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## **Adopting a reflexive approach to researching sensitive subjects: parental experiences of stillbirth and neonatal death**

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### **Abstract**

In this article I am going to discuss the challenge in researching sensitive subjects and some of the ways this can be overcome by adopting a reflexive approach to conducting qualitative research. These particular challenges are detailed in relation to data collected from in-depth interviews from men and women bereaved by the death of their child following stillbirth and neonatal death. I discuss how a reflexive approach when combined with a voice centred relational method to analyse data, can be used to manage both the breadth and depth of the data as well as unearthing some of the ways in which men and women contextualised their experiences in relation to aspects of their lived biography. I propose that these combined approaches permit an explicit account of how the analysis was conducted and critically, how the researcher impacts upon the research process and product.

**Keywords:** Reflexivity, stillbirth, neonatal death, grief, narratives.

### **Introduction**

In this paper I discuss the value of employing a reflexive approach to researching parental experience of stillbirth and neonatal death. While there are several accounts of parents' experiences of stillbirth and neonatal death which can be found in the literature (Aho et al, 2009; Don, 2005; Finkenbeiner, 1996), much less has been written about the way in which these stories are captured or the processes researchers engage in when conducting qualitative research. In this paper stillbirth is referred to as a death in the UK which occurs following 23 weeks and 6 days gestation. Neonatal death is referred to as those deaths which occur in the first four weeks of life (Centre for Maternal and Child Enquiries, 2011).

The research on which this paper is based was conducted as part of a doctoral thesis in which both men and women's experiences of the death of their stillborn child or child who died on the neonatal unit, were captured in interviews and focus groups. The aim of the research was to explore the extent to which parents' bereavement experiences were mediated by the dominant discourses of the culture such as medicine and employment and the social networks to which parents belong and the implication of these bereavement experiences for theory and practice.

With both theoretical and practical concerns in mind it was vital that the method of analysis employed to analyse men and women's bereavement experiences was able to handle the breadth and depth of the vast body of qualitative data that was collected. There was the practical reality that the narratives could be read in so

many ways. This is why I valued the approach of Mauthner and Doucet (1998: 125) who propose the notion of 'relational ontology' in which the individual is embedded in a complex web of intimate and larger social relations (See also, Riches and Dawson, 1997:53-75).

Following from extensive research and work by Brown and Gilligan (1992) on *Womens' Psychology and Girls' Development*, Mauthner and Doucet (1998:125) describe how they analysed data from their own doctoral research, about the experiences of motherhood and postnatal depression within a sociological framework. This involves employing a 'voice centered' approach, which involves re-reading each interview transcript at least four times to 'hear' the different voices that are represented including those of the researcher and person being researched.

The voice centred relational method was an attempt by Mauthner and Doucet (1998:126) to transfer relational ontology into their methodology and data analysis by considering respondents' narratives in relation to the people around them and to the broader social, structural and cultural context in which they live. I employed the voice centred relational method developed by Mauthner and Doucet (1998) to analyse men and women's narrations about grief and loss following stillbirth and neonatal death in my own doctoral research, since it had the potential to provide not only an additional dimension to the analysis, it also permitted an exploration of men and women's accounts in considerable depth.

The purpose of this paper is to provide an example of a novel and analytical approach to researching sensitive subjects such as stillbirth and neo natal death (Lee, 1993). I propose that when researching sensitive subjects, the voice centred relational method when combined with a reflexive approach to research, enables a consideration of the relationship between researcher and respondent and its impact upon the research process and product.

## **Background**

My doctoral research involved 28 open-ended, in-depth interviews and 6 focus groups with men and women who had experienced the death of their child following stillbirth or neonatal death (Jones, 2013). I provide accounts of this form of loss based upon parents' own subjective interpretation since a proportion of the professional literature concerning parental bereavement following stillbirth and neonatal death is written by health practitioners' who have been involved in bereaved parents' care. For example, Lewis's (1998) interpretation of parents' perception of loss on the neo natal unit is discussed in light of the emotional challenges in providing care for parents of dying infants'. Similarly Lundqvist and Nilsun (1998) in their survey of Swedish neonatal wards question the ethical justification given by nurses who are inclined to persuade women to hold their dying or dead baby. Lundqvist and Nilsun (1998:246) suggest that more knowledge about the experiences of parents who have lived through such a traumatic event is required to innovate the most appropriate and sensitive practice around the time of a baby's death. Schott et al (2007) have attempted to address the absence of parents' experiences in informing professional practice. Based upon parent's accounts of their care and the recommendations of clinicians Schott et al (2007:5), developed a series of guidelines aimed to improve care for parents' experiencing miscarriage, stillbirth or neonatal death. Elsewhere, parental accounts of loss in qualitative research has shown that the impact of stillbirth and neonatal death is long lasting (Lovell, 1983; Layne, 2003) and that support provided at such a critical juncture can mediate responses to loss (Davidson, 2008; Lovell, 1997).

To explore parents' accounts of experiences of stillbirth and neonatal death, as part of my own research, my initial research question centred upon what is distinct about experiencing the death of a child few people would have known or met and what are the implications theoretically and in practice? Second, to what extent are a parent's experiences and responses to the death of their child mediated by the dominant discourses of our

culture and to the social networks parents relate? The data collected about experiences of loss suggest that a way of understanding the impact of such deaths is to focus upon the way men and women narrate their experience. For example, I interpreted the use of metaphor as a way in which parents found meaning and also as a way of emotionally distancing themselves from their story as it was being told. Conversely, I noted that pauses were often a precursor to a tearful re-telling of a particular narration. In attending to these particular aspects of a narration, I therefore sought an approach that acknowledged the subjectivity of parents' narrations and my role as the reflexive researcher.

### **Reflexivity**

A number of texts within the qualitative methodological literature discuss varying approaches to qualitative analyses but much less about the process and how this is mediated by the researcher. Etherington (2004:25) points out that traditionally, academic research has been considered an impersonal activity with researchers tasked with approaching their studies objectively and taught that rigour demanded distance and non-involvement such that subjectivity was a 'contaminant.' Much like Etherington, I find this view difficult to connect with since without sight of the person at the core of this work, I feel no particular relationship with the writer, even if I am interested in the topic. This is a personal view, and much like any view, guides my choice of method as well as the topic of research I choose to pursue. In adopting a reflexive methodology to my doctoral research I therefore valued the approaches of both Etherington (2004) and Letherby (2003) and also those of Morley (1996:139), who argues that: 'we need to acknowledge that as researchers we are people with our own responses, values, beliefs and prejudices'.

While reflexivity has become an increasingly significant issue in contemporary social research (Etherington, 2004:30) with some researchers embracing the principle as the primary methodological vehicle for inquiry such as in autoethnographic and autobiographical accounts (Ellis, 1995; Ellis and Berger, 2003; Letherby, 1993) for others (Stiles, 1993), reflexivity involves little more than checking for subjective bias in a survey. These 'reflexivities' as Lynch (2000) suggests, imply a variety of meanings. Researcher reflexivity as I understood it as part of my doctoral thesis, concerns my own capacity as the researcher to acknowledge how my own experiences inform the process and outcome of inquiry. I concur with Etherington (2004:32) who posits: 'If we can be aware of how our own thoughts, feelings, culture, environment, social and personal history inform us as we dialogue with participants, transcribe their conversations with us and write our representations of the work, then perhaps we can come close to the rigour that is required of good qualitative research.'

Employing reflexivity in research for some such as Frank (1995) and Josselson (1996) is a moral and methodological obligation. Reflexive feminist researchers such as Etherington, (2004:32), and Letherby (2003:8-9) encourage the transparency in researcher's writing of the interaction between themselves and the researched so that the work can be understood not only about what has been found but how the researcher came to discover what they found. Readers, who are then informed about the researcher's position, can better understand and validate the interpretations which have been derived by the researcher. Yet, even where researchers agree that critical reflexivity is essential to rigorous qualitative research, either do not include it in their research or tend to in a limited way (Denzin and Lincoln, 2000:3). Greater transparency of personal involvement may be too challenging for some. As the sociologist Giddens (1991:21), notes, challenging familiar practice is *existentially troubling* for ordinary individuals. For my part, being reflexive in my doctoral research has been insightful and challenging since I have been caught between two conflicting notions. In my work (with bereaved men and women) I have been encouraged to be reflexive and to see my 'self' and my knowledge about the subject as a tool. Yet, in researching this subject I have questioned the legitimacy of this approach to wider academia such that this reflexivity would be viewed as self indulgent, narcissist even, and thus, lacking in objectivity, which in more positivist approaches is highly valued. I was somewhat reassured

by the ruminations of Okley (1992) who argues that reflexivity is neither a form of 'navel gazing' nor a means of 'self adoration'. On the contrary, 'self adoration' is much different from engaging in a critical scrutiny of the 'self' in research and thus, having insightful self awareness.

By acknowledging myself in the research here my aim was to make explicit the multiple identities I owned as researcher, bereavement counsellor and parent and this has influenced the research process and product. Indeed, my initial outlook towards this research subject was one of excitement and anticipation. The former owed much to my own experience of working with bereaved parents who often stated they felt misunderstood and this provided a way in which to redress the balance of competing voices. I have found that I was able to refer to the similarities and differences between my 'self' and respondents and about the way this research led to changes in my own feelings and understanding about stillbirth and neonatal death experiences. I was reminded by each interview with respondents how I needed to locate myself as the researcher. These processes (interviewing, transcribing) meant I was also faced with the question of how I reconcile myself with the various roles and positions I occupied as a researcher, parent and data analyst. Behar (1996) suggests observing these differing roles and positions not as separate beings but as entities which are intertwined, albeit in a complex way. In the context of this research, this meant being prepared to expose biases, and held assumptions and in this research, my emotional responses in the collection of data. Thus, while there were opportunities to talk (briefly) this facilitated a period of self reflection which was recorded in my field journal yet, discussed more widely in supervision and clinical supervision sessions.

This came to be a way of writing and voicing the concerns I had. For example, in one interview I had felt uncomfortable due to the negative reference by a respondent towards another bereaved parent. I left feeling disappointed and bewildered by someone who I thought would be more empathic. This interview exposed the ongoing negotiation of my status as an 'insider' and 'outsider' in the research process. While the former meant my approach was appreciated for being less voyeuristic (since my interest was genuine and personal), my 'outsider' status as a researcher from an academic background meant I had to experience the discomfort of the perspective that was provided as part of the interview. I had to contend that this comprised not only the complexity inherent in research but an understanding of loss according to one's own personal values, perceptions and beliefs. Further, it was evident that while experience of the subject matter could in most instances facilitate rapport and enable connections, the previous experience meant that disclosing one's own interest in the research is not always desirable. Moreover, what this interview showed is that while the subject matter is an issue that the researcher and respondent may both have a connection with, it does not follow that the researcher identifies with the respondent's sentiments or perspectives.

For Letherby (200:14), finding a balance in research is critical not least since it is not always evident who holds the power. I was reminded of the tension in this power relationship from this interview and of the work of emotion in distilling one's sense of discomfort such that, it was to Lee et al (1993:6) I turned, since they assert that a personal experience such as bereavement is emotionally charged and that research into this area may be distressing for both respondent and researcher. I viewed this in light of reflexive ethnographies where the researcher begins a study based upon their own experiences.

As Etherington (2004:180) explains: 'Our personal history, when it is known to us and processed in ways that allow us to remain in contact emotionally and bodily with others whose stories remind us of our own, can enrich our role as researcher. Our 'empathic resonance' allows us to hear the others' experiences without the need to defend ourselves against that knowing.' Etherington's reference to 'empathic resonance' follows from a way of being with respondents' as well as with the 'self'. For Ellis and Berger's (2003:162): 'the researcher often feels a reciprocal desire to disclose, given the intimacy of the details being shared by the interviewee.' While I disclosed my own personal reason for this research when asked, compared to the interview described earlier, other interview encounters evoked intensely sad emotions within my 'self'. I felt much moved and had

the utmost respect for such profound stories and to the men and women who shared them. Yet, unlike the more private moments with transcripts in a single occupied office, I felt I could not fully express the impact of these interviews until I attended therapeutic sessions with a counsellor as a means of coping with these processes. Drawing on Fontana and Frey (2000:57): 'interviewers must necessarily be creative, forget 'how to' rules and adapt themselves to the ever-changing situations they face.' Indeed, I was reminded that no two research situations are the same. Further, that both respondent and researcher are affected by this encounter. This explains why I felt the need to 'check in' with respondents in the days following the interview, and inquiry as to their sense of well-being. In conducting this research I was concerned with bringing about a topic in which men and women may find it emotionally difficult to talk about. Having obtained these wounding narratives, would I do justice to these experiences? While these issues were at the forefront of my priorities in previous research, it was to the narrators (respondents) of stillbirth and neonatal death where I felt a particular responsibility around researching a potentially sensitive subject.

### **Conducting sensitive research**

Over the past few decades there has been increasing interest in researching 'sensitive' social issues such as child abuse, sexuality and domestic violence (Parkes, 2011) the other) and which are emotionally laden and inspire feelings of dread (McCosker et al, 2001). In researching these topics, the central aim has been to gain an understanding and awareness of the impact of the experience of sensitive subjects on people's lives (Decker et al, 2011). In determining what is sensitive to research of course depends on both the context of the research itself and on cultural values. Lee (1993) suggests that those issues which cause concern about sensitivity in research are those considered private and sacred (sexuality and death), issues which cause stigmatisation and fear (illegal behaviour), and sensitivity in relation to social conflict (political threat). Further to these considerations, I would suggest that sensitive studies are those in which there are potential consequences or implications for researchers and respondents (Jordan et al, 2007). Concern then is not confined to that of the researcher, but more commonly on all who are involved in the research process. Studying sensitive topics creates methodological challenges such as defining and accessing the sample, and factors such as concealment and dissimulation between researcher and respondent. Despite such an important topic and one which occupies a considerable amount of researcher time, particularly when undertaking ethical procedures for research approval, little has been written about safety issues in relation to researching sensitive subjects such as death. While Paterson et al (1999) outline a protocol for researcher safety, and Burr (1996) on the psychological impact upon researcher's, these discussions are not typically reflected in many research processes, particularly the concern of *all* of those involved in the research at risk of coming to harm.

Researching death can be considered a sensitive topic not least because of the emotions which are raised and the impact upon both the respondent and researcher and this was an issue which was considered at length. For example, by providing contact details of supportive organisations following interviews with respondents and contacting them a few days later, sending out letters of thanks were all ways in which I attempted to take care of respondents in the research as well as conducting separate clinical supervision for the emotional impact on myself and as the researcher.

Just as the possible impact of the research was a key factor in determining the way in which the research was carried out, the way in which respondent's were approached to take part in the research underwent considerable consideration. Following ethical approval with the University of Bristol ethics committee where I was based undertaking my thesis, parents were approached with permission from supportive organisations, through trained facilitators of support groups for bereaved parents.

## **Recruiting respondents**

Accessing respondents through facilitators who led support groups was a critical starting point in which to invite parents into the research. Indeed, I was aware from other research that obtaining respondents becomes more difficult, the greater the sensitivity about the subject under investigation (Lee, 1993:60). I was therefore reliant on group facilitators to hand out information sheets, consent forms to prompt potential respondents to make contact and seek clarification for the aims and outcomes of the study. While a consent form was used this did not detract from the need to seek verbal and ongoing consent throughout the interview process (Lee, 1993:103).

Of the six support group contacts provided, I met and spoke with three facilitators who distributed information about the research to support group members. This was repeated with a further group facilitator who submitted information to the support group committee for review and approval prior to distribution. As one parent was interviewed, so others shared their experiences of the process which generated further interest in the study and therefore recruitment. This 'snowball' method of recruitment meant parent's were not approached by me, yet could contact me and ask specific questions about what is involved and ask questions about what happens to the data.

While this way of approaching men and women who had experienced the death of their child, generated interest from 28 parents who were interviewed and took part in focus groups, the sample comprised of 7 men and 21 women who were articulate and self-reflexive and who were able to voice their experience. I was unable to obtain the perspective of bereaved parents from ethnic minorities or from those of parents who had experienced the stillbirth or neonatal death of their child as an adolescent (i.e.13- 17), young adult (18-24) or as an older person (65 and above). While the point was not to consider narrative accounts by age, I was aware of a dearth of literature surrounding the impact of such deaths on young women and on those women who may never know where their child was buried and the consequences of this in both the short and longer term. This reflected the practical issues in conducting research where access to potential respondents in part, is limited by the sensitive subject matter. The criteria in which respondents were recruited ensured that they were not approached around the time of significant anniversaries or if the death occurred less than six months prior. Of those men and women who took part in this research, each had something in common (death of their child) which they could relate to particularly during focus groups. Yet, how these deaths came about varied and occurred in utero, during labour, soon after birth or in the first few hours, days and weeks of life and as a result of varying complications. In revealing an aspect of these experiences and concerned with the emotionality in narrating stories about death and dying, respondents were asked about their motivation to participate in research.

## **Respondents' Motivations**

Respondents' motivations for participating in the research ranged from wanting to help the researcher while others felt they wanted to 'raise awareness' and 'educate people'. Those wanting to assist the research stated that their 'voice would be heard' and that 'people need to understand this' (impact of the death of a baby). It was at this juncture that it became evident that while my motivations were similar to respondents (in terms of raising awareness) they also differed in that I had 'intellectual privilege' over that of respondents. This is not to suggest I had superiority. Rather, I had the resources and materials available to transcribe and disseminate experiences which many respondents did not. This does not suggest either that respondent's are unable to represent their selves; on the contrary some did so willingly (such as lobbying parliament or publishing their own stories through supportive organisations). Rather, it was to my 'self' as the researcher who respondents turned to make their anonymous voices more 'public'. It was for this reason that interviews provided the basis by which to engage reflexively and consider notions of power and the work of researching such sensitive

issues. This reaffirmed the sense of ethical and moral obligation that this subject demanded during interviews and later representing their experiences adequately.

### **Representing others**

My concern with representing experience influenced my decision to avoid 'cleaning up' original text. My interest was not with 'polished' or grammatically correct accounts but with all of the '*erms*', '*ums*' and '*ye know?*' and '*it were like*' of respondent's regional accents which formed a part of their everyday conversation. To delete such words would feel like deleting an aspect of a lived experience. Further, repeated exposure to these words was an essential part of being immersed in heuristic research, since the details added depth to the quality of the narratives:

As Etherington (2004:80) asserts: 'we are rarely aware how much of the English language is made up of incomplete sentences and incorrect use of grammar or language generally.' Within the narratives, this 'incorrectness' provides a clue and proffers a sense of meaning behind a particular aspect of a story. The purpose of listening to someone's story and analysing their narration is to explore and understand the subjective world in which the respondent lives. The interview, and the story which emanates from within it, provide a rare glimpse and therefore a rich opportunity to shed light on the psychological and social realities of the respondent's life. Further, in giving voice to parents as respondents in this way, there is an ethical and moral obligation to ensure that a narrative is not reconstructed or indeed marginalised. I mention this in light of Lawrence Langer's (1991:168) criticisms of other writers' interpretations of sensitive interviews. For example, in writing about Holocaust testimonies, Langer argued that there was a tendency of writers (1991:28), in coping with such testimonies to devise 'softening' language which diminished the severity of the impact of these experiences. Further, that the traditional historical narrative which is reflected upon in such testimonies overemphasises the 'good ending' of a story such as being liberated from the death camps.

Langer provided an example of this from one of the prisoner of Ebensee concentration camp which was liberated by the Americans. Sol who was the respondent stated that he and his friend who had been together from the beginning clung to each other not for joy because: 'now really the truth is going to have to come out. Up until then, it was all speculation that our parents [had] not survived, or my sisters or brothers, or anybody. Now the day of reckoning was coming and it was very frightening.... So as much as we were happy once that we were getting freed ... the fact is that we got to go home to find out' (Langer, 1991:169). Indeed, they found that their families had perished and this fact alone altered the relationship to the reality they tried to convey in the interviews. The lesson for me here was that where there was hope, now there was very little way in which writers such as Gilbert (1985) could make consolatory use of despite their attempts to do so. Following this criticism of Gilbert's work with holocaust testimonies evoked much caution in my approach with respondent's narratives which is why I turned to narrative inquiry as a means of engaging with the data concerning subsequent pregnancies. I was only too aware in listening to bereaved parents that a child born after the one who has died was assumed by others around them to be a replacement.

In part, this is explained by professional interpretation of an article by Cain and Cain (1964) concerning 'replacement child' syndrome. While dated, they suggest that a child born following the death of another somehow replaces the pain of the loss of the child who died. This has been challenged by many including Grout and Romanoff's (2000) study of bereaved parents who had subsequent children following the death of a baby. Their findings suggest that it is not the child which is replaced; it is the space that is created by the loss. While this may represent a physical space per se, the accounts given by respondents about their experiences in this research, suggest that they continue to experience an emotional void despite the birth of subsequent live children. This represents the grief and the loss of the child who died which is felt continuously over several respondents' life courses.

Several respondents in this study shed light on current assumptions about replacement children as the antidote to the pain of loss to the previously deceased child:

‘There is always something missing, my family isn’t complete, it’s never going to be complete because she is not here. It’s how you feel.... a complete and utter emptiness and that is how I felt after I had Lucy [baby who died]. That hole has been left here now, there is a permanent gap there where there is a whole part of my life that should have been.....’

Isobel, mother of baby girl Lucy (stillborn at forty-two weeks)

‘....The thing I remember is in the bed opposite me there was obviously a girl who’d had a little boy and I had lost a little boy. All I can remember now is the grandmother saying what a lovely grandson you’ve given me and that just did it for me. I knew I had a healthy little girl, but.....’

Susie, mother of baby boy Billy (born at thirty-eight weeks, lived for nine hours).

In her ‘wreckage’ are the faint words echoed by Langer (1991) earlier in this paper that it was now her troubles were about to begin. I have referred to a narrative concerning subsequent children and have heeded Langer’s warnings on misinterpreting people’s stories such that I moved beyond the premise that the narratives could only be read in one way. In this reflexive model, it was possible to move beyond any premise that this research could only be read in one way (Mauthner and Doucet, 1998:122). I have found Langer’s criticisms particularly useful in that they reveal the instability of particular words and how they could be used or misused to support various researcher perceptions and deceptions. This does not suggest that the testimonies I refer to are comparable to those of the respondents in this study, on the contrary, such experiences need to be viewed in their own light. Indeed, when we research sensitive subjects we have a duty not to soften or indeed, make more dramatic what we hear which is why Frank’s reflexive account of his own narrative research fits well with my approach despite the difficulty in listening to wounded and chaotic narratives: ‘One of our most difficult duties as human beings is to listen to the voices of those who suffer. These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening. The moment of witness in the story crystallizes a mutuality of need, when each is for the other’ (Frank, 1995:25). In listening to and reading narrative accounts of grief and loss, the silences and pauses are unearthed to reveal emotionality in telling a story. Narrative inquiry has a particular value since it permits respondents to remain close to the depictions of their own experience and to tell their story with a heightened sense of insight.

### **Narrative Inquiry**

The methodology within this research is based upon narrative inquiry and underpinned by a heuristic framework. Narrative heuristic research is a term that encompasses a large and diverse range of approaches and, thus, there is no single agreement as to what this constitutes (Mischler, 1999). For the purpose of this study a heuristic method is about collecting, analysing and re-presenting people’s stories as told by them. Heuristic frameworks assist in disentangling stories by recognising the concerns being addressed. For Frank (1995:24) these heuristic frameworks are not the truth of stories which has been the tendency of modern researchers to present their typologies. Rather, the frameworks I present from respondents narratives are a means of heightening attention to stories which are their own truth. The stories which are told may be those of wreckage and of chaos, but they are not necessarily about lives as they were lived, but as experiences of those lives (Frank, 1995).

Thus, a narrative of stillbirth and neonatal death is not confined to the death itself but becomes the experience of that death. Life moves and so stories change with that movement. The narrative inquiry I employed was influenced by both Frank (1995:3) and Etherington's (2004:75) reflexive approaches and also of those with the following world view:

- competing narratives represent different realities not simply different perspectives on the same reality (Freeman, 1993);
- narratives give voice to who we are, and represent and shapes social reality (Frank, 1995; Ochberg, 1994);
- the telling and re-telling of an aspect of one's life story enables a person to create a sense of meaning (Bruner, 1990);
- we live in a storied world and lead storied lives (Sarbin, 1986).

These approaches proffer that one's reality and knowledge is socially constructed and based upon knowledge which is entrenched in historical and cultural stories, beliefs and practices.

Narrative inquiry is particularly relevant to this research, since it portrays parents experience in relation to their culture. Similarly, for Josselson (2004:2) narratives are where the memories, the representation of others and time are all interlinked through stories into a way people can tell as a life story. Narratives then become the linguistic means by which to connect to an experience which has been lived and its meaning made explicit. In this research I was interested in exploring different stories (a father and a mother's account of the loss of their child) for their different realities not competing perspectives about the same reality. Narrative inquiry has a particular value since it provides respondents with the opportunity to tell an aspect of their life story in their own words without censure. A central feature of interviews was parent's sense of relief about being able to talk about a member of their family (deceased child) without being reprimanded or being considered morbid. Similarly, research on miscarriages (Frost, 2004:7) suggests that interviews provide parents with the opportunity to talk more openly about their experience in ways in which they would not usually with others.

At the forefront of my reflexive approach I was aware that these stories are reconstructions of life events which has a bearing on how the stories are shared, which particular part of the story is told and how it is presented and interpreted. An example of this can be observed in the following part of a narrative by a respondent. One is from an interview and another from a focus group which occurred several months later when she talked about the death of her son following stillbirth:

'I just felt completely and utterly detached as though no one could possible reach me now. It's impossible to know how to deal with it; you just have to do things you have to. I lost a lot of weight, I was thin as a rake and I couldn't sleep.....'  
Briony, mother of baby boy Samuel (stillborn at forty- three weeks).

Which she reiterated again at a later date in a focus group:

'I still don't sleep particularly well. I think after the first few months that is when you really need the support because all of a sudden physically you are mended but all the details come back to you... all the haunting details. Even now... it can't have all happened it must have been a nightmare...'  
Focus group 4, Briony

What these narrative parts demonstrate is the meaning of past events which has changed over time but not the impact and it is this which reshapes a story as it courses towards its end which is always in process. Such in-depth accounts required an approach which is relational in focus.

### **Voice Centre Relational Model**

Mauthner and Doucet (1998:125), voice centred relational method proposes the notion of ‘relational ontology’ in which the individual is embedded in a complex web of intimate and larger social relations. This means that respondents’ narratives in this are explored in relation to the people around them and to the broader social, structural and cultural context in which they live (Mauthner and Doucet, 1998:126). By adopting this interdisciplinary sociological social constructivist epistemological approach to develop an understanding of the experience of self, some of the ways respondents attempt to give meaning to and contextualise their experience is elucidated. In this ‘voice centred’ approach to research, a transcript is read four times whilst listening to the original tapes. As the readings are explored so the different voices of a complex web of interactions with the world are heard and represented.

#### **The first reading: Plots and Sub Plots**

The first reading concerned the plot and sub plots to a story so in this study, the central plot to respondent’s stories was the death of their baby yet, how this came about (in utero, feticide, stillbirth, neonatal death) differed and formed the sub plots. In this reading the researcher is tasked with considering how she responds emotionally and intellectually to this person. This allows the researcher to examine how and where some of her own assumptions and views – whether personal, theoretical or political might affect the interpretation of the respondent’s words.

For example, one respondent discussed another support group member to which she belonged in a negative light. This challenged my view of what I felt support groups were about which were to all intents and purposes meant to be mutually supportive and not a space where negativity towards another was meant and felt. Yet, this revealed the very real, raw and difficult emotions that are present around such a profound loss.

#### **The second reading: The voice of the ‘I’**

The second reading represents listening to how respondents feel and speak about themselves. In paying attention to the use of the pronoun ‘I’, the researcher stays close to the multi-layered voices and perspectives of the respondent. In listening and reading for the ‘I’ particular attention is given to the pauses and the gaps in speech as people try to articulate how they feel, and also to metaphors as exemplified by the following narrative:

‘It’s a strange beast grief isn’t it? You will read a story and there is something in there which strikes a chord and you sort of ... it brings everything back to you. It’s like physical healing, the scar tissue gradually builds up and it heals over but sometimes old scars get knocked and they hurt, it’s the same with emotions as well. I wacked my knee in the swimming pool years and years ago, but if I knock it at the right angle it’s still excruciating and it’s the same thing. If you read something or see something on the wrong day at the wrong time, just in that not quite right frame of mood it can bring everything back with a vengeance.....’

Ruth, mother of twin baby girls Melody and Joy (born at twenty-seven weeks, lived for two hours).

The previous account demonstrates how metaphors work in bereavement narratives by drawing upon another embodied experience of injury to describe grief thereby establishing another story line. This compares when referring to relationships within narratives such as those with spouses, parents, health professionals, and some of the ways these encounters mediate parental responses to loss.

### **The third reading: Relationships**

The third reading comprises listening to the way in which respondents talk about their interpersonal relationships, be it with their partners, their relatives (in particular their parents), their children, and the broader social network within which they live. This form of reading is particularly useful for exploring any perceived grief differences among men and women in the research. Further, the extent to which the personhood of the baby and the parents were validated were seen in light of the relationships with others such as health professionals, friends and work colleagues. The following narrative exemplifies a third reading since I was concerned with a respondent's interaction of health professionals involved in her care and that of her stillborn child, Abbie:

'K: With the midwife she was the morning staff and very bustly. I was just an ordinary patient on an ordinary ward. When she brought Abbie [baby who died] in to me in this Moses basket there wasn't even any compassion shown to 'A', there wasn't any comment made. The midwife the previous night treated her like you know a live baby, she took a photograph of her, she wrapped her up, she looked into her face. She didn't sort of think oh this baby's gone you know. She even made the comment that even out of stillborn babies that she has delivered that Abbie had a very pretty and peaceful face.....

Tina, mother of baby girl Abbie (stillborn at forty weeks).'

This narrative was one of many which referred to the dissonance between more positive and negative perceptions of approaches to their care while in hospital. While it was clear that parents appreciated more empathic encounters since they felt acknowledged as a grieving parent, this soon ebbed into dismay and despair when empathy was followed by much less sensitive care from another health professional. Clearly, such experiences to some extent mediated parents responses to loss. Following from reading for relationships, I turned to placing respondent's experiences according to the social and cultural milieu to which they belonged and in so doing unearthed other mediating factors upon parents expression and experience of loss

### **The fourth reading. Placing people within cultural contexts and social structures**

Respondents experiences of grief and loss in this reading are placed within the broader social, political, cultural and structural contexts surrounding bereavement which can lead to varying interpretations of the death of a baby and to differing grief reactions.

I argue that some of the problems bereaved parents face arises from the dissonance between mainstream culture and the culture of bereavement. The consequences of the differences between these two cultures are the lack of sensitivity, avoidance and impatience with bereaved parents' perceived preoccupation with the death of their baby. This reading enables an exploration of the mother and father's changed sense of self and identity and negotiating their bereaved status in relation to the location of the baby within the family:

'R: I remember someone saying to me once, would you rather it never happened, wouldn't it be better if that year you were pregnant with Thomas [baby who died], and lost him, none of that had happened? I can remember saying to them well no because I feel the joy of having had him outweighs the loss of having lost him. I've got something a lot of people haven't got. I've got a child in heaven who is in my heart all the time and who I love as much as I love Thomas [living child], and wouldn't ever want that taken away.....'

Anna, mother of baby boy Thomas (stillborn, twenty-four weeks).

As a mother of a son who died in stillbirth this respondent is aware that there is little in the way of the potential for an external dialogue with others by which to construct a memory and find meaning, as her son was seen by very few people. The previous narrative demonstrates that the mother does not seek out the support of friends to provide meaning to her loss, rather she engages in a social process by which she renegotiates who her son was, what he meant to her and what he represents to her in her everyday life. On one level, this may reflect a personal faith in a place such as heaven, in which the child can be pictured or construed as being safe. On another, her focus upon her changed self suggests her son was and continues to be an abstract presence in her life and which represents a continuing bond with her child. Thus, while grief is felt over the life course a sense of coping does not come from a severing of such bonds, rather, learning to live again and cope is for some about integrating the child into the parent's life and into their social world.

While other respondents found similar ways to integrate the deceased child into their life, the following narrative reveals the struggle some respondents face in trying to find ways to parent in their ambivalent status as a parent of a dead child, Jack:

'R: There were things like designing a headstone to go on his grave and things like that. That was hard and put a lump in my throat designing a headstone for my son. That didn't feel anything like right. It was the best we could have done for Jack and we always try and make sure Jack's grave is always tended nicely and kept clean and that the flowers look nice. There are no nappies to change. There is nothing we can do for Jack practically, he is always in our minds and in our hearts, he is with us everywhere we go but there is nothing we can do for him.....'  
Dan father of baby boy Jack (born at forty weeks, lived for two days).

This account demonstrates that in trying to come to terms with the ambivalent bond with his baby, the father in the first instance separates his son from his sense of self. He talks about being unable to physically care for his child yet his son has been transformed into the father's inner world in his mind, in his emotional self and in his daily life. Continuing a bond with the child is not only about renegotiating a relationship but making sense of others' responses to the death. Moreover, it is a way in which respondents reintegrate into the social world following the privacy of the family. These are ways to becoming accepted again while continuing a bond, which as one example demonstrated, was represented by the more physical task of parenting a grave.

## Conclusion

In taking the readings each in turn, the aim has been to unravel the multiple meanings to those narratives and to uncover the relational context of their reality. The narratives demonstrated the struggle to negotiate ambivalent self identity following loss. One way to mitigate this was to continue a bond irrespective of others responses and to find ways to parent, even if this means tending a grave.

To be with these narrations is thought provoking testing out my own realities and previously held assumptions. But much like Frank, I agree, these stories are hard to listen to, because they at times remind us of that which we are vulnerable to which is to the pain of the past which is retained in the present and which we know will endure for the future. So while it is hard to listen to voices of struggle, of chaos and of a vulnerability deeply felt, there is a mutuality of need between the researcher and researched when one is for the other.

What my research has also shown is some of the difficulties in researching a subject that exists primarily in the private realm of family life with no language or public discourse of its own. This raised questions about some of the ways in which to explore socially invisible phenomena and to bring out silent voices. This meant that the entire research process was guided by the subject matter and thus, employed a reflexive model as a

way of conducting interviews and transcribing data. In analysing this data I was confronted by my self and my own central role in shaping the outcome by following certain leads and seeing where it took me. Why as researchers we choose such leads might not always be obvious to us, since we are arguably influenced by our own personal, political and theoretical biographies. Yet it is at the critical stage of data analysis where we can choose to amplify respondent's voices and prepare an account that transmits those voices and be explicit about our responses to it. Other ways of conducting research would not have enabled me to demonstrate the richness of these narratives. It is a novel approach which can be used in other studies to construct a comprehensive body of theory regarding men and women's bereavement experiences and which I have argued is missing from the literature concerning bereavement following stillbirth and neonatal death.

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## **Biography**

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