. However, despite this, my own experience of researching a subject that "you cannot talk about" has demonstrated a number of potential ways forward.

### **Research you can talk about**

Despite the various difficulties I have encountered in researching an area that remains problematic for many people, there are numerous lessons for transforming “research you cannot talk about” into research that can be freely discussed, as well as contributing towards original knowledge.

I believe that one of the keys to this lies in recognising the potential consequences of splitting the academic from the personal (Bochner, 1997). My own bearing of heavy academic armour in the initial stages of my research helped to protect me from the dismissiveness I had feared (Vickers, 2002) but also prevented any knowledge or learning to be gained from my personal experience. Building on this, Bochner (1997, p.421) argues that:

Academic life is impersonal, not intimate. It provides a web of distractions.

The web protects us against the invasion of helplessness, anxiety and isolation we would feel if we faced the human condition honestly. Stability, order, control -these are the words that social science speaks. Ambiguity, chance, accidents-these are the terms that life echoes. Suppose we achieved the stability, order and control we seek, what then? No variance-no differences-no chance-no fun-no adventure-no vulnerability-no deniability-no flirtation-no love.

Death is perhaps one of the greatest challenges to control that life presents us with – particularly when that death is one in childhood, which was not previously anticipated and for which there was no warning. It seems to go against the natural order of things. Facing this honestly as Bochner suggests, as a part of the human condition calls for great courage, but the more researchers are enabled to work in these ways, the greater the opportunities to heal the

split between the academic and the personal and to contribute to research which can be talked about freely and openly as part of creating new knowledge and thereby reducing anxiety.

Writing about his father's death, Bochner (1997) described having taught "loss" for years within his own institution, but only with his own loss, realising that "the research literature offered me data, labels, categories, and theoretical explanations, but it didn't express how loss felt and it didn't invite engagement with the particularities of the experience" (p.424).

Choosing to include the experience of Joe's death within my research work (, 2014) has meant inviting readers to share closely in the particularities of my experience and it has also meant confronting my own pain, which at times has been tortuous. However, as bell hooks (cited in Hoggett, 2000) so powerfully describes, this may be a necessary process in creating new knowledge from traumatic experience:

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 ( p.122).

As hooks suggests, being courageous enough to represent both our own pain and those of others within social science research changes the discourse into something capable of change and growth. It also represents a challenge to "the myth of vulnerability" (Cottle, 2002, p. 536) which decrees that "people of certain groups or those having had certain experiences are so 'damaged' that they cannot speak for themselves." My own experience of Joe's death and those of the eight parents whose narratives form the heart of my research work (, 2014), challenge this myth of vulnerability by offering both strong individual and collective voices,

which demand to be heard. In these stories, the deaths are not “dangerous knowledge” but lived experience which demonstrate the triumph of meaning making over tragedy, and a humbling acceptance of death as part of life. Terri, whose son died suddenly during the night, aged six, from a previously undiagnosed condition, illustrates this powerfully (, 2014, p.158) in her story of a fox killing the family’s pet rabbit, shortly after the death:

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 okay, 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.

At a time when the UK child death rate is causing such significant concern (Global Burden of Diseases, Injuries and Risk Factors, 2013) it is vital that academic research is able to facilitate greater discussion and understanding, thereby improving both practice and outcomes. For this to occur, there has to be a shift away from the impersonal culture of fear and control described by Bochner (1997) towards one which can accept naturally occurring child deaths as a part of life, as Terri illustrates, and also as a significant priority for research. Whilst the deaths of children are certainly no longer commonplace, the poor mortality rate amongst under-fives in the UK (Global Burden of Diseases, Injuries and Risk Factors, 2013) demonstrates a need for death education, information and for prioritising child death not only as research you can talk about but as research which must be talked about.

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