

Meaning-making after Neonatal Death: Narratives of Xhosa-speaking Women

Colleen Sturrock
Department of Psychology
University of Cape Town

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Abstract

The death of a neonate (an infant less than eight days old) can be traumatic for mothers, resulting in profound grief which ruptures their sense of coherence and identity. A narrative approach was used to explore how bereaved mothers tell stories about the death of their baby in order to help them to understand the significance of the loss. Eight Xhosa-speaking women were invited to tell the stories of their bereavement, and how they made sense of the loss in the context of their lives. Three individual narratives are described in detail to explore how narrative construction reflects and reinforces meaning. Common meaning-making processes and sources across the narratives are discussed with attention given to the influence of contextual factors. The narratives reflect their struggle to establish a sense of their baby as a person to be mourned, to redefine their own identity which has been fragmented by the loss of part of themselves, and to find reasons for the death. Their subjective experience of meaning-making is influenced by the baby's father, older women in their community, social stories, and the context of deprivation in which they live. Meaning-making follows some of the patterns suggested by constructivist grief theorists, but particular social meanings and strategies which these theories do not explain, seem to affect the mothers' grieving. It is clear from the narratives that grief is not a linear process which reaches a conclusion, but an ongoing search for meaning which may take many years.

Keywords: neonatal death, traumatic loss, bereavement, grief, narrative, meaning-making, context.

Meaning-making after Neonatal Death: Narratives of Xhosa-speaking Women

The death of a neonate (an infant less than eight days old) can have a profound psychological and psychosocial impact on parents. This, and other forms of perinatal loss (miscarriage and stillbirth), has been termed a “disenfranchised grief” (Willick, 2006, p. 295) not adequately acknowledged either by society or the medical establishment. Prior to 1970, little research was done on the effect of perinatal loss on parents. The earliest research arose out of a concern to establish an effective way for medical staff to respond to parents’ short term needs (Zeanah & Harmon, 1995). Most of these studies used traditional quantitative research methods and investigated factors such as the intensity of grief, and mental health problems over various periods of time after the loss. The tendency has been to conduct studies which include all three forms of perinatal loss, although there have been questions raised about the differential effect of gestational age on parental grief (e.g. Elklit & Gudmundsdottir, 2006; Lin & Lasker, 1996). This study focuses specifically on grief which follows neonatal death.

Effects of Loss

The death of an infant is often accompanied by a range of secondary losses, such as the loss of an anticipated future, the loss of one’s identity as a parent, and the loss of a sense of the world as a benevolent place (Wing, Burge-Callaway, Rose Clance, & Armistead, 2001). Grief can be unexpectedly pervasive and enduring: although intensity of grief subsides after the first year, many parents still feel sad, guilty, and angry after one to two years. Preoccupation with thoughts of the baby who died can continue for even longer (Elklit & Gudmundsdottir, 2006; Lin & Lasker, 1996). Mothers experience the grief as profoundly personal, as if they have lost part of themselves, and emotional distress frequently affects the experience of the subsequent pregnancy and birth. In an attempt to reduce distress, many parents seek to find reasons for the loss, and often resort to blaming themselves (Covington & Theut, 1993; Wing et al.). The intensity of grief can lead to social isolation. Other people do not seem to understand the enormity of the loss, and parents report feeling abandoned by their community (Abboud & Liamputtong, 2005; Wing et al.).

Factors Affecting Grief Outcomes

Although the loss of a baby causes deep psychological distress and psychosocial disruption, not all parents are at risk of developing enduring adjustment problems. Several studies have tried to identify factors which affect grief outcomes. The most salient of these is familial relationships. The quality of the couple’s relationship is a significant predictor of

grief response, as parents rely on each other for emotional and practical support after the loss (Wing et al., 2001; Zeanah & Harmon, 1995). Existing children also play a part in post-loss adjustment; parents who already have other children grieve less than those who don't. A significant decrease in the intensity of grief occurs after the birth of a viable baby subsequent to the loss (Hughes et al., 1999; Lin & Lasker, 1996; Theut, Pedersen, Zaslow, Cain, Rabinovich, & Mohirisa, 1989; Zeneah & Harmon).

Another important factor in helping parents grieve is empathic support, from both their friendship circle and medical staff. Conversely, the responses of medical staff can exacerbate their distress, and affect both short and long term grieving. Responses which diminish the loss, withhold information, or imply that the parents are in some way to blame engender a painful sense of powerlessness. Parents who feel they have been listened to, given as much information as possible, and been allowed to make their own choices, experience interaction with medical staff as supportive and helpful in dealing with their loss (Corbett-Owen & Kruger, 2001; Covington & Theut, 1999; Klier, Geller & Ritscher, 2002).

The Effect of Parent-Child Bonding on Grief

Based on John Bowlby's theory of attachment and loss, a different line of study examines the nature of the bond which the parents have formed with the baby as an influence in grief outcomes (Krueger, 2005; Uren & Wastell, 2002). A healthy attachment is thought to facilitate healthy grieving. This theory has led to practices in hospitals which reinforce a sense of the baby's personhood, such as encouraging parents to hold him or her and providing physical mementoes (e.g. a lock of hair, photograph, footprint and handprint). Modern technologies such as ultrasound foster greater attachment early on in a pregnancy, as parents begin to develop a mental image of the baby. The length of time and effort taken to conceive, experiencing foetal movement, naming the baby *in utero* and preparing the nursery, may also serve to create strong attachment (Bennet, Litz, Lee, & Maguen, 2002; Brownlee & Oiken, 2004; Klier et al., 2002).

Trauma and Meaning-Making

A new wave of grief theory, based on social constructivist approaches, highlights the role of meaning-making in grieving. Janoff-Bulman's (1992) assumptive world theory posits that traumatic loss shatters fundamental beliefs about the world, and disrupts the ability to make sense of life. The bereaved person is left with a frightening sense of meaninglessness and personal vulnerability (Neimeyer, Burke, Mackay & van Dyke Stringer, 2010; Uren & Wastell, 2002; Willick, 2006). Perinatal loss is a very particular kind of trauma. Although it does not always pose a physical threat to the mother, it is an unexpected reversal of an

assumed trajectory and shatters hopes, expectations and identity. An additional complication is the very real sense in which the mother loses part of herself as she is bereft of the baby who has lived within her for many months. The strange and contradictory juxtaposition of life and death which occurs when a baby dies heightens the intensity of the trauma experience (Uren & Wastell; Willick).

Pre-existing meanings contribute to the traumatic nature of the loss. The meaning of the pregnancy to the parents affects both their level of attachment to their baby, and their experience of grief. Parents for whom pregnancy holds significant meaning are likely to experience perinatal loss as traumatic (Corbet-Owen & Kruger, 2001; Uren & Wastell, 2002). In Western society, motherhood is regarded as the “ultimate goal for all women” (Kruger, 2003, p.198), and therefore pregnancy is personally and socially desirable. Similar attitudes seem to be present in African constructs of motherhood, with motherhood being considered as the core of a woman’s identity (Walker, 1995). When being a mother is something that a woman longs for, the loss is devastating. For women who do not want to be pregnant, the experience of loss is very different, often ambivalent or bitter-sweet (Corbet-Owen & Kruger).

Drawing together trauma and meaning-making theories, the grieving process of parents following perinatal loss can be seen as a search to integrate the death of the baby into their lives in a meaningful way. If parents are unable to find meaning, they experience prolonged and seemingly irresolvable grief. Meaning reconstruction involves sense-making (finding concrete and existential reasons for loss), benefit-finding, and restructuring identity (Gillies & Neimeyer, 2006; Neimeyer et al. 2010). However, as Krueger (2005) cautions, mourning is an individual experience, and not all parents undertake meaning construction in the framework described above. Personal and contextual factors also come into play.

Context: a Missing Dimension

Although many of the studies cited above pay attention to immediate context (such as pregnancy history, the parental dyad, available social support) none give serious consideration to the effects of the broader context, such as cultural or ethnic practices and discourses, poverty and unemployment. Moreover, most studies have been conducted in Anglo-European cultures, with the sample coming from well-educated, middle class backgrounds. There have been a few small qualitative culture-specific studies, but no attempts have been made to develop a theory which incorporates context into grief models pertaining to perinatal loss.

South Africa has a perinatal mortality rate of 32.8 per1000 births. (<http://www.hst.org.za/healthstats/75/data>). No statistics reflecting the racial distribution of

these deaths are currently available, but considering the demographic make-up of the country, it is reasonable to assume that the majority of these losses are within the black African population. At least two previous South African studies included coloured women (Friedlander, 1986; Corbet-Owen & Kruger, 2001), but no formal studies have been conducted among the Xhosa-speaking population.

The central purpose of this study was to explore Xhosa-speaking mothers' narratives in order to understand how they grieve following the death of a neonate. The research assumed that meaning-making was central to the grief process, but did not exclude the possibility that mothers might follow very different patterns of grief to what constructivist models suggest. The intention was, firstly, to explore individual meaning-making processes by examining narrative structure and within-narrative themes. A second aim was to identify common meaning-making strategies, sources and themes across the narratives. It is hoped that insights gained will help health care professionals in addressing the needs of grieving mothers.

Methods

A narrative approach was used for this study, based on constructivist epistemology which holds that people use narratives as a way of organising life events into a form that gives meaning and coherence to their lives. A narrative is not necessarily a story, as is popularly understood, with a beginning, middle and end. It may follow a circular rather than a linear structure and include descriptions of episodes, ideas, reflections, and comments on events and people. Narrative arrangement of time seldom follows the sequence of real time, as past, current and hoped-for events are arranged in ways that makes sense to the author, or help to explain a particular issue. Personal narratives are formed in the context of social and cultural narratives which profoundly influence the way individuals interpret their own lives (Albright, Duggan, & Epstein, 2008; Gilbert, 2002; Parker, 2005). Traumatic loss disrupts the narrative flow as the anticipated sequence of events is violated. This can result in a sense of confusion and an inability to place the event meaningfully into the narrative as a whole. Recovery from trauma involves the "re-storying" of life experience, so that the traumatic event can be incorporated into the narrative, and a sense of meaning and identity can be restored (Wigren, 1994; Neimeyer et al., 2010).

Exploring the narratives of women who have experienced the death of a neonate is a valuable way to gain understanding of how meaning-making occurs after this kind of bereavement. Narrative analysis preserves the context and form of individual stories rather than breaking them into thematic segments, so that the narrator's perspective is retained. The

way in which the experience is integrated into narratives through chronological placing and connection with other events has the potential to reveal what the central meanings are as well as how they are derived. By listening for social and cultural voices within the narrative, it is possible to gain an understanding of both subjective experience and contextual influence. Thus it is an approach well-suited to exploring in depth how women engage in meaning-making following neonatal loss (Albright et al., 2008; Gilbert, 2002; Riessman, 2005; Willick, 2003).

Although the methodology of this research was directed by the aims of the study, an overarching concern at each stage of the process was the well-being of the mothers, as talking about their loss had the potential to engender emotional distress. Decisions about which participants to include, where and how to conduct the interviews, and how to conduct follow-up, were all influenced by this concern.

Participants

The study was limited to women whose babies had died within seven days of birth. Although this study makes no attempt to generalise, the choice of participants who had had similar losses more naturally allows parallels to be drawn between their experiences by comparing their stories. Permission was granted by a state Maternity Hospital (MH) to look through their records of neonatal deaths and identify potential participants. Only Xhosa-speaking women whose babies died between one and four years ago were considered, as studies have shown that grief is still acute within the first year of loss, and interviews within that period could be very upsetting for the women (Lin & Lasker, 1996). The women all lived within the greater Cape Town area.

Twenty women were contacted by telephone, with the assistance of a Xhosa speaker. The purpose of this was to ask them if they were prepared to talk to me about their loss, and to ascertain whether or not they were comfortable to conduct the interview in English. Eight agreed to participate in the study. The rest did not participate either because they did not want to, or because they spoke very little English. Two interviews were subsequently excluded because the poor quality of English made them difficult to understand.

Although I did not conduct any formal assessments, I judged all participants (with the possible exception of one) to be of lower socio-economic status on the basis of their dwellings and jobs. Only one has a tertiary education. One of the participants is married, one lives with her partner, two are still in a relationship with their baby's father (although not living together), and two currently have no partners. Two have had other babies since their loss, three have older children and one has no children.

Procedure

This project followed the guidelines for research with human subjects as set out by the University of Cape Town. Permission to conduct this study was obtained from the University of Cape Town Psychology Department. Data collection was done through informal interviews ranging from 25 to 50 minutes in length. At the outset, the participant and I discussed and signed the informed consent forms (see Appendix A). She was reassured that any information given by her would be kept confidential. Participant's details have been kept anonymous and pseudonyms are used, except for the names of the babies, as these are relevant to the discussion. Participants were made aware that the interview might be distressing for them, and that counselling would be available if necessary. Interviews were recorded and transcribed into text for analysis. After each interview, I made brief notes on my impressions of the interaction. A few weeks later, I contacted each participant and took her a copy of the transcription and a small gift. We spoke briefly about how she had experienced the interview, and how she was doing generally. I checked whether she was interested in having counselling. None of the participants took up this offer.

Data collection

Venue. In interviews which deal with sensitive topics such as death, venues can make a significant difference to the comfort or discomfort of the participant. For example, I spoke to Nontombi at her employers' home. They are very supportive of her, and we were able to conduct the interview in privacy. As a result, she was relaxed and articulate. I had planned to interview her in her shack, but she made it clear that a visit from a white woman would have drawn unwanted attention to her. This alerted me to the potentially uncomfortable impact on the women of my mere presence, and I subsequently discussed possible venues more carefully with the participants. Two women were interviewed at work, with their employers' permission, two at home, one at MH, and one at the tertiary institution where she is a student. These all proved to be adequate venues.

Constructing stories. I started the interview with "motivating information sharing" (Rogan & de Kock, 2005, p. 633). I explained the purpose of the study, and that I hoped that the information gained from them would be used to help other women who had lost babies. Following Willick (2005), I told them right at the beginning that I had lost a baby three days after birth in 1990, as this is part of the reason why I have an interest in this topic. Without exception, this disclosure helped to open conversation, but was not referred to again. After the introductory comments, I asked the participant to tell me what had happened when her baby died, and how she had coped with the loss.

Narrative researchers influence the construction of stories because they constitute a particular kind of audience which affects the way the participant frames the story, and because they make particular comments and ask questions which can shift the story line (Gilbert, 2002). In addition, differences in home language, race, culture, and age between us expanded the possibility of misunderstanding (Rogan & de Kock, 2005). I tried as far as possible to allow the narrative to flow without interruption, but I did not always fully understand what was being said, especially as some participants struggled to express themselves in English. I used some of the conversational techniques suggested by Rogan & de Kock (2005), which included negotiating meanings by question such as “I am not sure I understand. Can you tell me more?”, supplying linking statements to clarify meanings, and giving supportive or reflective comments. In each interview the participant was asked what she would say to another woman who had lost a baby. The purpose of this was to focus on the most significant aspect of her experience. Although I had prepared a list of questions as guidelines (see Appendix B), I seldom referred to these. When participants became very tearful, I asked them if they wanted to take a break or stop. In most of the interviews there were prolonged periods of silence until the participant felt ready to speak again.

Data Analysis

Because I had a small sample, I was able to use both structural and thematic analysis. Structural analysis gave insight into individual meanings and meaning-making strategies, while thematic analysis helped identify common meaning-making processes across the participants (Riessman, 2005). I began the analysis by following the outline suggested by Fraser (2004) that incorporates aspects of structural and content analysis.

Interpreting individual transcripts.

1. Identify the type and direction of the stories: are they circular, linear, thematic? Do they appear to be rehearsed, or is this first telling? Are there any contradictions present? How coherent are they?
2. Identify the beginning and end of each line. Lines were numbered for reference purposes.
3. Break the script into specific narrative segments, by looking for particular sets of ideas, plots unfolding, characterisation or chronology.

Identifying different domains of experience. Personal and social influences on the narrative were explored by identifying different aspects of experience. *Intrapersonal aspects* were evident in the narrator’s comments on herself, her actions, and her feelings. *Interpersonal aspects* were all references which involve other people. *Cultural aspects* refer

to popular ideologies or conventions. *Structural aspects* suggested the involvement of particular societal structures or institutions, such as the medical establishment.

Identifying dominant discourses. Attention was given to language linked either overtly or subtly to popular discourses.

Comparing stories. Similarities and differences between the content, tone and structure of the different stories were explored. Common meaning-making processes and themes were identified.

Finally, encouraged by the openness of narrative methodology to adapt an existing system or develop a new one (Smith, 2000), I devised a method of diagrammatically representing each narrative in order to clarify the relationship between temporal ordering and real time, and to identify patterns in narrative structure. This was a highly interpretive way of dealing with the data, and thus needed to be used in conjunction with the established methodology of Fraser (2004). See Appendix C for a more detailed explanation of how this was done.

Discussion

In this discussion, I look firstly at the core meanings and meaning-making strategies evident in three individual narratives. Secondly, I suggest and discuss commonalities in meaning-making processes and sources across the narratives.

Unique Meanings

Most recent grief theorists agree that grief is idiographic, and that processes and meanings differ vastly (Krueger, 2005). Some of the themes in the mothers' stories can be said to be universal, but the ways that these are experienced and expressed are unique to each of them. Several of the participants made comments supporting support this idea.

Each and every one of us is different (Zanele).

You don't know what I'm going through. You went through this and me is me and it's not you (Nontombi).

People tell stories to achieve personal goals: the way the women chose to tell their stories – highlighting some events, minimising others, and linking these to each other – demonstrates something of how they make sense of their loss, and how they construct narratives which serve their needs in some way. Zodwa stated her goals quite explicitly:

I just want to speak about it for someone to know that I went through something like this – and that's it, I think. Not to speak about her in a way that I need someone to help me get over her or something. It's just to let a person know that Zodwa had a child in 2008 and the baby didn't live.

The purpose of this section is to achieve a deeper understanding of individual meanings. I have selected three interviews for this purpose. These were chosen primarily because they differ significantly from each other in structure and central meaning. No grammatical corrections have been made to the extracts. The bracketed numbers (e.g. 12N) refer to narrative segments. Pauses are indicated by (pause); where words have been omitted, an ellipsis (...) is used.

Nontombi. Nontombi's meanings revolve around the mishandling of her daughter's birth, and looking after her first child, a four-year-old boy. Her narrative begins with the story of her labour, and continues uninterrupted as she describes in great detail the birth of her daughter at the local Midwife Obstetrics Unit (MOU); their subsequent transferral to MH; veering between hope and despair as the baby was dying; paying the hospital R250 to bury her; and finally going home alone. She concludes this story by describing again, with increased emotion, what she perceived to be the incompetence of the nurses at the MOU.

They didn't even help me. I gave birth on my own. And they didn't even care...and maybe if they had come and checked the baby properly... He is crying and crying. And checked why he was crying for so long, they didn't even care. The baby cried and cried and cried until it stopped crying.

Her narrative returns repeatedly to this event to thicken the description either by repeating the same phrases or telling new details. In total, the story of her traumatic loss takes up 14 of the 32 narrative segments. This, along with her tearfulness throughout the interview, indicates how painful the memories still are for her. After the baby's death, when her friends told her that she was going to be fine, she retorted, "No, I'm not going to be fine, because I wanted that baby –it was **my** baby."

She questions what caused the baby's death and she discusses at length why women should go to the doctor rather than the clinic. The repetition of this narrative, and the vehemence of her comments ("if you go to the clinics, they don't even care"; "don't depend on the clinics, don't depend on the clinics") reflect her need to find a reason for the death, and her anger towards the MOU. Grief theory suggests that finding reason for what has happened helps to protect the bereaved person from pain, and to restore order, security and predictability (Gillies & Neimeyer, 2006). In Nontombi's situation, the reasons for her baby's death are not absolutely clear, and blaming the medical staff at the MOU appears to increase her anguish and helplessness. She turns this blame onto herself, as she regrets not having booked into MH, where her first baby was born. Later, she questions if MH is not also to blame. She compares the experience to her son's birth, and wonders why things were fine

with him and not with her daughter. There were problems with her first baby (he had jaundice) but the hospital sorted him out; why couldn't they sort things out the second time (16N)?

Her son is a central figure in her story. He is used as a reference point, from which she tries to understand who is to blame. He is also a reference point for her imagining a future for her daughter. She looks at him and wonders how they would have played together (26N). In addition, she regards him as the purpose of her life, and the reason she needs to be overcome her grief. She says, "So I tell myself, I have to be strong. I have to work and I have to provide for this one." Although she does not explicitly state this, her responsibility as his mother seems to be what currently gives her life meaning.

Her concluding lines aptly sum up how she is trying to accept her lot and get on with life. Her neighbours had told her that everything was going to be fine and that God was going to take care of her. She responded, "Even by that time I was thinking, no, you don't understand (*sighs*). But fine." Her narrative counterbalances deep unsettled grief, exacerbated by anger at the medical establishment, with the need to get on with life for the sake of her son.

Bongeka. Bongeka's story is one of fear and liberation. Her narrative is much more linear than Nontombi's, and although her account of her son's birth and death is horrific (6N-11N), she seldom returns to it once she has told it. Her narrative begins with speaking of her pregnancy. Almost immediately, the story focuses on her boyfriend.

...where am I going to start? My boyfriend drank a lot and when he drank, he liked to beat me over small things.

Riley and Hawe (2005) describe the phenomenon of the "supporting cast" (p. 230) in a narrative, people who have a purpose or reason for being in the story. Nontombi's son takes on this role in her narrative. In Bongeka's story, her boyfriend is a prominent presence, featuring in 10 out of 24 narrative episodes. He appears even in stories which are not centrally about him: for example, beating her (1N), being drunk and unable to take her to the clinic (6N), being unavailable (12N), and telling her she had killed their baby (13N). There seems to be a sub-narrative, operating alongside the loss and recovery narrative, interwoven with it, but distinct from it. When she is pregnant, she gets a court interdict to keep him away from her (2N), but she goes back to him as she is fearful of parenting alone (3N). He is drunk when she goes into labour and she has to find her own way to the clinic (6N). He is furious with her that the baby died (13N), but they nevertheless get back together, and he tries to pressurise her into getting pregnant again (22N). It is almost as if this narrative supersedes the bereavement narrative. Her story is as much about the struggle to leave him as it is about her baby's death.

Once the baby has died, she manages to enrol for a course at a tertiary training institution. Fourteen months after the bereavement, she finally leaves him. She describes herself now as being ‘very, very free’. She is focussed on completing her studies, and her advice to bereaved mothers is:

...they must know it’s not the end of the world – and look forward to life. And keep busy with something else.

The linear structure of her narrative reinforces this forward movement in time.

There is a central irony in her narrative: she returned to her boyfriend because she wanted the baby to have two parents; the baby’s death freed her to leave him to pursue her own life. She explains the death of the baby as something which protected her from further pain.

That boyfriend of mine was very abusive and maybe he (God) decided to take away the baby because he knows that I am going to suffer for the rest of my life with the baby.

Her prime meaning is in forging a good future for herself. This has enabled her to put her loss behind her, even though she still feels sad, and was very tearful at times when she spoke. She describes her studies as helping to fill the space left by his death (13N).

...then this Tech took me. That’s when I started to be like myself every time, not thinking like every time.

She is taking on a new role which promises greater independence and enhances her sense of self. Interestingly, Gillies and Neimeyer (2006) speak of identity *change* following loss, but she expresses that she is “like herself” now. When I asked her how she felt the death of her baby had changed her, she was unable to answer my question.

Nonkululeko. If Nontombi’s narrative is circular, and Bongeka’s is linear, Nonkululeko’s is a chaotic combination of the two patterns. I found it difficult to listen to Nonkululeko, and analysing her narrative was a great deal more difficult. This is undoubtedly due in part to the fact that she spoke in her second language, but it seems as if there was more at play. Possibly, I wanted to hear something different from what she had to say. She seldom developed narratives which I initiated, and seemed reluctant to initiate any herself. I asked her what had happened when her babies died. She immediately responded “there’s nothing happened exactly”, and proceeded to describe briefly, almost dispassionately, how she waited so long for the ambulance that she ended up delivering her first twin in her boyfriend’s car on the way to the MOU. Once there, she quickly delivered a stillborn daughter. She and her boyfriend took their surviving baby (a boy) to MH, where he died three or four hours later.

This story took only 3 narrative sections out of 21. She concluded: “it’s only God know I’m supposed to get that child or I am not supposed to.” I subsequently asked questions to thicken her description of the experience. This generated some painfully evocative images. For example, she describes waiting to be discharged:

I was sitting waiting with those 11 babies. They were having babies, and I was the only woman who was just folding my arms with no baby.

Descriptions like this suggest that the experience is still very vivid for her. However, she also expresses that she has put it behind her: “I must be okay now. It’s over.” Her orientation is to the future. When I asked her what advice she would give to another bereaved mother, she said: “She must look to the future. Life goes on.”

Over and over again, she referred to the three losses which resulted from the birth and death of the babies: her job; schooling for her daughter (who then had to earn money for the family); and the father of the babies who left her soon after their death. All of this she blamed on herself for falling pregnant.

I think, I dunno, with me is the cause of everything that is damaged in my house and my future. Because my child is not in school because I fell pregnant and I don’t even have those babies. Maybe, I lose the job; I get the babies and that is something that caused me to be without a job is these babies. Now I don’t have those babies and I don’t have a job. Everything is fucked.

Another insistent, although quieter, voice is the one which she uses to tell herself that she must accept it and that it is God’s will. Perhaps the reason behind the lack of clear structural pattern in the narrative is that these two conflicting voices, one of pain and anger, and one of resignation, defy integration. Her two central meanings are at odds with each other. The struggle for univocality tends to push a narrative towards essentialism changing stories of ambivalence into ones of certainty (Kruger, 2003). By saying that her painful experience is God’s will, Nonkululeko may be attempting to achieve just that.

Examining the three individual narratives illustrates how structure can demonstrate and even create meaning. Nontombi’s circular narrative takes her back to her most salient concerns; Bongeka’s linear narrative shows her orientation to the future; Nonkululeko’s “chaos narrative” (Frank, 2007) reflects how much the loss has fragmented her life. Nontombi and Bongeka’s stories contain dominant characters that influence meaning; Nonkululeko’s is a more solitary story. The narratives contain few reflective statements dealing directly with what the loss has meant for them: these meanings are implicitly embedded in the narrative structure.

Common Meaning-Making Patterns

Comparing the narratives did not yield clear common meanings, but certain patterns of meaning-making emerged. Firstly, three aspects of ruptured meaning were central in each of their accounts: losing a baby who was not yet an acknowledged person; being a mother without a child; and trying to make sense of a death that shouldn't have happened. Secondly, common influences on meaning-making emerged: fathers, older women, social 'stories', and the context of deprivation.

Restoring shattered meanings.

Acknowledging the baby as a person to be mourned. Literature on perinatal loss indicates that grief is compounded because it revolves around a relationship in which "all aspects await future realisation" (Uren & Wastell, 2002, p.282). One of the meaning-making tasks of grief is to validate the reality of the child (Neimeyer et al, 2010), especially when no other friends or family members have seen him or her. The women seem to do so by describing the birth and death in vivid detail; naming the baby; engaging in mourning rituals and having mementoes; mentally comparing their dead baby to other children; and fantasising about how they would have played together.

The women give moving descriptions of their babies which suggest the extent to which they view them as individuals, separate from themselves, who need to be mourned. Nosandla's description of her baby moving shortly after his birth gives a strong impression of him as a living, active person. In a slow, almost reverential tone, she says, "...the baby was breathing, breathing, breathing." Later, she explains how she and her husband "...saw him moving his hands, opening and closing his eyes." Bongeka's description evokes the sense of a person with his own thoughts: "The baby was very small. Even forgetting to breathe. He thinks he's still inside my womb."

Four of the women gave names to their babies which held significant meaning for them. Zanele called her baby "Lihle" (beautiful), Nontombi called her baby Bayilitha (light), and Bongeka called her baby Onakho (God can). Zodwa named her baby Sibongile, which means "we are grateful". To her distress, the gravestone was marked as "Simbonile" which means "we have seen her". She says she has accepted this as the baby's name because her family found it very meaningful. She has, however, never been to visit the grave again.

Funerals are important rituals which acknowledge the short life of the baby. Nontombi, Bongeka and Nonkululeko could not afford a funeral, and this is a source of great sadness for Nontombi. Zanele chose not to have a funeral. Zodwa and Nosandla both buried

their babies in Gugulethu. Nosandla visits the grave regularly to clean it, which she says helps her to deal with her loss.

Personal rituals are also evident in the narratives. For weeks after the death, Nontombi regularly washed and re-packed the baby's clothes. Zodwa watches SABC news at midnight as often as she can because the presenter represents to her what her child would have looked like. MH offers to take photographs and make hand- and footprints of the babies as mementoes. Zodwa, Nontombi, Nosandla and Bongeka chose to take these when the baby died. Zodwa and Nosandla look at them with their partners, and use the photographs to compare the features of the baby with their surviving children.

Fantasies about the babies give a sense of their continued presence in the women's lives. All the women, except Nonkululeko, sometimes look at other children and imagine what their babies would be like at that age. Nosandla and Nontombi, who both have older children, imagine the siblings playing together.

These practices affect meaning-making by acknowledging the baby as a person with whom the mother had a relationship. This validates the need to grieve. It is striking that Nonkululeko, who has such strong ambivalence and even anger towards her babies, is the only one who has done none of these things. It is possible that in her desire to live out her vehement statement "it is **over**," she is choosing to forget rather than remember.

Pregnancy, motherhood and identity. The meaning of pregnancy and motherhood for a woman affects the meaning of the loss. Corbett-Owen and Kruger (2003), in a study conducted in the Western Cape, found that an unplanned, unwanted pregnancy results in a more ambivalent grief response. In this study, although only Nosandla's pregnancy was planned, none of the pregnancies were regarded as unwanted. The other five women were 'surprised' to discover that they were pregnant. None of them mentioned considering termination; Zanele pointedly said that she thought it was wrong to take away a chance of life. Different factors enabled them to accept, and even be happy about, being pregnant. Zodwa and Nontombi were happy because they were in stable relationships. Zodwa was especially pleased because she had thought that she was infertile. Bongeka was happy, despite being in an abusive relationship, because she was "a little bit older, 27 by that time". Nonkululeko, although she already had two children, was pleased at the prospect of another baby, as it would increase her status: she would be "better than her mother" who had only had two children.

Underlying this attitude toward pregnancy is a strong social meaning around motherhood. There seems to be an assumption that all women should have babies. Zodwa's

mother is delighted her child is pregnant, despite her not being married. Bongeka, although she is currently not in a relationship, says that she does want another child at some stage. This resonates with Walker's (1995) suggestion that motherhood is regarded as the core of womanhood: the loss of a child therefore profoundly damages a woman's core identity. It follows that identity can only be restored with the birth of another child.

The fact that you have lost a baby pulls, pulls you apart. Something in you goes with the baby. And (pause) probably (pause), I think I am complete now. It comes back when you have other babies (Zanele).

Motherhood creates particular roles and behavioural expectations. In the words of Gertrude Shope (president of the ANCWL):

Women bring life to this world and they have a duty to make sure that this life is preserved and protected (quoted in Walker, 1995).

Being unable to fulfil this role is painful for women whose babies die.

When someone tells you you can't protect your baby, (pause) you feel like (pause) if I can't protect my baby, who is going to protect my baby. You feel useless (Zanele).

Bongeka describes a similar feeling of uselessness in hospital.

They called me to give love to the baby. I did not know what to do after giving, because I can't take him to me. He was lying there (Bongeka).

Nosandla explains how she needs to nurture her child, even though she is exhausted:

I can't go and rest whereas my child is here. I can't be far from my child. I have to give him the support that he can feel I'm here (Nosandla).

Losing a baby puts a woman in the confusing position of being a mother with no one to mother. It is difficult to go back to being a carefree woman with no responsibilities.

...before I had my second child, that mentality of being a mother never went away, even though I didn't have child. So I changed from the person I was, because before that I was reckless. I was a drinking girl, going out all night partying. And after my daughter, that all changed (Zodwa).

After the death of their baby, the women engage in mothering either with their surviving children or with other children. Mothering can restore purpose (Nontombi says she has to be strong for her four year old son) and comfort (Bongeka finds comfort in looking after her nephew, Onke).

These meanings – the link of motherhood to womanhood, the role of mother as responsible protector and supporter – imbue the baby's death with particular significance. The loss deprives women of their identity and role. In restoring meaning to their lives, they

seek to recreate that identity through their relationships with their own children, or with others' children. In the case of Bongeka, she chose a new role as a horticulture student, but she still hopes to have her own child some day.

Gillies and Neimeyer (2006) see the reshaping of identity as one of the three tasks of meaning-making after loss. There were very few direct references to personal identity in the narratives, and only Zanele understood instantly what I meant when I asked her if she had changed or grown as a result of her loss. It seems as though identity issues for the women in this study revolved primarily around motherhood. It is premature to say whether this is different for Xhosa-speaking women compared to westernised women, who (arguably) believe they have control over their futures, including choices around pregnancy. A comparative study could be of value in clarifying this.

Finding reasons for the loss. A common theme in the narratives is the search for a reason for the death. Sometimes this entails looking for a concrete cause. Sometimes it means trying to answer the existential question: “why did this happen to me?” Trying to find medical answers does not always clarify the cause of death, and often leads to blaming doctors or nurses for not giving adequate care. Existential searches draw largely on religious discourse. The “answers” found in this way do not always co-exist logically or comfortably with other meanings.

Concrete causes. Unresolved questions about cause of death can prolong grieving indefinitely (Krueger, 2007; Willick, 2006). Nosandla and Nontombi both blame the MOU for their loss. They display great distress, weeping deeply, when they speak about this. Nontombi was told that her baby had an infection, and that if she had been transferred to MH earlier, he may have lived. Nosandla was in advanced labour when she arrived at the MOU at 2am, after waking up to find her bed soaked in blood. Although she could feel the baby crowning, the midwives would not allow her to deliver at the unit because she was booked in at MH. She was instructed to keep “breathing, breathing, and breathing.” She was obliged to wait for an ambulance to take her to MH. When her son was born, he was not breathing. Although he was resuscitated, he lived for only a day. She, her husband and the extended family see the cause of the death as medical incompetence. Zodwa had a Caesarean section when her membranes ruptured early. She and her boyfriend chose to have a post-mortem performed, and they returned to MH six weeks after the baby's death to have the results explained. They were completely confused by the explanation. She says she still doesn't know “what killed the other child” and blames the hospital for not dealing with them in a

helpful way. She is haunted by her lack of knowledge and her narrative is punctuated by the phrase: “I don’t know, I don’t know.”

Finding a clear cause can help to lessen feelings of grief. Zanele finally found an explanation for her failed pregnancy when she went to a doctor during her subsequent pregnancy, who told her that she had an incompetent cervix. She says, “When I knew what happened, I no longer felt angry.”

Bongeka could have blamed the MOU for mishandling her delivery, but she chooses instead to blame her boyfriend for damaging the baby when he abused her, together with the physical stress of her job. This explanation seems to satisfy her.

Existential meaning. Even for the women who have some idea of what caused their loss, the existential questions continue to be troubling. Restoring existential meaning involves either assimilating the experience into pre-existing belief, or adapting belief to understand the experience (Neimeyer et al. 2010).

Apart from Zodwa, who claims she is “not a great believer in God”, the women all believe in a spiritual dimension and derive meaning from that. Mostly, this means accepting that God is all-powerful and all-knowing.

I think my trust is in God. If a thing happen, just God likes to be happening (Nonkululeko).

I mustn’t lose hope in God and I must trust in what God is doing. He knows the reason why (Nosandla).

God knows what he was doing when he was taking away my baby (Bongeka).

The main function of this belief is to help them view the world as a safe place where it is possible to hope, as God is in control. However, it does not always accord with meanings or explanations the women raise elsewhere. For example, Nosandla blames the MOU for the baby’s death; yet says God is responsible for what happened. She claims that “if you have faith in God, you’ll have another child”, but on the other hand says that “my husband is planning to have another child.” Her husband is a dominant presence in her narrative. They share a strong religious faith. In the two statements above, she almost equates him with God in terms of power to achieve the goal of another baby. God and her husband provide comfort and hope. At one point in the conversation, she is weeping uncontrollably, and then stops (almost instantly) and comforts herself with the words: “but it’s only God, he give and it’s only God takes.”

Nonkuleko's faith in God seems at odds with her anger and distress over her multiple losses. Reasoning her way through this seems to help her to reach a point of acceptance. This could, however, be more an indicator of her own lack of power in the face of her situation than belief in God's control.

If you are supposed to get a baby, you are supposed to get it, but if you are not supposed to, only God knows why. Yes, I said that to my baby when she passed away. But it's the only thing that left to me. When I think that I lost my job at the same times (pause) and (pause) my girl is supposed to be in school, she is not in school yet. But even that, I accept it.

Zanele is ambivalent about the role of God in the trauma. She is still trying to accommodate her beliefs so that they fit in with her experience.

It distanced me to God... Because you are angry: why did he let that happen? The next minute you are crying to him for comfort.

The fact that she has more control over her life than some of the other women (she has a job as a financial analyst, and had medical aid to use private health care for her subsequent babies) could be why she is able to articulate and live with this ambivalence. There is less urgent need for someone/ something else to be in control.

Nontombi deals with the question of how a good God could allow tragedy in a very different way. She believes that evil spirits caused the death. In this way, she can keep the image of God as loving, but with diminished power.

A comparison with constructivist models of grief. There are some similarities between the meaning-making challenges of the bereaved mothers and the model of restructuring identity, benefit-finding and sense-making suggested by grief theorists (Gillies & Neimeyer, 2006; Neimeyer et al. 2010). The task of restructuring identity is evident in the women's struggle to come to terms with losing their identity as a mother. Looking for reasons for the loss parallels with the concept of sense-making. The need to acknowledge the personhood of the baby, which is strongly evident in these narratives, is a grief task unique to perinatal loss (Bennet et al., 2005). Noticeably lacking is the third dimension, benefit-finding. Further investigation is needed before comment can be made on whether this is typical of neonatal loss, or if it is a result of the context of the participants.

Influences on meaning-making.

Fathers. Fathers play a role in meaning-making by reinforcing ideas of motherhood and, together with the mother, acknowledging the baby as a distinct person to be mourned. Fathers' grief impacts the mothers' grief by validating the enormity of the loss.

Zanele's comment that "with us African women mostly, the minute you find out that you are pregnant, the partner just disappears", is not substantiated in the behaviour of any of the men other than her own baby's father. The fathers are a strong presence in all of the narratives. They feel excited at the pregnancy (Nosandla, Nonkululeko) and take their role seriously by giving practical support (Nontombi, Nosandla, Zodwa). Zodwa's boyfriend stops drinking and smoking when he discovers she is pregnant. Their response to the pregnancy reinforces its meaning as a valued and significant event.

The fathers all grieve for their babies in different ways. Zodwa is still angry because the hospital did not offer her distraught boyfriend counselling. He and Nosandla's husband cry at the time of the death and afterwards. They continue to talk about the baby long after the death, as does Nontombi's boyfriend. Nonkululeko's boyfriend leaves her, and then wants to get together again because he still regards her as the mother of his child. Bongeka's boyfriend experiences a complicated kind of grief as he weeps and accuses her of killing his baby.

The narratives of Nosandla, Zodwa and Nontombi leave an enduring impression of couples grieving together. Their partners are part of the process of reflecting on and trying to make meaning of the loss. Some of them are part of the ongoing conversation of whom to blame for the death and the discussion on the existential reason for the loss (Nosandla, Zodwa). They play a significant role in establishing a sense of the child's personhood, by buying clothes (Nosandla) during the pregnancy and talking about the baby after the death (Nosandla, Zodwa and Nontombi). Zodwa gives some indication of the content of these conversations.

Because till today, he is speaking about the baby's fingers and stuff; 'that baby had your fingers'.

It is beyond the scope of this paper to discuss fathers' grief and the couples' co-construction of meaning. In general, it remains an aspect of perinatal loss which is under-researched.

Older women and meaning-making. There is an underlying presence of older women in the lives of all the mothers, giving them advice and comfort, and passing on religious or cultural norms around mourning. Both Nosandla and Zodwa drew heavily on their mothers for comfort, staying with them at times. Zanele's mother lives in the Eastern Cape, but she phoned often after the baby's death to talk with her. Nontombi and Nonkululeko's mothers are both dead, but they received practical help from their aunt and stepmother respectively. Nosandla refused counselling at MH, because her mother is a lay counsellor and wanted to speak with her. The advice she gave – to accept the loss and trust God – were central to Nosandla's meaning-making. Some older women cautioned the younger women

(Zodwa, Bongeka, Nosandla) about speaking to me, in case it upset them. The overall impression I gained (from spontaneous, unrecorded conversations as well as the transcripts) is that the older women generally thought it would be best for the mothers to stop thinking about their babies and put the experience behind them.

Bongeka's aunt told her to burn the photos as it is bad luck to keep pictures of a dead baby – something she bitterly regrets doing. Zodwa's mother told her she would not fall pregnant if she kept the photo of the baby on her phone, so she transferred it to her own. I asked Zodwa if this was a customary belief and she laughed and said, "I think it is an old woman being superstitious." She then went on: "I deleted the photo. Soon afterwards, I fell pregnant. I don't know why!" This incident is illustrative of what Nadeau (1997) calls "coincidancing", in which two or more people engage in "sense-making about a seemingly random event in the context of common loss" (Neimeyer et al., 2010, p.77).

Social stories. Social stories, found in social conversation or the media serve to substantiate personal meaning. Zanele referred to a story to justify her annoyance that the staff at MH had not put her baby on a ventilator because she was "too small". She told how a friend's 0.8 kg baby (smaller than Lihle) had been put on a ventilator at a different hospital. Nontombi's friends told her positive stories of other women who had lost babies, as a way of trying to make her feel better. She strongly resisted the comparison, but expressed grief by referring longingly to stories on TV where the hospital makes a mistake, and a person thought to be dead is actually alive. Nosandla told a story she had witnessed on a TV channel, which she watches everyday, where an infertile couple were prayed for and subsequently conceived. This reinforces her belief that God will give her another child. Lastly, Zodwa watches the late night news on SABC 2 because the presenter reminds her of her baby. These social anecdotes are drawn into narrative to reinforce meaning, or possibly are in themselves a source of meaning (as in the case of the TV evangelist).

Poverty and meaning-making. Poverty profoundly affects the women's grief and meaning-making. Zanele seemed to take on the role of spokesperson in the regard.

If you can't afford, you just have to accept things that happen to you without any explanation. That is how it is with the life we are living; if you are less fortunate, things happen to you and you don't even understand why they happen.

There were three general patterns of influence. Firstly, poverty puts pregnant women at risk of losing their babies, and can exacerbate the traumatic quality of the loss. Secondly, it renders them unable to perform rituals which could provide long-lasting comfort. Thirdly, it

generates a sense of helplessness. Thus it plays a role in event of the baby's death and in hindering the meaning-making process.

The risk the women face has as much to do with lack of choice over health care as it does with poverty per se. Unable to afford private care, the women are obliged to attend MOU's in the townships. These are not all uncaring and inefficient, but the women's stories point to a serious malfunctioning in the system (see also Abrahams, Jewkes, & Mvo, 2001). Despite Nontombi's insistence that something was wrong, the nurses ignored her daughter's condition until she was critically ill. Nosandla was not allowed to deliver at the MOU despite being far into labour. Bongeka was mocked and told to go home when she came in after her membranes had ruptured. Nontombi reflects on the unreliability of the MOU's:

I think the doctors are the best, if you can afford that's all I can say. If you want the best for your baby, you must be prepared to go to the doctor. Don't depend on the clinics, don't depend on the clinics.

A further complication is that women have limited access to transport, and have to wait for an ambulance to take them to hospital. Nosandla and Nontombi both tell of waiting for a long time at the MOU for an ambulance to take their baby to MH. Bongeka describes her difficulty in getting to the MOU, as she had no money for transport.

On the way, I was like lying in the road. I was losing the energy. I walked. I walked a long way, and then I managed to get there and then I asked her to go and ask the ambulance, but they say the ambulance will take too long, and then he went to another guy who has got a car and they take me to (MOU).

The women struggle to find out what is medically wrong with their babies, although it is not clear if this is due to inefficiency, lack of sympathy, or poor communication. Bongeka resorted to borrowing money to go to a doctor after her membranes had ruptured. Zanele found out from a private doctor about her incompetent cervix. Finding a concrete cause for the death is an important and often difficult part of meaning-making: the women's financial situation exacerbates this difficulty.

Lack of adequate funds also means that the women are obliged to work throughout their pregnancy, often in physically taxing jobs (Bongeka). Losing a job because of the physical strain of pregnancy can be devastating. In Nonkululeko's case, this compounds the complicated grief she experiences after the death of her babies.

Neither Nontombi nor Bongeka could afford a proper burial. Bongeka wept when she told me that, and Nontombi's explains how difficult this is:

If I had more money and buried my own child, maybe every time I miss her so much I should go to the grave and talk to her and just visit. But I couldn't afford the funeral, I

can't do anything, I don't even know what happened and what they did to the baby, I just don't know anything.

Possibly losing a child when you cannot afford to “do anything” and “don't know anything” requires different grieving strategies. Nonkululeko's litany of “I just accept it” and Nontombi's' concluding sigh “But fine”, could indicate that simply resigning oneself to suffering may be an adaptive way of dealing with loss when deprived circumstances restrict meaning-making.

Conclusion

This study explored how bereaved mothers tell stories of their loss in order to help them to understand its significance for their lives. Despite the fact that the women spoke about painful issues in their second language, their often poetic use of English created moving and evocative accounts of their experience. The narratives reflect their struggle to establish a sense of their baby as a person to be mourned; to redefine their own identity, fragmented by the loss of part of themselves; and to find reasons for the death. Their subjective experience of meaning-making is influenced by the baby's father, older women in their lives, social stories, and the context of deprivation in which they live. It is clear from their narratives that grief is not a linear process which reaches a conclusion, but an ongoing search for meaning which may take many years.

Three areas of further research are suggested by these findings. Firstly, the grief of fathers and the way couples grieve together is an under-explored area. Secondly, it appears that emotional support offered to bereaved mothers by state health care services is not always adequate. A focussed investigation into this may help planning more appropriate interventions. Thirdly, the effect on poverty stressors on parents' grief is little understood. Insight into this could contribute to more effective ways of supporting bereaved mothers.

The words of Zodwa, which trail off into a pronounced shrug, seem to sum up the importance of this study:

You know, I don't know whether people take it lightly or not, but losing a child is a very big deal. I don't know whether, since they think you don't know the child and you don't see the child, but the after effects of them not knowing how to deal with a situation like that, it does a great...

I hope that this study will help to alleviate some of the consequences of our “not knowing”.

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Appendix A

Informed Consent Form

1. Invitation and purpose

I am doing research on how mothers who lose babies through neonatal death deal with their loss. I am interested in interviewing people whose loss happened at least one year ago and I would value your participation in the study.

I hope that what I find out will help other women who experience this kind of bereavement as well as the professionals who work with them (such as, doctors, nurses, funeral directors, clergy, and therapists).

2. Procedure

The study will involve doing one-on-one interviews with women who have experienced perinatal loss. The interview will last for about an hour, although it may take longer. The conversation will be recorded, and then transcribed.

If you decide to participate, I will ask you to tell me the story of your loss in whatever way you like. I would like to hear whether (and how) you were able to make sense of your loss and resolve your grief, and whether the death changed you or affected your views and beliefs.

The interview will be held either at your home or in another venue where you feel comfortable.

Some time after the interview, I will phone you to clarify anything I am not sure about, and to give you the opportunity to add to your story if you wish. If there is a lot to discuss, we may meet one more time.

3. Risks, Discomforts, and inconveniences

There are no serious risks involved in the study, although it might be distressing for you to talk about your loss.

4. Benefits

There are no direct benefits to you from this study, but the knowledge gained will benefit other mothers who experience loss.

Although the purpose of the interview is not to provide counselling or therapy, talking about your loss may help you in dealing with your grief.

5. Privacy and confidentiality

If you decide to participate, I will keep your identity confidential, and will use a pseudonym in writing up the report. The recordings and transcripts will be kept in my office at home. Only my supervisor and I will have access to them.

6. Remuneration

You will not be paid anything for participating, but any costs that you incur (such as transport) will be paid back to you.

7. In case of emotional distress

If you find that talking about your loss causes you emotional distress to the extent that you would like to speak with a counsellor, I will refer you to someone who will be able to see you at no cost to yourself.

8. Right to withdraw

You are under no obligation to take part in this study. If at any stage you would like to withdraw, you have a right to do so. If, after the interview, you decide that you do not want your story to be used, you have a right to stop me from doing so.

8. Further questions

If you have any further questions or concerns please contact me (Colleen Sturrock).

Telephone: 083 321 7299

Email: strcol004@uct.ac.za.

10. Signatures

_____ has been informed of the nature and the purpose of the research described above including any risks involved. She has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the research participant.

Researcher

Date

I have been informed about this research study and understand its purpose, possible benefits, risks and discomforts. I agree to take part in this research. I know that I am free to withdraw this consent and quit this project at any time, and that doing so will not cause me any penalty.

Participant

Date

Appendix B

Interview guidelines

1. **Pregnancy.** Did you want to be pregnant? How did you feel? How did your pregnancy progress?

2. **Pregnancy Loss:** immediate events around the time of the loss. What happened? Did you see/hold your baby? Did the medical staff speak to you/ explain to you? How did you feel? Names? Mementoes?

3. **Immediately afterwards:** funeral, burial, what did you do? Go home? Work? Feelings? Tears?

4. **Social support/response:** immediately around loss, in months afterwards? Did you talk about your loss? Do you talk now?

5. **Relationship with partner.** How was this affected? Did you support each other, did it change?

6. **Family rel/ with other children.** Did you tell the children about loss, how did they deal with it, how did it affect the family.

7. **Do you believe on God/ go to church?** Has this loss changed the way you think about God? Has believing in God helped you to cope with this?

8. **How do you think about you loss now?** How has it affected you? Did it touch you deeply or not a great deal?

9. Do you think it has changed the way you think about yourself? Has is changed your personality?

9. Has the loss changed the way you think and feel about life?

10. What has helped you to understand or deal with your loss?

11. How has your grief changed over the years? Is it different? How would you describe your feelings about the baby and the loss now? Do you still think about your baby? Is he/she part of you now?

12. What would you say to another woman who has lost a baby?

13. How do you feel now after talking about the loss? Was this interview different from what you expected?

Appendix C

Using a diagram as a tool for analysing a narrative

1. A foolscap page was divided into four longitudinal sections, labelled 'past', 'chronology', 'future', and 'reflections'
2. I drew small blocks referring to individual narrative segments, identified by number and title, and placed them according to whether they referred to past (pre-baby) events, future events (things still hope for, or imagined for the baby), reflections (existential comments on why the baby died) or were part of the sequence of events on real time.
3. When a narrative referred back to a previous narrative, I drew a line indicating this, and placed the narrative block alongside the first one. This enabled the identification of clusters of narratives which dealt with similar material.
4. Where there appeared to be a sub-narrative, I drew a line under the "chronology" and plotted references to the sub-narrative along it.
5. Blue lines indicated narrative shifts which I initiated. Where these did not develop, I drew a broken line. Shifts or new narratives initiated by the participant were indicated by black lines.

Attached is an example of how this was done.