

‘Not behaving as a grieving mother should’: Exploring the ethical pitfalls of identity construction within an insider study of sudden, unexpected child death.

‘But I thought you were the mother?’

In March 2005, my son Joe, the eldest of twin boys, died suddenly and unexpectedly during the night. This was not, as many have later come to term it, a ‘cot death,’ but rather the result of some chronic and undiagnosed problems which stemmed from his premature birth nearly nineteen months earlier, when he had suffered from a collapsed lung and was variously suspected of brain damage, hearing loss and digestive disasters. Despite these tentative diagnoses and the exigencies of both his birth and early weeks in the world, Joe remained apparently unaffected by any long term difficulties. Just six weeks after his untimely entry into the world, both he and his twin brother Dan were allowed home to join their four year old sister, Amy, who had recently started school.

Joe grew into an affable and bright toddler who by the time of his death could build impressive brick towers, answer the telephone and who added new words to his developing vocabulary on a daily basis. He and his brother Dan liked to explore the world and how it worked, memorably by covering the kitchen floor with dried food and pushing whole potatoes down the toilet. A week before he died so suddenly I remember watching Joe padding about the kitchen in his socks and commenting to my daughter then aged six, how miraculous it was to think that he had once so nearly died. With hindsight as I gaze back over the years, I wonder if this was some form of premonition, or simply that despite Joe’s apparent good health I had never lost the fear which had accompanied his birth. In the intervening nineteen months despite his robust stature he had suffered from a constant stream of colds and chest infections and I had consequently become a regular visitor to the GP who pronounced Joe a ‘Happy Wheezer.’

There was nothing ‘Happy’ however about the scene which met my eyes that March morning. Amy had shouted to me that she was going into the boys’ room to say good morning whilst I went downstairs to prepare milk. When I entered minutes later it was immediately obvious that the still, ashen form lying in Joe’s cot was cold and lifeless and more obvious still that Amy had not yet realized this, as she glanced up from reading to Dan and announced that Joe was still asleep. My mind in that harrowing moment did the reverse of what I may have expected, becoming almost diamond sharp with clarity. I knew that Joe was dead and I knew too that I had to negotiate Dan and Amy out of the room without alarming or frightening them. Although I have little memory of how, I do remember settling them both happily in front of the television only moments later, whilst an ambulance was called and a ‘Rapid Response’ investigation was thereby initiated.

In the UK all sudden, unexpected child deaths are subject to this form of Rapid Response investigation, by police and other professionals and this includes contemporaneous forensic investigation of the death scene, together with 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 on Appeal.

Having previously trained and worked as a Social Worker, I had an in- depth knowledge of the harm that people could visit on their children and of the corresponding need for rigorous

procedures to ameliorate this. However, on the morning of Joe's death, still in shock and terrified about the effects of his death on my surviving children the awful realisation that we may be under suspicion for harming him came into slow but dreadful focus only as I decided to take my daughter away from the scene. At this point, still only 8 o'clock in the morning, Amy did not realise that she had been sitting in the room with her dead brother, but thought instead that Joe was ill and the ambulance crew were present to help him. As the realisation gradually dawned that we may be under suspicion for harming Joe, my instincts to protect Amy from witnessing this, strengthened and I resolved to take her to school, where she would be away from all that was to take place in her home. She did not realise Joe was dead and I judged I could tell her later, once the forensic and other investigations were over. However, the paramedic refused to let me leave with Amy and we became locked in an argument which I eventually ended by throwing a coat over my pyjamas and taking her to school. When I returned, a marked police car was parked outside my house and a uniformed officer filled the space of the narrow hall way. In my front room, a sea of faces bobbed and blurred in front of me as my home became a 'crime scene' (Fox, 2007:146) filled with investigating officers and other professionals.

The police dub the immediate aftermath of a child death, 'the golden hour' and during this time the child's 'body itself is always designated as a [crime] scene', whilst their room or place of death is subject to forensic examination and guarded by police or 'locked and sealed until a proper investigation can be carried out with crime-scene investigators' (Fox, 2007, p. 148). When Joe died his room was cordoned off, photographed and the bins searched for his last nappy and any other 'evidence' whilst his bedding and clothing were stripped and taken away for investigation. Joe's father and I were interviewed separately by Police officers, leaving me like Davies (2010:7) feeling 'undermined, disbelieved and threatened', driven by random tragedy into a surreal drama of forensic investigation - a suspect in my own home, only minutes after finding my son dead in his cot.

As that morning wore on, a female Police officer took me aside and told me that there may well be social workers on the way. Remembering my belligerent display earlier when I had argued with the paramedic about taking Amy to school, I tried to counter this by telling her that I was a social worker myself. She seemed confused and then rapidly looking me up and down as I stood opposite her in my pyjamas, she stuttered; 'really, but I thought you were the mother?' Despite the trauma of the morning, there was something almost tragi-comic in the police officer's overt struggle to reconcile this devastating and unpredicted child death with someone who themselves was a social worker. It was as if the two identities were simply incompatible - that child deaths only happened to nameless, profession-less 'others.' This was one of my first encounters with the identity positioning and re-positioning that can occur when a child dies. Speedy (2008:148) suggests that one of the primary duties of the bereaved is to 'shape up to normalizing judgments about bereavement processes' and as the years passed after Joe's death I began to understand how deeply these 'normalizing judgments' are linked to the behavior and identities of those who continue living after their child has died.

'You'll never get over it': Constructing the bereaved mother

Dent and Stewart (2004: 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. In the immediate aftermath of Joe's death and in the weeks which followed, I was fiercely determined that this was not going to be the case for my two surviving children. Despite feeling the pain of Joe's death acutely, I was still their mother and determined not to let the

damage already wrought, have an ongoing corrosive effect on my children's lives. The difficulty I experienced, however, was in finding useful advice on how to achieve this goal. Hindmarch (1993:100) suggests that 'whatever their role, any visitor to the home of a bereaved family is likely to feel apprehensive' or even 'terrified' and this was my experience following Joe's death when most of the professionals around us seemed less able to cope with the death than we could ourselves. My Health Visitor initially sobbed down the 'phone, whilst others like the Coroner and the Registrar relied on brusque use of procedure, or on simply saying nothing at all. I was offered several referrals to counselling, but almost no practical help with how to register the death or arrange a funeral – the tasks which felt almost overwhelming at the time.

On a social level, I was perhaps fortuitously forced out into the world by the demands of my children but here too, I found that many people were afraid of me, crossing the road to avoid me, or simply ignoring the apparent disappearance of one of my three children. People queried variously whether I had 'broken down yet?' Or whether the death had 'had hit me' and almost everyone chorused that "I would never get over it." I began to feel, in response, an almost driving need to 'get over it' whatever that meant, as I did not wish to be condemned to this no-man's land of sorrow in perpetuity.

In the absence of immediately effective support networks following Joe's death, 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. What I failed to find, was accounts like my own, of parents who had experienced a sudden, unexpected child death and who sought ways to live a positive ongoing life, both for any surviving children but also for themselves and the child that had died. I had no doubt in my mind that Joe, such a cheerful and stoic little boy himself, would want us to remember him with warmth and by making the most of the lives that he so sadly could no longer share with us. Eventually this dearth of parental narrative led me to begin a part time PhD research focusing on parents' experience of the professional response to sudden, unexpected child death (Turner, 2014).

'The myth of vulnerability'.

When I began my PhD research in September 2007, I hoped initially to create a resource for parents like me who, following sudden, unexpected child death sought for 'books in which people shared their experiences and told what helped' (Doka, 1989:132). Additionally I aimed to provide an alternative narrative to the prevailing 'you will never get over it' which in the initial weeks after Joe's death had terrified me, condemning me to what felt like a lifetime of acute emotional pain. However, although Joe's death had introduced me to the potential trials which the aftermath of sudden, unexpected child death might produce, with hindsight I can see that I was naïve at this time, lacking awareness of the difficulties I would face in carrying out the research, particularly those connected with the challenging nature of the subject. One of my first encounters with this arose as part of the process of seeking ethical approval. Having decided not to recruit participants through the NHS or other statutory bodies, I made an initial application to my University ethical review board. In completing this

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initial application I had already been made aware by literature in the field that the subject was often treated as ethically sensitive. Raphael, for example, suggests that:

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

This is a perspective supported by Dyregrov in a 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' (2004:5). I was mindful of this, but at this point and inexperienced in the process of ethical review I completed the application forms believing that it was mostly a procedural matter. However, I was soon confounded when this original submission for ethical clearance, was rejected on the grounds that the Committee had not been satisfied of the ethical case made. Whilst some of their comments reflected my status as a 'novice researcher' (Gray, 2004:16), there were others that introduced me to particular challenges which would become recurrent themes in the ongoing research process. Key amongst these was the Committee's repeated descriptions of the research as 'ethically sensitive' and the participants as 'vulnerable.'

These descriptions were simultaneously troubling and enlightening to me, as prior to this process I had not been fully aware of how 'ethically sensitive' the subject of my research could be for people. As an 'insider researcher' who had experienced sudden, unexpected child death, I was already conscious of the potential conflicts of having multiple identities, not least because of the police woman's comment on the morning of Joe's death. However, despite my own distress, my experience of pervasive 'vulnerability' had mostly been encountered in others, many of them professionals. As I described earlier, numerous people had found it difficult to deal with the aftermath of Joe's death, yet in the comments of the Ethics Committee it was the parents in my research, who were exclusively constructed as 'vulnerable.' I was troubled by this, as this unchallenged description of parents seemed to construct both the research and the participants in a particular way before I had even embarked on fieldwork. Additionally the construction of parents as 'vulnerable' and in need of protection also failed to address the potential damage wrought by investigation which all parents, like me, had endured following their child's death. The language of 'golden hour' and 'crime scene' made no allowance for vulnerability and yet in this alternative context parents were suddenly constructed exclusively as 'vulnerable.'

Cottle (2002:536) explores what he dubs as the 'myth of vulnerability', 'whereby people of certain groups or those having had certain experiences are so 'damaged' they cannot speak for themselves.' This very 'myth' seemed to resonate in the ethical review boards repeated use of the term 'vulnerable' in describing bereaved parents who needed protection in case they were traumatised by narrating their lived experience. Whilst I certainly endorsed that such parents could be vulnerable, my experience told me that this was by no means universally the case and rather that professionals could be equally if not more so when encountering child death.

Dyregrov's study (2004:8) endorses this suggesting that whilst research into vulnerable populations may habitually be considered 'unethical because it may rip open old wounds', a growing body of evidence has shown that 'instead of causing distress, research may be educational, enriching, therapeutic or empowering'. In the aftermath of the ethical review process then, I was left wondering 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*' (2010:50). 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 (2010:50). The potential consequences of this undisclosed vulnerability for what is researched then may result 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.

This chimed acutely with my experience following Joe's death when people crossed the road to avoid me, or simply pretended that one of my children had disappeared. Whilst I would not deny my own vulnerability at this time, it was those around me who exhibited a vulnerability which literally left them speechless or unable to acknowledge me at all.

Following my initial application for ethical approval and its rejection, I eventually made the necessary amendments and my second application, allowed me to commence fieldwork. In accordance with my ethical approval, I advertised for participants on the websites of relevant charities and asked interested people to contact me directly via email. When they did, I sent them an 'Information for Participants' sheet, also in accordance with my ethical approval. Many people did not contact me again after receiving this, 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, but Van Den Hoonaard (2002:185) 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.' This was later borne out in my fieldwork where some more specific aspects of the ethical agreement did cause problems, particularly where participants did not wish to be anonymised as they specifically wanted their story to be heard and to make a difference. As Van den Hoonaard suggests, the consent forms, which had formed part of my ethics agreement also felt 'obtrusive within the field threatening to introduce an atmosphere of formality and mistrust' (Van den Hoonaard, 2002:10). Although this was quickly dispelled during the interview, I was left reflecting on the ethics of trying to decide so much in advance on behalf of those who generously agree to participate in research.

Perhaps most strikingly, the interviews left me with an enduring sense of the strength of the people I had interviewed. Certainly they were not without vulnerability, but they were all determined that their story should make a difference and certainly not, as the original ethics procedure suggested, too fragile to be interviewed. Rather they all presented as hopeful that the memory of their child could contribute in some ways to an ongoing process of improving practice in this area. Naturally they were not representative of all parents who experience the death of a child but neither did they represent the universal group of the 'vulnerable bereaved' which my original ethics application had identified – those who as Cottle describe are too damaged to speak for themselves (2002).

'Picking over people's words': Sudden, unexpected methodological vulnerabilities

The ethical approval process together with what I now identified as normative expectations of behaviour after the death of a child was lent another layer of complexity during the process of data analysis. In the initial phase of my research I had relied on the Biographic Narrative Interpretive Method (see Wengraf, 2011) which offers a very structured set of approaches to both interview and data analysis. Following transcription of the eight interviews the first stage of the analysis was accomplished via 'Kick start' panels, each consisting of three

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members and following BNIM guidance. Panel members were drawn from friends, colleagues and others, recruited through professional contacts and tasked both with initiating analytical scrutiny and challenging 'researcher autism' (Wengraf, 2011, p. 104). BNIM recommends that panel members should be 'non-specialists' capable of bringing diverse viewpoints to the process, which involves examining 'chunks' of the transcript (Wengraf, 2010).

I had initially provided panel participants with an 'Information Sheet' explaining that these transcript 'chunks' were at times highly emotive and challenging. However, despite this prior warning, for three of the panels in particular, these concerns led to acute emotional responses with members describing feelings of being chronically 'polluted' by the process of 'picking over' people's words, together with a general sense of unease.

One particular interview transcript with 'Andy' which focussed on the death of his young son 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', the panel member reported feeling the need to try and find some good in this, something, in her words, to hang onto. Similarly, the panels for two other interviews provoked emotional reactions ranging from distress to anger.

In retrospect, I find it hard to believe that neither I, nor the ethics committee, which concentrated solely on parent participants had considered the vulnerability of panel members. This unpredictability was mirrored in another part of the panel process, when panel members constructed research participants in ways which conflicted with my own assessments and which seemed to highlight the normative expectations of maternal bereavement that I had encountered after Joe's death.

The most powerful example of this took place in the very first panel I convened, to discuss the transcript chunks of a woman I had named 'Cathy.' Cathy's interview transcript concerned the death of her young son Dylan at just a few weeks old and during our meeting, whilst her anger was clear, it acted as her driver to improve parental experiences of sudden, unexpected child death. I felt I understood her anger and equally perceived Cathy as open, friendly and undefended in the telling of her story.

During the panel's discussion however a very different picture of Cathy began to emerge. I could see that the panel members and one in particular were enacting 'feelings of shock surprise and confusion' (Froggett & Hollway, 2011:2) as Cathy's feisty, painful and often relentless narrative did not convey her as 'vulnerable' but rather passionate and often angry. As their obvious unease with her story mounted, collectively the panel members suggested Cathy was both 'belligerent' and 'lacking in emotion', with one of the panel members declaring that she 'was not behaving as a grieving mother should.' Similar assertions were made in other panels where members were often uncomfortable with the unexpected content of the parents' stories.

In other work (Turner 2014) I have explored these panel reactions in the context of Klein's work on 'splitting'. In Cathy's panel, the assertion that this was not the 'story they expected to hear' and their associated descriptions of Cathy help to split off the powerful emotions evoked by the story into Cathy herself, who becomes a bad object, saving them from the distressing repercussions of the story she tells. As a consequence of this Cathy's own identity shifts again from suspect, through vulnerable to become a threat – someone who is capable of

challenging normative expectations of a grieving mother by appearing 'belligerent' in what is an unexpectedly counter narrative.

The experience of the panels, whilst initially unpredicted by myself or the ethics committee, unearthed new ethical challenges which lend weight to Kellner's view that 'codes of ethics, or any codes, do little to inform us about taking... human aspects into account' (2002:31) and suggests that for processes to be truly ethical they should consider the emotional consequences for all those involved, not just those whom they construct as 'subjects.' This became accentuated acutely during the dissemination phase of my research when I found myself placed as the 'subject' within an impromptu, online version of the panel process, following a newspaper article.

'This tragic club.'

In the summer of 2014, nine years after Joe's death and after the completion of my original research work, I was offered the opportunity to be interviewed for The Guardian newspaper in the U.K as publicity linked to a Conference presentation. I was slightly anxious about appearing in a popular newspaper but the professional necessity to make 'impact' from research work encouraged me and after reflection and discussion I decided I should take the opportunity offered. I was duly interviewed by the journalist, who skillfully chatted with me about my personal experience and the ways in which I had come to make meaning from this in the intervening nine years. The ensuing article was published later in the week, as the front page of the Family section with a rather alarmingly large portrait of me, an inaccurate surname and the headline 'Can a parent get over the death of a child?' (Moorhead, 2014). It was both overwhelming and exciting to be storied in print and although neither the article nor the headline were what I would have produced, it was a salutary lesson to me as a researcher who so often storied people myself.

What I did not predict was the emotional furor that would be caused by the article and in particular the headline. Only minutes after the article appeared online the first comment was 'removed by moderators' because of its abusive content. This moderator removal became a common occurrence as the Comments section grew from one to hundreds over the next few days. What most seemed to exercise people was the idea that I either did not care about Joe or that I thought myself above what one commentator described as 'this tragic club' to which they themselves belonged. These views were often accompanied by indignation that I thought I had 'got it right' and others had 'got it wrong' as this example illustrates:

I do not feel anybody, whatever their loss has the right to assign themselves as a spokesperson for grief, loss and bereavement (Comments, Guardian Family, 2014)

I thought such comments particularly ironic as during my years of research work and even when agreeing to the Guardian interview, I had been attempting to do precisely the opposite and rather to oppose fixed assumptions of how bereaved people should behave.

In the wake of the Guardian article I was also contacted directly by numerous parents, all bereaved by the death of a child who were universally supportive of what the article had attempted to convey. These were parents with their own stories to tell, and many of them had done so, writing books, poems and other accounts of their experiences.

The article also provoked correspondence from various educators and professionals working in the field. One academic writing to me, explained how distressed the article had made people with whom she was in professional contact and she apportioned much of the blame for this to the headline which implicitly suggested that it may be possible to 'get over' the death of a child. Within her email she stated that 'It's a difficult topic with a fragile group,' thus dislocating me from this group as if I had not experienced sudden, unexpected child death myself. This mirrored the police woman on the morning of Joe's death who had also been unable to believe that I could be both a social worker and the mother of a child who had died. In referring to 'this fragile group' the corresponding academic also seemed to re-assert Cottle's 'myth of vulnerability' as a universal norm, whilst separating me from this group despite the article's emphasis on the death of my own son. By appearing in this article it seemed that, like Cathy, discussed earlier I was 'not behaving as a grieving mother should' and thus membership of the 'tragic club' was denied me.

In a similar account of her research becoming ensnared within a media noose, Sikes (2008) suggests that one of the chief purposes of qualitative research within the social sciences is to introduce private concerns into the public domain in order to provoke debate and bring about positive change. However, as both her experience and my own demonstrate, this change in attitude may be produced at considerable personal cost to the researcher. Whilst I agree wholeheartedly with Sikes that 'moral research practice involves showing one's own positionality' (2008, p.250) the perfect storm evoked by the Guardian article highlights the limitations of institutional ethical review procedures which apply universal protocols to research projects, rather than considering the individual complexities of each. In my own case, the original ethics application considered the participants as universally vulnerable, thus determining one of the key findings before the research had even got into the field. The vulnerability of those others who would come into contact with the research material was not considered and, as I have discussed, this became problematic at the data analysis stage. Similarly, to be truly ethical, the review process would have been iterative, thus allowing me to return to the review board during different phases of the research. This would have been advantageous in increasing the learning of the review board and their concomitant capacity to give truly ethical advice to researchers. Additionally it would have helped me to consider my status as a bereaved parent myself, both in relation to participants but more importantly to prepare me for the impact of my work reaching the public arena. In UK institutions, the Research Excellence framework (REF) requires academics to create professional and public 'impact' from their work, a drive which may involve them with the media. If institutions wish to care ethically for staff involved with such 'impact enhancing' activities then ethical processes should also be engaged with the potential complexities of this, particularly where very 'sensitive research' meets the public arena.

Conclusion

This chapter has explored the different ways in which maternal identity can be constructed according to different individual and institutional needs following a sudden, unexpected child death. From the instant brutality of the 'golden hour' where parents are viewed as guilty until proven innocent, a range of differing social identities may emerge – from the 'vulnerable' to the 'belligerent' or to group members of an enduringly 'tragic club', all dictated by normative views of how the bereaved should behave.

Building on Van Den Hoonaard's suggestion that ethics could be made more 'ethical' by including 'the perspectives of the populations being studied' (2002:183) the chapter suggests that institutional ethical review should consider multiple viewpoints from amongst these populations, rather than keeping to one conformist view - in this case one which dubs all bereaved parents as singularly 'vulnerable.' The chapter also recommends that ethics committees' consider their own vulnerabilities with respect to certain sensitive subjects, in order that research into these areas is not prevented by collective committee failure to emotionally manage certain topics.

The chapter then discusses the potential ethical implications for researchers when 'sensitive research subjects' collide with the public sphere facilitated by popular media. In a contemporary culture which requires UK institutions to demonstrate the pervasive 'impact' of research, researchers may unwittingly stumble into the public domain, with little awareness of the potential consequences (Sikes, 2008). As I discovered in the wake of a perfect storm caused by a newspaper article, research can be used in ways that border on the unethical when it meets the public arena and I suggest that one of the duties of institutional ethical should be to help researchers consider this.

Finally, the chapter suggests that if the purpose of ethical review is fundamentally an ethical rather than a procedural one, the process should be both more holistic in considering the temporality of the research and the range of people involved across this time span. This can only be achieved if the process becomes iterative, where researcher and review board are learning from and informing the other, rather than the current format which exists as a one off governance exercise, performed before the research sees the light of day.

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