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**Rituals surrounding the care of the dying pre-viable baby in labour ward
a critical interpretive synthesis of the literature**

Cameron, Joan Elaine

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Rituals surrounding the care of the dying previabile baby in labour ward

a critical interpretive synthesis of the literature

Joan Elaine Cameron

2011

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**RITUALS SURROUNDING THE CARE OF THE DYING PREVIABLE
BABY IN LABOUR WARD: A CRITICAL INTERPRETIVE SYNTHESIS OF
THE LITERATURE.**

CHAPTER ONE: INTRODUCTION AND CONTEXT OF THE THESIS

The purpose of this chapter is to introduce the thesis and to contextualise some of the issues surrounding the death of previable¹ infants in labour wards. The reason for pursuing this theme extends from my own experiences and personal accounts of practicing as a midwife. My aim in this thesis is to offer the reader a glimpse of what appears to be, more than other types of death, a particularly taboo and ‘uncomfortable’ subject in the National Health Service (NHS). I will argue that the effect of this ‘discomfort’ has, I believe, limited the attention given to the needs of the complex spectrum of parents and babies experiencing this situation. To make my case, I will illustrate how this type of death receives only fleeting attention in professional training, literature and policy. I will suggest that this lack of attention appears to have produced a process of care that is poorly evidenced, one that may not always be meaningful or comfortable to the complex spectrum of parents, dying babies and health professionals involved. Of course, this lack of attention is understandable, as accounts of dying previable babies in labour wards are usually emotive and the experiences described by parents are harrowing and passionate, yet, from my own experience the gap in evidence surrounding these ‘monumental’ parental experiences is one that should, in the delivery of appropriate care, be thoroughly explored and attended to. It is this gap in the literature and the reasons

¹ A previable baby is one born alive at less than 24 completed weeks’ gestation

for them that I wish to address in this thesis. In particular, I will explore how the evidence base for care that has been developed appears to be more attuned to and representative of some parent groups and less so of others. This raises questions about the appropriateness of practices that might not attend to the needs of all parents affected by the death of a baby, or be in the best interests of the baby or the maternity care professionals trying to attend to them.

This chapter will explore the role of autobiography in research and how it is being used in this doctoral study to make explicit the rationale for the study, through exploration of my own personal professional practice. The theoretical framework which underpins the study and the methodology used will be described briefly in this chapter, although both aspects will be addressed in detail in later chapters in the thesis. This chapter will conclude by describing the structure of the thesis and summarising the study.

Autobiography as a research method

The use of autobiographical material in research may mean the use of data generated by another person. In the context of this doctoral research project, autobiographical data refers to data generated by my personal experiences as a registered midwife from 1986 onwards working in a London teaching hospital. During this time, I collected data using a reflective journal and through my participation in an informal professional reflective group. The writing exercise is an occasional diary which I still complete. It contains personal reflections on work. It was started after being

prompted by a midwife whom I respected. She demonstrated how she used her notes to reflect on her practice and philosophy. In particular, she used her journal to examine painful or difficult experiences. She would share some of these reflections at an informal professional support group and would invite others to comment on them. Her ability to be open about situations where her beliefs or practice were challenged is fundamental to autobiographical research (Tenni et al, 2003). Encouraged by her honesty and determination, I too started a reflective journal.

This doctoral project has its roots in my feelings of unease when caring for a dying pre-viable baby on labour ward, after a decision had been taken by the medical team not to resuscitate the baby. My insecurity stemmed from never knowing whether my approach with parents and the babies was meaningful to them in terms of what they needed to help them to endure the death of their baby as parents. Tenni et al (2003) suggest that: 'It is with the physical and emotional in particular, that we often get the first clue that something is happening and may be worthy of exploration.'

From my perspective, engaging with the data in autobiographical research is challenging because there can be no question of being objective. What I have written here are my own experiences which I have tried to contextualise with some of the relevant medical and social science literature surrounding this area. What helped me also to find some additional degree of externality was having the opportunity to discuss the data with colleagues and supervisors. This is what has happened throughout my doctoral project as I laid my accounts before my supervisors. Their

questions helped me to explore my understandings of the situations and prompted me to investigate further the reasons for my behaviour and feelings.

Rationale for the study

The impetus for this doctoral study into the care of dying pre-viable babies in labour wards arose from my clinical practice as a midwife. Perinatal loss takes different forms: miscarriage², abortion³, stillbirth⁴ and neonatal death⁵. I had professional experience of dealing with situations involving a range of perinatal loss. Although birth and death seemed at opposite ends of the caring spectrum, the elements of caring appeared to be similar. Women in labour required emotional and physical support and women who were bereaved required this, too. Providing care in both situations required me to try to interpret the cues that women gave and to try to meet their physical and emotional needs.

The following vignettes illustrate two very different situations of caring for dying babies and the comparison, I hope, will help to provide the background to some of the issues I wish to explore and the questions I will raise for discussion in the thesis. In particular, I will explore the use of ritual in relation to the care of the dying baby (van Genneep, 1960; Romanoff & Terenzio, 1988). I use the term 'ritual' to denote practices that are carried out in a manner that is meant to be meaningful, as opposed to procedures which are carried out from a purely clinical perspective. The nature

² Miscarriage refers to the spontaneous loss of a pregnancy before 24 completed weeks of gestation.

³ Abortion is classified as the deliberate termination of a pregnancy.

⁴ A stillbirth is a baby born after 24 completed weeks' gestation who shows no signs of life after complete expulsion from the mother.

⁵ A neonatal death is the death of an infant within the first 28 days following birth.

and meaning of the rituals relating to care of dying and dead babies will form the focus of the thesis.

Vignette 1: Focusing on a dying baby in Labour Ward

One evening, while working in a labour ward I was asked to care for a woman and her partner. The woman was in preterm labour⁶. She was 23 weeks pregnant and attempts to slow or stop her labour had failed. It was inevitable that the labour would progress and the baby would be born that night. She and her partner had already been informed by the obstetrician and paediatrician that the baby would not survive and would not be admitted to the neonatal intensive care unit. Although the baby would not be resuscitated, the consultant paediatrician had asked to be informed when the birth was imminent. This was not part of the local protocol for the care of pre-viable babies but this particular consultant told me that he personally felt that it was an important gesture and demonstrated that the baby's birth was still a significant event, even though the baby would not be resuscitated.

The woman's labour progressed very quickly. The paediatrician entered the room as the baby was born - it was a boy. The baby looked blue and very scrawny. I dried the baby and wrapped him in a blanket. The paediatrician asked the parents if he could check the baby and he placed the baby in a cot. He unwrapped the baby and listened to the baby's heart using a stethoscope. He wrapped the baby again and gave the baby to the mother to hold.

⁶ Preterm labour refers to the onset of labour before 37 completed weeks' gestation.

I remember he explained to the parents that the baby was very small and bruised and that it would be 'kinder not to stick tubes and needles' into him. He did say that the baby was alive but would die soon and that it 'would be best' if he stayed with his parents. The parents held the baby and unwrapped him and examined him very carefully. It was obvious that the baby was breathing as his chest was moving. As he was leaving the room, the paediatrician asked me to call him when the baby died as he would return and certify the baby's death.

Normally, following the birth of a baby, the routine tasks of clearing up and completing documentation are carried out. This practice happens whether the baby is a healthy term infant or stillborn. The notes can be written up in the room but computer work is carried out at the desk. Midwives usually tell the parents that they're going out of the room to 'finish the notes' and that they are within calling distance if they are required. This gives parents the opportunity to spend private time with their baby.

On this occasion, however, I felt loathe to leave the room. The baby was alive but he was not healthy, His death was imminent but I could not predict exactly when it would happen. I felt confident that the parents wanted some time alone with their baby but I had a feeling that the moment when they realised that he was dead could precipitate a crisis. I thought that I should be there to support them. Eventually I did leave the room but I left the door ajar and took the father to the door of the room to show him where I would be sitting at the computer.

Completing the paperwork took about 15 minutes and I went back into the room. I asked the parents how they were and the father said: 'he's still alive'. The baby was still blue but was definitely breathing and his limbs were moving. The baby's father asked me how long the baby would live. I told him that some babies would live for perhaps an hour or two but I reinforced the inevitability of the baby's death because of his prematurity. The mother asked me if there was anything that could be done for the baby. I told her that being held would be comforting for the baby. It felt like the right thing to say but I had no way of knowing if it were true.

Over the next hour, I entered and left the room on several occasions. I was the only person who came into the room. This differed from live births where other midwives would come in and congratulate the parents on the birth of their baby. Each time I left the labour room, my colleagues would ask me if the baby was still alive. When I replied in the affirmative, they would grimace as a way of indicating their understanding that this was a difficult situation. Although the labour ward was busy, I was not asked to help out. There seemed to be a tacit understanding that the situation I was involved in was complex and unpredictable, although at times I was sitting at the reception desk apparently doing nothing.

Each time I entered the room, the baby's father would inform me that the baby was still breathing. I tried to downplay the importance of this observation and stressed the inevitability of the baby's demise. On one occasion, he asked me what would

happen if the baby continued to breathe. I told him that this would not happen. I was aware that he was hoping the baby might continue to live – to be a ‘fighter’- but I knew that this was impossible and I believed that it would be kinder to take away any expectation of a happy ending.

When the baby was just over an hour old, it became apparent that he was dying. His breathing became more sporadic and his colour changed. He became very blue. I decided to remain in the room to support the parents. His parents noticed the colour change and started to comment on his appearance and make reference to his death. Their comments were directed at me so I felt that this justified my presence in the room. Soon, the baby was dead. I called the paediatrician and he came and confirmed what was obvious to us. He made comments about how nice it was for the parents to have had time to ‘get to know’ their baby and for the baby to have had a peaceful death.

I was shocked at my relief at the baby’s death. I moved into a routine that was directed by the protocol following the death of a baby on labour ward. I suggested to the parents all the practices that were associated with the death of a baby on a labour ward. ‘Would they like to bath the baby?’ ‘Did they want to dress the baby in their own clothes – or would they prefer hospital clothes?’ ‘Would they like to keep the baby’s name bands?’ I did not know if the parents were aware of my sense of relief or if they realised that the quality and nature of the performance had changed. But I

could sense my confidence in the role that I was playing and this enhanced my feelings of safety and comfort.

Following this experience, I cared for several other parents and babies in similar circumstances. In those cases, the babies died very soon after birth. Each time, I was filled with a sense of relief when the baby died. I started to talk to other midwives who had experience of caring for dying preterm babies in labour wards and I found that they, too, expressed feelings of confusion as how best to deal with the situation.

Vignette 2: Focusing on a dying baby in the neonatal unit

Jack was born at 23 weeks' gestation at a neighbouring hospital. He had been resuscitated at birth and, after developing complications, had been transferred to the Regional Neonatal Unit when he was almost a day old. He was now almost 4 months' old and had undergone repeated surgery for intestinal complications. However, after the last episode of surgery, the surgeons had decided that further surgery was impossible. Jack's parents had come to terms with the decision. It was agreed that Jack would continue to have respiratory support using a ventilator and to have intravenous nutrition, as he was unable to tolerate gastric feeding. However, when he developed complications requiring treatment, as he inevitably would, no active treatment would be provided. Instead he would be given pain relief and sedation to enable him to die peacefully.

When I came on duty one morning, I was informed that Jack's condition had deteriorated overnight. The intestinal complications had recurred. His parents had been contacted to inform them of the situation and they had arrived at the neonatal unit in the early hours of the morning.

The neonatal unit was a large room with ten incubators placed around the wall and a workstation in the centre. The internal 'walls' were made of glass. This was supposed to facilitate easy observation of the babies. However, the room was never left unattended. It did mean, however, that visitors to the unit – porters, delivery staff, and cleaners, as well as families visiting babies on the other rooms tended to peer into the unit, reducing privacy for babies, staff and parents. On this occasion, one of the night staff had pulled down the blind at the window next to Jack's incubator. This was something I'd seen happen before. It was an attempt to give him some privacy as he lay dying.

I took over the care of Jack from the night duty staff. They outlined his care. He was to continue to be ventilated mechanically. If he needed supplementary oxygen to maintain his oxygen levels, he was to be given it. His intravenous feeding would continue and he was receiving intravenous Morphine. The night duty staff said that he 'didn't like' handling. This meant that he became agitated, his oxygen levels dropped and his heart rate fluctuated dramatically every time he was touched. His abdomen was very tense and it was assumed that the changes in his vital signs were a response to pain when he was touched. Jack was intubated with an endotracheal

tube: this meant that he was unable to cry so pain assessments were based on changes in his vital signs.

The staff on night duty in the neonatal intensive care unit came over to Jack's incubator before they went off duty. Every one of them mentioned that they thought he would not be there the following night. They all said that they hoped he would be out of pain soon. The staff coming on duty stopped by Jack's incubator. Again, they mentioned that they thought Jack must be in pain. The phrase 'poor little thing' was heard being said repeatedly. Everyone asked if he was having pain relief and were reassured when they were told that it Morphine had been prescribed 'on demand'. This meant that the drug could be given whenever the person caring for Jack judged it to be necessary, rather than having to wait four hours in between doses. The fact that I could give Jack pain relief whenever I felt he needed it was very reassuring to me as it meant I could ensure that he did not suffer unduly. I would also be able to reassure his parents that Jack was comfortable.

Jack's parents had been in the neonatal unit since the early hours of the morning. They were given the use of a bedroom on the unit. This allowed them to come and see Jack whenever they wanted. The night staff had already warned me that his parents had asked how long Jack might live. This was one of the hardest questions to answer. Some babies with intestinal complications could die within a few hours of diagnosis, while other babies could live for several days. I knew from past experience that while parents wanted to spend time with their dying baby, when that

time turned into days, the stress of waiting for the baby's death often became unbearable. In particular, the parents would sometimes ask if it were possible that the diagnosis of a lethal condition might be wrong. In Jack's case, it was known that he could not have any further surgery so his death was inevitable.

I knew Jack's parents well. I had been involved in his transfer from the hospital where he was born. I'd cared for him on many occasions while he was in the unit. He was their only child and the shock of his premature birth had been considerable. At first, they had referred to him as 'a little fighter' – a very common term used by parents to describe their baby's struggle while they were in the intensive care unit. Sometimes I thought that the analogy was particularly appropriate when the babies were bruised and bleeding from the procedures that we carried out. Jack's parents had not used this term for a long time.

His parents came into the unit shortly after I had started the shift. They were clearly distressed and when I asked them how they were, his mother came to me for a hug. His father was very tearful. They asked me what I thought and I told them that Jack was very ill. They asked me if I thought he might die that day. I told them that he was very ill but that it was impossible to predict when he might die. I was reluctant to offer them the opportunity to hold Jack since this meant removing him from the incubator and it was clear from his behaviour when I touched him, that movements were painful. Instead, I suggested to his parents that they could stroke his hands or

his forehead. His heart rate remained stable so this reassured me that he was not reacting adversely to these interventions.

Parents generally did not visit the neonatal unit in the morning as this time was taken up with medical rounds and investigations. This enabled Jack's parents to have some privacy in the unit, although staff were always around. During the medical round, Jack's parents remained with him. They knew most of the medical staff well and they were aware of his prognosis. There was no need for the doctors to disturb Jack to examine him. Normally babies in the neonatal intensive care unit were bathed – or at least washed with cotton wool balls and water – and had their bedding changed every 8 hours. However, Jack appeared to find handling distressing so I decided not to bathe him. His skin was clean – there was no dried blood from investigations – and his kidneys were failing so he hadn't passed urine to soil his nappy. His mother seemed relieved when I said that I would not disturb him.

Over the course of the morning, Jack's condition continued to deteriorate. He required 100% oxygen but eventually that did not prevent him from becoming cyanosed. His parents noticed that he was changing colour. This seemed to confirm to them that Jack's death was near. His heart rate was also slowing and this was a sign to us that his body was failing and that death was near. However, it was impossible to predict exactly when it would happen. Jack's parents remained with him. We had the option of using screens to give them privacy but when they were

offered, they refused. There were no parents in the unit and his parents seemed to find it comforting to have staff that they knew around them.

I started to discuss with Jack's parents about what they would like to do when his death was imminent. Because his vital signs were being continuously monitored, his deterioration could be tracked and so it was possible to make preparations in advance of his death. It was possible that his death could take place in the afternoon or evening when the unit was busy with other families. Jack's parents were offered the option of a private room to be with Jack when he died. The unit had transport incubators which were normally used for transferring babies. By using a transport incubator, we would be able to continue Jack's respiratory support and monitoring outside of the neonatal intensive care unit. Alternatively, screens could be used to afford the family some privacy. Jack's family decided on the private room. The transport incubator was prepared and Jack was given Morphine intravenously to ensure that the transfer was as painless as possible.

Jack and his parents were moved into a private room beside the neonatal intensive care unit. The room was prepared for overnight stays and had a double bed so Jack's parents could remain with him throughout the night, if necessary. The unit had an alarm system which meant that staff could be summoned urgently. The transport incubator was moved into the room and I stayed for a short time to ensure that Jack was stable and his parents were happy to be left on their own with him. I checked to

make sure that his parents knew how to contact me if they needed me and reassured them that I would check every half hour to see how they were coping.

For the first hour, Jack seemed to be stable, although he was still quite blue – especially his hands and feet. His parents were touching him through the incubator doors and they seemed happy to be able to relax in the room. Soon afterwards, however, the monitor started to alarm and it was clear that Jack's heart rate was very low. In babies, a heart rate of less than 60 beats per minute is the equivalent of a cardiac arrest in an adult. I explained that Jack's condition meant that death was close. I asked his parents if they would like to hold Jack. I offered to remove the monitoring pads to make it easier to hold him. I also asked them if they wanted me to remove the endotracheal tube and stop the ventilator. Jack would still be technically alive when they held him but would be unconscious and would not be able to feel pain. His parents agreed and I removed the tubes and monitors, wrapped him in a soft blanket and handed him to his mother. Both his parents started to cry at this point. It was as though they realised this was the end of his life.

I offered to take a photograph of Jack as this was the first time that they had seen his face without the endotracheal tube. They agreed and I took a Polaroid photograph that they could look at straight away and another photograph with their camera. I asked them if they wanted some time alone with Jack and they said that they would like this. I reassured them that I would be nearby and would come back in 10 minutes to check on the situation.

I went back into the unit and spoke to the staff. They were all aware of Jack's imminent demise and seemed subdued. Other parents were arriving in the unit and it was interesting to note how staff tried to deal with them as normal while also being aware of the death of a baby nearby. They continued to ask the other parents about their lives outside of the unit and chat about siblings. The empty space in the neonatal intensive care unit had been set up with a clean incubator ready for another admission. We were all aware that some parents whose babies died in the unit found this particularly distressing but intensive care cots were in very short supply in the region and we were obliged to make available any spaces we had. I had already mentioned this to Jack's parents so that they knew that another baby might take his place in the unit – even before he had died. At the time, they seemed understanding but I knew that they might feel very differently about the policy when they noticed another baby in the space.

When I went back to check on Jack and his parents, he was very blue and floppy. I listened for a heart rate with a stethoscope and heard nothing. I told them that Jack was dead. They both nodded and were crying. I told them that they could hold Jack for as long as they wanted and if they wished, they could bathe him and dress him. They decided against bathing him but did want to put some clothes on him and take photographs. They had not brought their own clothes for him so his mother came with me to the linen room where we had a stock of tiny baby clothes. She picked a top and booties and went back to the room to dress him. I stayed in the room with

them as they wanted to talk about what would happen next. I explained about the legal procedures – the need for a death certificate and making arrangements for a funeral. I also told them that they could come back and see Jack any time they wished – and if other members of their family wanted to see him, arrangements would be made with the hospital mortuary for them to visit. At that point both parents seemed reluctant to involve anyone else but said that they would show his photograph to his grandparents.

The consultant in charge that day came into the room to offer his sympathy. He held Jack and started to talk about his appearance and how nice it was to see his face without the tube. I left at that point to give him some time with the parents alone. I went into the unit. I did not need to say anything – they all knew. Some said ‘It that it?’ or ‘Is it over’. When I responded, they simply nodded. One person said that it was ‘for the best’. Everyone asked how his parents were coping. I told them that they were holding him and they were crying. Several members of staff asked me to convey their condolences to his parents. It was as though they did not want to seem to crowd his parents at that time. It was the custom in the unit for members of staff to attend the funerals of babies who died and it was possible that some people felt that they would rather wait and see Jack’s parents then.

When the consultant came out, I went back into the room. Jack had been placed in a Moses basket. His parents told me that they were going home. I asked if they wanted to leave Jack in the room or if they wanted to wait until the porter came to take Jack

to the mortuary. They asked me if Jack would be on his own when they left. I promised them that someone would remain with Jack until the porter arrived. They nodded their agreement. They left the room, looking backwards at Jack. I reminded them that they could visit the unit or telephone at any time. They were clearly very upset and the consultant came to escort them out of the unit.

After they had gone, I used the telephone in the room to ask for help from my colleagues. I did not want Jack to be alone but I had to ensure that the paperwork for the mortuary was completed. One of my colleagues brought in a folder with the documentation and I started to complete it while she held Jack. It seemed as though she, too, wanted to see what he looked like without the equipment around him. She spoke to him in a very soft tone. Soon after the mortuary porter arrived with the small metal box used for babies. Jack's body had already been wrapped so his face wasn't visible. This was normal practice in the unit as it was felt to be unfair to the porters to expose them to the sight of a dead baby. I gave the porter the documentation and he checked it while I placed Jack in the box. I closed the lid and handed it to him. He left the room and I started to tidy it, ready for the next family.

The personal reflections of a midwife

I started to compare what had happened in the labour ward with my experience of caring for dying babies on the neonatal unit. In the neonatal unit, I usually (but not always) had time to develop a relationship with the parents and with the baby. However, the intense nature of the care in labour ward usually helped me forge a

relationship with the parents and I felt that this was true of the parents in the vignette. I was comfortable with the ethical decision making in each case – for both babies further intervention would have been futile and would have added to their pain. The main difference between the two episodes of care was that the protocol for care in the neonatal unit appeared to prioritise the needs of the dying baby. This included pain relief and supplementary oxygen. In comparison, the needs of the dying pre-viable baby in labour ward were not considered in the protocol.

In the labour ward, I felt as if the onus was to consider the needs of the parents rather than the needs of the baby. In fact, the procedure of looking after dying babies in the delivery ward and the neo-natal unit seemed at odds. This raised questions for me about why this was so and the rationale for it. After all, the physical and emotional needs of the parents and babies were the same, with the only difference being the venues. In the labour ward, there was, I realised, no way of assessing if the baby required pain relief or any other form of care to alleviate suffering. This appeared to me to crystallize the problem: the process of care was directed at the parents and not the dying pre-viable baby.

I began to question why the two processes were different: why did the protocol for the care of a dying baby in the neonatal unit put the baby's needs at the centre of care and the protocol for the care of a dying baby in labour ward focus on the needs of the parents? How did we, as professional carers, behave differently and follow different protocols when the needs of the baby were the same? I also began to

question why I felt comfortable in providing care for the pre-viable baby in labour ward once he was dead.

The protocol for the care of the dying baby in the neonatal unit had been formulated by medical, nursing and midwifery staff and spiritual care advisers and drew from the philosophy of palliative care developed by the World Health Organisation (WHO) which states: '*Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family*' (WHO, 1998). While this definition acknowledges the importance of the family in care, it places the needs of the child first. This was reflected in our neonatal unit protocol which required the baby's need for comfort to be considered over everything else.

The protocol for the dying pre-viable baby in labour ward had been formulated by midwifery and medical staff and spiritual care advisers. It was based on the guidelines for good practice in relation to perinatal loss formulated by the Stillbirth and Neonatal Death Society (SANDS). The guidelines from SANDS were based on the premise that the parents of dead or dying babies had only a short time to get to know their babies and that care should focus on making every opportunity for contact available to the parents to enable them to develop memories of their baby. This interpretation of the SANDS guidelines, while undoubtedly not intended, meant that clinicians were more inclined to focus on the parents' needs rather than the needs of the dying baby.

During my reflections on the incidents, what interested me was why, I, as a health care professional, and others, appeared to accept and adopt into practice, without question, user group guidelines on the care of the dying pre-viable baby. The adoption of protocols relating to perinatal loss based on SANDS guidelines was intended as good practice because of the unique perspective of bereaved parents. This perhaps explained my 'comfort' in dealing with the parents once the baby had died. I believed that the guidelines had legitimacy because of the authority of the user group.

For example, in the protocol relating to perinatal loss, the actions prescribed for care were imbued with meaning from the perspectives of the SANDS' representatives. Reference was made to past practices of 'whisking the baby away' and ignoring the needs of the parents. The new forms of care outlined in the guidelines emphasised that all perinatal losses, no matter what form they took, were the loss of a baby and that the baby was real to the parents. Because parents had only a very short time to get to know their baby, every effort had to be made to enable them to form a relationship and lasting memories. Naming the baby provided an identity, bathing, dressing and holding the baby enabled the parents to fulfil their nurturing role. In the thesis I have referred to these activities as '*rituals*' (van Gennep, 1960; Kobler & Kavanaugh 2007) as they were intended to be symbolic of parenthood rather than babyhood.

Caring for dying preivable babies: crystallizing the problem of ‘vulnerable’ subjects

I began to search the literature for information on this specific aspect of perinatal loss and found that it was absent from midwifery textbooks and user literature. When I raised the issue with midwives and doctors who had not experienced caring for parents and babies in this specific situation, they could not understand the difference and shrugged off my questions and concerns. In part this may have been due to their lack of exposure to the different scenarios. Staff working in labour wards rarely work in neonatal units and vice versa. Because I had experience of both environments at a senior level, this almost certainly brought the differences between the two situations into sharp focus. It seemed to me that one group of professionals managed to consider the baby as an individual with needs and rights in the neonatal unit, while maternity professionals in labour wards found it difficult to consider the baby’s needs separately from those of the parents. This reinforced my belief that the situation could only be fully understood by those who had experienced it, and in particular, those who had experience of the different health care approaches. I started to consider the possibility of carrying out research into this aspect of perinatal loss.

The difficulty of pursuing research in this particular area of perinatal loss was reinforced during the meetings I had with members of the University research community who were quick to point out the ethical concerns that would be raised when trying to involve families who might be perceived as ‘vulnerable’ on account of their bereaved status. I found that some user representatives working on behalf of

bereaved parents were reluctant for the study to take place. For example, one user representative who had participated in developing guidelines for the care of bereaved parents was adamant that the situation in the labour ward did not require a different approach and that it would be a futile use of my research time. When challenged about her evidence for this, she eventually conceded that her views were based on assumptions that she could not substantiate from her experience of working with bereaved parents. In particular, the organisation had very limited experience of working with parents who had experienced the death of a previsible baby and this was influencing her views. After much discussion, she conceded that it 'might' be worthwhile pursuing this line of enquiry.

Following my move to another University, I reflected on my experiences of attempting to research the care of dying previsible babies in labour wards. The subject was complex and I was not even sure that I understood what it was that I was trying to discover. As part of my professional development, I was given a research mentor and this enabled me to clarify my understandings of the conflicts in care I experienced as a clinician and to use the framework and support offered by a doctoral project to explore the issue in depth.

Purpose of the study: Answering the questions raised by professional experience as a midwife

My personal experiences as a midwife have demonstrated that there appears to be a lack of understanding of the care given to dying previsible babies in labour wards

and of the rituals surrounding perinatal loss. The purpose of this doctoral project therefore is to explore what I have termed the ritualistic nature of the care given to dying pre-viable babies and to explore the evidence base underpinning the care. My aim for doing this is to reveal the issues I have identified in a way that helps to open debate in this area. In other words, to provide an opening for parents to explore and explain their needs and wishes as parents and for clinicians to have permission to consider also the needs of the dying babies. The question asked in the thesis is:

How and why are rituals relating to the care of dying pre-viable babies in labour wards constructed, deconstructed, enacted and interpreted?

A **dying pre-viable baby** is defined as a baby born before 24 weeks' completed gestation showing signs of life at birth. **Labour ward** is defined as a place where labour and birth normally takes place. It is important to differentiate the normal or expected place of birth for pre-viable babies as some babies are born prematurely at home, without any professional assistance. The term '**constructed**' in relation to the rituals refers not only to the physical construction of the rituals in documentary form as they are detailed in guidelines, but also to the attempt to ascribe meaning to the rituals. '**Deconstructed**' refers to the apparently contradictory meanings that a ritual may hold. For example, in this doctoral thesis the rituals relating to the dying pre-viable baby will be compared and contrasted with those for pre-viable babies where resuscitation and supportive care is instituted. '**Enacted**' relates to the 'performance' given by health professionals. In particular the guidelines which form the scripts for the rituals will be scrutinised in an attempt to determine how health

professionals are directed in their performance of the rituals. **‘Interpreted’** relates to the conceptualisation and understanding of the meanings by parents and by health professionals.

To allow a more in-depth exploration of the issues I wish to raise I will draw attention to the idea of there being a relationship between what I will call *ideology*, *rhetoric* and *ritual*. Ideology is represented by the clinical guidelines, rhetoric is associated with what parents groups and clinicians say and consequently reveal about their beliefs and attitudes about dying pre-viable babies in labour wards, which in turn leads to a particular type of behaviour – clinical rituals and performances.

Western ideology, political and social movements have exerted a strong influence on medicine and childbirth in particular (Bourgeault et al, 2004; Kitzinger, 2005; Salter, 2004; Savage, 2007; van Teijlingen et al, 2009). The first half of the twentieth century was associated with a strongly technocratic and medicalised approach to birth. This was associated with limited personal autonomy and a ‘conveyor belt’ system of care that appeared to fail to acknowledge the emotional elements of childbirth (Rooks, 1997; Davis Floyd, 1994). In response to this and issues associated with feminism, maternity service users demanded the right to influence policy and clinical practice and this was recognised in the latter stages of the twentieth century (Dept of Health, 1993; Scottish Executive Health Dep, 2001; Scottish Government Health Directorate, 2005). The user views focused on the need for a humanistic and individualised approach to care (Kitzinger, 1984; Beech, 1991).

These views were then reflected in the ideology of perinatal loss which moved to emphasise the needs of bereaved parents (Lovell, 1983; Kohner & Henley, 1991; Kohner, 1995; Schott et al, 2007).

Ideology is often expressed through rhetoric: in particular the nature of pregnancy and childbirth are subject to different interpretations which can give rise to interprofessional conflict (Oakley, 1984; van Teijlingen, 2005; Hunter, 2006). For example, rhetoric has been used very effectively by perinatal loss support groups, such as SANDS, to portray the dead baby as a person as opposed to ‘products of conception’ or clinical waste (Schott et al, 2007). Conferring personhood on the baby, regardless of gestational age, supports the concept of parenthood claimed by the parents (Schott et al, 2007; Nuffield Council on Bioethics, 2006). With regard to perinatal loss, establishing parenthood and the loss of a baby is important as this can be associated with ‘rights’ – the right to be regarded as being bereaved and to be treated with compassion (Schott et al, 2007). I will argue that ideology and rhetoric have been heavily influenced by perinatal support groups which have in turn influenced the development of clinical rituals in labour wards.

Ritual is a complex term which has been used in nursing and midwifery interchangeably with ‘routine’. For example, Walsh and Ford (1990) state that ‘ritual action implies carrying out a task without thinking it through in a problem-solving, logical way’, In other words, thought and action are disconnected. In this doctoral study, I argue that the activities that are associated with the care of the dying

previably baby are ritualistic, rather than repetitive acts. The activities are meant to be symbolic and objectify the beliefs and thoughts of those participating in the rituals. Rituals in this instance are intended to integrate thought and action – exactly the opposite of what Walsh and Ford (1990) suggest. In the case of the dying previably baby, the rituals are meant to demonstrate the social worth of the baby: they are framed within the wider meaning system relating to autonomy and choice in the maternity services and they act as a means of imposing some kind of order on a situation that can appear chaotic and out of place – when death occurs at the time of birth (Bourdieu, 1977).

The point to which I will allude throughout this thesis is that the detailed information about the rituals relating to the care of dying previably baby is found in the guidelines produced by SANDS (Schott et al, 2007). SANDS is a charity which was established to support parents bereaved through the death of a baby around the time of birth. Like many other groups, SANDS brings a service user perspective to the maternity services, as do groups like the National Childbirth Trust (NCT) and the Association for Improvement in the Maternity Services (AIMS). What makes SANDS different from the other service user groups is the way in which its representation of service user experiences has informed policy making at a national and local level and has led to particular behaviours in the maternity services throughout the National Health Services in the UK. More specifically, groups such as AIMS and the NCT are often charged with being overly concerned with the views of white, middle class women and this appears to allow health professionals and

policy makers to question the validity of their claims (House of Commons Health Committee, 2003). Of interest to this thesis, however, is that the representativeness of SANDS and other related groups, which appears to be similar to that of the NCT and AIMS, does not, however, appear to be questioned by health professionals. The doctoral thesis will explore possible explanations for this.

The rituals relating to perinatal loss have become more elaborate over the past three decades (Kohner & Henley, 1991; Kohner, 1995; Schott et al, 2007). While the guidelines emphasise the need for individualised care that is respectful of parents' beliefs and wishes, there has been a tendency for professionals to integrate rituals into guidelines (Cameron et al, 2008a) which, I believe, do not appear to fit with the needs of what is an extremely heterogeneous parent group. I found this to be of fundamental importance when considering ritual in relation to perinatal loss. If, as I have argued, the activities relating to perinatal loss are ritualistic and convey specific meanings, where parents have different understandings of that loss, the meanings of the rituals may be lost and meaningless for them. Worse still, they may signify counter behaviours that feel alien or even offensive to some parents. For example, the rituals are frequently cited as 'good practice' and have been incorporated into checklists and aide memoires for professionals. I argue that they are used ubiquitously by clinicians with, at times I believe, devastating consequences for parents (McHaffie, 2001; Robinson, 2002).

Much of the data I have found in the literature seems to be anecdotal and is not inclusive of parents who are at most risk of experiencing perinatal loss: those living in poverty and from minority ethnic groups. Furthermore, I also want to make the point that the rituals in labour ward focus almost exclusively on the parents, rather than the needs of the dying baby compared with the neonatal unit. In some respects this echoes the tensions inherent in the palliative care movement which appears to place the needs of the family on an equal footing with those of the patient without acknowledging the primacy of the patients' needs (Randall & Downie, 2006). The pattern is that compared with a dying adult or child, it is arguably more difficult to interpret and address the needs of a dying pre-viable baby in labour ward. This difficulty, it appears makes it easier to avoid attending to their needs as seems to be the case in labour wards. My wish in this thesis is to raise awareness of this gap, rather than to suggest specifically that the needs of the dying pre-viable baby are consciously neglected. The point is that an exploration of the rituals associated with the death of a pre-viable baby may be a useful way of revealing any failures by health professionals to attend all the needs concerned.

To address the question, Critical Interpretive Synthesis (CIS) of the literature was undertaken (Dixon-Woods et al, 2006). CIS was selected as an appropriate research tool for this PhD study because it offered the opportunity to include a broad range of material, including theoretical papers, from a range of disciplines and enabled the evidence relating to perinatal loss to be interrogated as an object of inquiry in itself, rather than as an objective statement of fact. This was important as the starting point

for the study was investigating taken-for-granted practices in care provision for dying pre-viable babies. CIS also demands interpretation of the data and the creation of new arguments and this fitted the intention of the PhD thesis.

The methodology has been used to investigate sensitive subjects. Dixon-Woods et al (2006) used it to explore vulnerable subjects' access to healthcare. Since it used existing data and did not require my presence in the labour ward to observe a sensitive and very personal event, it was very appropriate for this doctoral study. A full explanation and justification of the use of CIS in the doctoral study follows in Chapter Two.

Formulating the question

The final research question was arrived at as a result of an iterative process that began with questioning why the care of dying pre-viable babies appeared to replicate aspects of caring for stillborn babies and their parents. The refinement of the research question was undertaken as the search strategy evolved, in line with CIS methodology. A comprehensive explanation of the process can be found in Chapter Three.

Searching the literature; sampling; quality determination

The search strategy included a traditional electronic bibliographic approach to literature searching but was augmented by an 'organic' process which included contacts with experts, website searches, reference chaining and the use of expertise

within the research team. Using the principles of theoretical saturation during the sampling process enabled large quantities of data to be managed. Patterns of data were identified and informed the sampling strategy: when no new data was elicited from a particular search strategy, it was terminated.

Dixon-Woods et al (2006) recommend excluding poor quality studies from the review. In the PhD study, however, poor quality papers were identified using the critical appraisal tools developed by CASP (Public Health Research Unit, 2005) and retained. 'Poor quality' data included studies which used small sample sizes or had low response rates, papers which made recommendations based on anecdote or opinion rather than evidence derived from well designed studies, and papers which failed to provide information about the characteristics of participants. The inclusion of these papers was important for this study because it emerged that the literature that informed practice relating to the care of dying preivable babies was drawn largely from a weak evidence base (mainly anecdotal) and it was essential that this was identified and analysed in the thesis.

Data extraction

An Excel framework was used to collect the literature. This was eventually enlarged and used to collect information about the quality of the evidence and also to highlight the major features of each paper, including the context. As the search evolved, it became clear that the care given to the dying preivable baby was not the primary focus of many of the papers considered for the literature review. I decided

that only the relevant aspects of a paper were included, taking heed of advice of Noblit and Hare (1988) that sufficient information should be included about the context of the paper to allow meaningful conclusions to be drawn. In the thesis this enabled data relating to the care of dying preivable babies that was embedded in clinical guidelines for the care of extremely preterm infants who were to be resuscitated to be included in the study.

Interpretative synthesis and analysis

Analysis and interpretation of the data in CIS involved a two step approach (Dixon-Woods et al, 2006; Flemming, 2010). Using the approach specified by CIS, the literature identified was scrutinised to identify coherent arguments, as well as contradictions and flaws. During this process, tentative propositions or synthetic constructs were identified. It has been suggested that this step is similar to the first order constructs produced in meta-ethnography (Schutz, 1973). However, the major difference between CIS and meta-ethnography is the formation of synthesizing arguments. CIS does not produce discrete second and third order constructs (Flemming, 2010). Instead the key difference is that synthesis in CIS includes qualitative researcher interpretations. This is acknowledged to be controversial but the arguments to support this approach are detailed in Chapters Eight and Nine.

Findings

CIS allowed the synthetic constructs to emerge from the data, which in turn allowed me to demonstrate how and why the rituals in labour ward were constructed and

deconstructed, how they were enacted and how they were interpreted. In this way, the technique of CIS enabled a large and diverse body of evidence to be interrogated. It revealed also, the varied nature and poor quality of the evidence base and policy that seems to drive the care of the dying pre-viable baby and because of this, how difficult it may be to redirect styles of care. I will discuss this issue in more detail in Chapters Ten and Eleven.

The Theoretical Framework

In this study, the need to explore and understand the meanings behind the rituals in the labour ward was a major factor in the selection of the theoretical framework. From the angle I have taken to examine this theme, *performance* is an important element of ritual. Here Richard Schechner's and Victor Turner's work on the concept of performance theory seems pivotal to my ideas and experiences as a midwife and forms the theoretical framework for the study. I will examine performance theory in more depth in Chapter Two.

Performance Theory

Schechner's theory is an emerging theory which draws from anthropology and the dramatic arts. Schechner's fundamental belief is that dramatic performance belongs as much to everyday life as it does to the theatre (Schechner, 1995). Inherent in performance theory is the concept of '*performativity*'. This relates to the work of Austin who termed certain forms of sentences 'performative utterances' (Austin, 1976). Performative utterances are neither 'true' or 'false' but are 'speech-acts'

which have positive or negative effects. This can be seen when caring for parents who have experienced perinatal loss. For example, the Royal College of Obstetricians and Gynaecologists (RCOG) has provided a list of terms which may cause distress when used to describe perinatal loss and suggests alternatives (RCOG, 2006). These include the use of the word ‘miscarriage’ rather than ‘spontaneous abortion’ or ‘baby’ rather than ‘products of conception’.

Austin’s performative utterances – sentences that have an effect – appear to fit in with the idea of drama espoused by Schechner. He contends that performance is something in which everyone engages and includes theatre, social ceremonies and everyday life. Drama has been used extensively in medicine and healthcare as a means of transmitting information (Rice & Atkin, 2001; Silver, 2001; United Nations, 2004) and as a means of entertainment (Czarny et al, 2010). I will argue that these ideas of performance are echoed in the clinical rituals I witnessed when working as a midwife in labour wards. Thus, this study appears to be the first time that perinatal loss has been studied as a dramatic event using performance theory.

The theoretical framework developed from performance theory and used in this thesis enables the rituals involved in caring for dying pre-viable babies to be revealed and explored as dramatic performances. When Performance Theory is applied to the scenario of pre-viable birth and death in labour ward, the actors become the midwives and doctors and the audience are the parents, with the script represented as the guidelines and policies. This suggests also the passivity of the audience, or the

parents, who are having the performance done to them, irrespective of their needs and wishes.

Using this theoretical framework to analyse the literature, a synthetic framework was developed (Chapter Nine) to demonstrate that the ideological drivers for the care of dying babies in hospitals has evolved from the work undertaken by predominantly middle class support groups who represent bereaved parents. I suggest that the guidelines they have generated have been adopted and are being used by professionals in labour wards. At first glance, the idea of health professionals actually taking up and adhering to the advice offered by support groups seems impressive and something that one that should be encouraged. The phenomenon was reported in the UK, North America, Australia and New Zealand and contrasts with the frequently antagonistic relationships between support groups for women wishing more control over their birthing experience and professionals. In the case of dying babies, parents claimed personal authority which was superior to professional authority and clinicians appear to have bowed to this superior knowledge. Rhetoric was used to communicate this personal authority as parents asserted that the uniqueness of their experience meant that they were the only people who could inform care delivery. This explanation was accepted by health professionals and is demonstrated in the analysis of textbooks and professional guidelines (Chapters Five, Six, Seven and Eight). However, I want to suggest a rather different perspective. The literature review uncovered paradoxes in the ideology of user representation and public engagement in the health services and in relation to

perinatal loss in particular (Chapter Three). Women from marginalised groups for example, were less likely to be offered choices in childbirth (Bharj & Salway, 2008; Dept of Health, 2007; Richens, 2003) and were more likely to experience perinatal loss (Maternal and Child Health Research Consortium, 2001), however, participation in the user movement is strongly associated with being white and middle class and does not seem therefore to attend to the range of parents that hold varying attitudes and beliefs. This PhD thesis suggests that further research needs to be undertaken to reveal these issues to, in the process, promote inclusivity and representativeness of the range of parents involved with dying babies, and the opportunity for choice offered to them by the health professionals caring for them.

I found the ideology and rhetoric associated with a 'good death' (Ellershaw & Ward, 2003) was a pervasive theme throughout my research (Chapter Nine). Much of the rhetoric was borrowed from the field of palliative care. Initial findings of my review suggested that this might afford the dying previsible baby a pain free and comfortable death. However, I found that the primacy of the previsible baby's needs did not seem to be stated explicitly in the guidelines. References were made to 'supportive care' or 'comfort care' but the nature of the care and how the care could be provided was not covered in the guidelines (Cameron et al, 2008b). The PhD thesis reviewed the nature and quality of the evidence on which care for dying previsible babies was based (Chapters Six and Seven). The evidence base for supportive care was not identified in the guidelines, in contrast to the evidence base for active management of care for babies who were to be resuscitated. To address

this deficit, further research is required into meeting the care needs of dying preivable babies.

In this PhD thesis I have tried to expose some of the contradictions in palliative care which had been identified by Randall & Downie (2006). Their critique of palliative care demonstrated that some of the claims made for palliative care did not stand up to scrutiny. For example, palliative care claims that the family's needs are equal to those of the patient. However, their needs may conflict and in law and in professional practice the needs of the patient should always come first. Similarly, with regard to the care of the dying preivable baby, the guidelines usually use language that suggests doing things *to* or *with* the baby, rather than *for* the baby.

The rhetoric of the guidelines uses terms such as 'family centred care' suggesting that caregivers facilitate activities normally associated with parenting e.g. holding or bathing the baby. However, a strong body of evidence supports minimal handling in the very preterm baby to reduce the baby's stress and enhance wellbeing (Simons et al 2003; Lago et al, 2009; Vandenberg, 2007). From this standpoint, I would argue that there appears to be a limited regard for the wellbeing of the dying preivable baby in the guidelines (NMC, 2007; Royal College of Paediatrics and Child Health, 2004). Added to this, there appears to be a lack of evidence to support or refute the suggested parenting practices proposed by user groups and now made into guidelines that clinicians have to follow. For this reason I believe that this PhD thesis exposes the need for further research to explore the gap in the evidence base.

The use of performance theory and critical interpretative synthesis in relation to perinatal loss appear to be innovative. These methods have enabled a large body of evidence to be interrogated and thus challenges widely held beliefs and practices in relation to the care of dying pre-viable babies (Cameron et al, 2008a; Cameron et al, 2008b) and user representation in the health services. The need for high quality evidence to inform all aspects of practice is reinforced by the findings of the study.

The Structure of the Thesis

I suggest that the process of undertaking this research has been organic and non-linear and what I discovered on the way led me on to the next stage of exploration and could not be predetermined. This process appears to fit well with the philosophy behind CIS (Dixon-Woods et al, 2006). The iterative nature of exploratory research is commented on by Krathwohl (1985) who suggests that there is a 'chain of reasoning' between the discovery phase and that the confirmation phase and that the process of discovery is unlikely to be straightforward. The importance of the chain of reasoning is that a relationship is established between discovery and confirmation. Thus, this PhD study followed many leads into blind alleys and performed several about turns during the discovery phase and these are reported within the thesis to enable the reader to understand how the research evolved, however, the structure of the thesis follows a linear format to show progression of ideas. The thesis is difficult to locate in a specific discipline. It draws from anthropology, thanatology⁷ and

⁷ Thanatology is the academic study of death

midwifery scholarship. However, this eclectic approach, in my view, is necessary to investigate a phenomenon that crosses disciplinary divides.

Chapter Two considers the overall research design and methodology. Ethical issues relating to the PhD study are examined and explained. The selection and use of CIS is justified and the structure and nature of CIS is explained. Chapter Three describes and discusses the formulation of the research question. Four main sources of data for the PhD were identified. Chapter Four examines the selection and analysis of professional papers relating to previsible loss. Chapter Five analyses midwifery textbooks. Chapter Six examines obstetric and neonatal textbooks. Chapter Seven explores national professional guidelines for the care of dying previsible babies. Chapter Eight examines local guidelines for the care of the dying previsible baby. Chapter Nine interprets the analyses of the data and develops a Synthesising Argument or findings, drawing from the wider literature to inform the development and contextualise it within the Theoretical Framework for the study. Chapter Ten focuses on recommendations for research, policy and practice. Chapter Eleven is the concluding chapter of the thesis and in it the claims of the PhD thesis are examined, including the methodological limitations. The relationship between the study findings, practice, policy and research are examined, along with the case I make for developing a stronger evidence base for the care of the dying previsible baby in labour ward and a more heterogeneous approach to the care parents experiencing perinatal loss.

Chapter One: Summary

The links between ritual and evidence based care in relation to the care of the dying pre-viable baby have not been explored in a systematic manner. This thesis focuses on the relationship between the three elements. Isolating the care of dying pre-viable babies in a single case study has enabled the problem to be explored systematically by the more creative approach used in CIS. The findings demonstrate that the needs of the dying pre-viable baby are generally considered to be secondary to those of the parents and the practice base relating to the care of the parents is influenced by non-representative support groups, rather than empirical evidence. In particular, there was little evidence to show that the views of parents from poor and minority communities who are more likely to encounter perinatal loss were represented. While the difficulties I encountered through the ethics review process meant that I was unable to speak to the participants concerned, the process of undertaking the CIS allowed a much wider range of evidence to be interrogated than would normally be possible. While CIS does not claim to be replicable, the findings from this study stand as a beginning. The quality measures undertaken as part of the study are explicit in the hope that the study will add to the evidence base for the care of dying pre-viable babies and thus attend not only to their needs but also to those of their parents and the clinicians who care for them.

CHAPTER TWO: RESEARCH METHODOLOGY

Introduction to the Chapter

Chapter One provided the context of the study, based on my professional experience of being a midwife. From this, the following research question was developed:

How and why are rituals relating to the care of dying previsible babies in labour wards constructed, deconstructed, enacted and interpreted?

In a traditional PhD thesis, Chapter One would be followed by a summary of the literature. This PhD thesis, however, takes a different approach, reflecting the methodology selected for the thesis which uses the literature as data because interviews with parents and clinicians were not possible for reasons that will be explored later in the chapter. The purpose of this chapter, therefore, is to explain the methodology and research methods which were used to investigate the research question, as above. In this thesis, Performance Theory (Schechner, 2002) was selected as an appropriate theoretical framework because of its association with ritual and drama. The use of the theoretical framework will be justified and demonstrated later in the chapter.

Selecting the methodology: access and ethical issues

A number of factors influenced the selection of the research design for the study. An important factor to be considered was the nature of the data and access for data collection. Childbirth in the UK has moved into institutions over the past century (RCOG & RCM, 2007). A feature of birth in hospital portrayed in the literature is

the shift in control from the woman to the institution and the professionals. This is illustrated by the fact that access to labour wards is strictly controlled by institutional rules which are enforced by professionals. In some labour wards family members may be excluded, even if their presence is desired by the birthing woman (Edwards 2005). Lack of space is frequently cited as a reason for this rule. Paradoxically, women may have to tolerate the presence of a range of professional strangers who may not have any direct relevance to the birth but are there to 'witness' the event, particularly if the birth is complicated. In my position as a PhD student, even though a midwife, gaining access to a previsible birth would have been problematic from an ethical standpoint as observation would have meant intruding into a deeply personal and sensitive experience. It would also have been difficult to persuade labour ward staff of the legitimacy of my role, if I was seen to serve no useful purpose in relation to the previsible birth.

There were logistical problems, too, in trying to observe previsible babies being born. The overall numbers of previsible births are low (Macfarlane, 2003). Previsible birth is unexpected and labour in women giving birth to previsible babies tends to be faster than labour at term. Women at risk of previsible birth may be moved from hospital to hospital to try to ensure that they have access to appropriate care. This, too, reduced the possibility of observing the birth and death of a previsible baby. To overcome these problems, I decided to make use of the autobiographical material from my reflective diary. These reflections replaced the ethnographic material that would have been obtained in an observational study.

An initial approach was made to an ethics committee for permission for a study which would involve interviewing parents who had experienced the death of their pre-viable baby and professionals who had cared for dying pre-viable babies. The involvement of parents was rejected as it was felt that they were too 'vulnerable' to be involved in such a study. The reluctance of ethics committees to allow access to bereaved parents is well documented (Hynson et al, 2006) and so their refusal to permit the involvement of bereaved parents was not unexpected. Nevertheless, it does raise questions about how preventing bereaved parents from giving their perspective impacts on the evidence base and ultimately on the clinical care they receive. It also challenges current understandings about patient empowerment and autonomy. This is explored further in Chapter Eleven.

I was also obliged to take advice from the General Medical Council (GMC), Nursing and Midwifery Council (NMC). This advice related to the legal and professional risks to staff if they revealed information about failing to record the births of pre-viable babies as live births.

Article 2 of the Human Rights Act 1998 states that 'Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally....' Article 2 has been incorporated into the law in Scotland, England and Wales and in 2007, the NMC sent out a circular reminding all midwives of the need to uphold the law, particularly when defining a live birth (NMC, 2007). The definition of a live birth, according to the World Health Organisation is a baby which:

'after complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, which after separation, breaths or shows signs of life, such as beating of the heart pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached'

WHO, 1992

While these criteria may appear to be objective, the reality of everyday clinical practice is that they are open to interpretation by birth attendants. The RCOG produced guidelines on the care of very preterm infants (RCOG, 2005) which cautioned against accepting 'reflex movements' as a sign of life. However, the guideline offered no information as to how 'reflex' movements could be differentiated from 'voluntary' movements. This has led to confusion on the part of birth attendants and there is evidence in the professional literature that staff attending the births of pre-viable babies would ignore the signs of life if a decision had already been made not to resuscitate the baby (MacFarlane et al, 2003; McHaffie, 2001).

The reasons for classifying the baby's death as a miscarriage include trying to protect parents from having to register the baby's birth and death and undertake arrangements for a funeral since miscarriages are not registered and the baby can be disposed of by the hospital (Lovell, 1997; McHaffie, 2001); and preventing the baby from appearing in the perinatal loss statistics, since miscarriages do not appear in the statistics while pre-viable births do. There was also some evidence that medical staff

may manipulate the certification of a birth to meet the expressed needs of parents. For example, McHaffie (2001) described how a doctor altered the details of a birth in the casenotes so that the parents would be able to register the baby's death and have an official record of the baby's existence.

The pragmatic solution advised by the NMC and GMC was to ensure that the interview schedule did not encourage the participants to reveal the specific information about how the birth of the baby was classified. However, there was still the possibility that this could be inadvertently revealed by staff and this would be considered to be evidence that that they had broken the law and breached professional codes of conduct. As interviewer, I too would be implicated if I received the information. A discussion with a Supervisor of Midwives made it clear that I was expected to abide by my code of professional conduct and report breaches of the law. Failure to take action on my part could be regarded as professional misconduct by the regulatory authorities. When discussing my PhD study in informal settings with doctors and midwives, they made it clear that they wanted to discuss the problems of classifying perinatal loss as this contributed to the context of caring for dying pre-viable babies.

During the time when the application for ethical review was being made, I began to interrogate the literature identified in the initial search. The literature suggested general agreement in the approach to the care of dying pre-viable babies (BAPM, 2002) and bereaved parents (Schott et al, 2007). Rituals and responses to death,

dying and bereavement, however, are shaped by a number of factors including religion and culture. The literature was scrutinised to elicit the potential impact of personal belief systems on the findings of the papers identified in the literature search. The majority of papers retrieved in the initial search did not provide even basic descriptions of the characteristics of parents included in the studies. Where demographic information was given, the respondents tended to be white and well educated. A small number of studies specifically targeted parents who were black (Kavanaugh, 2005) or Asian (Fowler et al, 1996). These studies were characterised by low response rates. The study carried out on behalf of SANDS had one respondent from the Asian community. The respondents in the studies were also more likely to be better educated and of a higher socio economic class than parents who typically experience perinatal loss.

From my readings of the literature, it was apparent that the lack of participation of parents from different cultural groups in studies relating to perinatal loss was complex. Kavanaugh (2005) advertised in newspapers which served the African-American community to recruit parents to her study but recruited only one parent using this method. Fowler et al (1996) recruited one Asian woman to their study which investigated loss in ethnic minority families in Britain. This respondent explained that the subject of perinatal loss could be considered taboo in some families and that it would be unacceptable for women to talk about their loss, especially to an outsider.

The taboo nature of perinatal loss in some communities also explained the lack of attention paid to different cultural and social approaches in the media and this had important implications for the research methodology. Newspaper and television accounts of perinatal loss inevitably portrayed the rituals of holding and naming babies as desirable. Terms such as ‘angels’ were commonly used to describe dead babies (BBC, 2010). Advertising for parents to take part in the study or using accounts of perinatal loss in the media would have reinforced current beliefs and practices and would have failed to uncover the range of beliefs relating to perinatal loss.

The literature from the USA and the UK exploring the views of professionals in relation to caring for dying pre-viable babies and their parents generally addressed care given to parents whose personal characteristics were not specified. Where demographic data were given, parents were usually described as white. Reflecting on the literature led me to reconsider my approach to the PhD study. The initial purpose of the study was to explore the rituals relating to the death of a pre-viable baby, with a view to developing guidelines for staff to enable them to provide effective care for the baby and the parents. It now appeared that my intention to carry out interviews with parents and professionals would only reinforce current practices and would be unlikely to elicit new information. This led me to consider other approaches to answer the research question that would ensure that the hidden meanings of pre-viable loss were explored.

Reflecting on the influences on current clinical practice in relation to the care of dying pre-viable babies, I identified three sources. These were: research evidence professional textbooks, and practice guidelines. The research evidence accessed during the initial literature search appeared to focus on a very limited section of society. Widening the literature search to include anthropological literature relating to perinatal loss could allow explanations for the rituals to emerge. Textbooks can be seen as authoritative sources of information for professionals. They frequently carry detailed explanations to underpin care. Inclusion of textbooks as a source of data might permit the rationales behind the rituals to be uncovered. Textbooks are often produced as a series and examining different editions of the same textbook could be a source of longitudinal data, demonstrating changes in practice over time. In contemporary professional practice, guidelines are produced and used to direct care. Guidelines may be adopted by professional groups or health organisations and can be used as measures of acceptable standards of care. Table 1 shows the sources of data that were identified to address the research question.

Table 1: Sources of data for the study

Question	Data
Constructed	Textbooks Journal articles Guidelines
Deconstructed	Textbooks Journal articles
Interpreted	Textbooks Journal articles
Enacted	Textbooks Guidelines

The material identified as a possible source of data for the study was in the public domain. While this reduced the need for ethical review in terms of accessing the data, it did not reduce the need for an ethically sound approach to analysis and synthesis of the data.

Beauchamp and Childress (2009) outlined four elements to be considered in relation to fundamental ethical principles. These were: respect for autonomy, non maleficence; beneficence and justice. When applied to the data in the PhD study, the need to avoid harm and do good could be addressed through ensuring that the search strategy was rigorous to avoid bias; and that the analysis and synthesis was conducted in a robust manner to avoid wrongful interpretations and representations of the material. This will be discussed later in the chapter in relation to quality assurance.

Professional issues were also identified as being important in relation to the PhD Study. The Code of Professional Conduct (NMC, 2008) stated that as a professional I must always put the needs of the people for whom I care first; I must provide high standard of care; act with integrity to uphold the reputation of the midwifery profession; and be personally accountable for my actions. The professional aspect of the study was particularly important because the research was exploring professional practice relating to the care of dying babies and their parents. Preterm babies are an emotive and potentially controversial subject and there was a real risk of causing distress and harm (Kain,2007; Crawford & McLain, 2010). The use of institutional

standards in relation to the conduct of a PhD study within the institution, including supervision and monitoring, reduced the risk of poorly executed research being carried out and publication of papers in peer reviewed journals provided external scrutiny and provided reassurance about the integrity of the research process.

The research design

The research design in the PhD study concerns the purpose, research questions and methods of a study (Cresswell, 2009; Robson, 2002). In this study, the research question was about gaining insight into an aspect of care that was poorly defined and poorly understood. The lack of definition suggested that a more flexible approach to the study would be appropriate. Robson (2002) suggests that in flexible designs the framework emerges as the study develops and recommends that all the activities such as data collection, analysis and even the research questions are revised as the study progresses. In the doctoral study, the research question was clarified and expanded throughout the study in response to the emerging data. The evolution of the question is explored in detail in Chapter Three. Several different research designs were considered as part of the process of carrying out the doctoral project. These included case study and systematic review, before ultimately settling on Critical Interpretive Synthesis.

Research Design: Case Study

Case study can be considered both a form of research design and a research method (Yin, 2009; Stake, 1995; Gomm et al, 2000; Gerring, 2007). As a research method,

the case study has been defined as being weak within the traditional hierarchy of evidence (Greenhalgh, 2006). This relates to the exploratory and the descriptive nature of the method and its apparent inability to demonstrate causal relationships. Nevertheless, there is evidence that the case study can be a powerful tool for exploring experiences and that it does have an important place in the research repertoire (Greenhalgh, 2006). Serious clinical issues such as the use of Thalidomide in pregnancy were identified through case studies providing detailed information about a specific case (McBride, 1961).

I considered the use of a single case study design for the PhD study because of the uniqueness of the case of the dying pre-viable baby. In the UK, it is rare for a baby to die at birth. When a baby is born and shows signs of distress, the attending midwives and doctors provide resuscitative care to try to save the baby's life. When a very preterm baby is born, the usual response is for a team of experts to attend the birth in order to resuscitate the baby. The baby is then transferred to a neonatal intensive care unit where specialised staff and equipment are used to afford the baby every opportunity to survive (Sinha et al, 2008). In the case of a dying pre-viable baby, the decision not to attempt resuscitation and ongoing care may be made in advance of the birth (Royal College of Paediatrics & Child Health, 2004; Batton, 2009). The baby remains with the parents until death occurs (Thames Regional Perinatal Group, 2000; MacDonald et al, 2002; BAPM, 2000). The pre-viable baby, therefore, is unusual and the single case design approach could allow the case to be isolated and explored.

A significant feature of case studies is the need to define the 'unit of analysis' and the boundaries of the case (Yin, 2009; Gerring, 2007). Yin (2009) warned against the use of 'idiosyncratic' definitions. By this, he meant definitions that do not relate to the literature. This was important because of the need to compare the study's findings with those from other research studies. In the case of the PhD study, the use of the term 'preivable baby' was derived from current literature. A range of terms were used to describe preterm babies at the limits of viability. The term 'preivable' was gaining widespread acceptance in the professional literature and, for the purpose of the PhD study was defined as 'a baby born before 24 weeks' completed gestation showing signs of life at birth'. The case was further defined as relating only to babies who were dying and whose death took place in labour ward, thus isolating the case from those babies born before 24 weeks' gestation and who were resuscitated and then transferred to neonatal units for ongoing care and who subsequently died.

After considering the theoretical advantages and limitations to case study as a research design, I decided to pilot it and assess its effectiveness in practice. Immediately, I began to encounter problems with the design. Although it is proposed as a flexible approach to research, it actually appeared to be quite restrictive in practice. My initial literature search using the case study framework did not allow me to make the connections with the data that I knew was 'out there' because of my contact with other researchers and writers. Instead I found myself being limited to extremely clinical information about decision making in relation to resuscitation of

preivable babies. Drawing in data from other sources weakened the case study design and excluding the data I knew existed weakened the PhD study. I decided therefore to abandon case study as the research design and seek an approach that would allow multiple sources of data to be combined to answer the research question.

Research Design: Systematic review

Review methodology appeared to be a possible means of approaching the study. Within the healthcare community, the term ‘systematic review’ is often reserved for reviews which have tightly controlled selection criteria and consider only quantitative studies with a view to determining the effectiveness of interventions. However, within the wider research community, the term ‘systematic review’ is used to define an overall approach which is typified by a rigorous approach to selection of material for the review and transparent methods of analysis (Hemingway & Brereton, 2009; Gough, 2007). This wider definition is the one that is used within the thesis.

Pope et al (2007) describe a range of approaches to reviewing the evidence. They describe a continuum from descriptive reviews, effectiveness reviews through to interpretive reviews which synthesise evidence with a view to generating new meanings. The type of review which could be used as a research design for the doctoral study was determined by the range and nature of evidence available and the type of answer I required. In an attempt to resolve the difficulties I encountered in

dealing with an expanding and diverse range of data, I considered other methods of reviewing and interpreting the evidence. Noyes et al (2008) have explained clearly the challenges of synthesising qualitative research. These include formulating appropriate search strategies, quality appraisal of the studies and methods for synthesising the evidence. Qualitative research is a broad term which covers a range of approaches e.g. phenomenology, grounded theory to name but two. The situation was complicated by the nature of the evidence I was uncovering. This included textbooks, guidelines and thanatological and anthropological literature, as well as clinical evidence. Some of this data fell into the category of qualitative evidence and could be approached using methods such as meta ethnography (Noblit & Hare, 1988) but textbooks and guidelines did not fall into this category. I considered these to be important sources of information for the PhD study and so I sought to use a design that would allow them to be included.

Descriptive reviews summarise the literature. While these can be useful in providing an overview of the subject, they lacked the critical approach required to be able address the focus of the thesis (Hemingway & Brereton, 2009; Gough, 2007). Effectiveness reviews are a good way of answering questions about the effectiveness (or not) of interventions. However, their tightly controlled inclusion criteria and the lack of an identified intervention in the doctoral project meant that they were not a suitable method for this study.

There was evidence from the initial case study pilot that there was a mix of quantitative and qualitative data available to answer the question so this helped focus the search for a research design. Realist Synthesis (Pawson et al, 2006) tests explanations to elicit 'what works'. The process of realist synthesis includes both theory and empirical evidence and starts by identifying the question and clarifying the intervention before moving on to exploring how the evidence translates into policy and practice. It appeared to me that my study was almost at the pre-realist synthesis stage – where I was trying to work out what the question was and the nature of the evidence, rather than attempting to determine policy. This led me to reject realist synthesis as a possible design. Because my data would include both quantitative and qualitative data, meta ethnography was discounted as a method as it focuses exclusively on qualitative data.

Research Design: Critical Interpretive Synthesis

Dixon-Woods et al (2006) proposed Critical Interpretive Synthesis (CIS) as a methodology which could allow data from a range of different sources to be included in a review. CIS draws heavily from meta-ethnography in its approach but diverges in the way it approaches synthesis. Meta-ethnography uses three techniques to arrive at a synthesis: reciprocal translational analysis, refutational synthesis and lines of argument synthesis. It has been argued that this approach means that meta-ethnography is only suitable for synthesising studies within a single paradigm (Jensen & Rodger,s 2001) but Campbell et al (2003) demonstrated that it can be used for synthesising studies from different qualitative paradigms. McDermott et al

(2004) highlighted a further difficulty with meta-ethnography: even though it was possible to incorporate studies from different paradigms, the level of interpretation within the studies had to be taken into account. In the study by McDermott et al (2004) the obvious differences between the conceptual levels within the studies led them to abandon both reciprocal translation synthesis and refutational synthesis. Within the PhD study, it was clear that not only were there a range of different qualitative paradigms with both 'thick' and 'thin' interpretations (Geertz, 1973), quantitative evidence would be included, too.

Dixon-Woods et al (2006) suggested that CIS was a methodology that addressed many of the potential limitations associated with meta-ethnography and meta-synthesis of qualitative research. In relation to the PhD study, it offered two potential advantages. Firstly, CIS allowed a diverse range of experiences and evidence to be incorporated into the review. Secondly, the two-stage approach to synthesis which CIS employed allows the constructs that emerge to be linked to existing literature to form powerful synthesising arguments. This is explored in detail later in the chapter. Dixon-Woods and colleagues made the point that CIS was more than an approach to synthesis: it was in itself a systematic approach to review (Dixon-Woods et al, 2006).

It is recognised that CIS is an emerging methodology and one which Dixon-Woods and others recognise requires further evaluation (Dixon-Woods et al, 2006; Flemming, 2010). Given the highly exploratory nature of the PhD, and after much

critical debate with my supervisors and others, I decided to apply CIS to the problem and attempt to both address the research question and evaluate the use of CIS as a methodology.

The structure of CIS outlined by Dixon–Woods et al (2006) and used in the PhD study is shown in Table 2.

Table 2: CIS approach to review

Step
1. Formulating the question
2. Searching the literature
3. Sampling
4. Determining quality
5. Data extraction
6. Conducting the interpretive synthesis: development of synthetic constructs
7. Conducting the analysis: development of synthesising arguments

Formulating the question

For the purpose of CIS, Dixon-Woods and her colleagues suggested that the question should *not* be defined precisely at the outset of the CIS (Dixon-Woods et al, 2006). Instead a broad statement should be formed to enable the literature to be identified. According to Eakin and Mykhalovsky (2003), the question in CIS was a compass - not an anchor. It was meant to guide the search, rather than ‘fixing’ it to one area. This approach was conducive to the iterative process that underpinned the doctoral study: the final question evolved during the study in response to the

evidence that emerged during sampling and analysis. Chapter Three outlines the development of the research question in more detail.

Searching the literature

The initial search was conducted using a range of keywords and phrases and used electronic databases to access evidence. Evidence was defined very broadly because I wanted to find out how and why the rituals had evolved. However, it soon became apparent that the typical model of literature searching was producing very traditional evidence that described the incidence of previsible births and the ethical and clinical decision making in relation to previsible births. This provided limited descriptions of the clinical performances. The evidence base did not, however, explain or explore how or why the rituals may have evolved. What was apparent was that the accounts of care given in previsible births across the UK and North America were homogenous.

As a result of discussions with my supervisors and reflecting on my own clinical experiences, I decided to look at textbooks as possible sources of evidence. Textbooks can be seen as instruments of enculturation for the intending midwife and a means of promoting cultural homogeneity (Apple, 1991). It was apparent that analysis of information relating to previsible births and perinatal loss in midwifery textbooks could be a possible source of explanation for the clinical rituals. Because previsible births are associated with high risk pregnancy, the search was widened to include obstetric textbooks and neonatal textbooks. The textbooks provided

information about the clinical rituals but this was largely at the level of first order constructs (Noblit & Hare, 1988) where the understandings demonstrated in the texts were really everyday understandings, rather than the second order constructs associated with social science interpretations.

Guideline construction in relation to clinical care requires an evidence based approach which expects that evidence cited will have been appraised in relation to reliability and validity. I believed that exploring the guidelines produced by national professional organisations might provide a more detailed examination of the evidence than that found in the textbooks. Copies of guidelines from professional organisations in North America and the UK were obtained and interrogated (Chapter Seven). Following on from this, in an attempt to explore what was happening at local level, clinical guidelines for dealing with previable births from every region in the UK were obtained and analysed (Chapter Eight).

There was a great deal of agreement between the guidelines (local and national), the textbooks (midwifery, obstetric and neonatal) about the clinical rituals performed at a previable birth. After reflecting on this during supervision, I began to question if these could be the only understandings of previable birth. I then started to explore literature relating to birth and death in different cultures. This evidence was mainly drawn from anthropologists and thanatologists studies of different cultures but it highlighted that in many societies, a previable baby would not acquire personhood at birth and this would affect how the baby's body was cared for and then disposed of

after death. It would also influence the care given to parents and the way in which the communities to which they belonged would respond. The data from these papers resembled the second order constructs referred to by Noblit and Hare (1988) and provided rich data for the analysis. Chapters Four, Five, Six, Seven and Eight provide detailed descriptions and discussions of the search for evidence for the CIS.

Data Collection

Unlike the traditional review which restricts the range of evidence sampled through the application of tightly formulated inclusion and exclusion criteria, CIS generates large quantities of information. Dixon-Woods et al (2006) referred to sampling in CIS as ‘a constant dialectic process’ which was highly iterative and was concurrent with theory generation. Since this was an explanatory study which would draw on diverse literature, this further supported the use of CIS as the research design.

In CIS, data comprises literature but this is defined very broadly. It includes traditional clinical or professional evidence, conference publications as well as personal knowledge (Dixon–Woods et al 2006). Dixon-Woods et al (2006) also referred to ‘adjacent literatures’ which may not be ‘obviously relevant’. In this case, although the CIS was directed at understanding the care of pre-viable babies in a setting where resources to care for very preterm babies were available, literature relating to the care of pre-viable and stillborn babies born in resource poor settings was also explored in an attempt to understand the influences on ritual development. The wider thanatological literature was also explored to examine how different understandings of death and dying are constructed. The literature exploring public

participation was included to examine how this may have influenced ritual development. Because CIS involves extensive searching of a range of literatures, it is suggested that it was not possible to produce an exhaustive account of the literature. Instead Dixon-Woods et al (2006) proposed that the literature search should aim for ‘saturation’ using a theoretical sampling approach. Saturation is a concept that relates to ‘data adequacy’ according to Morse who defined the term (1995). However, the concept has been used as a ‘catch-all’ to excuse the use of small samples. Within this PhD study, criteria developed by Charmaz (2005) were adapted for to ensure the adequacy of the sampling strategy for the literature search and review.

Table 3: Criteria for achieving data saturation derived from Charmaz (2005)

Criteria	Explanation
Credibility	<ul style="list-style-type: none"> • Intimate familiarity with the study data is demonstrated. • Range, number and depth of data is sufficient to support the claims. • Data covers a wide range of empirical observations • There are logical links between the data and the arguments proposed • Sufficient evidence should be provided to allow the reader to make their own assessment and agree with the researcher’s claims.
Resonance	<ul style="list-style-type: none"> • The search should portray the fullness of the literature. • Taken –for-granted meanings are explored
Usefulness	<ul style="list-style-type: none"> • Social justice implications are examined

Determining quality

Appraising the quality of the evidence is complex. There is debate as to the method of appraisal (Dixon Woods et al, 2007) and the inclusion of poor quality papers. Dixon-Woods et al (2006) compared three different methods of appraisal and synthesising evidence and found that personal professional judgement was as effective as structured appraisal of studies. Her investigation suggested that existing techniques needed to be evaluated and modified, rather than developing new approaches. I felt that it was important for the PhD study to use explicit quality assurance tools. Firstly, it would provide reassurance that quality appraisal had taken place. Secondly, it would provide an audit trail so that the process of CIS could be quality appraised: this was important as the methodology was being evaluated, too. Thirdly, it became apparent that a great deal of the evidence that informed the care of dying pre-viable babies could be considered to be of 'poor quality' using the criteria and methods outlined in the following section. I felt strongly that it had to be included in the study because it was already being used to inform practice and that the review had an important part to play in demonstrating the poor quality of the evidence, as opposed to ignoring it. By providing explicit information about the quality of the evidence, I felt that I could justify its inclusion in the study and ensure that any reader would be able to understand how and why it had been used.

Journal articles and the professional guidelines were appraised using the critical appraisal tools produced by the Critical Appraisal Skills Programme (CASP) (Public Health Research Unit, 2005). The tools consist of a series of focused questions

designed to enable a judgement to be made about the quality and effectiveness of a study and its applicability to clinical practice. Appendix One contains examples of the CASP tools used in the PhD study. Application of the tools is demonstrated in Chapters Seven and Eight.

The professional guidelines were appraised using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2001). This tool has been developed and validated for the evaluation of clinical guidelines (AGREE Collaboration Writing Group, 2003). The AGREE instrument provided a structure to assess the quality of the process of guideline development and the quality of the recommendations. The incorporation of quality assurance tools such as CASP and AGREE was consistent with the need to quality assure data included in the review.

The AGREE instrument consisted of 23 questions organised into six domains (Appendix Two). The domains addressed different aspects of guideline quality (AGREE Collaboration, 2001). Each item had a four-point scale that ranges from strongly agree to strongly disagree, with two mid-point scores. Each item also had accompanying explanatory notes to enable the appraiser to clarify the meaning behind the questions. It was recommended that each guideline was appraised by a minimum of two people using the instrument. For maximum reliability, four appraisers were recommended. Application of the AGREE tool to the data analysis is demonstrated in Chapters Seven and Eight.

Data extraction

Before undertaking the analysis of the guidelines, the AGREE tool was piloted with a group of students undertaking doctoral programmes of research in the College of Medicine, Dentistry and Nursing at the School of Nursing and Midwifery. As a result of carrying out the pilot analysis, it was established that only the part of the guideline relating to the care of the dying pre-viable baby should be evaluated. Most of the guidelines had embedded this information in the wider framework addressing decision making and care of babies who were to be resuscitated. From the pilot, it was clear that there were potentially significant differences in the way the different outcomes were considered. Analysing the guideline as a whole would lead to skewing of the results related to the care of dying pre-viable babies.

Several guidelines addressed the needs of pre-viable infants who were to be resuscitated and provided recommendations based on randomised controlled trials (MacDonald et al, 2002; Canadian Paediatric Society, 2000). Where there was a lack of evidence in relation to specific approaches to care, this ambiguity was clearly acknowledged (MacDonald et al, 2002; Canadian Paediatric Society, 2000). The section on caring for dying pre-viable babies, however, did not acknowledge the evidence base (or lack of it). It was decided that it was important that the section on caring for dying pre-viable babies should stand on its own in order to be reviewed in each of the guidelines to enable the specific data to be extracted. The method of sampling was consistent with CIS methodology and was then applied to all the data included in the study (Dixon-Woods et al, 2006). An Excel framework was

constructed to allow the literature to be collected and collated in a systematic manner. Having the data in a spreadsheet form allowed it be organized and manipulated which facilitated analysis and synthesis.

Conducting the Interpretive Synthesis: development of synthetic constructs

In order to decode or deconstruct the textual materials used as data, further analysis was required. Initially content analysis was considered as a possible method. Content analysis has been described as a research technique for the objective, systematic and quantitative description of the manifest content of communication' (Bereleson, 1952). Essentially content analysis is about classification and counting of a 'unit of text' until, eventually, a large quantity of text is distilled down and described. The 'objectivity' referred to in content analysis does not relate to the concept of validity as it is understood in research: as in determining a single meaning. The 'objectivity' refers to the reduction of the textual data to a code. Because of the reductionist nature of content analysis and the fact that once it has reduced the text to a codified form, the original nature of the data is lost, it was apparent that it would not be suitable for extrapolating meaning from the data in this study, where a multi-layer analysis was required.

McCloskey (1994), an economist, proposed a very structured approach to documentary analysis using nine different elements. However, an initial exploration of a set of guidelines demonstrated that the McCloskey model assumed an understanding of the situation within which the guidelines were constructed. While

this might be acceptable for an audience of neonatologists and midwives, it is unlikely that a wider audience would share the same understanding of the situation.

Leach (2000) suggested an approach to rhetorical analysis that included exploration of the situation allowing underlying assumptions about the context within which the rhetoric was constructed to be explored. This included who produced the rhetoric, where and how. According to Leach (2000) there are three elements to consider in analysing the rhetorical situation:

- Exigence
- Audience
- Persuasive Discourse

Exigence has been defined by Bitzer (1968) as a 'defect or something waiting to be done'. It can be further sub divided into *kairos* and *phronesis*. Kairos means timeliness and phronesis is about the appropriateness of the particular piece of rhetoric: it is about saying the right thing at the right time. The audience is the intended recipients of the rhetoric.

Persuasive Discourse refers to the type or genre of rhetoric. Three types have been identified:

Forensic (legal) which centres around past events

Deliberative (policy) which relates to the course of future action;

Epidictic (contemporary) which relates to censure, praise and blame.

Traditionally, rhetoric is considered to have five ‘canons’: Invention, Disposition, Style, Memory and Delivery. Some canons have further categories allowing for close examination of the rhetoric. Table 4 describes the canons used in the rhetorical analysis.

The form of analysis suggested by Leach (2000) was piloted using a set of guidelines to test its applicability (Appendix Three). This demonstrated that rhetorical analysis would be a useful tool in the development of synthetic constructs.

Table 4: Canons of rhetorical analysis

Canon	Description
Invention	<p>This relates to the form and the content of the rhetoric. It is highly significant that journals respected within the medical community prescribe the same format for publications</p> <p><u>Ethos</u> This relies on establishing the credibility of the author(s). While it could be argued that the authorship of a paper is less important than the content, part of the persuasion element of a text may rely upon the credentials of the author.</p> <p><u>Pathos</u> Pathos is the appeal within a text to emotion.</p> <p><u>Logos</u> Logos relates to logic – the ability of the text to persuade the audience of the merit of a particular point of view.</p>
Disposition	Disposition relates to how the text is organised. The underlying assumption is that the organisation of a text can be part of the persuasive argument. it is similar to the canon of ‘invention’.
Style	Style refers to the relationship between form and content. It represents the way in which the authors present the information and the deliberate use of forms of language to persuade the audience of the worthiness of the paper.

	<p><u>Metaphor and analogy</u> Metaphors are used to transfer meaning from one concept to another and are used widely in literature. Metaphors work by creating analogies between two separate concepts.</p> <p><u>Metonymy and synecdoche</u> Metonymy and synecdoche are figures of speech where we use a 'part' to represent a 'whole'. For example, the use of 'Scotland versus England' in a football matches.</p>
Memory	This relates to length and recall. For example a great orator would talk for a long time and then be able to repeat the speech. In contemporary society, it relates to the reproducibility of the text.
Delivery	Delivery relates to the dissemination of the content.

The method of analysis used by Dixon-Woods et al (2006) included inspecting the literature, identifying recurring themes, patterns and categories. In their study, the multidisciplinary team involved in the review produced a dialogue that prevented only one perspective framing the review. Noblit and Hare (1988) highlight the importance of 'refutational syntheses' in assessing competing explanations of the data. They suggest that 'explicit refutations' are designed not only to present alternative findings but also to challenge the significance of the findings. They propose that refutations may be driven by dogma and may themselves be dogmatic. For that reason, they suggest that refutations should be analysed and not simply presented as an opposing argument. In the doctoral study, the evidence was assessed during the supervisory process and themes and patterns were identified during discussions about the nature of the evidence, as well as the theoretical positions taken by authors.

Three broad synthetic constructs emerged from the data: User Involvement, Performance and Choice, together with the themes of Ideology, Rhetoric and Ritual which permeated the thesis. The process of developing synthetic constructs is discussed in detail at the end of each of the data analysis chapters.

Conducting the analysis: development of a synthesising argument

In CIS, the final step is the development of synthesising arguments. According to Dixon-Woods et al (2006) the development of a qualitative ‘Synthesising Argument’ in comparison to a quantitative synthesis approach is under-pinned by an iterative process that evolves as the data is analysed and interpreted.

In this doctoral project, the emerging data was explored and critiqued. I was encouraged to adopt what Dixon-Woods et al (2006) call ‘a critical and reflexive stance’ towards the data and the emerging theory by my supervisors as part of the supervisory process. I also presented at conferences and seminars nationally and internationally (Appendix Four) and published papers (Appendix Five) to facilitate external critiques of the research process and the emerging theory.

As well as critical analysis and interpretation, the synthetic constructs that emerge from the data were ‘translated’ into a synthesising argument by drawing on a wider body or ‘adjacent literatures’ of evidence to frame the argument (Dixon-Woods et al, 2006; Flemming, 2010). In the doctoral study, I drew on evidence relating to

palliative care, user involvement in health care, risk management and evidence based care in formulating the synthesising argument.

Palliative care has frequently been cited as being the ‘gold standard’ in relation to patient centred care. However, there are a number of challenges to this perception, not least because the evidence base appears to be weak and palliative care is notoriously selective about who is allowed to access it (Randall & Downie, 2006).

User involvement in healthcare was an important element of government policy both in relation to healthcare provision and health service research. The issues of authority and representativeness were considered in the development of a synthesising argument. Evidence based care was a central tenet of healthcare policy and provision in the UK. The nature and construction of the evidence base relating to dying pre-viable babies was explored using current guidance from the Scottish Intercollegiate Guidelines Network (SIGN) and the National Institute for Health and Clinical Excellence (NICE). ‘Risk’ emerged alongside evidence based care. The use of evidence in practice was perceived to reduce risk to both the individual and the organisation. The concepts that evolved for me were: ideology, rhetoric and ritual and these are used to explore and explain the synthesising argument (Chapter Nine).

Quality Assurance of the CIS

Dixon-Woods et al (2006) state that traditional systematic review methodology provides explicit criteria to enable its methods and findings to be reproducible. They also admit that CIS may not meet the criteria for reproducibility and suggest that this

is not important since their intention is to produce an interpretive account rather than a summary of what the literature said. It is also the case that some qualitative researchers question the need for validity to be established (Rolfe, 2006). Morse et al (2002) state that it is important that any research process provides an account of how it was conducted so that a judgement can be made as to its integrity and worth. I agree with these sentiments and believe that this is especially true when using an emerging methodology.

Sandelowski (1993) uses the term 'trustworthiness' to describe the process by which a researcher makes visible the steps that they have undertaken so that they can be audited through the use of a decision trail. In this doctoral study, care has been taken to account for and justify each step so that the reader can make their own judgement as to the trustworthiness of the study. Detailed explanations have been provided to demonstrate how decisions were made and the impact this had on the data. Worked examples of analyses are provided. These can be regarded as being akin to the reliability tests of member checking and peer checking suggested by Guba and Lincoln (1989). The threats to the study are considered in detail in each of the chapters where the CIS is explicated. The final chapter of the PhD thesis considers these threats in relation to the study limitations and addresses them in turn.

The Theoretical Framework

To attempt to understand how and why the rituals have been developed and used, I sought a theoretical framework to help me make sense of the data and explain the

relationship between the data and the analyses (Denzin & Lincoln, 2003a; Denzin and Lincoln, 2003b). There was a strong sense of performance in the data because of the focus on ‘what to do’ and ‘what to say’. Frameworks which drew on elements of theatre or drama were considered in relation to the research question to elicit which framework would be the most effective in supporting the study.

Dramaturgy

Using a dramaturgical approach, Goffman conceptualized human beings as actors performing or acting out a part in a drama. He suggested that individuals would modify their behaviour and language in particular ways, depending on the audience and the setting, in order to create a specific impression (Goffman, 1956). Goffman suggested that this ‘front of house’ behaviour contrasted with ‘backstage behaviour’ where an individual could relax, let down their guard and be themselves.

The strength of Goffman’s theory lies in the interaction between individuals – in this case, health professionals and parents; and the drama unfolding as a previsible baby is born and then dies in the labour ward. This could be conceptualized as being ‘front of house’ with health professionals putting on a ‘caring face’ for the parents (Deery, 2009). My experience, however, was that health professionals did try to engage meaningfully with parents and their ‘backstage’ behaviours when they left the labour room did not differ significantly from their behaviour in front of the parents. Published accounts by health professionals of their experiences in caring for dying babies and their parents report genuine emotion (Gold et al, 2007; Kavanaugh

et al, 2009; McHaffie & Fowlie, 1996). This suggested to me that Goffman's theory would not be appropriate for the PhD study.

Emotion Work

Hochschild (1983) explored how workers were expected to manage their emotions to fit with organizational rules. 'Emotional labour' was used to describe the work which employees undertook in order to manage their emotions and create a public display. Similar work has been undertaken in midwifery (Hunter, 2004; Hunter, 2005) to investigate and explain how midwives manage their emotions in complex situations. However, as with Goffman's model, there was no suggestion from my clinical experience or from the literature that health professionals were managing their emotions or presenting an institutional view and this led me to reject emotion work as a possible framework for the study.

Performance Theory

Performance Theory is an emerging theory arising from collaborations between a dramatist, Richard Schechner, and an anthropologist, Victor Turner (Schechner, 1995; Schechner, 2002). Turner (1967) studied the use of ritual within Ndembu society which led him to conceptualize ritual as a means of expressing deeply held social attitudes and values.

Turner (1967) described ritual as 'prescribed formal behaviour' and 'a stereotyped sequence of activities involving gestures, words and objects, performed in a

sequestered place' (Turner, 1977). The 'gestures, words and objects' were symbols which are imbued with meaning. Turner (1968) suggested that meaning and information was stored within the symbol which added authority to the ritual making it a deeply meaningful and transformative experience for those involved. Turner's understanding of ritual informed the development of performance theory by Schechner (2002). Schechner redefined 'performance' as a broad range of human actions which could include dance, theatre, painting, literature, as well as everyday life and that 'any action that is framed, presented or highlighted or displayed is performance.'

Performativity is an essential element of performance and Performance Theory. Austin (1976) used the term 'performative utterances' to describe what he called 'speech acts'. He contended that performative utterances were imbued with meaning. Their use in a performance was deeply symbolic. Austin used the example of the wedding vow, 'I take this woman to be my lawful wedded wife' to demonstrate how words could also be acts – that is they have meaning beyond the simple utterance of the words. Thus the use of words becomes an important part of the performance. This can be seen in the rhetoric that has developed around perinatal loss where the use of certain words or phrases has become taboo e.g. referring to the baby as 'products of conception'. Textbooks and guidelines also had lists of helpful phrases for health professionals. I would argue that these resemble scripts for performance.

Using performance theory to explore ritual, I argue, may facilitate a deeper understanding of the actual performance – how it is scripted and enacted. Within performance theory, Schechner (2002) explored the concepts of ‘twice behaved behaviours’ and ‘restored behaviours’. As with any performance, ritualized performance allows rehearsal and revision to take place, rather than regarding the performance to be fixed. The participants may train and rehearse but no performance can ever be exactly the same since no event can replicate itself. Exact replication is not the focus of the performance. Instead the reflective or critically conscious performance – ‘being’ - is the ultimate goal (Schechner, 2002).

A major feature of Performance Theory was the position adopted by the researcher. According to Schechner (2002), Performance Theory allowed the researcher to be distant and study the performance, using ‘criticism’ or ‘irony’ but it also permitted the researcher to undertake ‘sympathetic participation’ in the performance. This description resonated with my position as during the study. I had been engaged as a performer participating in the rituals of caring for dying preivable babies but as the study evolved, I adopted the role of researcher, studying the rituals at a distance and critiquing them in order to understand them.

Turner identified six areas of performance theory:

1. Transformation of being
2. Intensity of performance
3. Audience performer interactions

4. The whole performance sequence (training, rehearsals, performance, cool-down, and aftermath)
5. Transmissions of performance knowledge
6. Performance evaluation

While much of what Turner wrote has been critiqued, these six areas can still allow a 'soft' direction in the analysis process. In relation to the doctoral study, the rituals used in the care of the dying previsible baby transformed the woman and her partner into 'parents'. The rituals were designed to reinforce their claim to parenthood by enabling them to care for their dying baby and participate in the kinds of decisions that all parents make, for example, the choice of clothes in which to dress the baby. The intensity of the performance was heightened in the case of the dying previsible baby because there was only a limited time during which the baby would be alive. After death, time was limited because of the changes that take place in the baby's body and the inevitable separation brought about by the funeral. This meant that decisions made at the time were irrevocable – whether or not to see or hold the baby and to take photographs. This knowledge helped shape the interactions between the performer (health professional) and the audience (parents). Because of the knowledge that decisions cannot be undone, professionals may have thought it important that parents make the 'right' decisions – that is they do not later regret the choices they make around the time of the baby's birth and death and this may have influenced the way in which 'choice' about care is presented to the parents.

Unlike 'normal' birth, caring for a pre-viable baby is a relatively rare event. There is little opportunity for health professionals to practise and revise their skills in real life situations. Simulation may be used to help health professionals develop their skills in caring for dying pre-viable babies. I would argue that part of the role of guidelines is to provide a script for health professionals to adopt and adapt as part of the rehearsal for the performance. Begley (2003) demonstrated that student midwives were often excluded from caring for parents around the time of perinatal loss because registered staff wanted to 'protect' them from the situation. A midwife's first encounter with a dying pre-viable baby might be as the 'performer' having never seen a performance. The guidelines would therefore be important in transmitting knowledge about the performance since the events are rare and some health professionals may not have the opportunity to observe the care of a dying pre-viable baby before being required to participate as an 'actor'.

Evaluating a performance is usually done by critical review by someone who has seen the performance and could be considered to be 'external' to the event e.g. a drama critic. In the performance being studied in the doctoral thesis, the only observers were the parents. Evaluation of their views can be sought through audit and research but I have already demonstrated that permission to seek the views of bereaved parents is likely to be withheld by ethics committees because of their perceived vulnerability. Parental complaints may also be used as a measure of performance evaluation. The checklists of activities recommended for staff to undertake with parents are used as part of the risk management procedure can be

used to measure compliance with the guideline and can also be used to counter parental complaints by demonstrating that everything that could be done, had been done.

Summary

The result of CIS is to ‘produce (a) coherent and illumination theory of a body of evidence that is based on detailed critical study of that evidence’ (Dixon Woods et al, 2006). In relation to the doctoral study, a wide range of literature was sampled, analysed, appraised and synthesised to produce a reflexive and unique account of the development of care of dying preterm babies in labour wards in the UK. This chapter described the process of selecting and applying CIS and the application of a theoretical framework to the doctoral study. The following chapter demonstrates question formulation - the first step in CIS.

CHAPTER THREE: CRITICAL INTERPRETIVE SYNTHESIS – FORMULATING THE QUESTION

Introduction

The previous chapter set out the case for using Critical Interpretive Synthesis as the methodology for the PhD thesis. This chapter explores the application of Critical Interpretive Synthesis to construct and answer the research question:

How and why are rituals relating to the care of dying pre-viable babies in labour wards constructed, deconstructed, enacted and interpreted?

In particular, this chapter describes the formulation of the research question, how it evolved during the study and how it relates to the CIS process.

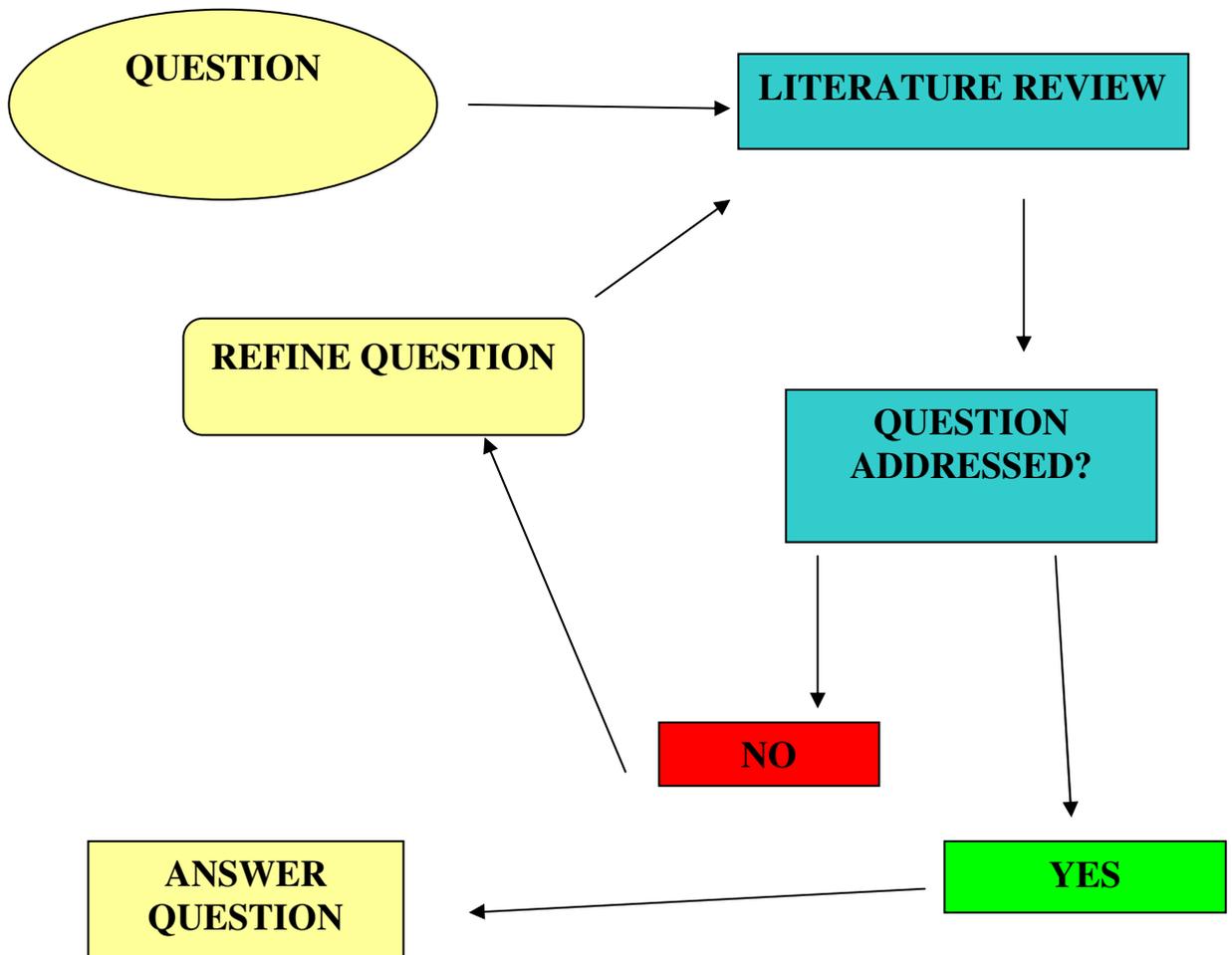
Critical Interpretive Synthesis: Question Formulation

Traditional quantitative systematic reviews focus on developing a very tightly defined question which in turn drives a highly specific and sensitive search for evidence to answer it. Dixon-Woods et al (2007) suggested that the purpose of a traditional systematic review is to summarise the data, while the purpose of CIS is to interpret data. Unlike traditional summative reviews which limit themselves to one specific methodological approach, CIS lends itself to mixed method reviews. The interpretive approach associated with CIS means that the research question can evolve and develop in response to the data rather than the other way round. Dixon-Woods et al (2007) suggested that while the research question ‘anchors’ the data in traditional reviews, in CIS it was a ‘compass’ which provided general directions for

data collection and developed in an iterative manner in response to the data collected.

The following figure shows the relationship between the data and the evolving research question in CIS.

Figure 1: Question formulation in CIS



The initial question for the doctoral study was exploratory in nature:

‘Perinatal death at the threshold of viability – what are the experiences of parents and professionals?’

The initial aims of the study were to explore the experiences of parents and professionals providing physical and emotional care for babies born at the threshold of viability during their brief life and immediately afterwards. I intended looking at the similarities and differences between local and national policies and guidelines for the care of parents and babies born at the threshold of viability, the impact of policies on professional practice such as the factors that parents found helpful when they were caring for their dying baby, and the way in which health professionals, particularly midwives, contextualised the care given to parents as their baby dies.

The literature that emerged from the initial search highlighted practices such as holding and naming the baby. This led me to reflect on the emergence of the practices within the context of my own professional practice. As a student midwife in the 1980s I had a vivid memory of the body of a stillborn baby being rushed out of a birthing room and taken to the sluice, with the midwife issuing strict instructions that I was not to enter the sluice under any circumstances. At the time, I was less concerned about the stillborn baby – I had trained as a nurse prior to becoming a midwife and had seen dead bodies - than the instruction not to enter the sluice. As a junior student midwife, most of the tasks I was allocated required access to the sluice and I was worried as to how I could explain my reluctance to undertake tasks to senior members of staff.

A few weeks later, a stillborn baby was born. Unlike the previous occasion the baby was left in the room with the parents. I recall the staff questioning the midwife who was at the birth about the reactions of the parents and her positive responses as to how the parents had responded. All the midwives in the staff room seemed to view the sudden change in practice favourably. I regret to say that I did not question why the practice had changed. However, a few days later, a local newspaper ran a front-page story about the case. The informant was the grandmother (who had not seen the stillborn baby) who told how ‘nurses’ had ‘forced’ her daughter to hold her dead baby. The story caused great consternation and upset in the maternity hospital. I remember that the midwife concerned was keen to tell everyone that she had asked the parents if they had wanted to see and hold their baby and they had wanted to do this. After that incident, it seemed to become part of accepted practice that parents would be offered the opportunity to see and hold their dead or dying baby, despite the reactions of the grandmother.

As a result of discussions with my supervisors about the significance of the practices, I began to question the nature of the practices that took place – were they ‘routines’ or ‘rituals’? That is, were the practices carried out because they were prescribed by guidelines or did the practices have meaning for the parents and the professionals? These reflections led me to locate the change in practice in relation to time (the early 1980s) and also suggested that some explanation for the change might be found in midwifery textbooks as they were the main source of information

for midwives and midwifery students and this then directed the literature search towards midwifery texts.

The question evolved thus:

‘Perinatal death at the threshold of viability – routines or rituals?’

In order to address the research question, I started to explore anthropological and thanatological literature. The differences in the way childbirth and death are treated in different societies is highly suggestive that culture and beliefs, rather than physiology alone, shape them. The literatures suggested that there was a ritualistic element to the practices – that is the practices which appeared to be driven by guidelines were intended to be deeply meaningful experiences and had been designed to reinforce the parenting role. This, in turn, led to the development of a question that asked about the nature and origin of the rituals:

How and why did rituals relating to the care of dying pre-viable babies develop?

As the anthropological and thanatological literature was explored, questions about the understandings of the clinical practices emerged. In particular, I began to question how the rituals formulated for stillborn babies came to be adopted and applied to the care of a living, albeit dying, baby. The research question was then further developed to become the final research question which specified the focus

of the research - rituals relating to the care of dying preivable babies in labour wards and their development:

How and why are rituals relating to the care of dying preivable babies in labour wards constructed, deconstructed, enacted and interpreted?

Summary

This chapter provides an account of the research question for the doctoral project and attempts to describe how research questions in CIS evolve from the data. The following chapter addresses the next step: data collection and focuses on clinical and professional literature.

CHAPTER FOUR: CRITICAL INTERPRETIVE SYNTHESIS DATA COLLECTION AND ANALYSIS – CLINICAL AND PROFESSIONAL LITERATURE

Introduction

The previous chapter set out the development of the research question for the doctoral study and demonstrated the relationship between the research question and the data. This chapter addresses data collection through exploration of the professional literature.

Search strategy

The initial search strategy was designed to elicit relevant published materials relating to the care of dying pre-viable babies and was carried out between September 2005 and September 2010. There was little agreement in the literature about terms used to describe babies of less than 24 weeks gestation. Terms used in the search included ‘pre-viable’, ‘per-viable’, ‘extremely preterm’ ‘very preterm’, ‘non viable’ and ‘extremely low birth weight’. To capture the care of the dying pre-viable baby the terms ‘perinatal loss’, ‘neonatal loss’ and ‘perinatal death’ were also used to search to ensure that the relevant literature was identified.

Databases

Relevant databases identified for the search included: CINAHL, PubMed, Science Direct, MIDIRS midwifery database; SCOPUS, ASSIA, Cochrane library of

reviews, PsychInfo and the British Nursing Index. Catalogues from the Royal College of Nursing, Royal College of Midwives, National Library of Scotland and the Kings Fund Library were searched. The websites of the Royal College of Obstetricians and Gynaecologists, Royal College of Midwives and Royal College of Paediatrics and Child Health were also searched.

Inclusion and Exclusion criteria

No time limits were placed on the review. This decision was taken because I wanted to identify when rituals relating to perinatal care emerged in the literature. Papers were eligible for inclusion if they were written in English and described the care given to dying babies in labour wards or neonatal units and were published in professional and clinical journals. The initial search yielded very little information. Only one paper from the USA addressed the specific research question. The remaining literature related to ethical decision making about resuscitation of pre-viable babies or the care of babies who died in neonatal units. The search was then widened to include all forms of perinatal loss to ensure that the explanations of ritual development were captured.

Sampling strategy

Databases were searched using the keywords and phrases. Papers which had the search terms in the title or abstract (where this facility was available) were located and read. Some databases offered incremental searching facilities to link to related papers and these were followed until no new papers were identified. References

were examined and followed up through ‘chaining’ to ensure that all relevant papers were captured.

Results

This section provides information about the analysis of the data from the search. References were entered onto an Excel spreadsheet, along with relevant contextual information and findings. The accuracy and relevance of the contextual information and findings was reviewed by the two supervisors. While this did not substantially alter the findings, it did lead to additional information being included for greater clarity and understanding.

The spreadsheets were then reviewed to look for emerging patterns in the data. At this stage, I began to identify links between the data using the information on the spreadsheet. Appendix Six is an example of a spreadsheet showing how the themes were identified from the data. The initial patterns were developed from both the manifest level (directly observable) and the latent level (Boyatzis, 1998). This process captures obvious patterns in the data and also allows for interpretation. During this phase, an integrative table was developed (Table 5). This identified the evidence base, the issues and sub themes and from these, the main themes were developed.

Table 5: Relationship between Themes: Clinical and Professional Literature

Theme	Sub themes	Issues	Evidence	Critique
Determination of Gestational Age	Mortality and morbidity Objectivity of data	Completeness of data Perceptions of morbidity	Cohort studies Perinatal databases	Data under represents babies who die in labour wards. Death Rates of previable babies higher than data suggests. Lack of agreement as to what constitutes serious morbidity within and between studies.
Signs of Life	Definitions Objectivity of data Clinical judgement	Registration of the death Baptism	Professional statements Ethical statements	Lack of monitoring of adherence to professional standards. Disagreement between professionals and parents as to the implementation of recommendations in relation to feticide and recording of live births
Non Intervention	Withholding / Withdrawal of care Euthanasia	Best interests Suffering Futility of interventions Parental involvement / agreement	Professional statements Qualitative studies Personal opinion reports	Parental satisfaction with decision making and outcomes appears to be high with consistent findings in the UK and North America. Lack of representation of parents from minority groups in research studies.
Human Rights	Autonomy Personhood Consent	Best interests Parental involvement / agreement Clinical judgement	Professional statements Ethical statements Guidelines	Lack of consideration of minority viewpoints. Lack of an effective evidence base e.g. qualitative research to explore professional and parental views.
Theory of Loss	Models	Medicalisation Institutionalisation Critiques Normal and abnormal grief	Research: cohort studies Opinion papers Professional statements	Samples not representative of the range of parents who experience perinatal loss. Vested interests – user groups oppose evidence which contradicts their

				position Lack of evidence to support the use of models to perinatal loss – both established and emerging models.
Ritual relating to loss	Caring Uncaring Non event - event	Meanings Routines Contested views	Professional anecdotes Qualitative research Cohort studies	Samples not representative of the range of parents who experience perinatal loss. Professional anecdotes represent only positive outcomes.
Dying Right	Good death	Dignity Compassion Choice	Case studies Professional statements	Palliative care model presented as providing optimum care. Lack of critique of the palliative care model. Acceptability of model across a range of client groups not explored.
Representation	Authority Autonomy	Seldom Heard voices Inclusiveness	Professional statements User group literature	Samples not representative of the range of parents who experience perinatal loss. Vested interests – user groups oppose evidence which contradicts their position

This process was iterative and the patterns that were identified initially were reviewed by my supervisors. During this process I was challenged to explain and refine the patterns. This involved identifying the patterns and providing explanations for the relationships between them. The interrogative process continued until there was agreement on the themes. The following themes emerged from the data.

Table 6: Clinical and Professional Literature - Themes

Theme
Determination of gestational age
Signs of life
Non intervention
Human rights
Theory of loss
Ritual relating to loss
Dying right
Representation

Determining gestational age

This theme was associated with the relationship between the gestational age of the fetus or baby and mortality and morbidity. The gestational age referred to the time between the last menstrual period and the birth of the baby (Committee on the Fetus and Newborn, 2004). Early ultrasound scans were more accurate in dating the pregnancy than relying on the last menstrual period (National Institute for Health and Clinical Evidence, 2003). Having an accurate assessment of gestational age was seen as important for professionals and parents when making decisions about intervention at the time of birth of preterm babies because of the increase in mortality and morbidity associated with very preterm births (Wilkinson et al, 2008; Batton, 2009; Peerzada et al, 2004; ILCOR, 2006; Pignotti, 2008).

The evidence for mortality rates for pre-viable babies was drawn from studies carried out in Europe and North America. The evidence suggested that there is consistency in relation to survival rates across the continents. Babies born at 25 weeks gestation or greater had a survival rate of about 67% (Marlow et al, 2005; Pignotti, 2008; Larroque et al, 2004). At 24 weeks gestation, the survival rate dropped to 41% (Swamy et al, 2010; Field et al, 2008). Babies born at 23 weeks gestation had a survival rate of about 18% (Swamy et al, 2010; Field et al, 2008). Babies born before 23 weeks gestation had almost 100% mortality (Costeloe et al, 2000; EPICure 2 Perinatal Group, 2008). The mortality rates for babies born between 24 to 25+ weeks gestation improved significantly over the past 10 years (Marlow et al, 2005; EPICure 2 Perinatal Group, 2008; Swamy et al, 2010; Field et al, 2008). However, the situation for babies termed 'pre-viable' remained virtually unchanged (Vanhaesebrouck et al, 2004; Field et al, 2008).

The data on which the mortality rates were calculated were drawn from a range of sources. These included Regional Maternity Service databases (Swamy et al, 2010); perinatal databases (Field et al, 2008) and research databases (Costeloe et al, 2000; Marlow et al, 2005; EPICure 2 Perinatal Group, 2008). While these were presented as being 'well populated' (Swamy et al, 2010) and accurate and 'factual' representations of the outcomes of preterm births, there was evidence that the data under-represented the number of pre-viable babies born alive and who subsequently died (Macfarlane et al, 2003; Evans & Levene, 2001). Macfarlane et al (2003) found that 8% of the very preterm babies in their study who showed signs of life at birth

consistent with the World Health Organisation (WHO) definition were not registered as live births and subsequently were not recorded as deaths. This suggested that the overall rates of preterm births and deaths could be higher than recorded on 'official' databases. Ultimately this meant that the number of pre-viable births was higher than official statistics suggested. It also meant that the parents of pre-viable babies did not receive birth and death certificates. The implications of this will be discussed further in Chapters Ten and Eleven.

Morbidity rates were also calculated for very preterm babies and are generally expressed as 'serious morbidity', 'major morbidity', 'serious disability' and 'minor morbidity' or 'minor disability' (Costeloe et al, 2000; Marlow et al, 2005; De Groot et al, 2007; EPICure 2 Perinatal Group, 2008; Swamy et al, 2010). At twenty four weeks gestation, half of all survivors had moderate or severe disabilities (Costeloe et al, 2000; Wood et al, 2000; Marlow et al, 2005; EPICure 2 Perinatal Groupk 2008). Of the rare survivors of pre-viable birth before 24 weeks gestation, almost all had major disabilities. This data was based on longitudinal studies which assessed development at between two and six years of age (EPICure 2 Perinatal Group, 2008).

As with the data for mortality, morbidity data was not as objective as the reports suggested. Firstly, there was considerable debate as to what constitutes serious morbidity with parents, professionals and survivors disagreeing about the incidence, nature and impact of morbidities (Saigal et al, 1996; Saigal et al, 2002; Allin et al,

2006; Saigal & Doyle, 2008; Cooke, 2004). Swamy et al (2010) demonstrated in their analysis of preivable births that many babies who survived in the short term developed serious morbidities, some of which ultimately were associated with the death of the baby. These morbidities would not have been recorded but would have been subsumed into the mortality data. Swamy et al (2010) argued that parents might see survival as a clearly defined issue but their data demonstrated that preivable babies who subsequently died spent an average of 3.7 days in intensive care during which time they experienced a range of serious morbidities, some of which required surgical treatment. This may be important to parents who might not understand that the death of their preivable baby may be preceded by pain and ultimately futile interventions.

Signs of life

This theme incorporated legal and clinical signs of life in preivable babies. The definitions of signs of life as determined by the WHO (1992) and the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) (CESDI, 1996) were objective and verifiable. However, the literature demonstrated disagreement between professional and regulatory bodies as to the interpretation of the signs and also the desirability of acknowledging signs of life. There was also an indication in the literature that, in certain circumstances, it would be desirable to take steps prior to birth to kill the fetus to avoid the birth of a live born child.

The Nursing and Midwifery Council (NMC, 2007) stated that all babies born alive according to the WHO definition had the right to be treated as persons in their own right and cited Human Rights legislation in support of this stance. The RCOG guidelines on the management of late medical abortion of the previable fetus stated that movements in previable babies might be ‘reflex movements’ and could be discounted. The RCOG guidelines on the management of previable babies stated:

‘a previable fetus despite showing signs of activity ex utero is unable to sustain a separate existence and is thus not legally considered above...Registration or reporting to the Coroner is therefore not required, even when there are prolonged signs of activity.’ (RCOG, 2006)

The Nuffield Council on Bioethics (2006) suggested that there should be flexible interpretation of the definition of what constitutes a live birth. In reality ‘flexible interpretation’ can lead to interprofessional conflict (Kennelly,1999; Drazek, 1999; Drazek, 2000; Pedder, 2000; Welch, 2000; Vadeyar et al, 2005) and those arguing for a less didactic approach to defining a live previable birth have failed to indicate what the potential benefits of this approach are to the baby, the parents and to the health service and society.

Live birth following termination of pregnancy was described in the literature. Vadeyar et al (2005) audited births over a six year period and found 31 cases of neonatal death following termination of pregnancy. The authors questioned if

parents were offered the option of feticide⁸ and if they understood the implications of having a live born child. There was some evidence from parental narratives that they were aware that a previable baby may be born alive and may live for several hours (Schott et al, 2007). For some parents, particularly those making the decision to terminate a pregnancy because of a fetal abnormality, having a live born baby was important because it gave them an opportunity to see and hold their baby. For professionals, however, the situation was more complex. Any deliberate action that caused the death of a child was murder, even if the act precedes birth. A doctor who performed a termination of pregnancy resulting in the birth of a live infant that died because of prematurity could be accused of murder (Vadeyar et al, 2005; Breeze et al, 2007). It is possible that this explanation accounted for the desire of medical practitioners to undertake feticide prior to termination of pregnancy and avoid the recognition of signs of life since the registration of a live birth and subsequent neonatal death could provide additional evidence of the result of their actions. It accounted for the problems encountered in the Ethical Review of the study and lent weight for the need to adopt unobtrusive approaches to gathering data in the first instance.

Non-intervention

This theme embraced withdrawal or withholding of care and euthanasia. Decision making in relation to initiation of treatment in previable babies was a major element of the literature relating to previable births and was closely linked with outcomes (Wilkinson et al, 2008; Canadian Paediatric Society, 2000; Higgins et al, 2005;

⁸ Feticide is the deliberate killing of the fetus in utero prior to birth

McHaffie et al, 1999; Royal College of Paediatrics & Child Health, 2004; Thames Regional Perinatal Group, 2000). The need for appropriate decision making was related directly to the poor outcomes experienced by preivable babies. Within the literature, there was an expressed wish to avoid unnecessary suffering on the part of the preivable baby (Wilkinson et al, 2008; Coughlin et al, 2007; Nuffield Council on Bioethics, 2006; Royal College of Paediatrics and Child Health, 2004). The nature of the suffering was directly related to the futility of invasive treatment (Nuffield Council on Bioethics, 2006), Thus, where it was anticipated that invasive and potentially painful interventions would result in the survival of an infant with only minor or no morbidity, the suffering was deemed to be worthwhile and in the best interests of the neonate. If the baby was deemed likely to die whether or not treatment is initiated, the interventions were considered to be the cause of unnecessary suffering and were withheld in the best interests of the baby.

Ahluwalia et al (2008) demonstrated in a review of 'best interests' of neonates that there was considerable disagreement between parents, professionals and clinicians as to how the outcomes of care were perceived. Cultural and legal factors also influenced how best interests were interpreted. For example, Ahluwalia et al (2008) presented evidence that the courts in the UK were generally supportive of medical opinion when making decisions about withholding and withdrawing care. However, in the USA, the situation was reversed. This led to conflict and uncertainty for both parents and professionals. Payot et al (2007) in a qualitative study of decision making relating to the birth of preivable babies in Canada found that parents needed

more than objective data about survival when making a decision about resuscitation. Parents were more comfortable with the decision they made if they felt that the medical staff understood the situation from their perspective, rather than simply focusing on the baby.

Despite the overwhelming evidence that suggested that resuscitation and intervention was futile in pre-viable babies, the recommendations from professional and ethical literature suggested that the approach to decision making should not be didactic (Wilkinson et al, 2008; Nuffield Council on Bioethics, 2006; Royal College of Paediatrics and Child Health, 2004). In particular, the role of parents in decision making was emphasised. This appeared to be partly related to the need for parents to understand and feel comfortable with the decision to withhold care (Wilkinson et al, 2008). The success of this approach in relation to parental satisfaction with care and decisions in relation to withholding or withdrawing care was documented in large qualitative studies in the UK (McHaffie, 2001; McHaffie & Fowle, 1996; McHaffie et al, 1999) and North America (Couglin et al, 2007) which found that parents were satisfied with both the decision making process and the decision itself when care was withheld or withdrawn.

Euthanasia⁹ in babies was addressed in two publications. Verhagen and Sauer (2005) described the Groningen protocol for deliberate life-ending procedures in neonates in the Netherlands. This protocol had not been used for pre-viable babies but the protocol permitted life ending measures in babies for whom survival was hopeless.

⁹ Euthanasia is the deliberate ending of life for the benefit of the person.

The Nuffield Council on Bioethics (2006) mentioned euthanasia and dismissed it as being unacceptable in the UK but did not elaborate on its reasons for arriving at this conclusion.

Human Rights

The theme of Human Rights incorporated personhood, autonomy and consent. Professional guidance (NMC, 2007; Royal College of Paediatrics and Child Health, 2004), ethical statements (Nuffield Council on Bioethics, 2006) and practice guidelines (Wilkinson et al, 2008; Canadian Paediatric Society, 2000; Higgins et al, 2005; Thames Regional Perinatal Group, 2000) all emphasised the need for the baby to be seen as a person. This was reinforced in descriptions of how staff should refer to the baby (by name, if one had been given) and the way in which staff should encourage the parents to care for their baby. The care of dying pre-viable babies reflected the rituals outlined in the care of stillborn babies and this will be addressed later in the chapter. The evidence base for the baby to be accorded the status of a person was based on Human Rights legislation in the professional guidance (NMC, 2007; Royal College of Paediatrics and Child Health, 2004).

Autonomy and consent were addressed in the guidance from professional organisations (NMC, 2007; Royal College of Paediatrics and Child Health, 2004). This was related to Human Rights legislation and child protection legislation. The rights of parents to exercise autonomy and give consent on behalf of their child were explored in professional guidance. These documents also described the limits of

parental autonomy. The ‘messy’ aspects of human rights permeated the guidelines and were closely bound up with professional autonomy and responsibility, particularly where these aspects of practice appeared to conflict with parental autonomy and choices and appeared to conflict with the ‘best interests’ and the needs of the vulnerable baby (NMC, 2007; Royal College of Paediatrics and Child Health, 2004). Professional medical organisations were also clear that didactic guidelines would not be in the baby’s best interests and clinicians had to have the freedom to exercise clinical judgement in individual cases (Nuffield Council on Bioethics, 2006; Royal College of Paediatrics and Child Health, 2004).

Theory of Loss

This theme included the use of theoretical models of grief, medicalisation of loss and healthy and pathological grieving. Theories of loss were most commonly described and referred to in textbooks and this is covered in Chapter Five. This section refers specifically to the use of theories in journals.

Professionals, usually nurses or midwives, reflected on the care that they gave and made specific mention of a theory of loss (Powell, 1997a; Powell, 1997b; Baker, 1998; Kavanaugh et al, 2006). The theoretical model was used to describe how and why care was given (Schott et al, 2007). Descriptions of theoretical models of loss were used in literature produced by parents to illustrate how they might experience the loss and to explain their feelings (Schott et al, 2007; SANDS, 1995).

Griefwork theories were cited by some authors (Sparshott, 2009; Schott et al, 2007; Mander, 2006). In the case of Mander (2006) and Schott et al (2007), the theories were in context of providing an overview of theories of grief and loss. Sparshott (2009) used griefwork theory to recommend that parents undertake specific tasks to come to terms with their grief:

‘both parents need to express their anger before they can experience the pain of grief’.

Griefwork theories will be explored further in Chapter Five.

The attachment theories of Bowlby (1961) and Parkes (1987) were described by Mander (2006) and Schott et al (2007). They were also used as theoretical models to underpin research into parental responses to perinatal loss (Rådestad & Christoffersen, 2008; Rådestad et al, 1996a). Attachment theory was used to support holding and caregiving activities by parents. As with other theoretical models, the work undertaken to develop these theoretical models was not with bereaved parents and this limited the applicability of the models to the care of the dying previsible baby.

The theoretical model most commonly cited in the clinical and professional literature was that devised by Kübler Ross (1969) which focused on stages of grief through which the bereaved must pass before finally ‘accepting’ their loss and ‘moving on’. The initial work for the development of the theory was undertaken with people who had been given a terminal diagnosis. The stages identified

included: denial, anger, bargaining, depression and acceptance. The theoretical model was suggested as a framework for practice (SANDS, 1995) and for specific activities (Sparshott, 2009). Sparshott (2009) stated authoritatively:

‘parents who have reached the stage of inertia need to be helped to move on to full bodied and painful grief’.

How this could be achieved and the ethical and professional issues around inducing ‘full bodied’ grief are not explored. Robinson (2002) reported that bereaved parents were sometimes labelled according to the perception of the ‘stage’ of grief and received a diagnosis of being ‘locked’ in a particular phase or stage if they appeared to exhibit specific characteristics.

The work of Kübler Ross has been critiqued extensively. Churchill (1979) expressed concern that the theory has an ‘aesthetic’ appeal to practitioners because of its focus on progression and acceptance and this could lead them to ‘categorize and control’ patients. Other researchers have demonstrated that the findings of Kübler Ross have not been replicated in dying patients (Garfield, 1978; Schultz & Aderman, 1974). The lack of clearly defined criteria to assess stages and the lack of reliable evidence to support the existence of the stages were major flaws in the model (Garfield, 1978; Fitchett, 1980). In relation to the application of the theoretical model to the care of dying preivable babies, there was no reliable evaluation of the use of the model in this situation.

Emerging models of grief and loss were explained by Schott et al (2007) and Mander (2006). These included the ‘dual process’ theory developed by Stroebe and

Schut (1995) which had not yet been applied to perinatal loss and the 'continuing bonds' theory (Klass, 1984; Klass, 1988; Klass & Walter, 2001) which had emerged from work with bereaved parents (Klass, 1984) but its application to perinatal loss had not been evaluated. However, it did appear to give bereaved parents permission to continue to maintain links with their dead baby, rather than relinquishing the memories without being labelled as 'failing to move on'. While this theory had not been tested with the parents of dying pre-viable babies, it could provide a rationale for the rituals related to holding and caring for the dying baby.

Medicalisation of loss emerged from the literature relating to healthy and pathological grief. It was closely related to the theories of grief and loss, particularly where parents were seen not to have 'moved on' or 'accepted' the loss. It also overlapped with the rituals relating to loss where checklists were employed within institutions.

Bourne and Lewis reported on the psychological outcomes for women following perinatal loss (Bourne & Lewis, 1984; Bourne & Lewis, 1991). They emphasized the normality of feelings of grief following perinatal loss and during subsequent pregnancies (Bourne & Lewis, 1984). They described abnormal grief as being characterized by persistence of feelings such as self reproach. (Bourne & Lewis, 1991). However, they also indicated that most women would have within themselves 'healthy resilience' that would enable them to deal with the loss and that this should be encouraged. They cautioned against medical and social responses to pregnancy

loss where *'every miscarriage (is) magnified into a catastrophe, requiring the full panoply of Christian burial to do it justice.'* (Bourne & Lewis, 1991 p 1167)

What constitutes normal and abnormal grief was not clearly defined in the literature. Lin and Lasker (1996) carried out a study to investigate the progression of grief after perinatal loss. The study involved almost 200 parents but only just over 50 per cent completed the study. Their study demonstrated a wide variation in the onset and progression of loss. Almost 41 per cent of participants experienced a decline in symptoms over time and this was termed the 'normal' pattern of grief. Other patterns included increasing grief scores, delayed grief and low grief scores that remained low during the study. These patterns were termed 'abnormal' grief.

Condon (1987) described 'risk factors' for 'psychological decompression' after stillbirth and related these to the need for psychiatric referral. However, no empirical data was used to underpin the recommendations which appeared to be based on observations from a single case study. Murray and Callan (1988) studied the factors that affected the grief experience of bereaved parents in an attempt to identify those at risk of abnormal grief. The study involved 130 parents and found that those who were well supported were more likely to recover faster. 'Recovery' was associated with an absence of long term grieving. However, the study focused only on professional interventions and did not consider support from parents' social networks.

Mander (2006) described the impact of medicalisation on outcomes. By this she meant the adoption of practices that were designed to 'make things better'. This included the incorporation of practices into care, without considering the impact on individuals. Robinson (2002) and Mander (2006) suggested that the practice of holding a dead or dying baby which some parents have found to be helpful has become institutionalized so that parents are handed their dead or dying baby in a 'rigger pass'. The lack of preparation and consent may have contributed to the psychological distress experienced by parents who participated in the study carried out by Hughes et al (2002).

While the literature was unequivocal in stating that normal and abnormal patterns of grief existed following perinatal loss, there was little evidence to support the development of risk scoring, pathways for grief and specific interventions that might augment or minimize grief responses in parents experiencing perinatal loss. The conceptualisation of normal and abnormal grief appeared to differ between researchers and this, together with cultural and personal influences made it difficult to state with any certainty what was normal or abnormal in relation to individual responses to the death of a baby.

Perinatal Loss Rituals

This theme incorporated 'caring' and 'uncaring', as well as the effectiveness of rituals and the evidence base to support them. The literature reporting this theme

included professional accounts of rituals as part of care provision and research investigating the effectiveness of rituals.

Professional accounts described the rituals performed by an individual (Campbell, 2010; Horn, 2009; Roehrs et al, 2008; Dunford, 2003; Kobler & Kavanaugh, 2007; Clarke & Mander 2006; Alexander 2001; Schott et al 2007) or a service unit (Edi-Osagie & Evans, 2005). The ritual activities included taking photographs, holding the baby, collecting mementoes such as locks of hair, handprints and footprints, giving leaflets and planning or participating in blessings or baptisms and funerals. Generally, the story tellers recounted care for either an individual woman or parents (Alexander, 2001; Schott et al, 2007). Frequent references were made to ritual activities prescribed by user support groups such as SANDS (Schott et al, 2007). These stories inevitably had a 'happy ending' and thus supported the use of rituals. Rich descriptions of the parents were generally missing from the stories so that the reader is unaware of the parents' perspectives and cultural and social backgrounds. The assumption inherent in the stories was that all parents would benefit from participating in the rituals.

Dunford (2003) undertook a small scale study of staff views of one ritual in relation to perinatal loss: that of photographing the dead baby. She asked midwifery staff to provide their views on taking photographs, particularly in relation to seeking consent for the procedure. Her findings showed that some staff questioned if parents could be trusted to make a decision relating to care around perinatal loss:

'The parents are given a choice, whether they are actually able to make the right choice is questionable'.

Other staff members began to question if the ritual had lost its meaning and had become routine:

'Maybe we are fulfilling our own needs because at these times we always look for practical tasks that might make the parents feel better.'

The need for meaning in caring activities relating to perinatal loss was described by Kobler and Kavanaugh (2007). Their review of rituals associated with perinatal loss set out clearly the need for meaningful rituals to 'symbolically connect people and events'. They suggested that bathing and dressing a baby was something that communicated the values of parenting and the uniqueness of the child, since this was something that would normally be the domain of parents caring for a child in the home. They also suggested that because of the uniqueness of the occasion of caring for a dead or dying child, commonplace items became symbols. For example toys, blankets and photographs became symbolic for what they represented, rather than what they were.

Kobler and Kavanaugh (2007) stated that it was important that staff caring for parents took time to relate to them to understand what was important and had meaning, otherwise, it was possible that the rituals could lose meaning and be turned into routine – practices performed without meaning. Lang et al (2005) suggested that the incorporation of rituals into checklists gave staff a 'false sense of security' and

that the lists of 'do's and don'ts' that maternity units produced actually interfered with 'caregiver empathy' as staff could become distracted with the checklist. This could cause further distress to parents who might sense that the care had become routine and meaningless. This is an argument that will be pursued further in the following chapters.

Cacciatore et al (2008) undertook a web based study to investigate experiences of perinatal loss. Almost three thousand women completed the questionnaire. This study was important because it recorded demographic information. In the study 90% of respondents reported themselves as being white. Eighty per cent of women were married. Ninety five per cent of women saw their baby and ninety per cent of women held their baby. Women who did not see and hold the baby tended to regret this. Lack of choice was associated with increased feelings of regret in the respondents in this study who attributed their lack of choice to staff behaviours. They cited that staff indicated to them either by word or through body language that they should not see or hold the baby.

Rådestad et al (2009) described a study of over three hundred women who had experienced perinatal loss in Sweden. Women in the study who did not see or hold their baby reported being influenced by staff behaviour. Women who had late (more than 37 weeks gestation) pregnancy losses were more likely to report having derived benefit from seeing and holding their baby than women who experienced mid trimester (24 – 36 weeks) pregnancy losses. All women had to be able to

communicate effectively in Swedish to undertake the study and no information is given about ethnicity. However, the study did record educational attainment and found that women who had lower educational attainment were less likely to be offered the opportunity to see and hold their baby.

The evidence base for the effectiveness of some of the rituals associated with perinatal loss is contested. Hughes et al (2002) compared psychological outcomes of 60 women who had experienced pregnancy loss after 18 weeks gestation with 60 matched controls. No demographic data was given. The researchers found that adverse psychological sequelae were more common in women who had seen and held their dead baby. The authors admitted that their overall study sample was limited but that it did lend support to amending guidelines so that parents should be 'offered' the opportunity to see and hold their dead baby, rather than being 'encouraged' to do this. They also recommended that bereaved mothers should be told that some women find the experience distressing, while others would find it helpful but that there was no way to predict the outcome.

Matthews and Kohner (2002) questioned the methodology used by Hughes et al (2002). Schott and Henley (2007) stated that Hughes et al (2002) had not provided conclusive evidence that holding the baby and collecting mementoes were detrimental to the mother's health. They cited 'an abundance of anecdotal evidence' that parents found these practices helpful (Schott et al, 2007). They did, however, accept that by being expected to conform, parental choice could be reduced and this

could add to parents' distress. This was confirmed by Robinson (2002) who cited her experience as a patient advocate that parents reported being 'expected' to hold the baby. She stated that this turned the practice into a 'rote procedure' to help staff rather than being a meaningful experience for parents.

The transformation of pregnancy loss from a 'non event' (Bourne, 1968) into a meaningful experience through the use of ritual and symbolism is a feature of westernized cultures from the 1970s onwards (Layne, 2003). The literature which formed the evidence base for the use of ritual was drawn from studies in which demographic data was rarely given. Yet birth and death are rooted in culture. Anthropological literature offers different accounts of perinatal loss. Some cultures attributed human status only to babies which showed signs of life at birth (Cecil, 1996). Within these cultures pregnancy loss could be ignored or even feared (Kimane et al, 2009). The physical remains of pregnancy loss could be regarded as polluting or evil (Sobo, 1996; Jeffery & Jeffery, 1996).

There was also evidence that some parents who were unfamiliar with practices in the UK and who did not conform to the expected norms promoted by guidelines were marginalised within the maternity services (McHaffie, 2001). In the study by McHaffie (2001) a father reported being unhappy at the disrespectful behaviour of a member of staff who spoke to his dead baby as though he were alive. These cultural representations of pregnancy loss were not reflected in clinical practice guidelines or in the professional literature. The concept of 'inclusiveness' in the professional

literature appeared to focus on incorporating all parents into a specific pattern of care, rather than appreciating multifarious understandings of the situation.

Dying right

Having a good death and dying with dignity featured in this theme. This theme incorporated both the philosophy of dying espoused by hospices and palliative care and the practices associated with them. The literature described two forms of care: the perinatal hospice and perinatal palliative care. The use of the term ‘perinatal’ served to distinguish caring for the dying newly born baby from caring for older babies and children and incorporated aspects of care in pregnancy and birth (Roush et al 2007; Leuthner & Jones, 2007; Sumner et al, 2007, Breeze et al, 2007; Hoeldtke & Calhoun, 2001).

The concept of a ‘good death’ and dying with dignity was implicit in all five of the papers that discussed the concepts of perinatal hospice and palliative care. Roush et al (2007) explicitly stated that dignity around the time of death could be achieved by treating the baby and the family with ‘humanness and compassion’. Sumner et al (2007) mentioned dying with dignity but not explain what they meant by it, nor how it could be achieved. These omissions may be partly explained by the fact that the authors aligned and compared perinatal hospice and palliative care provision with traditional views of hospice and end of life care. The references to seminal works by Kübler-Ross (1969) and Saunders (1996) in the papers could suggest that the

perspectives championed by them are now so well understood in professional practice that there was no need to further explain them.

In the literature a 'good death' was associated with choice and planning (Roush et al, 2007; Leuthner & Jones, 2007; Sumner et al, 2007; Breeze et al, 2007; Hoeldtke & Calhoun, 2001). Hoeldtke and Calhoun (2001) and Leuthner and Jones (2007) suggested that the involvement of parents in planning care for their dying baby could help alleviate moral confusion that might be experienced by parents who did not support abortion but where interventionist care for the baby would be futile. In particular, Hoeldtke and Calhoun (2001) emphasised that care provided within the context of hospice care was not about 'letting nature take its course' but was an active form of care that could be 'interactive' and 'intense'.

With the exception of the paper by Leuthner and Jones (2007) the focus of palliative care was on the parents and extended family and related to their needs for information and support (Roush et al 2007; Sumner et al, 2007; Breeze et al, 2006; Hoeldtke & Calhoun, 2001), as well as establishing memories and collecting mementoes of their baby (Roush et al, 2007). Leuthner and Jones (2007) described comfort care for the baby, including blow-by oxygen, where 'air hunger' experienced by the dying baby is alleviated by holding an oxygen mask near the baby's face, the use of sub lingual morphine to alleviate pain and skin care for babies who may have skin lesions.

Three of the papers reviewed for this theme described services that were already established. One was based in England (Breeze et al, 2007) and two in the USA (Leuthner & Jones, 2007; Roush et al, 2007). One paper reviewed the services that were available (Sumner et al, 2007), while the paper by Hoeldtke and Calhoun (2001) was essentially a service proposal. Breeze et al (2007) provided a description of the pregnancy outcomes and the medical conditions causing the babies death but only very limited information was provided about actual care received by the babies. None of the papers reviewed provided feedback or evaluation from the parents. While this might seem remiss, it has to be remembered that bereaved parents may be perceived as vulnerable by Ethics Committees and this may have limited the evaluation of the services. Nevertheless, given the overwhelming support for the perinatal palliative care and hospice programmes from health and social care professionals, some evaluation should take place before the programmes are expanded further, since they are costly in time and experience and there is very limited evidence to support their acceptability in different communities.

Representation

This theme included parental authority, cultural hegemony and '*seldom heard voices*'. Pregnancy and user self help groups emerged in the literature from the UK and North America in the 1970s (Layne, 2003). Within the UK, the Stillbirth and Neonatal Death Society (SANDS) published a leaflet for parents in 1979 called 'The Loss of Your Baby'. The purpose of the leaflet was to help parents make sense of the loss of their baby and also to introduce SANDS as a source of support for

bereaved parents. SANDS also published 'Guidelines for Professionals' (Kohner & Henley, 1991; Kohner, 1995; Kohner & Henley, 2001; Schott et al, 2007). The 'guidelines for professionals' was designed to enable healthcare professionals to understand the parents' perspectives of care relating to the death of their baby. The most recent edition of the guidelines contained quotes from parents about their experiences of perinatal loss. They provided graphic accounts of what it meant to experience the death of a baby:

I knew my baby was alive and safe inside me but I also knew that when he was born he would die. It made pushing the last thing I wanted to do. It was a truly horrendous situation to be in. Mother quoted in Schott et al (2007).

The impact of the statements was powerful, allowing the reader to experience the harrowing grief of the parents.

The term 'hard to reach' is sometimes used to describe under - represented groups e.g. people from black and minority communities. However, the use of the term has been challenged since it can be used as justification for failing to be inclusive. Instead it has been suggested that 'seldom heard voices' may be more appropriate and highlight the lack of representation of groups and communities (Carr, 2004). A feature of the user literature was the absence of data to indicate who was being represented. The SANDS guidelines presented a list of people who provided testimony for inclusion in the document but the information is very limited e.g.:

‘Sarah Cruikshank, mother of a baby who miscarried at 8 weeks on November 17th 2004 and Jonathan who wanted to be a big brother (Schott et al 2007).

While the descriptions told us a little about the parents and the type of loss, they did not provide the demographic information that was essential to understand the cultural and social backgrounds of the parents.

Narratives of pregnancy and motherhood commonly assumed that parents were heterosexual. The literature had limited accounts of pregnancy loss in lesbian or bisexual women and none in relation to pre-viable birth and death (Peel, 2010; Wojnar, 2007). From the limited literature that existed in relation to pregnancy loss in women who are lesbian or bisexual, specific needs were expressed that were not always met. These included the needs of partners for support, the possibility of the baby’s father being included along with the social mother in the birth and death of the baby. The SANDS Guidelines for Professionals (Schott et al, 2007) made no direct reference to the needs of women who were lesbian or bisexual in relation to pregnancy loss. This omission was particularly noticeable since the guidelines stressed the need for inclusiveness and listed a range of women who might be vulnerable or disadvantaged.

Summary of the professional and clinical literature

The professional and clinical literature from journals appeared to reflect a homogenous approach to care throughout northern Europe and North America. The

understandings of pregnancy loss appeared to be shared between the professional community and service user and their representative organisations. This was reflected in the development of rituals to demonstrate both the personhood and humanity of the dying preivable baby and the right of the parents to have their loss recognised by society. Limited information relating to the process by which the rituals came about was given but it appeared to have its roots in attachment theory related to loss (Kobler and Kavanaugh, 2007).

The evidence base for the development of the rituals was weak – many studies had small sample sizes or large drop out rates, and the range of perinatal loss included in the studies was diverse. Few studies provided demographic information while those that did provide demographic data tended to involve white, well-educated parents. There was a suggestion that women who had limited educational opportunities were less likely to be offered choice (Rådestad et al, 2009). While there was a critique of the evidence from psychological studies which suggested that holding a dead or dying baby might not always be of benefit to the parents, the data which purported to refute the findings tended to be anecdotal. However, it might be perceived as authoritative because it came from bereaved parents or organisations representing them.

Quality appraisal of the data

A critical step in CIS is quality appraisal of the data. For each paper included in the review, a quality assessment was made and included in the Excel spreadsheet. The

quality assessment was based on the CASP guidelines (PHRU, 2005). Anecdotal evidence was scored as a zero meaning it was 'weak' in terms of quality assurance. It is usual practice to exclude weak studies from reviews (Hemingway & Brereton, 2009) and this was the stance taken by Dixon-Woods et al (2006). After discussion with my supervisors, I decided that 'weak' data from the professional and clinical literature should be included in the doctoral thesis. My rationale for including it related to the fact that it was perceived as being authoritative (Nuffield Council on Bioethics 2006) and excluding it from the thesis could lay me open to criticism. I also felt that it was important to include it and demonstrate how the weak evidence base was influencing professional practice.

Development of Synthetic Constructs

The penultimate step in CIS is the development of synthetic constructs. These can be defined as unifying ideas (Flemming, 2010) which are derived through an iterative process where there is constant interaction with the data and dialogue as to its meaning (Dixon-Woods et al, 2006). In the doctoral study, the use of the Excel spreadsheet to organise the data and dialogue with my supervisors meant that provisional conceptual categories emerged during the analysis of the professional and clinical literature. These tentative synthetic constructs were developed from integrative grids which evolved from the Excel spreadsheets.

Table 7 shows the initial development of synthetic constructs from the professional and clinical literature.

Table 7: Clinical and Professional literature – Synthetic Constructs

Themes	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation
Constructs								
Professional practice	√	√	√	√	√		√	
Parental Authority					√	√	√	√
Choice						√	√	√
Performance						√	√	√

Professional practice was defined as clinical decision making and management of care. The evidence from the review of clinical and professional literature demonstrated that the evidence base in relation to clinical outcomes, determining gestational age and signs of life and decision making in relation to interventions at birth lay within the jurisdiction of health professionals. Professional practice was also implicated in theories of loss when clinicians either proposed theories of loss or used theories of loss to inform their clinical practice. Professional practice was part of ‘dying right’, since professionals drew on expertise from palliative care to develop rituals for the care of dying pre-viable babies. Dying right was closely related to the concept of dignity and the need for the dying pre-viable baby to be regarded as a human being with needs. However, this did not extend to the baby being accorded the right to have its needs assessed and met. This apparent contradiction was not recognised or addressed in the literature.

Parental authority was defined as the right of parents to influence care. Parental authority in relation to representation was based on the unique experience of perinatal loss – a rare and poignant event which user groups contend can only be

understood by those who have experienced it. This enabled parents (or groups claiming to represent them) to detail the rituals that could help them make sense of their loss and enable them to establish their claim to parenthood.

Parental authority was also related to theories of loss and in particular, the development of rituals derived from theories of attachment and continuing bonds. The rituals were designed to enable the parents to establish the reality of the baby's existence and form a relationship in the immediate postnatal period. This was regarded as being important in facilitating parents to come to terms with their loss.

Choice was defined as having the opportunity to express preferences about care. While choice was advocated in the professional and clinical literature, there was a suggestion that certain rituals such as holding and photographing the dying baby should be 'encouraged' because of their perceived benefit from anecdotal evidence and because they fitted with the ideology espoused by palliative care. This would appear to suggest an element of control rather than choice which will be explored in Chapters Five, Six, Seven and Eight.

Choice was aligned with dying right, rituals and representation. There was a degree of overlap with parental authority where the choices in relation to ritual were largely derived from user group guidelines. The guidelines presented a specific form of dying where there should be contact between the parents and the baby and the baby

should not be left alone. This form of dying informed the development of rituals such as holding, bathing and dressing the baby.

Performance was defined as acting out predefined behaviours and was associated with ritual, dying right and representation. Performance related to the rituals of holding, photographing and caring for the baby derived from evidence provided by user representative groups and professional accounts of care. Performance was strongly associated with the need for a good death, where the death was anticipated and care was planned. This included planning in relation to behaviours relating to the care given to the parents and the baby. It was assumed that the period before death was worthwhile for both the parents and the baby and that the baby was treated with respect and death was pain free. The period between the baby's birth and death was imbued with meaning for the parents and the performance enacted by professionals reinforced this.

CIS: The next step

The clinical and professional literature partially addressed the research question. The origin of the rituals and the meaning of the rituals were still unclear. In particular, the clinical and professional literature could not identify how user representatives came to be regarded as experts in relation to perinatal loss and how the rituals became part of professional practice. After reflecting on the evidence that could help answer the research question, I decided to explore other sources of data including professional textbooks for possible answers.

Conclusion

This chapter has explored professional and clinical literature to provide answers to the research question. The evidence thus far seems to suggest that while clinicians exert control in relation to decision making about interventions in pre-viable births, control reverts to user groups when considering the rituals that take place in relation to the care of the dying pre-viable baby. The origin and interpretation of the rituals is still somewhat obscure and this will be explored further in the following chapters which address other forms of data, including professional textbooks and guidelines.

CHAPTER FIVE: CRITICAL INTERPRETIVE SYNTHESIS DATA COLLECTION AND ANALYSIS –MIDWIFERY TEXTBOOKS

Introduction

The previous chapter attempted to address the research question for the doctoral project through the use of clinical and professional literature. Although several important themes emerged, the research question was not answered. This chapter considers data from midwifery textbooks in an attempt to answer the research question.

Apple (1991) suggested that professional textbooks could act as instruments of socialization for intending professionals. They can be a means of promoting homogeneity through the replication of knowledge. Textbooks are sometimes seen as authoritative sources of information, although there is no guarantee that the information is translated into practice. There is also the possibility of time lag between when they are written and when they are published. Nevertheless, they can provide information about prevailing knowledge and practices, although this may not be contemporaneous. Scrutiny of textbooks over a time period may describe shifts in ideology. I believed that they might illustrate how attitudes and practices relating to perinatal loss have evolved in the UK and North America. I selected midwifery textbooks for this part of the data collection process in CIS because of the critical role midwives play in supporting women in labour and immediately after the birth of their baby.

Search strategy

The search was carried out in two phases. The initial search focused on textbooks predominantly written or edited by midwives from the UK because I thought that midwifery textbooks were a means of sustaining the coherence of the profession through the dissemination of shared professional knowledge and values and might provide rich descriptions of the rituals relating to perinatal loss.

The second phase of the search included midwifery textbooks from North America. I included texts from these countries as the analysis of the professional and clinical literature suggested that the rituals were introduced around the same time in the different continents.

Databases

A search was carried out using electronic and on-line databases: BIDS, CINAHL, MIDIRS, FirstSearch and Medline using the following search terms:

- Midwives
- Midwifery
- Textbook
- Handbook.

The catalogues of the University of Dundee, National Library for Scotland, Royal College of Nursing, Royal College of Midwives and Kings Fund Library were also accessed and searched.

Inclusion criteria

The first phase of the search focused on midwifery textbooks written after 1902, since this was the date of the introduction of the first Midwives Act in any of the United Kingdom countries, when midwifery was formally regulated. Textbooks were eligible for inclusion if they were written by midwives (as opposed to doctors) and were published predominantly for the UK market. By including texts from the early 20th century, I hoped to capture information about perinatal loss when the number of babies dying was very high and where midwives would have had extensive experience of dealing with this clinical situation, through to the present day when perinatal loss is a rare event. I also focused on the UK because birth and death are rooted in culture and there are acknowledged differences between the UK and other countries such as the USA with regard to birth.

The second phase of the search focused on midwifery textbooks published between 1980 and 2009 and included texts for use in North America.

Exclusion criteria

Texts which had instructional content with no context or explanation were excluded. This was designed to exclude 'handbooks' which listed care and actions with no rationale given for care.

Results

A total of 30 textbooks was identified (Table 8). This included a series of two textbooks: Mayes' Handbook for Midwives and Myles' Textbook for Midwives. Mayes' Midwifery was first published in 1937 and had gone through 13 editions. Myles' Midwifery was first published in 1953 and had gone through 14 editions, making a total of 27 books. The continuity provided by these texts was important in establishing changes that took place over time in practice. Additionally there were three 'stand alone' textbooks, focusing on student and registered midwives who wished to investigate aspects of practice in more depth.

The second phase of the literature search identified four midwifery textbooks from North America focusing on midwifery practice. This comprised a series of midwifery textbooks published between 1981 and 2008. These are shown in Table 8.

Table 8: Midwifery Texts

Author	Year	Title
Mayes M	1937	A Handbook for Midwives and Maternity Nurses
Mayes M	1938	A Handbook for Midwives and Maternity Nurses 2E
Mayes M & Gannon M A	1941	A Handbook for Midwives and Maternity Nurses 3E.
Thomas F D	1953	Mayes' Handbook for Midwives and Maternity Nurses 4E
Myles M F	1953	A Textbook for Midwives
Thomas F D	1955	Mayes' Handbook for Midwives and Maternity Nurses 5E.
Myles M F.	1956	A Textbook for Midwives 2E
Myles M F	1958	A Textbook for Midwives 3E.
Thomas F D.	1959	Mayes' Handbook for Midwives and Maternity Nurses 6E

Myles M F	1961	A Textbook for Midwives 4E.
Myles M F	1964	A Textbook for Midwives 5E
Da Cruz V	1967	Mayes' Handbook of Midwifery 7E
Myles M F	1968	A Textbook for Midwives 6E
Myles M F	1971	A Textbook for Midwives 7E
Bailey R E	1972	Mayes' Midwifery: A Textbook for Midwives 8E
Myles M F	1975	Textbook for Midwives with modern concepts of obstetrics and neonatal care 8E
Bailey R E	1976	Mayes' Midwifery: A Textbook for Midwives 9E
Varney H	1980	Nurse-Midwifery
Myles M F	1981	Textbook for Midwives with modern concepts of obstetrics and neonatal care 9E
Sweet B	1982	Mayes' Midwifery: A Textbook for Midwives 10E.
Myles M F	1985	Textbook for Midwives with modern concepts of obstetrics and neonatal care 10E
Varney H	1987	Nurse-Midwifery 2E
Bennett VRB & Brown LK	1989	Myles Textbook for Midwives 11E
Bennett VRB & Brown LK	1993	Myles Textbook for Midwives 12E
Silverton L	1993	The Art and Science of Midwifery
Varney H	1997	Varney's Midwifery 3E
Sweet B	1997	Mayes' Midwifery: A Textbook for Midwives 12E
Bennett VRB & Brown LK	1999	Myles Textbook for Midwives 12E
Page LA	2000	The New Midwifery: Science and Sensitivity in practice
Fraser D M & Cooper M A	2003	Myles Textbook for Midwives 14E.
Henderson C & Macdonald S	2004	Mayes' Midwifery: A Textbook for Midwives 13E.
Varney H, Kriebs JN & Geger CL	2004	Varney's Midwifery 4E
Page LA and McCandlish R	2006	The New Midwifery: Science and Sensitivity in practice 2E

Analysis

As with the clinical and professional literature, data from the texts was entered onto an Excel spreadsheet. As well as including data relating to perinatal death, information was elicited relating to the political and organisational aspects of the maternity services to enable the data to be contextualised. This is considered to be an important aspect of data collection in CIS (Dixon-Woods et al, 2006).

The texts were analysed thematically using a coding framework to enable comparisons to be made within each series and between the series and the stand alone texts. To analyse the language, rhetorical analysis as described in Chapter Two was used to consider the development of plausible arguments relating to care in perinatal loss (Leach, 2000). The content analysis and coding was undertaken by me and then discussed and verified by my supervisors to ensure consistency in data analysis and interpretation.

Comparisons were made between different editions of the same textbook and between each series of textbooks and also between the stand alone texts. Using the Excel spreadsheet to document the social, political and professional contextual information enabled me to identify distinct time periods. The spreadsheet also facilitated the identification of themes from the data. These are shown in Table 9.

While analysing the data three themes emerged: *ideology, rhetoric and ritual*. In this thesis ideology refers to the system of values and beliefs shared by communities or

cultures. The construction of the values and beliefs is such that they appear ‘natural’ or logical – how things really are. Rhetoric can be said to be the expression of an ideology and concerns the use of language and the way that it shapes and reveals thought, knowledge and beliefs related to a particular ideology. Ritual gives meaning to actions or behaviours related to ideology, although the meanings may not be evident or understood by the participants. In this thesis, ritual also refers to midwifery practice in relation to perinatal loss and is intended to reflect professional and parental beliefs about such loss.

Table 9: Relationship between Themes: Social, Professional and Political Context

Period	Ideology of loss	Rhetoric	Ritual	Social, Professional and Political Context
Period 1 1937 – 1949	<ul style="list-style-type: none"> • Individual • Inevitable 	<ul style="list-style-type: none"> • Pragmatic 	<ul style="list-style-type: none"> • Registration of the death • Baptism 	<ul style="list-style-type: none"> • Second World War 1939 – 1945 • NHS Act (1946) England and Wales • NHS Act (1947) Scotland
Period 2 1950 – 1969	<ul style="list-style-type: none"> • Medical heroism • Collective loss 	<ul style="list-style-type: none"> • ‘Matter of fact’ 	<ul style="list-style-type: none"> • Registration of the death • Baptism 	<ul style="list-style-type: none"> • Cranbrook report (1959) • Association for Improvements in Maternity Services (AIMS) formed
Period 3 1970 – 1989	<ul style="list-style-type: none"> • Personal 	<ul style="list-style-type: none"> • Self-help • ‘Healthy’ grieving 	<ul style="list-style-type: none"> • Gathering mementoes 	<ul style="list-style-type: none"> • Peel report (1970) • Maternity Care in Action reports (1984) • Stillbirth and Neonatal Death Society (SANDS) established • Miscarriage Association formed

Period 4 1991 – 2009	<ul style="list-style-type: none"> • Individual • Inevitable 	<ul style="list-style-type: none"> • Merging of professional and lay perspectives • Limited critical analysis 	<ul style="list-style-type: none"> • Care giving • Gathering mementoes 	<ul style="list-style-type: none"> • Changing Childbirth: Report of the Expert Maternity Group 1993. • Move of midwifery pre registration education in Great Britain into Higher Education • Framework for the Maternity Services in Scotland 2001
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Findings

The results will be presented using the themes of ideology, rhetoric and rituals. Although the three themes are presented separately, they are closely linked with rhetoric and ritual being used to express ideological beliefs and values.

Ideology

This theme reflected beliefs and values. In the textbooks prior to the 1960s, there was a sense of inevitability in relation to perinatal loss. Perinatal mortality rates were very high – almost 60 per thousand births (MacFarlane, 1984). Maternal mortality rates were very high too, at 4 per thousand births in England and Wales (MacFarlane, 1984). The lack of comment in relation to these high death rates may have expressed the belief that nothing could be done. UK and North American societies were experiencing high rates of death due to war and it is possible that attitudes towards any kind of loss may have been shaped by this.

Post-war there was a marked reduction in maternal deaths. This was due in part to the introduction of antibiotics, as well as the improving health of women as social conditions improved. By 1950, the maternal mortality rate in England and Wales

was 0.79 per thousand births (MacFarlane, 1984). In England and Wales in 1950, the perinatal mortality rate had fallen to 38.7 per thousand births, as the health of women improved and basic neonatal intensive care was introduced (MacFarlane, 1984).

The marked reduction in perinatal mortality rates was associated with the concept of ‘medical heroism’ and feelings of optimism – technology was presented as having the wherewithal to reduce further perinatal deaths. In the 7th edition of Mayes’ Midwifery published in 1967, it was explained to the reader that the woman would be asked about previous pregnancies:

If she lost her baby, she is asked if she knows why. Though it will distress her to have to recall this unhappy confinement, she will readily co-operate, realising that this pregnancy and labour will be conducted with her previous misfortune in mind; and that every effort will be made to achieve a happier outcome (Da Cruz, 1967; p123).

In 1970, the Peel report recommended 100% hospital delivery (Department of Health and Social Security, 1970) and birth moved out of the home into the hospital. This was presented as political and social progress. Previously women could only access hospital birth if they had complicated pregnancies or if they could afford to pay. The maternal mortality rate continued to fall and this was mirrored by a fall in the perinatal mortality rate (MacFarlane, 1984). The ideology of medical heroism continued as new forms of technology were introduced including visualization of the

fetus through ultrasound and the use of cardiotocography to measure the fetal heart rate and detect fetal distress (Oakley, 1984).

The last two decades of the 20th century were characterised by increasing emphasis on the need for holistic care; a move towards consumerism and the rise of evidence based practice. As an indicator of the rarity of maternal death the maternal mortality rate for the United Kingdom was measured per 100,000 maternities and was 5.3 per 100,000 between 2000 and 2002 (Lewis and Drife, 2004) In 1999, the perinatal mortality rate was 7.9 in England, Wales and Northern Ireland (CESDI, 2001).

The Expert Maternity Group in England published 'Changing Childbirth' - a report that emphasised the need for woman centred care (Dept of Health, 1993). The Parliamentary Committee into the Maternity Services recognised that not only was childbirth safer now than it had ever been before, it also recognised the inevitability of perinatal death (House of Commons, 1991-92). No matter how much was spent on technology and staff, some babies would die. This was the first time that a public acknowledgement of the inevitability of perinatal loss has been made. There was little adverse public reaction to this statement which perhaps reflected the growing acceptance of the limits of science. Alternatively, it may have reflected the fact that very few people would experience perinatal loss and they had not considered the possibility.

As midwifery education moved into universities, the rise of degrees, especially postgraduate degrees in midwifery, focused attention on the need for critical debate and analysis, particularly in relation to taken – for - granted knowledge and ritualised practice. This will be considered later in relation to rhetoric.

Part of the ideology of health care in the last two decades of the 20th century and the first decade of the 21st century was the rise of the consumer user who defines the nature of the experience and directs care. This was reflected in the rhetoric surrounding perinatal death in this period.

Rhetoric

This theme represents the language used in the midwifery textbooks and expressed the ideology relating to perinatal loss.

Prior to the 1950s, references to perinatal loss related to the statutory responsibilities of the midwife around the registration of the death (Mayes, 1937; Mayes, 1938; Mayes and Gannon, 1941). The rhetoric in the textbooks reflected the inevitability of death. For example, in relation to the newborn baby where death is expected to follow soon after birth, the midwife was exhorted to ensure that parents are offered the opportunity to have their baby baptised. Mayes (1937) stated that:

‘an early recognition of the need for the administration of this sacrament will be appreciated by the parents’.

In the 1950s, the health of the baby was regarded as a national concern. Sutherland, an epidemiologist, wrote in 1950 about the continuing high stillbirth rate, saying: *'we can no longer afford to lose so many potential citizens'* (Sutherland, 1950). This was echoed by Myles in 1953, when she said:

'although the birth of a baby is a very personal matter to the mother, the ultimate health and well being of the nation depends on an efficient obstetric service.'

She went further and placed the responsibility for the well-being of the nation with the mother:

The high perinatal mortality rate in Great Britain is giving rise to grave concern and expectant mothers should be advised (...) regarding causes under their control that are known to be avoidable (Myles, 1964; p93).

The meaning inherent in these statements was that perinatal death represented a loss of potential to the nation, rather than a personal loss. Furthermore, the individual loss was potentially preventable and the mother could be seen as being culpable in bringing about the loss of her own baby.

The 1950s also saw the introduction of photographic plates in textbooks. Both Mayes' Midwifery and Myles' Midwifery showed pictures of stillborn babies with signs of maceration – the changes that take place in a baby who dies in utero. The

wording beneath the photographs drew the reader's attention to the changes and they were left in no doubt that they were looking at a dead body.

The language used in relation to perinatal loss was still very matter of fact and depersonalised. The words used to describe maternal feelings about perinatal loss in the textbooks included 'disappointed', 'unhappy' and 'frustrated'.

Between 1960 and 1981 there was little change in the rhetoric in the textbooks with regard to perinatal loss. Rather than being bereaved, women who experienced perinatal loss were 'disappointed', according to Myles who wrote:

Student midwives should be reminded that the loss of a baby at birth is a bitter disappointment to the mother: one of the joys of womanhood has been snatched from her grasp. She feels frustrated after the anticipation and preparation. (Myles 1968).

The minimisation of the impact of perinatal loss on the woman continued into the early 1980s. Writing in 1981, Myles said:

If the pregnant woman is not aware that her fetus is dead, some authorities consider that she should be told. Whether to tell her before labour is a debatable point and the husband's advice should be obtained. The pain and distress of labour will be more unbearable when added to the anguish of

being deprived of her child. Some paediatricians advise that the parents should see and handle the baby... ..Whether the mother should see a seriously malformed infant is controversial and should be left to the discretion of the father (Myles, 1981; p 687).

This statement seems quite shocking but it reflected the practice I encountered when I was a student midwife where the dead baby was whisked away. However in Mayes' *Midwifery* published a year later, Sweet discussed the need for women to be 'confronted' by their loss, including seeing the dead baby as part of building up a picture of reality. Sweet stated that this was important so that the '*parents would have no fantasy about how their child would develop*'. (Sweet, 1982).

This fear of the fantasy baby appeared across continents. Varney writing for a North American audience in 1987 also emphasised the need for parents to confront the reality of the situation. If they did not do this, then they would fantasise about the baby (Varney, 1987). Varney also suggested that there was a definite pattern in relation to grief and griefwork was '*essential to keep grief normal*'. Failure to undertake griefwork could lead to pathological grief, although this was not described.

In 1989, two new editors took over from Myles. The rhetoric relating to perinatal loss changed. The loss, readers were informed, was 'devastating'. Parents needed

support. The concept of healthy grieving was raised and the process outlined by Kübler- Ross (1969) was identified (Tickner, 1989).

This change in rhetoric continued throughout the 1990s. The importance and impact of all perinatal loss was emphasised in the 13th edition of Myles' Midwifery. Shiers (1999), writing about early pregnancy loss, stated that: *'The effect of the loss of a baby at this time is underestimated by professionals.'* The need for healthy grieving and the need to 'relinquish' the loss and 'move on' was apparent in all 3 editions of Myles' Midwifery published in the ten years between 1993 and 2003 (Bennett and Brown, 1993; Shiers, 1999; Mander, 2003). Sweet, writing in the 12th edition of Mayes midwifery, talked about the important task the midwife has in reversing the denial of death and listed the rituals that could be undertaken to aid this task (Sweet, 1997). These will be discussed later in the chapter.

The photographs used to portray the dead baby changed over this period. Photographs were no longer directed at informing the reader about the decay of the dead body. Instead they were given as examples of how a 'good memory' could be constructed. Tickner in 1993 described the photograph of a dead baby thus:

'By making folds in the blanket and exposing a little arm and hand the picture looks as if there has been movement...' (Tickner, 1993; p 767).

The rhetoric focused on presenting the baby as a human being who **could** be alive, as opposed to a dead body. This was important in constructing the personhood of the baby.

In the first decade of the 21st century, a slight change in the rhetoric could be detected. In the 14th edition of Myles midwifery some attempt at critical analysis of the ideology of perinatal death took place. Mander writing in 2003 touched on the effect of class and religion on mourning rituals and the effectiveness of self-help groups such as SANDS. However, the staged approach to healthy grieving was still presented as 'fact'. The language and photographs in the midwifery textbooks were indistinguishable from those used by voluntary organisations and self-help groups. It would seem that the rhetoric of perinatal loss was being shaped by user representative organisations. This represented a significant shift in the discourse of perinatal loss.

Ritual

In this section ritual as meaningful practice, as opposed to routine practice is considered.

When I started to investigate the development of ritual, I assumed that there would be rich descriptions of rituals in midwifery textbooks because midwives were so closely involved with birth and because of the high rates of perinatal loss prior to 1950. However in textbooks published prior to 1950, there was no explanation of

any rituals related to the loss of the baby – the preparation of the baby’s body for burial, for example. It is possible that perinatal loss was so commonplace that the authors of the textbooks believed that midwifery students would acquire the necessary knowledge through experiential learning, rather than through textbooks. Between 1950 and 1970, only routine practice was noted and this related to the care of the woman after perinatal loss. For example, Myles (1968) stressed the need for staff to keep the bereaved women out of sight and sound of other women with their babies in hospital. It is not clear if she believed it would be better for the bereaved women or because it would distress women who had given birth to healthy babies. It is also possible that removing bereaved women from the normal maternity environment would protect staff from the emotions produced by the loss. She went on to say that early discharge from hospital should be arranged – highlighting this in her text for additional emphasis.

In both Mayes’ *Midwifery* and Myles’ *Midwifery* towards the end of the 1980s, rituals relating to perinatal loss were introduced and became more elaborate as time passed. The rituals related to establishing an identity for the baby and included taking photographs and gathering mementoes such as a lock of hair. Funeral services and the involvement of spiritual advisers were advocated (Varney, 1987). These changes were documented in textbooks appearing in both the UK (Bennett and Brown, 1989; Sweet, 1982) and North America (Varney, 1987).

Sweet emphasized the need for choice in relation to the place of birth and care immediately afterwards. However, she did not mention the right to choose whether or not to see the dead baby. Instead she said:

The baby should be tidied up and presented to the mother....The baby should be called by name and may be placed in a cot. (Sweet, 1982).

Sweet later went on to cite a mother who experienced perinatal loss who says that parents should be 'offered' the opportunity (on more than one occasion) to hold their baby but that no pressure should be exerted to get them to comply. In Sweet's view the parents' encounter with the dead baby was important to establish a relationship and stop them developing '*fantasies about how the dead child would develop*' (Sweet, 1982).

The need for ritual to establish the reality of the death of the baby was a common theme in midwifery texts in the UK and North America throughout the 1980s and 1990s. Much of this ritual appeared to stem from the need for the baby to have established an identity in the critical period after the birth. For example, Tickner (1993) said '*the midwife should handle the baby respectfully as though he were alive*'. However, this ignored the fact that in some cultures, this might be perceived as being disrespectful and that dead bodies were themselves worthy of respect (McHaffie, 2001).

Recent textbooks suggest that mementos of the baby's life could be collected. These included footprints and handprints, cot cards and name bands. These tokens could

then be placed in a box or place that had special meaning for the parents. Other rituals were suggested: these included bathing and dressing the baby, taking the baby home and writing a letter or poem for the baby. The rituals were meant to be symbolic of parenting and mirrored some of the rituals in which parents of live infants participated. Taking the baby home and spending the first night alone with no professional support has become a rite of passage for some parents now that hospital birth has become the norm. Parents who take their dead baby home to place in the cot or nursery may be establishing their parenting credentials.

Summary of midwifery textbooks

It would appear that the midwifery profession has adopted an approach that involves increasingly complex rituals and the use of rhetoric to underpin the rituals. Professionals have adopted enthusiastically the ideology promoted by groups such as the Stillbirth and Neonatal Death Society which focuses on the rights of parents who have experienced perinatal loss. Within the textbooks, the term ‘perinatal loss’ is used to embrace all forms of death around the time of birth. The specific needs of pre-viable infants are not addressed in any of the textbooks, although my experiences would suggest that midwives are the primary carers of these infants.

Development of Synthetic Constructs

As with the clinical and professional literature, the data from the analysis of midwifery textbooks requires to be further interpreted and synthetic constructs developed. The themes of ideology, rhetoric and ritual were considered alongside

the constructs developed from the clinical and professional literature. In particular, the ‘fit’ of the themes was considered. The following table shows how the themes mapped against the emerging constructs from Chapter Four.

Table 10: Midwifery Textbooks - Synthetic Constructs

Themes	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation	Rhetoric	Ideology
Constructs										
Professional practice					√	√	√		√	√
Parental Authority						√			√	√
Choice									√	√
Performance					√	√	√		√	√

Table 10 reflects how the ideology of perinatal loss is reflected in professional practice. This includes adopting guidelines for practice produced by user groups. The analysis of the textbooks suggests that the primacy of the needs of the parents in perinatal loss is part of the ideology that has become rooted in professional practice in the UK and North America. This is reflected in professional rhetoric which uses the language of the user groups in practice. Offering choices, too, is part of the rhetoric, although the textbooks do not provide information as to how the choices should be offered. It is this part of the ‘performance’ where health professionals may experience stress and difficulty in offering choice in a situation where all or none of the choices may be accepted.

Giving an authentic performance is an essential element in the ideology and rhetoric of loss. The rhetoric of perinatal loss included developing the right words and

phrases for use by professionals. The textbooks provided practitioners with scripts of words and phrases to use and avoid and specific actions and behaviours were promoted as ways of imparting empathy and sympathy. For example, midwives were cautioned never to tell parents that they can have another baby by Tickner (1993) as this could suggest that their loss was being minimised and that the dead baby could be replaced by another. The rhetoric reinforced the ideological position of the parents as sources of authoritative knowledge in perinatal loss with their experience of a rare and unique response being cited.

The rituals seemed to be increasingly complex in relation to perinatal loss. Health professionals appeared to have adopted the rituals and incorporated them into practice. Many of the rituals developed as a result of parental prompting as they sought to establish both the identity of their baby and their right to be called 'parents'. While the rhetoric emphasized the need for choice, there is a strong suggestion in many of the textbooks that parents were 'encouraged' to participate or 'presented' with the rituals. In particular the participation of parents in the performance of these rituals may be 'expected'. Participation in the performance without understanding or consent may render the performance meaningless or even offensive. This suggests that the performances may actually limit choice and act as a form of control on parents.

CIS: The next step

The critical analysis of textbooks has partially addressed the research question. The origin of the rituals can be located to a period towards the end of the 1970s and coincides with a period where childbirth became safer for both the woman and the baby. This reflected a shift in focus from childbirth as event to be survived to become a potentially life enhancing experience. The growth of the rituals has been associated with a rise of user participation and the rhetoric of choice in governmental policies. The rituals appear to be designed to establish both an identity for the baby and for the parents. In relation to preivable babies, their specific needs are not mentioned. Although midwives are the primary caregivers for preivable babies and their parents, these babies are born as a result of complicated pregnancies. Since midwives are required to cede responsibility for the care of women with complex pregnancies to obstetricians and neonatologists, I decided therefore to explore the textbooks of these professional groups to assess other possible responses to preivable birth.

Conclusion

This chapter has explored midwifery textbooks and attempted to answer the research question. The textbooks have indicated when and some of the reasons why the rituals have evolved as they have done. However, the care of dying preivable babies is absent from midwifery textbooks. This will be explored in the next chapter which will consider data from neonatal medical and obstetric textbooks.

CHAPTER SIX: CRITICAL INTERPRETIVE SYNTHESIS DATA COLLECTION AND ANALYSIS – OBSTETRIC AND NEONATAL TEXTBOOKS

Introduction

The previous chapter attempted to address the research question for the doctoral project with data drawn from midwifery textbooks. The data suggested some possible answers with regard to the question of ritual development in perinatal loss. However, the specific care of dying pre-viable babies was not addressed. I surmised that this could be because extreme prematurity is a complication of pregnancy. Although midwives provide care for women experiencing complications of birth, they work under the direction of medical practitioners and this suggested to me that possible answers to the research question might be found in neonatal and obstetric textbooks. This chapter will explore textbooks for obstetric and neonatal medical practitioners in an attempt to explore the specific rituals related to the care of dying pre-viable babies in labour ward.

Search strategy

A search was carried out using electronic and on-line databases: BIDS, CINAHL, MIDIRS, FirstSearch and Medline using the following search terms:

- Neonatal
- Obstetric
- Textbook
- Handbook.

The catalogues of the University of Dundee, National Library for Scotland, Royal College of Nursing, Royal College of Midwives and Kings Fund Library were also accessed and searched.

Inclusion criteria

Obstetric and neonatal textbooks from North America and the UK published between 1999 and 2009 were eligible for inclusion. A total of 27 texts were included in the analysis (Table 11). Where more than one edition of the same textbook was published between 1999 and 2009, all the editions were included to assess how the data changed in the intervening period.

Analysis

As with the midwifery textbooks, information was entered into an Excel spreadsheet to enable comparison. Contextual information was entered and thematic analysis used to identify emerging themes. (11). Two themes emerged from the data: 'Perinatal loss as failure' and 'Failure to Care'. These were directly observable at the manifest level (Boyatzis, 1998) and there was agreement between myself and two supervisors with no need for negotiation or refinement.

Table 11: Obstetric and Neonatal Textbooks – Thematic Analysis

Author	Content	Theme
1. Arulkumaran S et al	Stillbirth and NND are outcomes of care	Loss as failure
2. Baker PN	Refer to specialist midwife	Failure to care
3. Barclay C	Tragedy – refer to SANDS	Failure to care
4. Baskett TF	No mention	Loss as failure Failure to care
5. Beckman CRB et al	Statistics	Loss as failure
6. Campbell S & Lees C	Refer to specialist midwife	Failure to care
7. Chamberlain G & Hamilton – Fairley D	Refer to specialist midwife	Failure to care
8. Chamberlain G & Brown – Simpkins P	Autopsy – helpful for future pregnancies	Loss as failure
9. Chamberlain G & Steer P	Refer to support groups	Failure to care
10. Cunningham FG et al	Outcomes	Loss as failure Failure to care
11. Cunningham FG et al	Outcomes	Loss as failure Failure to care
12. Edmonds DK	Parents need to grieve – refer to SANDS	Failure to care
13. Gabbe SG et al	Unsuccessful pregnancies lead to problems - refer	Loss as failure Failure to care
14. Hacker N F et al	Parents need emotional support – refer	Failure to care
15. Hamilton-Fairley D	Refer to SANDS	Failure to care
16. Impey L	Refer to support groups	Failure to care
17. James DK et al	No mention	Failure to care
18. James DK et al	Refer to counsellor or support groups	Failure to care
19. Jones M et al	Outcome	Loss as failure
20. Lathe M et al	Women with recurrent miscarriage – refer to miscarriage association	Failure to care
21. Llewellyn Jones D	Considerable grief reaction – need for specialist support	Failure to care
22. Luesley DM & Baker PN	Evidence base for care critiqued / care and consent SANDS	Failure to care
23. Oats J and Abraham S	Need for specialist support	Failure to care
24. O'Connor V & Kovacs G	Outcome	Loss as failure
25. Queenan JT et al	No mention	Failure to care
26. Rennie J & Robertson NRC	Doctors are busy – refer to midwives / support groups	Failure to care
27. Rennie J	Doctors are busy – refer to midwives / support groups	Failure to care

Results

Perinatal loss as failure

The rhetoric of the textbooks appeared to relate to failure and the language used seemed to reinforce the concept of failure for both the professional and the woman. A great deal of emphasis was placed on finding out what went wrong with the pregnancy. Frequent references were made to *'future pregnancies'* but it was not always clear if those were the future pregnancies of the woman who had just sustained the loss or pregnancy in general. The 'loss' related mainly to the poor outcome of the pregnancy, rather than the impact on the parents. Generally, however, the impact on the parents was minimized so that in three texts, no mention was made of any impact at all on the parents. Beckman et al (2002) exhorted the reader to move on to *'more pleasant statistics'* such as the birth rate and fertility rate, rather than dwelling on perinatal loss statistics.

In other texts, parental grief was presented in rather vague terms. The texts seemed to fail to convey the bewilderment and confusion associated with pregnancy loss. Some of the prescribed care appeared to be for the benefit of the professionals, rather than the parents – for example, the need to have a post mortem. Chamberlain and Bowen-Simpkins (2000) reported that autopsy was *'usual'* and was *'helpful'* to enable the doctor to learn more about problems. Other authors reported pregnancy loss in equally detached terms: *'Unsuccessful pregnancies can lead to problems'* (Gabbe, Niebyl & Simpson, 2002). And loss *'usually causes a considerable*

reaction' (Llewellyn Jones, 1999). The words used did not appear to demonstrate an understanding of the devastation that parents may experience when their baby dies.

Perinatal loss as failure to care

A common feature in texts that did acknowledge the feelings of parents was the suggestion that caring for the parents was the business of others. A whole range of people were suggested: counsellors, psychologists, specialized bereavement teams and especially voluntary organizations – SANDS in particular (Barclay, 2000; Chamberlain & Hamilton-Fairley, 1999; Hamilton-Fairley, 2004). One textbook that suggested the usefulness of the organization referred to it incorrectly in both editions published between 1999 and 2009, calling it the *Stillbirth, Abortion and Neonatal Death Society*, rather than Stillbirth and Neonatal Death Society (Chamberlain & Hamilton-Fairley, 1999; Hamilton-Fairley, 2004). Laing and McHaffie (2005) suggested that doctors were really very busy and portrayed nurses and midwives as '*experts*' who should take on the immediate business of caring for parents because: '*Doctors have many competing demands on their time*' (Laing & McHaffie, 2005). This again appeared to minimise the role that doctors had in caring for bereaved parents.

The evidence base for the care of parents appeared to be sparse compared with other aspects of care, citing evidence to support suggestions for practice and indicating where the evidence base for care was less robust. The text for preparation for membership of the Royal College of Obstetricians and Gynaecologists was rigorous

in its approach to perinatal loss, citing evidence, critiquing research methodologies and avoiding dogmatic statements in relation to parental care (Luesley & Baker, 2004). This contrasted strongly with other texts which referred to rituals and tended to report them factually with little mention of the meanings, cultural implications and evidence base behind them. For example, Edmonds (1999) said that parents '*must grieve for the lost child to avoid long term problems*' and they should be '*encouraged to see, touch and hold their baby*'. This view was reflected by Impey (1999), Llewellyn-Jones (1999), Oats and Abraham (2005) and Baker (2006) in equally dogmatic terms.

Reference to the stages model of grief was made (Llewellyn Jones, 1999; Oats & Abraham, 2005). There seemed to be a lack of evaluation of this model in relation to perinatal loss. For example, the authors did not consider the origins of the model and that it related to dying adults, rather than the bereaved parents. Instead, the stages of grief appeared to support the position of locating where parents were in the process of grief and how they were progressing to 'recovery'. The suggestion implicit in these textbooks was that the aim of care of the bereaved parents was to ensure that they 'got better'.

Summary

Contrary to what I expected, there seemed to be little new data to address the research question. It could be argued that the lack of reference to perinatal loss was in itself noteworthy. It suggested that caring for parents following perinatal loss was

not perceived to be an important aspect of obstetric and neonatal care worthy of inclusion in textbooks. This contrasted with the views of women who were interviewed by Moulder (1998) after experiencing a stillbirth. The women in her study felt that they had ‘failed’ to produce a healthy baby and were extremely grateful when doctors spent time with them – even if it was only a few minutes. They cited this as evidence of caring on the part of doctors and made them feel less like failures.

Textbooks directed at medical professionals had very limited information about the needs of parents and almost no information about the needs of the dying pre-viable baby. Caring was seen as other people’s business – notably that of nurses and midwives. Given the move towards evidence based health care demonstrated in other sections of the textbooks, there seemed to be a lack of rigour in the data relating to perinatal loss in the obstetric and neonatal textbooks.

Development of Synthetic Constructs

As with the data from the professional and clinical literature and midwifery textbooks, the data from obstetric and neonatal textbooks was subjected to further analysis and interpretation. Two themes emerged from the data: ‘failure’ as in pregnancy failure – the failure of the woman to have a live baby and ‘caring’. However, in relation to caring, it was evident from the literature that caring in perinatal loss was something that was delegated to other people. The ‘expertise’ of midwives and nurses and user groups was acknowledged and they were encouraged

to take on the responsibility for caring for bereaved parents. I termed this ‘failure to care’ because it suggested that ‘caring’ could be delegated by the doctor.

The themes that emerged from the obstetric and neonatal textbooks were considered alongside the synthetic constructs that emerged from the professional and clinical literature (Chapter Four) and midwifery textbooks (Chapter Five). Table 12 shows how the themes from the obstetric and neonatal textbooks mapped against each other.

Table 12: Medical Textbooks – Synthetic Constructs

Themes	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation	Rhetoric	Ideology
Constructs										
Professional practice					√	√			√	√
Parental Authority									√	
Choice										
Performance						√				

In this instance, the ideology of medical professional practice was related to failure: the failure to produce a live infant. The rhetoric related to the delegation of caring for the parents to others and the designation of these ‘others’ as experts. These ‘experts’ included other health and social care professionals, as well as parental self help groups. The rhetoric of the textbooks also focused on recovery. This was related in part to the need for specialist expertise to help parents deal with their grief appropriately and ‘move on’.

Limited information was available in relation to 'performance' because the textbooks suggested that other people – specialist staff and support groups should take over the care. One text questioned the nature of the evidence supporting the performance of ritual in perinatal loss (Luesley & Baker, 2004). It suggested that the evidence base was weak and that professionals should exercise caution before encouraging all parents to see and hold their baby. The textbook suggested that professionals should be led by the parents. The remaining texts that mentioned ritual performance did so without making reference to the evidence base (Impey, 1999; Llewellyn-Jones, 1999; Oats and Abraham, 2005; Baker, 2006).

CIS: The next step

While the exploration of obstetric and neonatal textbooks did not add significantly to the understanding of the rituals in relation to perinatal loss, it did highlight an apparent lack of interest in perinatal loss in the medical literature. The medical textbooks were all recent i.e. published in 1999 or later. This period was associated with increasing emphasis on choice and parental involvement in care, as well as the need to acknowledge perinatal loss as an important event in the lives of parents. It would seem that the authors and editors of medical textbooks overlooked this and suggests that information about perinatal loss and specifically care of dying pre-viable babies might be located elsewhere.

Within contemporary professional practice, policies and guidelines are important sources of information. They are expected to be rigorous in their use of evidence to support practice and may be used to direct and measure the standard of professional care. For those reasons, I decided to explore guidelines for caring for dying preivable babies as the next step in addressing the research question.

Conclusion

This chapter has explored obstetric and neonatal textbooks as a source of data to answer the research question. Although the textbooks have not provided a great deal of information in relation to the development of rituals and the care of dying preivable babies, they have reinforced the need for parental support and the use of ritual in providing a performance that is meaningful for the parents. The next chapter will explore professional guidelines as a means of addressing the research question.

CHAPTER SEVEN: CRITICAL INTERPRETIVE SYNTHESIS DATA COLLECTION AND ANALYSIS – PROFESSIONAL GUIDELINES

Introduction

The previous chapter suggested that there was a lack of information in obstetric and neonatal textbooks in relation to the care of dying pre-viable babies. It could be argued that contemporary professional practice relies less on textbooks than in the past and that in order to explore and understand professional practice it is necessary to review documentary evidence that has been produced specifically to influence current practice. Professional practice in the UK and North America is becoming increasingly informed and driven by guidelines, policies and protocols. The terms are often used interchangeably and their exact nature will be determined by local definitions and usage. However, for the purpose of this doctoral study, guidelines are defined as a statement by or for health professionals that outline recommendations for care for dying pre-viable infants. In the UK and North America, guidelines may be produced by national organisations e.g. Royal College of Paediatrics and Child Health, the British Association of Medicine (BAPM) and the American College of Pediatrics. These guidelines are then used to inform local guideline production based on local need and available services. In order to address the research question, I decided to explore professional guidelines as a source of data.

Search strategy

The following terms were used to search relevant databases: very preterm, extremely low birthweight (Marlow, 2004); threshold of viability, extremely preterm

(Macdonald, 2002); non viable (Macfarlane et al, 2003); border of viability, perivable (Higgins et al, 2005); previable (BAPM, 2000). The terms were combined with 'guidelines' using Boolean connectors or by using search limits, where available. Some databases also permitted the use of further limits. Where additional limits were allowed, those used included: 'English language', 'human', and 'title and abstract'.

The following databases were searched: PubMed, MEDLINE, CINAHL, Science Direct, SCOPUS and MIDIRS. The websites of professional organisations related to midwifery, obstetric and neonatal nursing, paediatrics and gynaecology from North America, New Zealand, Australia and the United Kingdom were also searched as were the following guideline collections: National Library of Guidelines, Scottish Intercollegiate Guidelines Network, National Institute for Health and Clinical Excellence and the National Guideline Clearinghouse. Midwifery online discussion groups and a perinatal network were contacted to ensure that guidelines not appearing in national collections or in the public domain were included.

Titles and abstracts were scrutinised. Where these indicated that the paper met the inclusion criteria, or if the title or abstract was ambiguous, the full guideline was obtained. The websites of professional organisations had search facilities but these were not specific enough to enable the identification of guidelines referring to the care of dying previable babies. This meant that each website was hand searched, with all potentially relevant documents being downloaded and scrutinised. Reference

lists (where available) were also examined for relevant guidelines. Guidelines that were excluded from the review were checked by three people (myself and two supervisors) to ensure rigour in the final selection of guidelines for the review.

Inclusion criteria

Previous research investigating parental participation in ethical decision making and visiting policies in Europe and Asia demonstrated that there were significant variations in practice between English speaking and non English speaking countries (McHaffie et al, 1999; Partridge et al, 2005). English speaking countries tended to share a common philosophy in respect of ethical frameworks and parental participation in care. For those reasons, I decided to include only documents produced in English and intended for use in North America, Australia and New Zealand and the UK. I also felt that translating guidelines from other languages into English for comparison could mean that subtle nuances or taken-for-granted meanings might be lost or misinterpreted.

Policies, protocols and practice standards which contained recommendations for the care of dying preivable babies born at 24 weeks' gestation or less were included. Recommendations for care might include explicit reference to tasks such as providing nutrition or pain relief, or they could include generic terms such as 'comfort care' (NMC, 2007) 'compassionate care' (MacDonald, 2002) or 'palliative care' (Nuffield Council on Bioethics, 2006). The guidelines also had to be in the public domain so that they were accessible to practitioners.

The EPICure study reporting in 2000 provided robust information about survival rates of babies born at the threshold of viability and this may have had an impact on the development of guidelines and clinical practice (Costeloe et al, 2000). This led me to limit the search to the period between 2000 and 2007. Guidelines developed or published before that date but identified as still being current and informing clinical practice were included in the review.

Exclusion criteria

Guidelines that focused exclusively on the ethical or clinical decision making process about the need for resuscitation and care were excluded from the review. Guidelines that referred exclusively to the withdrawal of care from infants without making specific reference to pre-viable infants were also excluded, as the intended focus of the review was the care of infants of less than 24 weeks' gestation. For example, the Report of Nuffield Council on Bioethics (2006) was excluded from the review as it made general recommendations about the need for professionals to agree guidelines for palliative care of pre-viable infants, while the guidelines produced by the Stillbirth and Neonatal Death Society (SANDS) were included because they made specific reference to forms of care that health professionals should deliver to pre-viable babies who were not to be resuscitated (Schott et al, 2007).

Results

Table 13 shows the total number of guidelines retrieved, exclusions and inclusions. The majority of papers excluded from the study focused on ethical decision making in relation to the provision of resuscitation and ongoing support in the case of pre-viable birth; and those which focused on withdrawal of care without making specific reference to the care of pre-viable babies. Some guidelines were retrieved from multiple sources. Where this occurred, the guideline was attributed to the first source and then excluded from later searches.

Table 13: Total number of guidelines retrieved, showing those included and excluded from each source.

Source	Total no. papers retrieved	Papers identified as potentially eligible	No. excluded after scrutiny	Guidelines meeting inclusion criteria and included in review.
PubMed	25	4	3	1
MEDLINE	17	2	2	0
CINAHL	328	4	4	0
Science Direct	128	0	0	0
SCOPUS	0	0	0	0
MIDIRS	250	4	4	0
Professional organisations	16	15	11	4
National Library of Guidelines	3	1	1	0
National Guideline Clearinghouse	1	1	1	0
SIGN	0	0	0	0
NICE	0	0	0	0
Online discussion groups	1	1	0	1

A total of 6 guidelines was identified (Table 14). Of the six guidelines retrieved, four were from the UK (Schott et al, 2007; Thames Regional Perinatal Group, 2000; British Association of Perinatal Medicine, 2000; Nursing and Midwifery Council, 2007). The remaining two guidelines were from North America (MacDonald, 2002; Canadian Paediatric Society, 2000). No guidelines from Australia were identified. Five guidelines were available on the internet. The guidelines for professionals developed by SANDS were available to buy at a cost of £16.99. After reflection I felt that the guidelines still met the criteria of being in the public domain and so they were included.

Table 14: Guidelines included in the review

Organisation	Date	Country
SANDS	2007	UK
Thames Regional Perinatal Group	2000	UK
British Association of Perinatal Medicine	2000	UK
Nursing and Midwifery Council	2007	UK
Canadian Paediatric Society	2000	Canada
Committee for the Fetus and Newborn	2004	USA

Analysis

To undertake the critical analysis of the development of guidelines, I used the AGREE instrument for the Appraisal of Guidelines for Research and Evaluation (AGREE Collaboration, 2001). This tool had been developed and validated for the evaluation of clinical guidelines (AGREE Collaboration Writing Group, 2003). The

AGREE instrument provided a structure to assess the quality of the process of guideline development and the quality of the recommendations (Appendix Two). It also enabled the predictive validity of the guideline to be assessed. However, it was unable to assess the impact on outcomes.

To explore meaning within the guidelines, rhetorical analysis was used. Leach (2000) proposed an approach to rhetorical analysis that included exploration of the situation allowing underlying assumptions about the context within which the rhetoric was constructed to be explored. Her model was piloted with a set of guidelines and it demonstrated that this approach would enable meaning to be deduced and understood by a wider audience as discussed in Chapter Two.

AGREE Analysis

The AGREE instrument consisted of 23 questions organised into six domains (Table 15). The domains addressed different aspects of guideline quality (AGREE Collaboration, 2001).

Table 15: AGREE instrument for the Appraisal of Guidelines for Research and Evaluation Domains (AGREE, 2001)

Domain	Focus
Scope and Purpose	Overall aim, clinical questions and population
Stakeholder involvement	Extent to which guidelines represents the position of intended users
Rigour of development	Process of gathering, synthesising evidence and the formulation of recommendations
Clarity and presentation	Language and format of the guideline
Applicability	Organisational, behavioural and cost implications of the guideline
Editorial independence	Acknowledgement of possible conflicts of interest in the development group

Each item had a four point scale which ranges from Strongly Agree to Strongly Disagree, with two mid point scores. Each item also had accompanying explanatory notes to enable the appraiser to clarify the meaning behind the questions. Before undertaking the analysis of the guidelines, the AGREE tool was piloted with a group of doctoral students and their supervisors. The decision to pilot the tool was made because I had not used it before and I had no knowledge of its use in the maternity services. The guidelines I planned to analyse were from different countries and in different formats and I was unsure if the tool could be applied effectively.

As a result of carrying out the pilot analysis, I was able to establish that only the part of the guideline relating to the care of the dying previsible baby should be evaluated. Most of the guidelines had embedded this information in the wider framework addressing decision making and care of previsible babies who were to be resuscitated. From the pilot it was clear that there were potentially significant differences in the way the different outcomes were considered and analysing the guideline as a whole would lead to skewing of the results related to the care of dying previsible babies.

For example, several guidelines addressed the needs of pre-viable infants who were to be resuscitated and provided recommendations based on randomised controlled trials (MacDonald, 2002; Canadian Paediatric Society, 2000). Where there was a lack of evidence in relation to specific approaches to care, this ambiguity was clearly acknowledged (MacDonald, 2002; Canadian Paediatric Society, 2000). The section on caring for dying pre-viable babies, however, did not acknowledge the evidence base (or lack of it).

It was recommended that each guideline was appraised by a minimum of two people using the instrument. For maximum reliability, four appraisers were recommended. For this evaluation, four appraisers participated. The appraisers included the two supervisors associated with the PhD thesis and, to overcome any inherent bias by those involved in the research, a colleague with expertise in neonatal care was included also. Each appraiser carried out their review of the guidelines independently and the results were collated. Agreement between reviewers was good. Table 16 shows the summary of the results for each paper.

Findings

To facilitate evaluation and comparison of the guidelines, the findings are presented using the domains specified in the AGREE instrument. Table 17 shows the percentage scores for each domain for the guidelines. The percentage scores were obtained using the formula advised by the AGREE Collaborative Group to obtain a standardised domain score (Appendix Two).

Table 17: Application of AGREE instrument to guidelines

Domain	SANDS (Schott et al 2007)	Thames Regional Perinatal Group	British Association of Perinatal Medicine	American Academy of Pediatrics	Canadian Paediatric Society	Nursing and Midwifery Council
Scope and Purpose	47.2%	50%	38.8%	61%	55%	38.8%
Stakeholder involvement	68.75%	22.9%	12.5%	16.6%	22.9%	22.9%
Rigour of Development	26.1%	10.7%	1.19%	21.4%	20.2%	30.9%
Clarity and Presentation	39.5%	2.08%	2.08%	14.58%	10.4%	18.75%
Applicability	19.45%	8.33%	0%	0%	5.5%	0%
Editorial Independence	12.5%	25%	12.5%	12.5%	20.8%	25%

To evaluate a guideline using the instrument, the score for each domain was added up and scored as a percentage. The AGREE Collaboration suggested that domain scores should not be aggregated and that it was impossible to set scores against a threshold score for ‘good’ or ‘bad’ guidelines (AGREE Collaboration, 2001). Instead it was recommended that the appraiser made an overall judgment about the quality of the guideline at the end of the assessment.

The application of the tool does not take into account the range of scores between the appraisers but combines all the scores to obtain an ‘aggregate’ score. The method of scoring does not allow for ‘deviations’ to be calculated and this is a potential weakness of the tool. In this particular assessment where there were low scoring domains, there was good agreement. However, there were variations between assessors in the domains that achieved higher scores. The reason for this was unclear and requires further investigation to explore different understandings of the application of the AGREE tool.

Scope and Purpose

The National Institute for Health and Clinical Excellence (NICE) recommended that guidelines should have specific aims and objectives and the expected health benefits or outcomes should be identified (NICE, 2007). The population for whom the guideline is intended should also be specified to enhance the use of the guideline (NICE, 2007). This information assists health professionals when searching for relevant guidelines.

Five of the guidelines indicated that the previsible baby was the focus of the guideline (MacDonald, 2002; NMC, 2007; Thames Regional Perinatal Group, 2000; BAPM, 2000; Schott et al, 2007). One guideline referred to the woman as the focus of care (Canadian Paediatric Society, 2000). It is possible that the lack of focus in the guideline title could mislead professionals when searching for information.

Stakeholder involvement

In developing a guideline for clinical practice, it is essential that those involved in its development have the relevant expertise (Woolf et al, 1999). The guideline development group should also reflect the range of disciplines using it. In evidence based care, the experiences and expectations of consumers of health care should be taken into account when developing the guidelines and the process should be included in the final guideline (van Wersch & Eccles, 2001; NICE, 2008). It is recommended that the guideline should make explicit reference to the target users. If

the target audience is not specified in the guideline, then it is possible that potential users may not be aware of the relevance of the guideline to their practice. As part of the guideline development, it is recommended that it should be piloted or tested with relevant user groups and this should be recorded in the published guideline (AGREE Collaboration, 2001).

Three of the identified guidelines indicated that they had been prepared on behalf of a professional organisation or committee but no further information was given about the individuals who participated in the development process (BAPM, 2000; NMC, 2007; Thames Regional Perinatal Group, 2000). Three guidelines gave details of professional employment details or professional qualifications of members of the guideline development group (MacDonald, 2002; Canadian Paediatric Society, 2000; Schott et al, 2007). One guideline included details of professionals and parents who had been involved in the guideline development (Schott et al, 2007). While this guideline did indicate that parent experience had informed the development of the guideline, there was no information about the representativeness of the group and how the parents had been recruited.

Two guidelines provided explicit information about the nature of the guideline and the target audience (Canadian Paediatric Society, 2000; MacDonald, 2002). Nurses and midwives were likely to be the main providers of care to the dying pre-viable baby. One guideline mentioned this group by name as target users (NMC, 2007). Generic terms such as 'clinicians' and 'other members of the health care team' were

used by guidelines (Thames Regional Perinatal Group, 2000; MacDonald, 2002; Canadian Paediatric Society, 2000). One guideline provided no information about the specific target group for the guideline but did refer to ‘obstetricians, paediatricians, midwives, nurses and other supporting professionals’ in the text (BAPM 2000).

Rigour of development

It is recommended that guidelines should be based on the best available evidence to enable practitioners to deliver care that is safe and effective (NICE, 2007). A guideline can only be as good as the evidence that informs its development. For that reason it is suggested that the process of gathering and analysing the evidence and formulating the recommendations should be included in the guidelines. It is also considered good practice to submit guidelines to peer review before publication (NICE, 2007). The AGREE collaboration suggested that this should include people with appropriate professional and methodological expertise (AGREE Collaboration, 2001). Some guidelines may be reviewed by consumer representatives at this stage in their development. Since guidelines need to be informed by current evidence in order to be effective, it is considered to be good practice to include information about the updating process or including a review date in the guidelines (AGREE Collaboration, 2001).

None of the guidelines provided information about search strategies or inclusion and exclusion criteria. One guideline was unsupported by any references (BAPM, 2000).

This guideline, however, was cited as ‘evidence’ by another guideline (NMC, 2007). None of the guidelines provided any critique of the cited evidence relating to the care of dying pre-viable babies or an indication of the quality of the evidence. One guideline stated that external reviewers had been consulted and listed them in the guideline; however, no information was given as to the appraisal process (Schott et al, 2007).

One guideline was in the process of being reviewed (Canadian Paediatric Society, 2000) and one guideline indicated a review date (MacDonald, 2002). None of the remaining guidelines provided information about updating procedures.

Clarity and presentation

This domain considered the way in which the options for care are presented and the dissemination and implementation strategy. It was suggested that the recommendations should be stated clearly and be easy to find. The guidelines need to be precise about which specific management approaches should be used as determined by the body of evidence. If there is uncertainty about management then this should be reflected in the guideline (AGREE Collaboration, 2001). This domain also covered the dissemination and implementation strategy for the guidelines.

In the previous section the evidence base for the guidelines appeared to be poor. This made it difficult for the guidelines to be specific about the potential ways of managing care. Moreover, the way in which care was described seemed to be vague

and unlikely to be helpful to practitioners e.g. *'the use of opiates to provide a comfortable and dignified death may be entirely appropriate'* (Thames Regional Perinatal Group, 2000). The guideline did not give any indication of how the need for opiates would be assessed, the dose and the possible routes of administration.

The recommendations for the care of the dying pre-viable baby were embedded in guidelines and were difficult to identify (NMC, 2007; Thames Regional Perinatal Group, 2000; MacDonald, 2002; BAPM, 2000; Canadian Paediatric Society, 2000). One guideline had an identified chapter on late pregnancy loss and the care of the dying pre-viable baby was given a heading that enabled it to be located easily (Schott et al, 2007).

Two guidelines had been published in journals read by a range of professionals (MacDonald, 2002; Canadian Paediatric Society, 2000). One guideline was distributed to key users (NMC, 2007). The remaining guidelines were available on a specialist website (Thames Regional Perinatal Group, 2000; BAPM, 2000). Only one guideline came with clear recommendations and suggestions for dissemination (Schott et al, 2007). This guideline was not available free of charge but the key recommendations were available on a website.

Applicability

Applying the guideline recommendations may require additional resources or changes in practice. This domain assesses the extent to which the barriers to

implementation have been addressed and how adherence to the recommendations can be assessed. This was missing from five guidelines. One guideline identified the need for staff training to implement the recommendations and criteria for review (Schott et al, 2007). None of the guidelines discussed possible audit or review criteria to assess how the guideline for the care of the dying pre-viable baby was being used in practice.

Editorial Independence

This domain refers to the need to make explicit the relationship between funders and the guideline development process. It also related to potential conflicts of interests experienced by members of the development group. The AGREE evaluation tool recommended that there should be an explicit statement relating to potential conflicts of interest (AGREE Collaboration, 2001).

None of the guidelines had explicit statements relating to the interests of the guideline developers or funding. One guideline was developed by a charity who then offered it for sale (Schott et al, 2007). It was recognised by the reviewers that the current focus on perinatal loss came about because of the work carried out by consumer groups and their prominent use of their logo could be regarded as an explicit statement about their 'interest' in the guidelines.

Overall Assessment of Guidelines

The AGREE evaluation tool suggested that there should be an overall assessment of the quality of the guideline based on scores achieved for each of the domains and the judgment of the appraiser (AGREE Collaboration, 2001). Four options were available: ‘strongly recommend’, ‘recommend with provisos or alterations’, ‘would not recommend’ and ‘unsure’.

The overall assessment for all six of the guidelines from each reviewer was ‘would not recommend’. The main reason expressed for this judgment was the apparent lack of rigour in the development of the guidelines which then impacted on the validity of the recommendations for care.

Rhetorical Analysis

Each of the guidelines was analysed using the model formulated by Leach (Chapter Two). This was carried out to assess how the guideline was produced. In particular, I wanted to explore the meaning of the guidelines: what did they say and how was meaning transmitted. Appendix Three shows an example of the application of Leach’s model to a guideline.

Exigence: Saying the right thing at the right time

In accordance with rhetorical analysis, I considered not only what was said but when it was said. The benefit of this approach is that it allowed me to attempt to analyse them in relation to their social, political and professional context. All the guidelines

were very measured in their use of language. While they indicated that the decision whether to resuscitate a baby or not was a difficult one, the guidelines did not reflect the deep societal divisions relating to the position of pre-viable babies. For example some individuals and organizations believed that every baby showing signs of life should be resuscitated and offered intensive care, regardless of gestational age (Sayed, 2005). These debates and controversies were not evident in the guidelines.

The presentation of the guidelines was similar. The format of guidelines reflected papers presented in professional journals and, some of the guidelines had been published in journals belonging to professional organizations (MacDonald, 2002). The language was technical and aimed at a professional audience. Some of the concepts implied specific understandings of terminology e.g. *compassionate care*.

Using the rhetorical approach allowed in-depth interpretation and, in this case, revealed that the overall tone of the guidelines was persuasive. They centered on a particular course of action that should be taken when a woman presents in very preterm labour and presented information as to what should be done and why. The use of 'levels of evidence' to justify specific approaches to care was intended to add authority to the recommendations and could even have a 'protective' element for health professionals who used the guidelines. They would be able to argue that there was sound evidence to justify their decision making. In relation to the care of dying pre-viable babies, however, the 'levels of evidence' information was missing. The lack of evidence was not remarked upon by the authors of the guidelines.

Rhetorical canons

Traditionally, rhetoric is considered to have five 'canons': Invention, Disposition, Style, Memory and Delivery. These relate to the form and content (Invention), the presentation (Disposition), the relationship between form and content (Style), reproducibility (Memory) and dissemination (Delivery).

Invention

As discussed earlier, the guidelines all followed a similar format which was recognizable to health professionals. It was possible that this structure had been chosen because it persuaded the reader or user of the guidelines that it has certain properties, in common with papers published in peer reviewed journals. In varying degrees, the guidelines established the credibility of the authors. For example several guidelines were attributed not to individuals but to committees, thus lending the authority of the committee to the guideline.

Disposition

The structure of the guidelines was generally logical. That is one thing follows on from another so that as the health professional asks a question, the answer follows. The information on the care of the dying preivable baby was usually considered separately from the care of the preivable baby for whom intensive care was to be instituted. Separate headings were used for this aspect of the guidelines.

Style

The language of the guidelines was generally deterministic, for example, the idea that a situation should be managed in a particular way. On occasions guidelines acknowledged that other courses of action were possible (MacDonald, 2002) but the language in which this is couched encouraged the reader to believe that the guidelines would usually be applied. The guidelines were usually written in the third person using a formal style. However, this changed to become more informal when the care of the dying previsible baby was discussed. This change of style appeared to mask to a certain extent the lack of evidence base for the care being suggested. The juxtaposition of 'compassionate care' alongside a grade of evidence would appear stylistically incongruous.

Memory

One of the functions of guidelines is that they should be reproducible in different situations by different people. The guidelines in this review were long and contained a great deal of information. However, in order to present the key information different strategies were used by the authors. These included the use of algorithms and diagrams to emphasise key aspects of decision making and care. Significantly, there was a lack of information about the care of the dying previsible baby.

Delivery

Delivery relates to dissemination. All the guidelines analysed were in the public domain and with the exception of the guidelines published by the user groups

SANDS, all were available free of charge. While it might seem strange that a user group should charge for their guidelines while professional organizations made their guidelines available freely, it had to be recognized that professional organizations charge their members a fee and this subsidises committee work and guideline production. There was no reason why a group representing bereaved parents should subsidise work to enable professionals to practice more effectively. This perhaps highlighted the power differential between professionals and user representatives.

Summary

The guidelines considered as part of the CIS to address the research question had been produced by authoritative groups and are influencing practice in relation to the care of the dying pre-viable baby. However, an argument could be made about there being a lack of rigour in the development of the guidelines which could then adversely affect the quality of care prescribed for dying pre-viable babies. In particular, there seemed to be a lack of evidence to underpin the care and, more importantly, a failure to acknowledge the need for a more robust approach to the care of the dying pre-viable baby.

Development of Synthetic Constructs

Using the emerging themes from the earlier investigations into clinical and professional literature and textbooks, the data from the analysis of national guidelines was mapped against these.

Table 18: National Guidelines - Synthetic Constructs

Themes / Constructs	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation	Rhetoric	Ideology
Professional practice						√			√	√
Parental Authority									√	
Choice										
Performance						√			√	√

As with the textbooks, Professional Practice was a key aspect of the guidelines. All the guidelines acknowledged the responsibility of the health professional in caring for the dying pre-viable baby. The ideology reflected the extent to which a professional should make decisions and the likely impact of these decisions. In relation to the care of the dying pre-viable baby, while the language stressed the futility of aggressive forms of treatment, a responsibility to continue to care by providing 'comfort' to the baby was emphasized. The guidelines highlighted the rituals outlined in the midwifery textbooks and professional literature. This included holding, bathing, dressing, naming, as well as giving pain relief and nutrition, although there was inadequate information in the textbooks as to how the latter two interventions could be used in the care of the dying pre-viable baby.

Parental authority was recognised in relation to decision making but again the limits of this were stressed. In particular, the guidelines made it clear that they could not insist on intervention to prolong the life of their baby. The argument to support this stance related to the concept of 'best interests' and the need to avoid intervention that might prolong suffering. The need to offer parents choice was presented in the

guidelines but this was only in relation to their participation in the activities outlined earlier. In particular, none of the guidelines offered the parents the opportunity to have their baby removed from the room in which birth had taken place. There was an assumption that all the parents would keep the baby beside them.

The guidelines were in many ways similar to 'scripts'. They provided clear direction as to what health professionals should do in specific situations. Suggested words and phrases were offered to be used to help the professional facilitate the parents' understanding of the situation. The guidelines even suggested behaviours and actions to ensure that the health professional presented themselves in a convincing manner to the parents to convey to the parents that the health professional understood their situation.

CIS: The next step

The analysis of national guidelines was informative because it provided a great deal of information that was missing from medical textbooks. This included information about the delivery of care for the dying pre-viable baby. The lack of evidence for care emerged from the analysis, as did the authority of the guidelines. The guidelines were produced to be used at a national level. Their impact on practice locally remains to be investigated. In order to do this, I decided to undertake a review of local practice guidelines to assess their comparability with national guidelines.

Conclusion

This chapter has explored the development of national guidelines for the care of the dying pre-viable baby. The methodology used (as above) has highlighted an apparent lack of an effective evidence base, along with an authoritative, directed form of care for both the dying pre-viable baby and the parents. The next chapter will consider the relationship between national and local guidelines in an attempt to answer the research question.

CHAPTER EIGHT: CRITICAL INTERPRETIVE SYNTHESIS DATA COLLECTION AND ANALYSIS – LOCAL GUIDELINES

Introduction

The previous chapter explored guidelines for the care of the dying pre-viable baby produced at national level in North America and the UK. The analysis of the guidelines found that there was general agreement between the prescribed approaches to the care of the dying pre-viable infant. This reflected the underlying ideology and the rhetoric which supported rituals relating to establishing the caring credentials of the parents. The analysis also found that there was a lack of good quality evidence to support the recommendations of the guidelines particularly with regard to ensuring the comfort of the baby.

The intention of the national guidelines was that they should influence care at a local level. However, the implementation of national standards of care in many clinical specialties is patchy, even where there is proven benefit from the interventions (Bick et al, 2009; Ryecroft-Malone et al, 2009). This led me to consider how the national guidelines for the care of the dying pre-viable baby might be incorporated into local practice. I decided to explore if and how the national policies were used to inform practice at a local level in the National Health Service in the UK.

Method

Maternity units were identified from websites from official organisations such as the Scottish Government Health Department, the Department of Health and voluntary

maternity organizations, as well as websites providing information about local maternity services. A structured response sheet was developed and was included with the invitation to participate (Appendix Seven). If units indicated that they had specific guidelines for the care of dying pre-viable infants, they were invited to send a copy for review. The invitations were sent out by post addressed to the Head of Midwifery and a self-addressed envelope was included for the response. Both the envelopes and the response sheets were coded so that the geographical location of the unit could be identified but anonymity of the unit was preserved.

Three hundred and twenty two maternity units in the UK were contacted and invited to respond. One hundred and sixty nine units (53%) responded. There are a number of reasons why units might not respond. Included in the mailout were community maternity units. These frequently close for periods without notice and it is possible that some units were closed when the invitation to participate was delivered. In some areas, units share guidelines and it is possible that a member of staff responded on behalf of more than one unit. It is also possible that some units which undertook only normal births did not respond as they did not think that the survey was relevant to them.

As with the national guidelines, the AGREE tool for guideline appraisal was used (AGREE Collaboration Writing Group, 2003) and the analysis was undertaken by my two supervisors and myself. Rhetorical analysis using a framework (Leach, 2000) was also carried out (Chapter Two).

Results

Within the 169 responses to the survey, I was able to establish that every health region in the UK had responded and that these responses included tertiary units which specialise in high risk births, as well as District General Hospitals which might provide care for pre-viable babies if a decision were made before birth that resuscitation would not be attempted. Ninety nine units (59%) responding stated that they did not have a guideline for the care of dying pre-viable babies. Some qualified their response stating that women in preterm labour were always transferred to another unit. One response indicated that they had never considered having a guideline on this aspect of care but were now doing so as a result of the questionnaire. One unit stated that they had found the guideline from a neighbouring region to be so comprehensive that they had asked for permission to use it in its entirety. Seventy nine units indicated that they did have guidelines relating to the care of pre-viable babies and a total of 45 policies covering 51 units was received for review.

Five guidelines were excluded from the review. One guideline contained only information about the measurements (length and weight) and swabs that should be taken from a dead baby. Four guidelines related to disposal of fetal tissue – i.e. it was assumed that that the pre-viable baby would be dead at birth.

As with the national guidelines, the information about caring for dying pre-viable babies was embedded in general guidelines relating to neonatal loss or preterm birth.

This information relating to dying pre-viable babies was extrapolated and considered separately. The results are reported using the headings from the AGREE analysis tool (Appendix Two) and those from the rhetorical analysis model (Appendix Four) used by Leach (2000). Table 19 gives an example of inter-rater reliability between two reviewers for Local Guidelines (LG) 1 – 6. As with the national guidelines, there is good agreement between the reviewers. In particular, there is agreement within the categories of ‘Agree’ or ‘Disagree’ for each item.

AGREE Analysis

Scope and Purpose

Twelve guidelines indicated that their focus was the management of babies on the threshold of viability. Eight guidelines embedded the information in general guidelines relating to perinatal loss and bereavement. These included information about late miscarriage and neonatal death. Seven guidelines referred to preterm labour, with information about care of the woman in preterm labour and care once the baby was born. Seven guidelines included information about dying pre-viable babies in guidelines relating to abortion. Four of these related to termination of a ‘wanted’ pregnancy e.g. where the pregnancy was being terminated because of the woman’s health or because of fetal abnormality. Three guidelines referred to resuscitation practice. These included information about decision making in relation to pre-viable babies. Three guidelines had no title at all but were part of labour ward guidelines.

Although the guidelines suggested that the focus was on the woman e.g. care in preterm labour or the baby e.g. management of a baby at the threshold of viability, the content was generally at odds with the title. Many of the guidelines focused on procedural issues e.g. the correct labelling of specimens. This will be covered in more detail later in the chapter.

Stakeholder involvement

Eighteen guidelines were signed off by senior medical and midwifery staff. Eight guidelines indicated that they had been prepared by a group e.g. clinical governance group. Two of these guidelines indicated that there had been involvement of spiritual advisors e.g. hospital chaplains. In one case a guideline had initials against it but there was no indication as to who this person was and their role in the guideline. The remainder of the guidelines (13) provided no information about the personnel involved in the production of the guideline or endorsing it. Four guidelines indicated the target audience for the guideline e.g. labour ward staff. The remaining guidelines gave no indication as to the staff at whom the guideline was directed.

Rigour of development

None of the guidelines presented information about their method of development. However, one guideline indicated that it had been approved by a Trust Guideline Review group. Five guidelines had review dates. None stated explicitly that they should not be used after that date.

Nineteen of the guidelines made no reference to an evidence base. Five guidelines used references from peer reviewed journals to justify treatment decisions in relation to resuscitating pre-viable babies, providing information about mortality and morbidity. Four guidelines made reference to the SANDS guidelines for health professionals (Schott et al, 2007). Seven guidelines cited documents from the Royal College of Obstetricians and Gynaecologists. These included topics such as the management of preterm labour, management of mid trimester medical abortion and feticide. One guideline referenced the Royal College of Paediatrics and Child Health Document 'Withholding and withdrawing care' (RCPCH, 2004). Three guidelines made reference to the Midwives Rules (NMC, 2004) and Code of Professional Conduct (NMC, 2008). References to the Nursing and Midwifery Council documents were made specifically to indicate the need for midwives to act with Human Rights legislation for a baby born alive at any gestation and also to ensure that a baby born alive and who subsequently died had both the birth and death registered.

Clarity and Presentation

The guidelines adopted a variety of presentations. The majority of the guidelines adopted a format comprising of headings followed by a series of statements relating to the heading. One guideline included a flowchart. Two guidelines were in the format of checklists and two guidelines were written in an essay format. The shortest guideline was a checklist two pages in length. The longest comprised 44 pages. In

most guidelines, the information about the care of the dying pre-viable baby was in a subsection of the main guideline. This made it difficult to locate.

The actual information about caring for the dying pre-viable baby varied. Three guidelines made reference to the use of warmth and facial oxygen e.g. *'a decision may be made to offer minimal support, warmth and facial oxygen'*. However, these were perceived as attempts at resuscitation and the guidelines went on to say *'in the absence of any response this support should be withdrawn'*. (LG20, LG33, LG39). Two guidelines stated explicitly that midwives could call on paediatric staff for assistance in caring for the baby: *'(there is) a duty of care to keep babies comfortable and the Paediatric reg can be called to help with that duty of care'* (LG 28, LG29). One guideline suggested that opiates could be used but no information was given to the midwife to enable her to assess when they might be indicated and how they might be given. Other than these comments, none of the guidelines made specific reference to the dying pre-viable baby's needs.

Offering the parents the opportunity to see and hold their baby was indicated in all of the guidelines. Most guidelines used the word *'encourage'* indicating that staff should promote this activity. One guideline stated that holding was important since *'creating good memories is essential for healthy grieving'* (LG29). Several guidelines stated that where parents did not accept the initial offer to hold their baby, they should be reminded of the offer during their stay in hospital.

Gathering mementos such as handprints, footprints, locks of hair, cot cards, name bands and photographs was mentioned in all of the guidelines. Several guidelines appear to ignore the concept of parental autonomy and consent and indicated that mementos should be collected even if parents did not want them: or *'Pictures should be taken of the baby even if the parents do not wish to have them'* (LG34).

The involvement of the multidisciplinary team varied in the guidelines. Two guidelines made an explicit comment with regard to midwives asking for pediatric assistance in providing palliative care. One guideline highlighted the need to call a doctor before the baby died so that the relevant paperwork could be completed. This information was capitalised and underlined: *'ALWAYS ASK A DOCTOR WHICH CAN BE AN OBSTETRIC SHO TO SEE THE BABY WHEN IT IS BORN ALIVE, IN ORDER THAT HE CAN THEN SIGN THE DEATH CERTIFICATE'* (LG38). If a doctor had not seen the baby when they are alive, then they cannot sign the death certificate. This created an administrative 'logjam' since the coroner or procurator fiscal and Registrar would have to be consulted before the birth and death could be registered. One guideline stated explicitly that the midwife should *'only call paediatrician if baby is breathing regularly'* (LG26). Since there was considerable debate over gasping and breathing movements in pre-viable babies, midwives were expected to exercise sophisticated judgment in these cases which happen infrequently.

Domestic staff were mentioned in two guidelines: *'To avoid embarrassment, all members of staff should be made aware that the baby has died. This includes domestic staff that often has close contact during the day. Staff should be encouraged to offer their condolences.'* (LG5) and *'Place forget-me-not sign on door to ensure that domestic staff know that the woman has lost her baby'* (LG7). Porter and mortuary staff were also mentioned in guidelines. This related to the transport of the baby's body after death. Direct instructions were given as to the receptacle in which the baby should be placed and how and when they should be moved to the mortuary. One guideline stated: *'Midwives should not be involved in physically placing the baby in the fridge'* (LG2) but did not give a reason for this.

Applicability

Two guidelines made specific reference to the need for training in supporting parents who were bereaved. Eight guidelines provided information about specific resources to help staff in supporting bereaved parents. These included Bereavement Midwives, Bereavement Officers, Counselling staff and Spiritual Care Advisors. One guideline indicated that all newly appointed staff would be given training in bereavement care as part of the induction package and that ongoing training in bereavement care was part of the mandatory updating for midwives working in the Trust. Five guidelines had review dates but none gave information about audit and effectiveness reviews.

Many of the guidelines made specific reference to additional resources, mostly for the parents. These included emergency contact numbers for support. Detailed

information was often included about the different formats of photographs that could be taken. Special clothes and cribs were mentioned, along with ‘memory boxes’ which could include keepsakes such as blankets. The use of a named room (Snowdrop Room, Forget-me-not Room, Lily Room) especially for parents experiencing perinatal loss was mentioned in more than half of all the guidelines. Two guidelines made reference to specific storage arrangements for the baby’s body after death with fridges being reserved for use by the maternity services. These were located near to the parents’ room so that they could have easy access to the baby’s body.

Editorial Independence

None of the guidelines addressed this aspect. It could be argued that the developers could not be ‘independent’ since they were expected to undertake this role as part of their employment and professional responsibilities. However, given the focus on public involvement in NHS policies, some form of public involvement might have been expected.

Overall Assessment of Guidelines

The overall assessment for all the guidelines reviewed was ‘would not recommend’. As with the national guidelines, the local guidelines were not rigorously constructed and this influenced their reliability.

Rhetorical Analysis

Rhetorical analysis of the guidelines was carried out to explore the meaning behind the words (Chapter Two).

Exigence: Saying the right thing at the right time

The format of the guidelines followed three main patterns: headings with a series of statements related to the heading, statements with a rationale justifying the statement, and checklists. It is probable that the format of each guideline would be influenced by the institutional style for guideline production.

The overall tone of the guidelines was didactic e.g. *'There is a bereavement card that must be filled'* (LG 24) or *'Pictures should be taken of the baby even if the parents do not wish to have them'* (LG34). Where a rationale for care was offered, its meaning was not always clear. For example, a statement relating to the need to complete documentation was followed by the rationale: *'To avoid unnecessary contact'* (LG 18). It appeared not to be clear from the documentation whether the guidelines were meant to be of benefit to the parents or the staff.

The checklist format included information about the 'rituals' as well as administrative information about documentation and communication with relevant agencies. One of the features of the checklists was 'tick boxes' with headings such as 'done' or 'not done' and 'completed' or 'not completed'. This suggested that the activities had to be undertaken. For example, the checklist would have a statement:

'Parents have seen / held baby' (LG2). There was no space to write 'offered but not wanted'. Instead a practitioner would tick the box marked 'not done' and someone coming along later might offer again, or the midwife might be questioned as to why the activity had not been carried out. Instead directions were given: *'The baby should be wrapped and given to the parents'* or *'Chaplain informed'* (LG 40).

Unlike the national guidelines where different levels of evidence were used in parts of the guideline relating to decision making and intervention in relation to pre-viable babies, explicit levels of evidence were not cited in any of the local guidelines. The five guidelines which made reference to peer reviewed papers cited statistics from them to support decision making in relation to starting or withholding resuscitation.

Rhetorical canons

Invention

As discussed earlier, the structure of the guidelines would be familiar to any health professional working in the NHS. The role of guidelines in influencing professional practice is the subject of much debate and this will be discussed in Chapter Nine. However, the format of the guidelines would imbue them with a sense of authority for staff using them.

Disposition

The overall structure of the guidelines was logical. However, some guidelines were very long - between 14 and 44 pages in length. It has to be questioned if staff could reasonably be expected to engage with guidelines with such a level of detail.

Style

The style of the guidelines appeared to be didactic with the exception of one guideline (LG22) which was written in a discursive style, providing alternative approaches to care. This guideline also had a caution about its use on the front cover stating that the guideline provided guidance but '*was not a substitute for clinical judgment*'. This was not seen in any of the other guidelines. Words such as 'should' and 'must' appeared regularly in the guidelines e.g. '*a set of footprints should be stored in the care records for parents who do not want mementoes*' (LG 32) and '*do not tell parents the gender*' (LG15). The latter statement about gender allocation related to the fact that in very preterm babies, the genitalia may not be fully formed and it can be difficult to discern the sex of the baby. Only one guideline provided this additional information as to why the parents should not be told the sex of their baby and none of the guidelines gave any indication as to how the health professional might respond to the parents' questions about the sex of the baby.

Memory

The reproducibility of the local guidelines varied. They varied in length from two pages to 44 pages. Many of the guidelines were very detailed and listed bloods and

other specimens that should be taken, people to be contacted and specific activities to be undertaken, especially in relation to the transport and storage of the baby's body after death. Most of the guidelines had checklists that could be detached from the guidelines, labelled and stored in the woman's notes. This would have enhanced the reproducibility of the guidelines. However, as discussed above, it could lead to duplication of effort since it was not always possible to record that parents did not want particular interventions.

Delivery

No information was available in any of the guidelines as to how they were to be disseminated. This may be 'taken-for-granted' information within the local organisations since they were provided for local use. The guidelines 'belonged' to local Trusts and Health Boards. Because of Freedom of Information legislation, all the guidelines can be requested by members of the public and thus placed in the public domain.

Summary

The local guidelines considered as part of the CIS to address the research question were developed to inform local practice. This thesis argues that the lack of rigour in their development echoed that found in the analysis of national guidelines. Indeed, it could be argued that this was only to be expected since the national guidelines were formulated to inform local practice. As with the national guidelines and textbooks, there was a lack of focus on the needs of the dying previsible baby and a significant

emphasis on parental roles and creating memories, along with procedural aspects of storing the body of the dead baby.

Development of Synthetic Constructs

Using the themes from the earlier analyses of literature, textbooks and national guidelines, the emerging themes from the local guidelines were mapped against these to develop synthetic constructs. This is illustrated in Table 20.

Table 20: Local Guideline - Synthetic Constructs

Themes / Constructs	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation	Rhetoric	Ideology
Professional practice						√			√	√
Parental Authority										
Choice										
Performance									√	

Professional practice remained central to the guidelines. Several guidelines were framed around statements of professional responsibility e.g. the Code of Professional Conduct (NMC2008) or the Midwives Rules (NMC2004). In particular staff were reminded about their responsibility to undertake updating in relation to care of parents who have been bereaved and the need to comply with Human Rights legislation. While the rhetoric of the guidelines stressed individual responsibility for the care the health professional carried out, the underlying ideology was of control as evidenced by the use of checklists to direct clinical care. The tensions caused by

apparently opposing ideologies could also be found in the rituals in the guidelines. The rhetoric of the guidelines made frequent reference to the necessity of being sensitive to the parents' needs. However, the use of checklists appear to make what should be comforting and supportive behaviours, mandatory. This may have the effect of disconnecting parents from the experiences of living through the death of their baby. In this way, it could be argued that while checklists are meant to ensure that staff offer parents a choice of activities to undertake when facing the death of their baby, the 'tick-box' approach may, in fact, reduce parental choice and thus reduce the potentially meaningful rituals of holding the baby and gathering keepsakes to routines that sometimes appeared almost banal. Moreover, this approach does not appear to touch upon the importance of 'patient involvement' as stipulated in policy guidelines (Department of Health2008).

Parental authority was not a feature of the guidelines. Choice was mentioned in relation to participation in the rituals in some guidelines but the concept of parental authority was missing. In fact, the local guidelines suggested that the authority lay with health professionals who were carrying out instructions from an authoritative source. Unlike the national guidelines which assumed that all parents would want to keep the baby beside them, some local guidelines acknowledged that some parents would want the baby to be removed from the labour room. In these cases, parents were not given a choice about where the baby should go. Instead the guidelines specified a location (never the neonatal unit) where the baby could be taken. If this

did happen, the guidelines inevitably stated that the baby should not be left alone but gave no direction as to what care should be given to the baby.

The local guidelines had ‘script-like’ qualities. As with the national guidelines, they provided explicit directions as to what health professionals should do in specific situations. However, the local guidelines were less likely to have the suggested words and phrases contained in the national guidelines which could help in the interactions with parents. These differences might account for some of the complaints about the lack of sensitivity of health professionals in caring for parents experiencing perinatal loss (Robinson2002).

Data Collection: Addressing the research question

At each stage during the data collection, I have explored the extent to which the data has enabled me to address the research question:

How and why are rituals relating to the care of dying pre-viable babies in labour wards constructed, deconstructed, enacted and interpreted?

At this stage, after analyzing professional and clinical literature, midwifery and medical textbooks and national and local guidelines, the question has to be considered in relation to the available data. The outstanding question at this stage is: does the data collected address the research question?

In Chapter Two, the terms used in the research question were defined. ‘**Ritual**’ was defined as a meaningful activity, ‘**constructed**’ related to the way in which the

rituals were developed and had meaning ascribed to them, ‘**deconstructed**’ referred to the contradictory meanings of the rituals, ‘**enacted**’ was defined as the performance given by the health professional and ‘**interpreted**’ related to the way in which the rituals were understood by parents and professionals.

The clinical and professional literature, together with data from midwifery textbooks and local and national guidelines has provided rich descriptions of activities that can be undertaken when caring for a dying pre-viable baby. This data have also provided information as to how the rituals might be understood by parents and contextualised activities that might otherwise have been regarded as clinical routines. The national guidelines offered direction and scripts for the performance given by health professionals. Finally, there was an abundance of contradictory meanings in clinical literature, medical and midwifery textbooks and the local and national guidelines in relation to the rituals as they are applied to the dying pre-viable baby and other perinatal losses. The following table shows how the data addresses the research question.

Table 21: Mapping of data against research question

	Constructed	Deconstructed	Enacted	Interpreted
Professional and Clinical Literature	√	√	√	√
Midwifery textbooks			√	√
Medical textbooks			√	√
National guidelines	√	√	√	√
Local guidelines	√		√	

CIS: The next step

The next and final step in CIS is the development of a Synthesising Argument from the Synthetic Constructs that have emerged during the data analysis. This is done by revising the synthetic constructs and exploring and interpreting them. In particular, Dixon-Woods et al (2006) stress the need to ‘adopt a critical and reflexive stance’ in considering both the data and the theory generated from the data. This will be addressed in the next chapter.

Conclusion

This chapter has explored the development of local guidelines for the care of the dying previsible baby. The local guidelines were directive, offering little flexibility for parents and health professionals. The chapter also assessed the adequacy of the data collected thus far to address the research question. The next chapter will focus on the development of a synthesizing argument to answer the research question.

CHAPTER NINE: CIS – DEVELOPING A SYNTHESISING ARGUMENT

Introduction

The previous chapters have analysed and interpreted a wide range of data to answer the research question. This chapter draws the data together and directly addresses the research question through the development of a Synthesising Argument.

CIS: Synthetic Constructs

The themes that emerged from the analyses of the data were compared and contrasted to explore the relationships between them to identify Synthetic Constructs. Table 22 shows the relationships between the data.

Table 22: Synthetic Constructs - Composite

Themes / Constructs	Assessment of gestational age	Non intervention	Signs of life	Human rights	Theories of Loss	Ritual	Dying right	User representation	Rhetoric	Ideology
Professional practice	CP	CP	CP	CP	CP / MIT / MET	MIT / MET / NG / LG	CP / MIT		MIT / MET / NG / LG	MIT / MET / NG / LG
Parental Authority					CP	CP / MIT	CP	CP	MIT / MET / NG	MIT
Choice						CP	CP	CP	MIT	MIT
Performance					MIT	CP / MIT / MET / NG	CP / MIT	CP	MIT / NG / LG	MIT / NG

Key
 CP = Clinical and professional literature
 MIT = Midwifery textbooks
 MET = Medical textbooks
 NG = National guidelines
 LG = Local guidelines

Synthetic Constructs

Performance 

User Involvement 

Choice 

Professional practice was strongly associated with performance which was linked to the need to establish the reality of the loss of a baby and the claims of the parents. This became a construct: **Performance**. National and local guidelines provided 'script like' instructions for health professionals, telling them what to say, when to say it and how to present themselves when interacting with parents who comprised the audience. This reinforced the construct of Performance.

The scripts were largely formulated from guidance issued by user groups based on the experiences of parents whose babies were stillborn (Schott et al, 2007). The same scripts were used for different audiences with little thought being given as to their reception. This led to babies who were still alive but dying being treated in the same way as babies who were already dead. The impact of this on the audience is not explored in the literature.

The importance of audience perceptions in relation to loss can be seen in the anthropological literature. Scheper-Hughes (1991) described how high perinatal mortality rates in Brazil led mothers to delay rituals of naming and baptism until they were sure that the child was likely to survive. McLean (1971) described how Nigerian society classified some infants who died as 'abiku' or 'born to die'. These infants were not mourned by their mothers as they were regarded as 'passing through' before going on to spend time with their spirit families. Similarly Kimane et al (2009) described how women in the villages in Lesotho would dispose of stillborn babies and those dying soon after birth on compost heaps within their home

compound. They were not accorded 'human' status and this meant that traditional mourning and funeral customs did not apply to them.

These practices contrast strongly with the scripts prevalent in the UK and North America where parents are encouraged to name babies, regardless of their gestation and where babies who are pre-viable or stillborn must have their births registered and their bodies buried or cremated. Accounts of performances using the scripts were related in textbooks (Kavanagh, 2003; Mander, 2003; Thomas, 2004) and in case histories (Horn, 2009; Hutti, 2005; Kavanagh et al, 2006) were similar in the UK and North America.

Because of the narrow focus of the research and narratives relating to perinatal loss in the UK and USA, the impact of the scripts on different audiences remains largely unexplored. Nevertheless, there are hints at discomfort at the lack of congruity between the script and the audience in the literature. For example, stigmatization associated with pregnancy loss can lead to women attempting to minimise the external impact of the loss (Hoy, 2009). The enforcement of rituals designed to confer personhood and the creation of visible reminders may be problematic for these women. It also assumes that there must be tangible proof of the loss in order for it to be regarded as real or important.

Religious advisors may find it difficult to reconcile the demands of the parents of pre-viable babies or stillborn babies for ceremonies normally accorded to full term

live born babies (Kennedy, 2008; Cacciatore, 2010). For example, the presentation of a previsible or stillborn baby as a 'real person' to the parents can lead to dissonance when this perception of the baby conflicts with religious tenets. For example, Cacciatore (2010) discusses baptism as a problematic ritual for parents whose babies are previsible or stillborn. Baptism is reserved for live born babies but parents may perceive the substitution of baptism with a service of blessing as being an attempt to minimise or negate their loss.

This study has touched on the complex nature of the audience in ritual in relation to the death of a previsible baby. Performance Theory challenges the traditional nature of the audience as passive recipients of the performance, separated from the actors. Schechner (1998) suggested that, rather than being fixed, a performance involves the formation of intricate relationships between the script, actors and audience across space and time. Because of the element of unknown in any performance, the audience cannot necessarily predict how they will react to the actor's performance of a script. Similarly, the actor cannot fully understand the impact of their delivery of the script each time they deliver it, since they may have a deep personal response to the situation. Despite the attempt of scripts to regulate performance, the interactions between performer and audience cannot be controlled and replicated. Thus, personal interpretations will always impose themselves on guidelines.

Parental authority was strongly linked to user representation and engagement and formed a single construct: **User Involvement**. This construct of User Involvement

included parental experience and was associated with choice. Parents used their experiences of the death of a pre-viable baby to inform the maternity services of the needs, expectations and experiences of bereaved parents through the medium of user groups. The user groups claimed authority because they represented parents who had unique experiences of the loss of a baby and this authority was recognized and accepted by health professionals and represented in textbooks and guidelines.

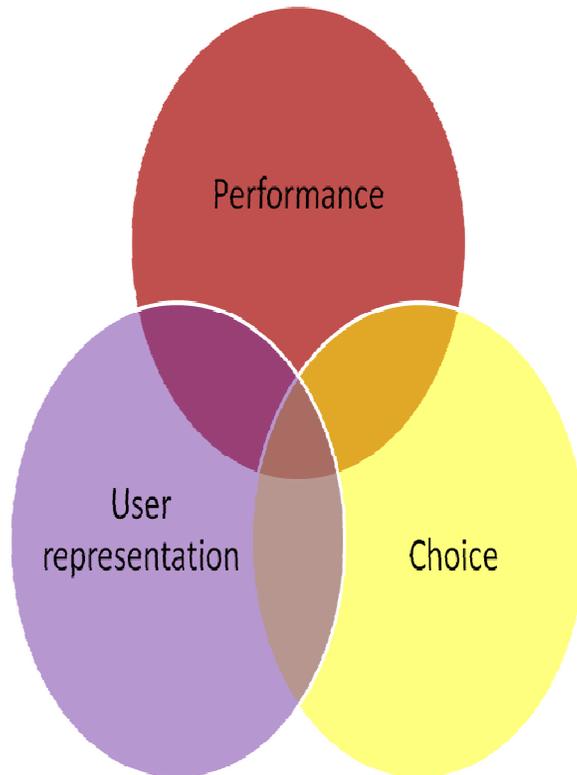
Also associated with this construct was the development of rituals to acknowledge the existence of the baby and to create memories of the baby for the parents. These rituals were described in detail in midwifery textbooks and local guidelines and were enacted in performances. Some local guidelines also provided information about specific language to use in encounters with the parents. The language reinforced the reality of the death of a baby and the impact on parental grief, as opposed to language which minimized the loss e.g. 'products of conception', or suggested that the parents could 'try again' and 'always have another baby' in the future.

Dying right was related to **Choice** which formed a separate construct. This construct was associated with the need to have a 'good death', where it was associated with the provision of palliative care. This involved undertaking the activities prescribed in the national and local guidelines. The meanings of the 'performance' for the health professionals who performed the ritual and the parents of the dying pre-viable baby who observed the ritual were explained in both midwifery textbooks and the local guidelines. Local guidelines, in particular, provided a 'script' for the ritual. It was

implied that by undertaking the rituals, the requirements of a good death would be fulfilled. Inherent in a 'good death' were the concepts of choice, control and acceptance of the death or 'moving on'.

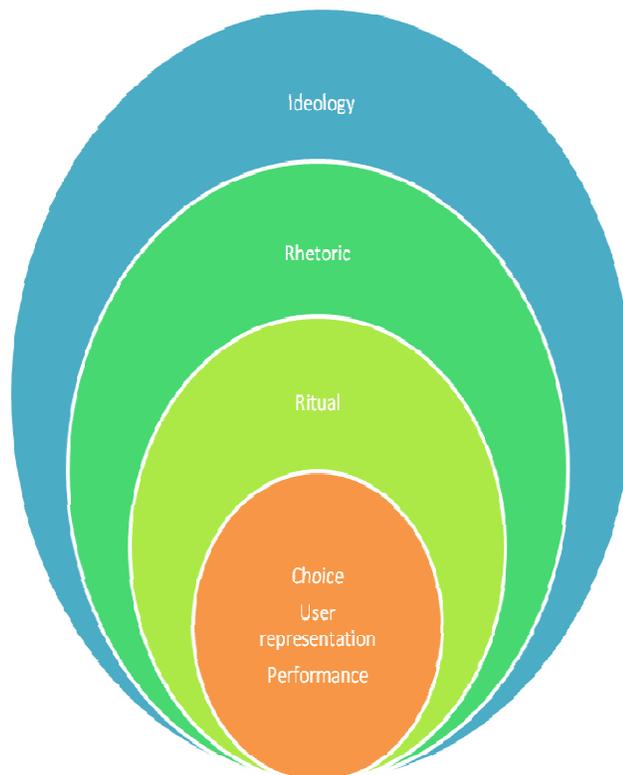
Although all three constructs are described separately, there were areas of overlap. For example, User Involvement informed the development of Performance and the inclusion of Choice in the repertoire of care. The diagram below shows the relationship between them.

Figure 2: Development of synthetic constructs



Pervading the thesis were the themes of **Ideology**, **Rhetoric** and **Ritual**. These themes helped explain the Synthetic Constructs. The ideology of user involvement and choice in maternity care was reinforced through the rhetoric of policy documents and guidelines. These were then interpreted through the performance of rituals. The diagram below demonstrates the relationships between the themes and the Synthetic Constructs.

Figure 3: Relationships between Themes and Synthetic Constructs



CIS: Developing A Synthesising Argument – Identifying Adjacent Literatures

To assist in interpreting the Synthetic Constructs and the development of a Synthesising Argument, Dixon-Woods et al (2006) recommended that ‘adjacent

literatures' are accessed. This, too, was an iterative process in the doctoral study. The identification of adjacent literatures is not haphazard but is facilitated by 'chaining' – following up references and consulting others working in related fields of research. Within the doctoral study, I was introduced to 'death studies' or thanatology by a colleague who attended the Sociology of Death, Dying and Disposal Conference. I presented at the conferences and gained insight from feedback from other researchers studying perinatal loss. This conference also introduced me to journals such as 'Death Studies' and 'Mortality' where different understandings of death were discussed. In particular, it enabled me to undertake a critique of the concept of palliative care and a 'good death' and apply it to the care of the dying pre-viable baby.

My experiences of being part of a working group producing a training programme for the resuscitation of the newborn made me consider carefully the way in which evidence was used to underpin recommendations. This led me to explore the concept of evidence based care in relation to the care of the dying pre-viable baby and the parents.

Risk management and clinical governance have emerged as features of the National Health Service ideology in the UK and the maternity services during my study. I was a member of a national Steering Group on Bereavement Care in the NHS and this helped me understand the national political and strategic decision making processes in relation to the provision of bereavement care. My discussions with clinical staff in

my role as a personal tutor for students highlighted these aspects of care and identified them being worthy of investigation when interpreting the study findings because of the relationship between evidence based care, risk management and the production and use of guidelines.

Public Involvement

The concept of public involvement in health care provision in the UK and North America emerged in the 1970s. The maternity services were among the first to experience this phenomenon which came about in part due to the institutionalisation of pregnancy and birth. This was associated with the dehumanisation of women using the services. Comaroff (1977) provided an account of one woman's experience of the maternity services in the UK:

'They really do put you in your place from the start...I walked in here the first time, feeling on top of the world.....Well, they just looked at my card and gave me a number – two thousand and something. ...You have to realise that you're just a number to them here. They're very thorough, but they're not interested in you personally. It's a conveyor belt and they want you to stand in line.'

The move of childbirth into hospital in both the UK and North America had seen an increase in interventions such as induction of labour, episiotomy and caesarean section. However, women were not provided with information to enable them to

make informed decisions. Instead they were advised to hand over the responsibility to doctors:

'You decide when to see your doctor and let him confirm the fact of your pregnancy. From then onwards you are going to have to answer a lot of questions and be the subject of a lot of examinations. Never worry your head about any of these. They are necessary, they are in the interests of your baby and yourself, and none of them will ever hurt you.' (British Medical Association, 1977).

Organisations such as the Boston Women's Health Book Collective (BWHBC) in the USA and the Association for Improvements in the Maternity Services and the National Childbirth Trust in the UK took a stance that pregnant women were entitled to unbiased information and had the right to make informed choices about their care. Boston Women's Health Book Collective summed up the need for user involvement in health care saying that their group was borne out of *'frustration and anger toward the medical maze in general, and toward those doctors who were condescending, paternalistic, judgmental, and uninformative in particular'* (BWHBC, 2010).

The arguments proposed by maternity services users about the need for increasing involvement in their care reflected arguments taking place about the need for professional accountability (Robinson 2004), as well as political and ideological moves to reduce the power of professionals within the health services (Cowden & Singh, 2007). The notion of the user as a 'consumer' came to the fore in the NHS in

England during the late 1980s with the shift towards the provision of healthcare based on a market model (Cowden & Singh, 2007). Choice was one of the three 'Cs' in the English policy document 'Changing Childbirth' published in 1993 (Dept of Health, 1993). It was closely linked to a second 'C': Control. The document advocated that women should be given information about options for care and allowed to exercise control over the decisions made about care. Choice and control became features of maternity service policy in Wales and Scotland shortly afterwards. The linking of choice and control assumed that the user was 'in control' and exercising power when making a choice. The reality of this will be explored later in the chapter.

As well as directing policy at the level of the individual, governments in three of the four UK countries mandated that maternity services established Maternity Service Liaison Committees (MSLC) to encourage dialogue between health professionals and maternity service users (Edwards, 2005). While the rhetoric of policy documents, including guidelines reinforced the ideology of user representation, some people began to question the assumptions inherent in the rhetoric of user representation and the reality of involving users.

One important point that was not addressed in any of the initial documents about user involvement was defining the nature of service user. Harrison and Mort (1998) describe the dilemmas in recruiting and involving users in the NHS in the UK. These include debates about the legitimacy and representativeness of users, the perceived

lack of reliability of users and the emergence of the 'professional user' who understood the rules of the consultation process. The representativeness of individuals and groups who claimed to represent service users has been questioned. Groups such as the National Childbirth Trust have been labelled as 'white' and 'middle class' and their views on normal birth dismissed as being unrepresentative of the views of the many users of maternity services. Their arguments of 'woman-centred care' and 'one-to-one support' by a midwife as a means of reducing intervention in labour are evidence based but have not been taken up by mainstream maternity services.

Women from poor backgrounds and those from minority ethnic groups are more likely to experience perinatal loss. There is little evidence that they have been consulted in the formulation of guidelines and because they are perceived as 'vulnerable' by Ethics Committees, there is little likelihood that their experience of the service they receive will be evaluated. User groups such as SANDS and the Miscarriage Association have found health professionals and governments eager to take up and promote their ideology and rhetoric in relation to perinatal loss. The legitimacy and representativeness of these groups is not questioned

The reasons for the acceptance of one set of user views (perinatal loss) and the rejection of another set (normal birth) is not clear from the midwifery and medical literature. The tokenistic use of users was acknowledged by respondents in Harrison and Mort's (1998) study. Phrases such as 'playing the user card' were used to

indicate the judicious use of user opinion to gain legitimacy for a course of action. It is possible that health professionals are uncomfortable around perinatal loss since it represents failure and are 'playing the user card' by adopting recommendations of perinatal loss user groups. This may serve to reduce the tensions between health professionals and parents when a baby dies.

A Good Death

The concept of a 'good death' has evolved throughout the centuries from dwelling on suffering and redemption to the current conceptualisation of a good death as one which is planned, controlled and dignified (Kastenbaum, 1995; Ellershaw & Ward, 2003; Jones and Willis, 2003). Much of the literature relating to the way in which a good death is conceptualised is drawn from palliative and hospice based care (Ellershaw & Ward, 2003; Randall & Downie, 2006). A feature of palliative care is that dying is diagnosed, although the trajectory once this has been diagnosed is not definite and may include a period of recovery. However, once dying is diagnosed, the patient and their family are encouraged to think about and plan care to alleviate suffering, to support the family of the dying person and to facilitate death in a setting of the person's choosing (Ellershaw & Ward, 2003).

The definition of a good death espoused by Ellershaw and Ward and the palliative care field generally is problematic. Many people die suddenly as a result of acute illness or accidents. They do not choose their place of death and have no control over their dying. In some circumstances, however, this may be seen as a good death

– especially if death was rapid and the person was unaware of their fate and was perceived not to have suffered. Jones and Willis (2003) highlighted another problem with the definition of the good death prescribed by the palliative care movement – some people may not wish to die and may ‘rage against the dying of the light’ (Thomas 2010). The lack of acceptance of their dying conflicts with the accepted notion of a good death.

In this doctoral study, the concept of the good death espoused in the textbooks and guidelines fits with the palliative care model. The idea that the baby should not be left alone and should be ‘comfortable’ appears to have resonance with the principles of palliative care, as does the focus on the needs of the family. However, if we look closely at what actually happens, it provides a rather different picture. The baby is unable to choose the place of death and the guidelines (local) make it clear that the parents should be ‘encouraged’ to keep the baby with them. If they do not choose this option, the baby is not allowed to leave the labour ward or enter the neonatal intensive care unit.

The local and national guidelines do not provide any information about assessing the dying pre-viable baby’s individual needs. The concept of suffering is not addressed. Instead it is assumed that being held will be comforting, although there is strong evidence that very small babies react badly to being touched, with significant alterations to their heart rate and oxygen consumption. ‘Wrapping’ is another feature of the ‘good death’ envisioned in the guidelines. This is associated with the security

of swaddling and a reduction in heat loss and is presented as ‘comfort care’. Again, there is good evidence that wrapping of very preterm babies does not decrease heat loss – very preterm babies require to be placed in plastic bag and then in an incubator to maintain their temperature (Smith et al, 2005).

The ideology and rhetoric of a good death as presented in the textbooks and national and local guidelines is very powerful. The imagery it conjures up presents a picture of caring parents holding a baby in a blanket in their arms. This contrasts strongly with the image of a previsible baby who is placed in a plastic bag to keep him warm. It is easy to see how appealing the apparently less interventionist model of care would be to carers and health professionals.

Evidence based care

The concept of Evidence Based Care (EBC) was developed by Sackett et al (1996) and was described as ‘the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients’. EBC has now become part of the ideology and rhetoric of health policy and professional practice.

The use of ineffective interventions is seen as wasteful of resources and inflicting ineffective treatments on patients is regarded as unethical and unprofessional. Political drivers for EBC in the UK include funding of the National Institute for Health and Clinical Excellence (NICE) in England and the development of the Scottish Intercollegiate Guidelines Network (SIGN) in Scotland. Both organisations

have a mandate to develop guidelines for practice based on research for implementation in the National Health Services in England, Wales and Scotland. The potential benefits of implementing EBC include health improvements, increased client satisfaction, a reduction in actual or potential harm, and potential cost savings. The guidelines produced by SIGN and NICE are intended for use locally to be translated into individual patient care. There has been considerable debate generated about the ‘power’ of the guidelines to direct care in the case of individual clients.

Sackett et al (1996) discuss the concept of autonomy in their editorial setting out what EBC is and what it is not. They stress the need for individual clinicians to have professional expertise in diagnosis and clinical treatments, as well as a good understanding of patients rights and preferences. In particular, Sackett et al (1996) state that *‘it cannot result in slavish, cookbook approaches to individual patient care’*. It has been argued that the ‘blanket’ approach to the implementation of guidelines denies both the autonomy of the client and the professional. In response to criticism of the way in which guidelines have been interpreted and implemented, NICE has now placed a ‘disclaimer’ on its guidelines which states: *‘Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient.’* (RCOG/ RCM, 2010).

Sackett et al (1996) go on to say: *‘Some fear that evidence based medicine will be hijacked by purchasers and managers to cut the costs of health care. This would not only be a misuse of evidence based medicine but suggests a fundamental misunderstanding of its financial consequences.’*

It is ultimately the responsibility of the local health care provider organisation to implement the guidelines and it is clear that some local providers are using guidelines for purposes other than the enhancement of individual client care. In England, NHS Trusts subscribe to the Clinical Negligence Scheme for Trusts (CNST) which pays litigation costs in the event of claims against the Trust. The premium paid is set according to the perceived level of risk. The CNST sets standards against which Trusts are measured. The standards relate to the implementation of policies and guidelines, measuring compliance and reacting to the results (NHS Litigation Authority, 2010). Any NHS Trust which achieves Level 3 receives a discount of thirty percent on its premium since it is perceived to have a lower risk of being involved in negligence claims. To achieve this level of ‘risk’ healthcare providers must adopt, apply and police guidelines rigorously. This suggests that the level of autonomy exercised by professionals and clients is reduced.

Risk

Managing risk has been a key element of maternity service provision for almost a hundred years, although the terminology is more recent. From the 1930s onwards

national enquiries were held into maternal mortality in the UK. The purpose of the reviews was to establish the leading causes of maternal mortality and consider ways of reducing maternal deaths. These reviews continue today under the auspices of the Confidential Enquiry into Maternal and Child Health (CEMACH) and now include reviews of stillbirths and deaths in infancy (CESDI). The model of the enquiry is to try to establish patterns in the deaths and suggest approaches to care to reduce mortality rates.

The concept of risk management now informs almost every element of practice in the National Health Service from care planning and delivery (Department of Health, 2010), managing information (NHS Connecting for Health, 2010) and corporate and strategic planning and management (Department of Health, 2010). This is reflected in local approaches to risk management. According to one NHS Trust, their aim *is 'the provision of a safe, risk free environment...'* (Barking, Havering and Redbridge University Hospitals NHS Trust, 2010). West Middlesex Hospital website (2010) states *'Everything we do carries a degree of risk, and having a baby is no exception. The Maternity Service proved to CNST that it minimises that risk.'* One Health Board has a strategic objective: *'To manage and control risk where acceptable, transfer risk where unacceptable or unavoidable.'* (Western Isles Health Board, 2010). What this means for individual service users or clinicians is not explained.

Heyman and Henriksen (1998) suggest that managing risk is about attempting to control and predict the future. They go further and compare the current fascination

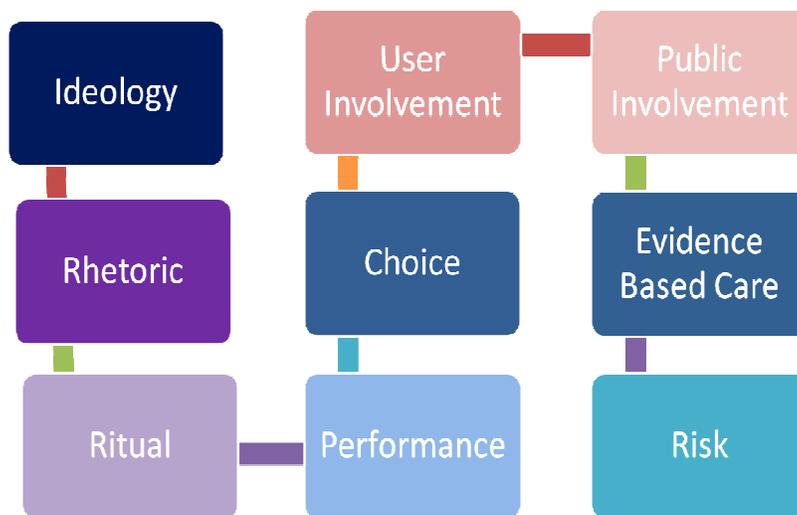
with risk management with astrology, necromancy, seers and soothsayers. The reasons for this scepticism with risk management as it is understood within the NHS include the different values and beliefs espoused by service users and service providers, the fact that the expression of disease or illness varies between individuals, and the difficulty in computing the effect of a range of variables and reducing it to a single 'adverse event'. The situation is further complicated when the risk to an individual is conflated with the risk to the institution to become a single risk factor that has to be addressed.

Risk management usually focuses on reducing mortality and morbidity. However, in caring for dying pre-viable babies, the main 'risks' appear to be failing to recognize the existence and loss of a baby. Thus the national and local guidelines focus on acknowledging the loss of a baby and facilitating the parents' relationship with the baby. Many of the guidelines (local and national) use the term 'encourage' in relation to offering the baby to the parents. The guidance issued by NICE suggests that there are some negative effects associated with holding a dying or dead baby and that 'offer' is a more appropriate term than 'encourage'. A very high profile campaign to change the NICE advice has been ongoing since the guidance was published. The campaign includes user organisations, health professionals and politicians. They do not dispute the evidence but are anxious that 'downgrading' of the advice to 'offer' rather than 'encourage' will mean that parents will be less likely to hold their baby. It is interesting to note that while NHS Trusts and Health Boards adhere to NICE guidance for the management of labour, they appear to reject or

ignore aspects of the guideline on perinatal loss. The reasons for this are not explicated in any of the guidelines but warrant further exploration.

Using the adjacent literatures helps make sense of the Synthetic Constructs. Links are shown between a good death and user involvement, as well as between evidence based care and risk management as shown in the Figure below.

Figure 4: Relationship between Themes, Synthetic Constructs and Adjacent Literatures



However, there are tensions between the different elements as a risk management approach could conflict with personal choice. The Synthesising Argument is therefore one which can capture both the agreements and contradictions in the data.

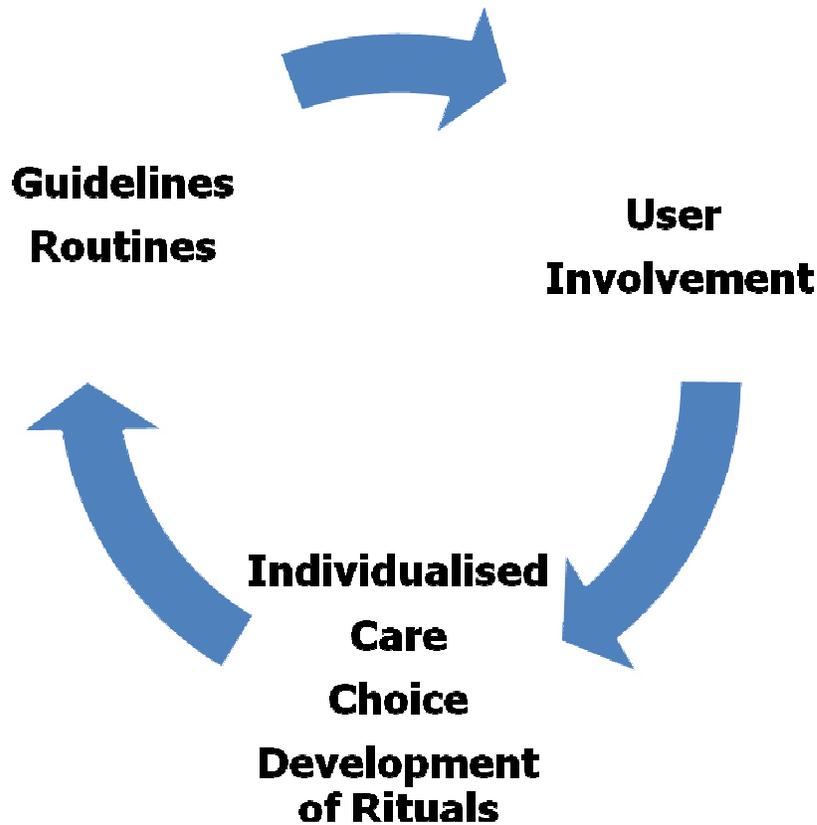
Development of the Synthesising Argument

In Chapter One, ritual was described as being opposed to routine, where ritual activities were imbued with meaning while routine activities were meaningless. Throughout the course of this doctoral study, it would appear that rituals were developed by parents to ascribe meaning to the death of their previsible baby. The rituals would appear to have become incorporated into the routines that may, at times, rob them of their meaning for both the health professionals and the parents. I propose therefore, that the Synthesising Argument relates to the imposition of **'Routine'** on situations and encounters.

In relation to the doctoral thesis, **Routine** may be used to describe a situation where the birth and death of a previsible baby takes place in a controlled environment such as a hospital labour ward. Although a previsible birth is an infrequent event and the death of a baby may be described as exceptional in most labour wards, **Routine** is imposed on the event through the implementation of guidelines. The guidelines may have originated with user groups who intended them to facilitate meaningful choices; however, they have been adopted to reduce the risk to the institution by limiting individual variations in the delivery of care. The use of checklists enables the institution to monitor care and serves as 'protection' by demonstrating that care prescribed by the guidelines has been delivered. It may be argued that the meanings behind the rituals may be 'lost in translation'. That is, they may not be relevant in all circumstances.

The original pathway of minimizing the loss which was challenged by user perspectives which valued choice and individualized care. However, the use of scripts to prompt staff in what they should or should not say to the parents means that it would be possible for a health professional to have a conversation with parents without having to respond on an emotional level to their responses. This may have the effect of transforming a meaningful relationship into a routine encounter. The Figure below demonstrates how we have come full circle in moving from routine to ritual and back again.

Figure 5: From Ritual to Routine



Addressing the research question

The research question asked:

How and why are rituals relating to the care of dying preivable babies in labour wards constructed, deconstructed, enacted and interpreted?

I would argue that the rituals were created to demonstrate that the birth and death of a preivable baby mattered to the parents and to the health professionals caring for the family. The intention was to assure parents that their baby, however small, was important and that the gestational age and the short duration of the baby's life need not detract from the need to provide care that was compatible with fulfilling basic human needs, for example the need for warmth and comfort. Because parents who found this comforting talked about it and wanted other parents to have the same opportunities, the rituals were taken up by user groups as examples of good practice and disseminated widely with the intention to offer parents choice and the opportunity to create meaningful memories in a complex and intensely sad situation.

As a consequence of changes within the maternity services brought about by an approach which sought to minimize the risk to institutions through the management of individual experiences, the rituals became standardized as routines that were to be repeated whenever a preivable baby was born. The risk of non-compliance with the routines was further reduced by providing staff with a series of set phrases which they could use to introduce the routines to parents. The checklists provided evidence

that they had completed the routines and could 'protect' staff and the institutions in the event of complaints.

Challenges of using Critical Interpretive Synthesis

Critical Interpretive Synthesis is a novel approach to systematically reviewing the literature. Using it in this doctoral project presented me with a number of challenges. Initially, I needed to understand the place of CIS within the wider context of systematic reviews. I was familiar with Cochrane review methodology and found it difficult to reconcile the approach used by CIS with the reductionist approach employed in effectiveness reviews. However, wider reading of review methodology helped me understand the extent and nature of systematic reviews (Harden, 2006; Thomas & Harden, 2008; Pope et al, 2007).

The traditional reductionist approach to literature searching was familiar to me and seemed to lend itself to being reproduced in text. However, it was clear that the traditional literature review format did not permit me to access the wide range of materials I required to answer the question and so the expansionist approach was liberating. It did, however, cause me some concern in knowing where to stop searching. The concept of data saturation was touched on by Dixon-Woods et al (2006) and the application of this concept helped me make decisions about the way in which I recorded the data uncovered by the search.

The next major challenge was the integration and interpretation of different forms of data. Gough (2007) provided a framework for this moving through mapping of the data, where the data were described, to detailed data extraction where judgements were made about the quality of the data, through to synthesis, where all the evidence was aggregated to provide an answer to the question. During the process of data extraction, I debated the place of poor quality evidence in the study. Initially I excluded the data from the synthesis. This produced a sterile answer to the research question. It did show the lack of an effective evidence base for the care of the dying pre-viable baby. However, it concealed the complex relationships between groups representing parents and professionals and the extent to which the appearance of offering choice while enforcing routine had become part of practice in the UK and North America.

While I understood the strong arguments supporting the exclusion of poor quality data, I also believed that systematic reviews needed to acknowledge the power of this data in shaping policy and practice. I am still undecided as to whether poor quality data should be included and bracketed in all CIS reviews but plan to write up my experiences of using this data within the context of perinatal loss for further debate within the research community.

The biggest challenge in using CIS related to the synthesis of the data. Downe (2008) described synthesis as 'knitting smoke' and this described exactly how the process appeared to me. I used iteration throughout the study in order to move back

and forward between the data and the emerging Synthetic Constructs, but describing how the Synthetic Constructs emerged was challenging. Discussions with my supervisors helped me make transparent the process through which the Synthetic Constructs and the final Synthesising Argument emerged. Diagrams were particularly helpful in enabling me to explain my findings.

On reflection, while using CIS was risky because it was novel, it did permit me to approach the research question that 'traditional' review approaches would not have allowed. It also increased my understanding of the range and extent of systematic reviews.

Summary

The analysis of the data suggests that meaningful rituals have been deconstructed into routine performances to be enacted in specific situations to provide evidence of caring to parents experiencing the death of their previsible baby. Ironically, the incorporation of activities that were intended to facilitate individual choice into routines has led to complaints about the lack of an individual response to the situation. The original complaints of service users about the 'conveyor belt' approach to care may be re-emerging (Robinson, 2002).

CHAPTER TEN: RECOMMENDATIONS FROM THE STUDY

Introduction

The thesis has explored rituals and the care of the dying previsible baby in labour ward through autobiographical and documentary data. The thesis has demonstrated the lack of good quality evidence to support effective care of the dying previsible baby. This chapter will explore the implications of the study and make recommendations for future research, policy and practice.

Recommendation: Care needs of previsible babies

Our understanding of the care needs of previsible babies is limited. Current practice and research into palliative care of the previsible baby tends to focus on the family, rather than the baby (Leuthner & Jones, 2007; Ramer-Chrasek, 2005). ‘Comfort care’ requires to be unpacked and made more explicit. The use of technology to provide an appropriate environment for the dying baby should not be disregarded and further work is required to assess the extent to which additional support such as thermal care and pain relief should be given to alleviate symptoms in the dying baby (Symington & Pinelli, 2011; Vhora et al, 1999; Smith et al, 2005). The parents’ perceptions of care also warrant further research. For example it would be worthwhile exploring the acceptability of interventions to parents.

Recommendation: Policy review

The current situation relating to the need to register live births occurring before 24 weeks’ gestation would appear to be explicit. However, it is clear that the law is

being interpreted in different ways (Nuffield Council on Bioethics, 2006; RCOG, 2005; McFarlane et al, 2005). Staff may refrain from attributing signs of life to the baby because of a desire to protect the parents from the burden of having to undertake the procedures of registering the baby's birth and death. There is, however, evidence that some parents may appreciate a birth and death certificate as formal acknowledgement of their baby's existence (McHaffie, 2001). Further work requires to be done in relation to understanding the meaning of registration of the birth and death of a pre-viable baby for parents.

The inclusion of the birth and death of pre-viable babies in perinatal mortality statistics as a measure of the effectiveness of neonatal care also requires to be reviewed. There is a suggestion that the reluctance of health professionals to accord live birth status to pre-viable babies stems in part from the need to ensure that perinatal outcomes are presented in the best possible light. Pre-viable birth is more closely associated with health inequality than substandard perinatal care (Gray et al, 2008). Graafmans et al (2001) study of perinatal mortality rates in Western Europe demonstrated the impact of different cut off points for registration or inclusion in perinatal data sets. These included very early gestational age or very low birth weight so that data relating to pre-viable babies were not routinely included in the perinatal mortality statistics. Consideration needs to be given to adopting such an approach in the UK as this would alleviate the pressure on health professionals to avoid registering births of pre-viable babies.

Recommendation: The role of health professionals as researchers

This study has demonstrated the ethical and professional dilemmas that health professionals may face when they undertake research in and on practice. While the public must be protected from poor practice and researchers must adhere to appropriate professional and ethical standards, there is a need to research areas of dubiety and controversy. Health professionals are often in a unique position, as I was, in observing practices that appeared to be at the very margins of legitimate professional practice. However, the constraints placed on researchers who are also on a professional register – in particular, the threat of being charged with misconduct – mean that those practices may never be investigated. Further work needs to be undertaken on the role of researchers who are also on a professional register to ensure that potentially valuable research which could contribute to protection of the public is encouraged and not inhibited by personal professional concerns. Professional bodies should consider issuing guidance for researchers and ethics committees to address the problem.

Recommendation: Support for professionals

The need for health professionals to have training and support in the care of dying preivable babies and their parents has been identified (Nuffield Council on Bioethics, 2006). The care of preterm babies is complex and highly specialised. It is unlikely that staff working in labour wards will encounter sufficient dying preivable babies to develop and maintain their competence in meeting their needs. Consideration should be given to involving the multidisciplinary team – especially

neonatal staff – to ensure that optimal care is given to vulnerable babies and their families.

Caring for dying pre-viable babies and their parents can be a source of stress for health professionals (McCreight, 2005; Kavanaugh et al, 2009; McHaffie & Fowlie, 1996). The need for support may not always be recognised by employers and professional organisations. Chan et al (2004) demonstrated that staff who had access to education and support were more likely to have a positive attitude towards bereavement care. Having access to support and training increases staff morale (Charles-Edwards, 2009) and enhances practice outcomes (Mackenzie and MacCallum, 2009). Because dying and bereavement is a relatively rare event in the maternity services, staff may not be able to develop the appropriate expertise through direct exposure to practice. Role play may be a way of addressing this aspect of care. The need for sensitively introducing students to situations where babies have died has also been highlighted by researchers (Begley, 2003).

Staff support need not necessarily be formal. For example, Medland et al (2004) found that informal peer support within an oncology team was effective in enhancing morale and effectiveness. Midwives have access to Supervisors of Midwives who can provide support and guidance (NMC, 2004). Further work requires to be done on the role of formal and informal support and counselling in enabling professionals to develop their skills and resilience in coping with these difficult situations.

Recommendation: Engaging with user representatives

Future research should focus on understanding the needs of parents who experience the death of a pre-viable baby and need to include parents from 'seldom heard' communities. Duff et al (2001) demonstrated how different understandings of taken-for-granted terms such as 'satisfaction with care' will influence participation in research projects, thus researchers must be prepared to take time to engage with individuals to inform the development of culturally sensitive research tools.

Consideration also needs to be given to training and funding user group representatives from all spectrums to develop skills in working with parents and families from different communities, and also to develop their skills in research methods, working in partnership with researchers from a range of disciplines to understand the impact of perinatal loss.

Conclusion

This study has demonstrated a lack of robust evidence to underpin the care of dying pre-viable babies and their parents. The recommendations in this chapter suggest aspects of care warranting further research. The need for professional and policy changes to support research and practice have also been highlighted. In particular, partnerships between user representatives, health professionals, researchers and policy makers should be pursued to enhance care.

CHAPTER ELEVEN: CONCLUDING THOUGHTS

Introduction

The thesis has explored rituals and the care of the dying pre-viable baby in labour ward through autobiographical and documentary data. It has established that rituals have been transformed into routines, potentially robbing the performances of meaning. This chapter will conclude the thesis by exploring the meaning of the findings for babies, parents and health professionals, as well as the strengths and limitations of the study.

Meanings for the baby

The rhetoric of the textbooks and guidelines expresses the personhood of the dying pre-viable baby and acknowledges the need to provide comfort care. Although babies who are admitted to neonatal intensive care have their need for pain relief met, this is a relatively recent phenomenon. Assessing the need for pain relief in neonates is complex and is particularly challenging when caring for the pre-viable baby. Ranger et al (2010), Coleman et al (2002) and Milesi et al (2010) document the difficulty in assessing pain in very preterm neonates. Traditional approaches to assessing pain in babies rely on facial expressions (Barr 1998; Sharek et al 2006). Viewing the face of preterm babies is problematic, either because they have face masks applied for the delivery of non-invasive respiratory support or because of limited lighting to reduce sensory overload. The sensitivity of the tools to detect pain is questionable (Ranger et al 2010) and debate continues over the use of opiates for pain relief in preterm

infants (Coleman et al 2002). While these debates centre on preterm babies receiving care in neonatal units, the same debates should be held in relation to the care of dying pre-viable babies on labour wards. The fact that midwives or obstetric staff generally provide this care rather than neonatal staff may be partly responsible for the lack of focus on the experiences of the dying pre-viable baby. It is therefore incumbent on midwifery staff to highlight the problems they face in assessing the need for supportive care and methods to deliver this care.

While there seems to be a general acceptance that dying pre-viable babies should not be admitted to neonatal intensive care units (Nuffield Council on Bioethics, 2006), this should not preclude experienced neonatal nurses and doctors from participating in the formulation of care plans and assisting in the delivery of care – particularly in babies who survive for several hours. Currently, there are moves to develop palliative care services for babies born with little chance of survival (Breeze et al, 2007). However, as with the guidelines for the care of the dying pre-viable baby, the main focus of care is the parents.

The lack of prioritisation of the needs of the dying person, whatever their age, over those of the family is not unique to the care of the dying pre-viable baby. Randall and Downie (2006) indicate the contradictions inherent in the palliative care movement relating to the priority given to families and point out that legally and professionally the needs of the patient must always come first. The introduction of palliative care

services for dying preivable babies provides an opportunity to state the primacy of the needs of the baby.

Parents already accept invasive care for their baby on the grounds that it is in the baby's best interests – even when the outcome is uncertain. Parents do ask if their baby is suffering as they die and there is no reason to doubt that they would accept interventions such as placing the baby in an incubator or giving the baby facial oxygen if it would reduce the burden of suffering on the baby. This care could form part of creating memories for parents that the current rituals serve.

Meanings for parents

The original intention of the rituals was to enable the dying preivable baby to be treated with compassion and dignity and provide parents with the opportunity to form meaningful attachments and memories with their baby in the brief time between the birth and death. The integration of the rituals into guidelines and policy documents appears to have eroded the autonomy of both parents and health professionals and has the potential to rob the rituals of their meaning. Although the ideology and rhetoric of guidelines state that choice is paramount, the language in textbooks and guidelines has moved away from that of offering choice, from words such as '*could*' or '*would*' to the more dogmatic '*should*'. '*Offer*' has become '*encourage*'.

The use of checklists has reinforced the expectation of compliance with the guidelines, thus removing the need for health professionals to engage meaningfully with the rituals. Perinatal loss is more likely to impact on the very young, the economically disadvantaged, and parents from black or minority ethnic communities. There is a wide body of evidence demonstrating that these are the communities who are most likely to experience discrimination or inappropriate care and that they are also least likely to complain (Advocacy Resource Exchange, 2009).

The NHS needs to clarify the concept of user involvement in care. SANDS, in particular, has been at the forefront of developing guidance and support for health professionals and parents. There appears to be significant gaps in the evidence base for care of bereaved parents in the guidelines they propose. It also must be acknowledged that the bulk of policy making with regard to perinatal loss has fallen to bereaved parents. Having explored the literature, it appears that no other voluntary organisation in the UK is expected to take full responsibility for producing the evidence and policy for care in the maternity services. This interpretation, I believe, raises important questions about why and whether the NHS should absolve, rather than share, the responsibility of making decisions about the care of parents and dying pre-viable babies. Moreover, it raises further questions about whether the 'transformation' of 'user' suggestions into objective, clinical practices can ever be successful or appropriate.

By exploring the literature associated with previsible death, I have argued that the current approach of the NHS to perinatal loss appears to be, whether intended or not, tokenistic and in the process to 'play the user card' while, in reality, actually failing to engage users as partners in the caring process. Instead, I suggest, that the NHS's uptake of guidelines produced by users groups in this situation is intended to prove that the organisation cares. In fact, it appears instead, that any in-depth exploration of the process of caring for parents and previsible babies has been avoided and is likely to remain so unless health professionals, ethics committees and policy makers accept that while researching and thus 'voicing' the experiences of death, in whatever form may be painful to all those concerned, a forced silence may be even more so.

In other words, this thesis suggests that the nature of perinatal loss means that it is complex. Research into perinatal loss has the potential to cause further distress. The labelling of bereaved parents as 'vulnerable' is common and usually prevents their participation in research. While it is desirable to protect research participants from harm, the lack of opportunity for bereaved parents to participate in research means that their views cannot be elicited. In the case of perinatal loss, it would appear that parents living in poverty and those from minority ethnic communities are less inclined to participate in user groups and are thus less likely to participate in research programmes. This suggests that they are doubly disadvantaged and raises questions about the reliability and validity of any research into perinatal loss that is carried out and which does not acknowledge the range of social and cultural

meanings of the loss. Devising and implementing research methodologies to capture the views of bereaved parents requires specialist knowledge and skills. Through my experiences as a midwife, I believe that there is an obvious opportunity for researchers to engage with and work with user groups to ensure that the spectrum of parents experiencing perinatal loss have the opportunity to participate in the research process, and to ultimately affect service delivery.

What matters to health professionals

The available evidence, along with my own experiences, suggest that health professionals care deeply about perinatal loss and are desperate to demonstrate that they care and want to cause parents the least distress possible. In other words, they are open to learning what to say and what to do. Sometimes it seems that they want to know the magic words that will ‘make things better’ for the parents and ease their pain and sorrow. Seale (1998) considered the scripts that people construct around dying and death and how people find it difficult to deal with situations where there is no script. In the textbooks and guidelines, an encounter with a dying previsible baby and the parents has been scripted by ‘borrowing’ rituals and symbols from other aspects of perinatal loss, including stillbirth. But when the baby is still alive these rituals seem awkward and out of place, leaving some health professionals with the dilemma of not knowing what to do and what to say.

Despite the protestations of the need for individualised care and an aversion to what is called the ‘cookbook’ approach to perinatal loss, it would appear that some

guidelines and textbooks do present a formulaic style to care, with phrases to use and words to avoid. The aim of the authors of these lists is to present health professionals with scripts for those awkward situations where it is hard to know what to say. These situations are uncomfortable and the uncharted nature of perinatal loss for each parent means that there can never be a pre-determined script to make things better. At times 'intuitive silence' may be more comforting than the hustle and bustle of formulaic procedures.

In my opinion, it seems odd that as we move towards an all graduate profession for midwives, where the Nursing and Midwifery Council insists that registrants are reflective and compassionate that the practice situation actually restricts the use of initiative and intelligence by demanding adherence to guidelines and policies that may not be responsive to individual needs during perinatal loss.

Implications for policy and practice

The quality of the evidence underpinning the care of the dying pre-viable baby needs to be located and cited explicitly in guidelines and policy statements. The most obvious effect of this would be to identify the weak evidence base on which current practice is based. Policy should be there to reflect the uncertain nature of human experiences and beliefs and facilitate health professionals to demonstrate the attributes of compassion and caring. This requires confidence and flexibility on the part of health professionals to exercise judgment and discretion in each case. The

study has demonstrated the necessity for the dying pre-viable baby to be placed at the centre of care, with a focus on their immediate needs.

The relationship between user groups and health professionals requires critical exploration across the healthcare sector. Ceding responsibility for the care of bereaved parents to user groups is contrary to the Code of Professional Conduct (NMC, 2008). The divisions between users and health professionals are often increased by the lack of opportunity to work together in a meaningful way. It can be compounded by a lack of clarity about roles and responsibilities and the limitations imposed by factors such as resources and professional, political or legal constraints. I believe that the current way in which perinatal loss user groups are involved in the maternity services is exploitative and masquerades as collaboration. User groups are 'allowed' to make their publications for parents available to the maternity services. There is some evidence to suggest that in some areas, maternity services have reduced the level of support they provide to bereaved parents and steer them towards user groups instead. If there was real partnership between the maternity services and user groups, this would involve dialogue between them and would include conversations about meeting the needs of parents from diverse backgrounds. The maternity services could provide support for user groups, including training and funding to enable user group representatives from all spectrums to develop skills in working with parents and families from different communities, and also to develop their skills in research methods, working in partnership with researchers from a range of disciplines to understand the impact of perinatal loss.

Limitations of the study and the need for future research

The most obvious limitation of the study is the fact that the data has emerged from documentary sources, rather than interviews or observation. While it would appear initially that the study lacks evidence of what actually happens in practice, I would argue that my involvement in clinical practice directly as a practitioner and also indirectly when supervising student midwives has enabled me to ‘know’ what is happening in practice and this is reinforced by the accounts of parents on websites and in journals and also published accounts by midwives of the care they give. This suggests that the rituals described in the evidence are, in fact, being carried out as detailed in the textbooks and guidelines.

Strengths and the contribution of the study

This study is, as far as I am aware, the first time that the rituals relating to the care of dying pre-viable babies have been studied. The use of Critical Interpretative Synthesis was both informative and novel in relation to exploring both historical and contemporary literature. The inclusion of poor quality data in the review was also novel. This enabled me to demonstrate the influence of the data on practice and highlight the need for caution when interpreting and applying it to practice.

Changing the Tide: is this a good thing?

Over the course of this PhD study, I have noticed a shift in the attitudes of some nurses and midwives with regard to their role in the care of bereaved parents,

particularly with regard to cultural considerations. A group of bereaved parents in Essex wished to distribute packs to all parents whose babies had died in a local maternity unit. The packs contained a card announcing the birth of an 'angel baby' and a letter addressed to 'angel parents'. The health professionals felt that it was inappropriate to distribute the pack to all bereaved parents since some parents might find the term angel either offensive or inappropriate. As a consequence of their decision the staff in the maternity unit have been subjected to criticism by Health Authority members, one of whom resigned in protest, and the editor of the professional journal of the Royal College of Midwives who questioned if the behaviour of the staff was 'political correctness gone mad'. Importantly, the discussion board hosted by the RCM contains a large number of comments from midwives who are supportive of the decision not to distribute the packs indiscriminately and cite the need to be sensitive to parents' feelings. Several posts are from professionals who are also bereaved parents who take issue with being told how they should regard their dead baby. This, to me, represents a significant shift in the need to enable bereaved parents to have the same autonomy afforded to parents of live babies who can choose whether or not to have gift packs offered by advertisers after the birth of their baby. The decision of the staff was, I would contend, extremely brave and is perhaps reflective of a move towards adopting a more critically conscious approach to the care of bereaved parents.

Conclusion

This study has demonstrated a need for the care of dying pre-viable babies and their parents to be re-evaluated in the light of the available evidence. Future research should involve parents from all spectrums, including 'seldom heard' communities who shoulder the greatest burden of perinatal loss. Collaborative partnerships between user representatives, health professionals, researchers and policy makers should be pursued in the endeavour to enhance care.

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