

CHAPTER 1: INTRODUCTION

1.1 Introduction

“Give sorrow words. The grief that does not speak whispers the o’er-fraught heart, and bids it break”.

Macbeth; Act IV Scene III, lines: 245-246

This thesis reports a phenomenological study of seven parents’ lived experience following the death of a twin in the perinatal/ neonatal period. It gives consideration to the issues important to the study. It provides a literature search to situate the study in the field of evolving bereavement theory and in the context of twin loss. A number of questions have been raised that led to the formulation of the research question (page 63). The descriptive phenomenological methodology adopted provides a framework for my ontological and epistemological positions. Through the method of analysis of the data from semi-structured interviews, the essence of the phenomenon was elicited and the fundamental structure was established. The phenomenon was presented in four main themes (1) Confronting death (2) Accompanied by others (3) Being Alone (4) Understanding the loss. The findings are discussed in terms of their contribution to knowledge, and practice. The research process is explored within the context of the self-conscious method which is an essential feature of phenomenology. Two voices are heard in this thesis. The dominant voice is that of the bereaved parents while the secondary voice is that of the researcher. The penultimate chapter provides a reflection on the process of completing this phenomenological study. Finally, the strengths and limitations of the study are considered and the impact of findings on areas for further research is addressed.

This chapter addresses my ‘disturbance’ and the research problem in practice. The catalyst for the study is considered and the rationale for the study is presented. This is

followed by the research question, the aims of the study are identified and the methodology and methods are introduced.

1.2 My Disturbance

As a practitioner with over twenty years experience in neonatal care I have become conscious of an increase in the number of twin admissions. A contributing factor is the increase in infertility treatment (ONS 2008; 2009). Other factors are related to preterm delivery (<37 weeks gestation), low birth weight (LBW) (<2500g), and very low birth weight (VLBW) (<1500g) which occur much more frequently among twins than among singletons (Keith 1994). An additional factor is that many more twins are conceived than delivered and the risk of stillbirth is over twice that for singletons, while the mortality rate is five times higher in the neonatal period (Botting et al. 1987; Luke & Keith 1992). A further causal factor to be considered is the presence of twin-to-twin transfusion (TTTS). TTTS is a recognised mid trimester complication occurring in 15% of monochorionic gestations (Sebire et al. 1997; Sueters et al. 2005). In a study by Lerullo et al. (2007) 74% of mothers with severe TTTS who received laser ablation delivered one live twin. If untreated the mortality rate exceeds 90% with significant neurological morbidity in 30-50% of surviving twins (NICE 2006; Wagner et al. 2009). In addition, second twins born at term are at greater risk of death due to complications of delivery (Smith et al. 2002). Thus, twin pregnancy carries significantly higher risks as compared to that of a singleton. Additionally, the higher mortality rate results in more bereaved parents (proportionally) of twins than singletons. The bereaved parent of a singleton may be able to direct all their emotional energy to the loss of their baby and receive unqualified support (Bryan 1995). The additional burden for the bereaved parent of a twin is the required division of emotional labour; grieving for one baby while parenting another potentially vulnerable infant. The presence of the surviving twin may lead to the perception by others that the parent's grief is lessened. Such perceptions may result in lack of recognition of their loss and a resultant lack of support.

For parents, a definite bewilderment follows the death of a newborn twin (Bryan 1986; Lewis & Bryan 1988) related to the conflicting emotions of mourning one baby and parenting the survivor. Managing these dissimilar roles may cause a sense of disorientation when considered against the anticipation of two live babies. A further complication arises where the surviving twin requires admission to the neonatal unit. Concern for the surviving twin demands energy from the parent and therefore lessens available energies and time for grieving. Where this happens the parent may be perceived to be coping well with their loss. Observation in my practice area of neonatal care tells me that parents who have experienced the death of a twin do not receive any additional care during the hospitalisation of their surviving twin. Indeed, they are cared for in a similar way to all other parents whose baby is cared for in the neonatal unit. That is, they are supported in the care of the surviving twin and in preparation for discharge. As I reflected on this situation I considered whether they may have additional needs and whether those needs remained unmet because we have not sought to explore the parents' lived experience. An understanding of the lived experience would be of benefit to health care professionals (HCPs) who care for these parents.

1.3 The research problem in practice

The death of a twin challenges parents to deal with conflicting psychological processes of grief at the loss of one twin and joy in the surviving twin. For these parents, birth and death are closely related. Bereavement theory provides some guidance in the care of families following the death of a child. Understanding bereavement has its origins in the work of Freud (1917), Bowlby (1980), Kübler-Ross (1969). Understanding from Freud (1917) and Kübler-Ross (1969) has its origin in studies of adult loss. While Bowlby (1982) has taken attachment theory from studies of childhood separation and applied those theories to bereavement. Furthermore those studies were completed in a different historical and sociological context. More recently studies of child death (Bluebond-Langer 1978; Klass 1996) give a perspective of continuing bonds with the deceased. Davies (2004) in a literature review on parental grief suggests that the traditional theoretical perspectives which dominated bereavement practice do not reflect the unique

experiences of parental grief. Theories which are unreflective of parental experience do not therefore enable appropriate care to be delivered and highlights a gap in the literature. This gap is evident in the area of perinatal grief where there is little systematic study (Forrest 1981; 1999) and little literature to guide practice. Current practice in my area of neonatal care seeks to address the important area of practical support to enable parenting of the surviving twin while ignoring the emotional needs of the parent or indeed seeking an understanding of what their emotional needs might be.

I became conscious of the disparity between pre and post loss care. In the former case there is an implicit acknowledgement that parents may have questions and require time to come to terms with the anticipated death. Professional care is aimed at supporting parents in their decisions, providing them with information as to what has helped parents who have been in a similar position. The practice of holding the baby (Lundqvist 2002), creating mementos and the taking of pictures (Riches & Dawson 1998), respect for cultural differences in coping with life changing events (Cowles 1998) are important features of the care in my practice area. These actions are supported by staff caring for the parents and guided by the multidisciplinary bereavement group. The focus of the group is on the management of the practical aspects of neonatal death, the immediate care, the registration of death, funeral arrangements and costs (Forest et al. 1981). This practice has arisen following feedback from parents regarding their lack of information concerning what needs to be done following death.

The bereaved parents continue their journey with the survivor while their emotional energies are divided between grieving and parenting (Lewis 1979; Bryan 1986; Lewis & Bryan 1988). Their grief is contained and mostly unseen as they refrain from showing their true feelings (Cuisiner et al. 1996). Not showing their true feelings may be a reflection on the available level of support and understanding or on the personal choice of the bereaved parent. Indeed there may be other reasons. My concern is that parents may be perceived as coping when in fact their reality suggests a different perspective. My disturbance is that we do not know how these parents experience their loss or indeed whether HCPs help or hinder their experience. In addition, we do not understand their on-

going need for support. I consider myself to be a skilled and attentive practitioner however; this lack of knowledge troubles me as my lack of informed care may leave their needs unmet. This suggests a gap in the knowledge required to provide appropriate care to meet the specific needs of bereaved parents of a twin

1.4 Catalyst for the study

The catalyst for this study arose from caring for parents of twins where one twin died within the first week of life. The evening prior to the funeral, the parents spent a number of hours with the surviving twin, who at that time was receiving life support treatment. As they left they said they would not visit the following day, as they wished to give the day to the twin who had died. It was the last opportunity to spend time together.

On the next occasion I cared for these parents and their surviving twin, we talked about the funeral and how they felt. They expressed the importance, to them, of dedicating time to their dead twin. There was an appreciation that this time was limited, in contrast to the unlimited time they envisaged they would be able to spend with their surviving twin.

During the intervening years I have cared for a number of parents following the death of a twin. I have become aware that as the surviving twin progresses from intensive to special care conversations about the dead twin lessen as the demands of parenting appears to take priority. The focus of care is on the survivor and supporting the parents to develop their parenting skills. The provision of parenting support stands in sharp contrast to the absence of care for the grieving parent. Evidence suggests HCPs find difficulty in speaking about death (Bourne 1968) and are disadvantaged by their lack of knowledge to guide their practice. The parent who has lost a twin unlike the parent who has lost a singleton returns to the neonatal unit as a grieving parent to care for the surviving twin. There is little understanding of their grief and how they would like to be cared for.

1.5 The rationale for the study

The fall in perinatal mortality over the past twenty years (ONS 2004) has resulted in an increasing concern for the plight of those parents whose baby is stillborn or who die shortly after birth. A cause of concern is the increasing rise in preterm births (Langhoff-Roos et al. 2006) and preterm birth is a major contributory factor to neonatal and infant mortality (Shennan & Bewley 2006). Preterm deliveries account for less than 1 in 10 births and most admissions to neonatal unit (Slattery & Morrison 2002). Among this group of parents, will be a significant number who have experienced the death of a twin.

Twins make up to 2% of live births and 9% of perinatal deaths (Dunn & Macfarlane 1996), although there has been a fall in perinatal mortality the differences between twins and singletons remain. The average length of a twin pregnancy is about 20 days shorter than a singleton one. Between 20 -30% of twins will be born prematurely (<37 weeks gestational age (Bryan 1999a). The mortality rate in twins as compared to singletons is five times higher in the neonatal period (Botting et al. 1987). Contributory factors are prematurity, intrauterine growth restriction affecting one or both twins and congenital abnormality (Peterson et al. 2002). Thus, proportionally more parents of twins than singletons will have experienced the death of a twin in the perinatal / neonatal period. An estimated 15% of twins grow up as singleton survivors (Swanson et al. 2002). Death of a twin is significantly higher than the overall mortality rate. The ONS do not provide figures for the % of twins that constitute preterm births and it is important to note that not all twins admitted to the neonatal unit will be preterm. The figures from ONS (2010) serve to illustrate the significant differences in mortality rates. The infant mortality rate for multiple births was almost five times higher than for singletons (20.5 compared with 4.2 per 1,000 live births). Death is most marked in the first 28 days of life (neonatal deaths) when the mortality rate for multiples was more than six times higher than for singletons (17.0 compared with 2.8 per 1,000 live births). These statistics served to highlight the meaning of this issue and in doing so caused me to reflect on what is as yet unknown from the parents' perspective. The research question seeks to address this deficit in our current knowledge base.

1.6 Research question

“How do parents experience the death of a twin in the neonatal period?”

1.7 The aim of the study

The aim of the study was to understand how the parents’ experience of death of a twin. I wished to understand the experience from the parent’s perspective. Research objectives:

- To identify what factors influenced or continue to influence the experience.
- To identify the advice parents would offer health care professionals.
- To identify the factors that have helped or hindered the process of bereavement.
- To identify what follow up care is required by these parents.

1.8 Methodology and methods

I utilised a phenomenological approach based on Husserl’s (1900/1901) descriptive phenomenology to describe the lived experience of parents who have experienced the death of a twin in the perinatal/neonatal period. Seven parents were recruited to the study. The parents were recruited from the Twins and Multiple Births Association (TAMBA) and my own practice area. Data were generated from two semi-structured interviews. The second interview was to validate the researcher’s understanding of the data from the first interview and to integrate further new knowledge. Transcripts were analysed using Colaizzi (1978) method of analysis. Findings were written up as a description of the experience death of a twin and the fundamental structure elicited. The experience of my role as a developing phenomenologist was addressed.

1.9 Structure of the thesis

The thesis is formed of eight chapters.

1.9.1 Chapter 1: Introduction

This chapter presents the reader with an introductory background to the disturbance and the research question in context. It introduces the reader to the neonatal environment and highlights the lack of knowledge to guide and inform our practice in the care of bereaved parents following the death of a twin. The issue in practice is considered and the research question is presented as a means of addressing this deficit in our knowledge base. This lack of knowledge may impact on the role of the HCP to provide appropriate and timely support to the bereaved parent. This sections ends with the identification of the methodology.

1.9.2 Chapter 2: Background to the study

This chapter presents the literature review and situates the study within the body of existing literature. The method of literature searching is addressed. Relevant literature is critically appraised with a resultant identified gap and rationale for the study.

1.9.3 Chapter 3: Methodology and methods

This chapter presents my world view and the emergent decisions regarding the methodology to address the question. Included in this section is a discussion on the ontological and epistemological issues and the philosophical underpinning to the research. The methods related to conducting the study are addressed. This is followed by a discussion on the choice of analysis. The final section discusses issues of credibility and ethics.

1.9.4 Chapter 4: An illustration of the method of analysis

This chapter provides the reader with an introduction to the method of analysis. A section of one transcript is used to illustrate the first three stages of analysis following a period of immersion in and coming to know the raw data:

- Significant statements from the transcript
- Formulating meanings from the significant statements
- Exhaustive description

1.9.5 Chapter 5: The essential essence of death of a twin

This chapter presents a progressive display of the analysis of all the transcripts. In keeping with Husserl's phenomenology an exhaustive description of the phenomenon is presented. This is a description encompassing the exhaustive descriptions for each transcript. This description reflects the complexity of the loss. This chapter ends with the empirical phenomenological reflection and serves to provide the fundamental structure of the phenomenon of the death of a twin in the neonatal period.

1.9.6 Chapter 6: Discussion of the phenomenon

This chapter addresses the importance of the findings. The clinical relevance of the research question to the researcher is considered. This is followed by a discussion of the findings and their contribution to practice and their substantiation of Continuing Bonds. A conceptual framework is offered which pulls the findings together and presents a new understanding of death of a twin. The final section considers scholarship in practice by addressing the findings in the context of the methodology used.

1.9.7 Chapter 7: Reflection on the research process

The experience of conducting phenomenological research is addressed. Scholarship in practice is considered. This is followed by addressing the following issues; bracketing, reflexivity, impact on practice, user involvement and dissemination.

1.9.8 Chapter 8: Conclusion

This chapter returns to the research questions and verifies how I have met the aims and objectives of the study. Publication of findings and dissemination strategy is considered and progress to date is reviewed. The impact of the study is considered and areas for further research are suggested.

1.10 Summary

This chapter has presented my disturbance and the research problem in practice. The catalyst for the study is acknowledged and the rationale for the study is justified. This is followed by an introduction to the methodology and methods. The final section presents the structure of the thesis

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The introductory chapter presented the origin of my disturbance and situated the research question in my practice area. It addressed my concerns from a practice perspective. The incidence and significance of the problem was identified and the rationale for the study presented. The purpose of this chapter is to provide an overview of the literature pertaining to death of a twin. Evolution of bereavement theory is considered, understanding of perinatal loss is made explicit and studies related to twin loss are scrutinized.

The literature suggests there is a move away from the psychoanalytic model of bereavement. That movement is towards an understanding of grief that is represented by continuing bonds. Continuing bonds has a resonance with the expression of grief in the Victorian era. Within the literature there is an understanding of parents' grief that has its origins in the measurement of grief and of what parents find helpful. However, the review has identified an absence of literature which provides the perspective of the lived experience of the bereaved parent of a twin.

An initial exploration of the literature on bereavement uncovered understanding in terms of bereavement theory, specifically the psychoanalytic model. Tracing the history of the analytic model over the last century it became obvious to me that other factors impacted which caused me to question whether the psychoanalytic model fully explained the grief process. Of particular interest to me was the fact that the psychoanalytic model stood in sharp contrast to Victorian practices following death and the place of the dead in the lives of the living. However, the psychoanalytic model appears to have a resonance with the response to death following the Great World War 1914-1918 and the Second World War 1939-1945. A cultural shift was evident in the 1970s with the inception of self-help groups e.g. SANDS. Indeed this latter perspective was reflected in the 'Continuing Bond'

(Klass 1996) where the dead are carried forward in the lives of the living. This represents a different perspective from the psychoanalytic model. I believe this sociological development over the last century has paved the way for an understanding of death of a twin, an understanding that is rooted in the experience of those parents who have experienced the death of a twin. Grief has come to be understood through bereavement theory. However there is a body of knowledge relating to grief loss in the Victorian era and through the World Wars that has a resonance with the findings of the study. That literature suggests that the dead are held within the continuing lives of the bereaved. This aspect of loss does not appear in bereavement theory. An overview of this literature is presented in Appendix 1. It is included because the findings suggest similarities with the Victorian practice of remembering the dead.

2.2 Timing of the literature review

The literature review was conducted in two phases. In keeping within Husserlian phenomenology the researcher is required to bracket their knowledge about the phenomenon under study. I took the view that extensive exploration of the literature around death of a twin would make bracketing a more difficult task. However, a preliminary review (Polit & Beck 2004) to establish the background of bereavement theory against which the study was conducted was required. The second phase in keeping with the reflexive approach to phenomenology (Munhall, 2007; Steubert & Carpenter 1999; Oiler 1982) was completed following data collection. Understanding the lived experience of the parents in the research study was incompatible with the first phase of the literature review. Therefore it was imperative to do another in-depth review. The psychoanalytic model experienced a largely unchallenged period until the 1970s and its resultant dissolution resulted in a cultural shift and paves the way for understanding death of a twin

2.3 Data sources

Medical Subject Settings (MeSH) were utilised for Cinahl and Medline. Boolean logic was applied to other key words in other databases. Contact was made with author Patricia

Swanson in Australia. Computerised searches were conducted using the following MeSH headings: death, twin, neonatal, parents, perinatal. The following text words were also used: death of a twin, loss of a multiple, loss; bereavement. The literature was sparse and I therefore made a decision to initiate my search from 1970. All potentially relevant titles and abstracts identified by the reviewer were retrieved. The reference lists/ bibliographies of each article were reviewed independently for additional relevant titles and these were also retrieved.

Table 2.1 Search Keywords

Population	Keyword (loss)	Keyword (effect)	Keyword (theory)
Neonatal	Death	Impact	Social context
Twin	Loss	Isolation	Health history
Parent	Bereavement	Reaction	Theory
Baby	Grief	Changes	Death history
Childbirth	Mourning	Distress	
Multiple births	Hurt	Pain	
	Pain		

A total of thirteen studies were reviewed. I excluded one study from the review which measured anxiety and depression. This study included one set of twins however; the results did not specifically refer to the grief associated with twin loss.

2.4 Areas to be addressed in the literature review

The following review serves to place the study within existing scholarship and as a means to introduce the research method. The literature review is informed by the very personal nature of the response to the loss, the experience of ‘being robbed’ and societal response to that loss. Loss is therefore understood in the context of both personal and societal construction of loss.

The first topic selected for this review is bereavement theory. Bereavement theory informs us as practitioners as to what is 'normal' in relation to grief. However this phenomenology is specific to those parents who have experienced the death of a twin. Therefore it is unknown as to whether bereavement theory has applicability for all bereaved parents in contemporary society.

The second topic selected for this review was perinatal death. The specific review highlights the following areas: 1) complexity of emotions, 2) isolation, 3) creating memories. These categories were included because birth and death are closely linked and the resultant loss may be experienced as isolation. Maintaining a sense of reality following the loss is mediated by creating memories.

The third topic selected for this review relates to studies on twin loss. The existing literature provides a lens through which the death of a twin is explored. This topic explores what is known and its ontological perspective. Death of a twin as a phenomenon is an object of experience of parents who have lived the loss of a twin. The point of contact between the object (death of a twin) and the subject (bereaved parent) is the focus of this research. A phenomenological description of the subject's acts of consciousness (thinking) (noesis) as related to the object (what is thought) (noema) is very different from that derived from purely descriptive accounts of subjective experiences. The relationship between noesis and noema is that which is being investigated in this study, this is described by Husserl as the phenomenological attitude and by Thévanaz (1962) as the point of contact. It is therefore the description that identifies the parents' subjective acts that constitute an objective world. The parents were asked to share their experience of the death of their twin. As a phenomenological researcher I am guided by the theoretical perspective that grounds my research method and therefore review the literature related to the phenomenon being investigated (Quallis 1998). The review that follows serves as a further grounding of the phenomenon as a way to describe its many features and as an introduction to the research method.

2.5 Acute grief - the psycho-analytic model

While the history of bereavement in the twentieth century has yet to be written (Walter 1999) our understanding of bereavement is shaped by theories, culture and tradition. Bereavement theory had as its basis the psychoanalytic model (Freud 1917). Grief appeared to be a process and completion resulted in detachment from the deceased and location of energies in a new object. This aspect of requiring separation from the dead troubles me, as it suggests leaving behind the loved one, a shared life and shared memories. I believe this to be an important point in understanding grief. The lived experience of the bereaved moved from the individual response in the Victorian period to a response that was analysed and medicalised. Thus grief became a condition that required medical care rather than a normal process and a part of life. I consider the meaning of grief as expressed by CS Lewis (1961:10) *“I not only live each endless day in grief, but live each day thinking about living each day in grief”* as grief that is all consuming.

2.6 Acute grief

The medicalisation of grief continued within the psycho-analytic model. The object of grief work was to emancipate the bereaved from the deceased. Lindemann (1944) in his classic article “Symptomatology and the management of acute grief” coined the phrase ‘grief work’ and described symptoms associated with grief. He also described a time frame of four to six weeks for the resolution of grief. To continue beyond that period suggests pathological grief. It is important to note that Lindemann’s study was conducted on those bereaved who had survived the Coconut Grove fire and therefore the findings must be treated with caution. Thus, grief was further medicalised, defined by symptoms that required treatment (Attig 2000). Grief work constituted liberation from an overly strong link to the deceased, a new adaptation to the surroundings and establishment of interpersonal relationships.

In the 1960s another psychiatrist Kübler-Ross contributed innovative understanding of death and dying. Kübler-Ross (1969) sought the personal experience of patients dying

from cancer. Her approach was one of understanding the lived experience of the individual who was faced with death and the identified stages have a commonality with the psychoanalytic model. The result of her work was a model of grief which elucidated five discrete stages: denial, anger, bargaining, depression and acceptance. Her five stage model which related to the dying has been taken and applied to grief. Focusing on the discrete stages may preclude us from understanding grief in its totality and its impact on the individual person.

The limitations of conceiving mourning as relinquishing emotional ties and progression towards recovery has been recognised by an increasing number of those involved in understanding grief (Attig 1996; Neimeyer 1998). New models hold that the outward manifestations of grief which Neimeyer (2001:4) suggest “*Can be understood only in terms of the struggle of bereaved people and their social domain to accommodate to a changed (inter)personal reality resulting from the loss*”. The work of Klass (1996) speaks of maintaining a bond with the dead, a concept that has a connectedness with the expression of grief in the Victorian era. The need for this bond is ‘normal’ for bereaved parents, however challenging it may be to the wider society. Society that is embedded within the psycho-analytic model does not acknowledge the long term grief of a parent whose child has died (Klass 1996). Lack of awareness of parents’ reality means both a denial of their continuing loss and access to meaningful support. New models seek therefore to understand grief as a normal process rather than a process that lends itself to medicalisation. I view this new model of grief as a means of gaining understanding of bereavement that has its roots in the lived experience of the bereaved.

2.7 Loss understood through attachment theory

The concept of detachment from the dead was further developed from a different context. John Bowlby (1982) developed attachment theory to understand a child’s response when separated from his mother. The child responds by protesting, despairing and yearning and eventually protecting themselves by detaching from the mother. It was this work that led him to apply attachment theory to bereavement. Detachment is a defence or the result of a defensive process. Bowlby (1980:21) states “*defensive processes are a regular*

constituent of mourning at every age and that what characterizes pathology is not their occurrence but the forms that they take and especially the degrees to which they are reversible". Defensive processes are not new to dealing with loss having been used extensively in war time in order to forget the traumas and enable a return to civilian life. A notable example of this defensive process was evident in German political, educational and cultural life following the Holocaust. Bowlby (1979) suggests that over time some measure of emotional detachment from the dead person occurs. Unlike Freud, Bowlby does not suggest total detachment; attachment theory is therefore an important concept to inform my research study.

I also consider whether others who are close to the bereaved also use detachment as a means of self-preservation. It is possible that this detachment is employed by HCPs as a means of coping. If this is true HCPs may use detachment in isolation or in addition to lack of knowledge resulting in the denial of loss and lack of provision of available support to the bereaved parent.

2.8 A changing perspective on loss

Until the 1980s the psychoanalytic model dominated bereavement care and the conventional held view was that grief resolution occurred through separation from the dead (Walter 1999). In *Continuing Bonds* Klass et al. (1996) presented a challenge to the held belief of separation and the requirement for the bereaved to put death behind them. What emerged was not a stage of disengagement but rather a new phenomenon; of people altering and then continuing with the lost or dead person (Klass et al. 1996). This new belief has a resonance with the Victorian era of maintaining the dead in the life of the survivors. It appears when the bereaved are asked to describe their experience it produces a contrasting picture to the conventional held belief of separation from the dead. Thus we can see a shift towards an epistemology that has its origins in the ontological position of the bereaved.

My personal view is that it is impossible to forget the dead. The dead while alive were very much part of a shared life. They are present in memories, to deny them would for me mean denying aspects of one's own life. And in remembering them it is not too far a thought to wonder what if they were now here. As a practitioner I have seen parents respond by talking and remembering the dead twin. For these parents grief does not break bonds with the dead rather it seeks to maintain the memory of the dead. However, I have also cared for parents where they appeared not to wish to dwell on the dead twin. My experience tells me that parents respond differently and that difference may be personal, the reasons for their response I do not as yet understand. I would suggest that there are times that the loss is so personal and so deeply felt that parents are not at a stage of readiness to share. They may also wish to maintain their composure in the public area of the neonatal unit and choose their own space and time for sharing.

The cultural change in the perception of grief (Silverman & Klass 1996) has its roots in science which Khun (1962) argues is not value free but, reflects the world view held by the dominant group in society. The psychoanalytic model therefore reflected the dominance of the scientific method and the dominance of the medical profession. I suggest the changing perspective on grief as expressed in *Continuing Bonds* is due to the explication of bereavement by those who experience it. I believe it suggests a shift in dominance and thus the ability of the bereaved to have their voice heard.

2.9 Revolutionary stage in bereavement theory

This shift in dominance as Kuhn (1962) argues is due to the fact that science develops through 'normal' and 'revolutionary' phases. Normal science accepts a basic paradigm and on the basis of this many papers and scientific experiments are conducted. This is evident in the dominant paradigm of the psychoanalytic model from the early 1900s until the 1980s (Walter 1999). Findings that challenge the dominant paradigm are dismissed until such time as the body of 'rogue' papers becomes difficult to ignore. What follows is a period of turmoil until 'normal' findings are explained by a new paradigm. Walter (1999) suggests such turmoil has been characteristic of the field of bereavement since the

1980s. Rather than dismissing the psychoanalytic model Tahka, (1984) suggests that psychoanalytic theory be expanded to include more healthy ongoing bonds with the dead. I believe such an approach would enable the bereaved to freely express their grief, make known what they consider 'normal' and enable society to have a broader understanding of bereavement.

Stroebe et al. (1992:1210) suggest that understanding grief grows from a "*newly developing consciousness, which may be termed post modern*". This new consciousness acknowledges a multiplicity of perspectives shaped by culture, personal values and retaining ties. They suggest three ways to develop understanding of grief not through new theories but rather through the integration of what is already known.

- Conceptual integration: a cohesive model based on the amalgamation of both the psycho-analytic and continuing bonds to reflect the breadth and depth of the individual response to death.
- Culturally embedded practices: a recognition of the ethnic factors that influence bereavement, to reflect the personal, family and societal practices.
- Expansion of responsibility: care of the bereaved is maintained through family, society and health care professionals.

This section of the review has outlined the major models and theories that inform the work of grief. This review has shown that bereavement theory is in flux. I conclude by acknowledging openness to both the psychoanalytic model and *Continuing Bonds*. I believe my approach is important so as not to prejudge the response of the bereaved parents. It remains to be seen where the experience of the parents will be situated on the continuum from the psychoanalytic model to that of *Continuing Bonds*.

The next section addresses perinatal loss and the complexity of emotions associated with this loss.

2.10 Perinatal Loss

The death of a child is an uncommon event, more deaths occur in the first days of life than at any other time in childhood; death at that time tends to occur in hospital intensive care units (Davies 2004). For some parents death may be unexpected, causes may be due to poor antenatal care, undiagnosed congenital abnormalities, difficult delivery, or an intra-partum (during delivery) event resulting in hypoxia (lack of oxygen to bodily tissues). For others death may be the result of prematurity and may take place in the neonatal intensive care unit. Admission to a neonatal intensive care (NICU) unit alters parenting. This technological environment is unpredictable, stressful, noisy, and public and dominated by HCPs. The experience of parents is mediated by the medical condition and immaturity of their baby as well as the presence of the HCPs. Parents may start their grief journey from many different positions. For some parents birth and death are closely related. Not every parent will have had the opportunity to hold their baby prior to death, or indeed do have been in a position to do anything practical for their baby.

2.11 Complexity of emotions

Perinatal loss gives rise to a unique grief (Callister 2006). The mother, has grown her baby from her own body, has marvelled at the changes as pregnancy progresses; the first movement and the relationship she develops with her baby; his / her personality. There is no other relationship as close or intimate as this, total dependence by her baby, total giving by the mother to this new life. The unborn baby gives identity to the parents on both a personal and social level; it is also a part of a transformation process of becoming a parent. For the pregnant mother the baby shares her body and becomes part of her internal space. She physiologically and psychologically nurtures her child in preparation for birth (Raphael-Leff 1991). Loss following soon after birth may make bereavement difficult to cope with. Affectional bonds are already established between mother and baby prior to birth, (Kennell et al. 1970). The development of this relationship is facilitated by new technology providing detailed images of the unborn baby, while knowledge of the sex may enhance that relationship. Affectional bonds which are enhanced through contact and care giving might therefore lead us to consider that the grief experienced following the death of a baby may be less than that experienced following the death of a child. It

appears it is the intimacy of this relationship that results in the parents transforming the bond to keep the child as an important aspect in their lives (Klass 1999). Understanding the parent's experience of this intimacy may provide greater understanding of their loss and serve to inform HCPs in the provision of care.

Perinatal loss shatters the expectation of a healthy outcome of pregnancy and represents a unique loss for parents, loss of their baby, a foothold into the future and their role as parents. Such a death has been demonstrated to be as profound and as significant as any other type of bereavement (Gardner 1999; Chambers & Chan 2000). In spite of the evidence the parents' loss is frequently dismissed as not being perceived as a true bereavement, (Stillbirth and Neonatal Death Society (SANDS) 1991; Chan et al. 2004). SANDS have provided an understanding of stillbirth and neonatal death as painful, difficult and experienced as a deep sense of loss requiring support. Memories of this loss are recalled with clarity (Githens et al. 1993). Understanding which is rooted in the lived experience of the bereaved provides a voice of authenticity and therefore enables HCPs to grasp the impact of this loss from the parents' perspective, (SANDS 1991; 2007). Seeking to understand perinatal bereavement began in the 1960s (Bourne & Lewis 1991) and there is as yet a partial understanding of this loss.

A partial understanding of perinatal loss results in challenges to HCPs and parents to manage the immediate painful reactions and enable mourning to occur (Bourne & Lewis 1991; 1984). A focus on the practical management enables funeral arrangements and registration of birth and death to take place (Forrest et al. 1981). The provision of counselling can reduce psychiatric and psychosomatic disorders of bereavement (Parkes 1965; Lindemann 1944), however newly bereaved parents find difficulty in accepting counselling and support (Forrest et al 1981). The reasons for these difficulties are not stated. Understanding those reasons may enable the provision of a service tailored to the needs of the parents.

Understanding of perinatal grief has its origins in the study of stillbirth whereas the practical management following death lacked information and guidance. Indeed, the

major informants of care were the personal response of the HCPs and common assumptions and customs that arise from a mixture of traditions, state health laws and medical advances (Kennel et al.1970). Thus care was delivered for the convenience of the institution and its staff. The voice of the grieving parent was notably absent in shaping the management and care following their loss. This was not a surprising situation as there was a commonly held belief that the length and intensity of mourning was proportionate to the closeness of the relationship prior to death (Parkes 1965). The belief was undermined by the work of Kennell at al. (1970) who established mourning occurred in parents following the death of a newborn irrespective of their weight or the time lived. There was a substantial degree of affectional bonding which preceded tactile contact between mother and infant. My experience as a practitioner is that parents are deeply distressed following the death of their baby irrespective of gestational age or duration of life. However, an opinion expressed in my practice area is that one can accept the death of a preterm infant more readily than that of a term infant. I do not believe the parents see this view. Kennell et al. (1970) highlights the fact that parents are usually unprepared for death. They are therefore dependent on the HCP to support and guide them, to explain what is possible and to share what other parents have found helpful. Thus care may be variable and as Kennel suggests dependent on the values and beliefs of the individual HCP and indeed their experience. In my clinical practice area the bereavement audit focuses on the practical aspects of care. By our actions we appear to give greater value to practical care and have difficulty in evaluating emotionally supportive care. The difficulty in evaluating emotional care is I believe due to the lack of knowledge of the lived experience.

2.12 Isolation

The bereaved are isolated by lack of knowledge and understanding of their loss. The result of which is avoidance of discussion of the baby's death and the liberal prescription of sedatives for the bereaved mother (Giles 1970). The loss is viewed through a different lens by HCPs who may through medication seek to dull the distressed sense of loss in the bereaved. Their actions seek to deny the pain rather than seek its explication. Where

HCPs view the parents' loss through their own lens they may arrive at a way of knowing that is not congruent with the bereaved parent. Failure to see the experience through the lens of the bereaved has led, as Lewis (1976) suggests, to a well-meaning conspiracy of silence, the bereaved mother is isolated and discharged as soon as possible.

Isolation is reduced by acknowledgement of loss and the beginning of mourning (Klaus & Kennell 1976). Isolation may also be reduced by preparation of the parents which facilitates attachment through touching, holding the infant even while on a ventilator (Benfield et al. 1978) and should begin before death. Their study found that informed parents can participate as partners even when death results (Benfield et al. 1978) and participation enables adjustment to their loss and resultant healthy grieving. Memories give substance to the absent baby and feelings of emptiness (Lewis 1976) and may serve to reduce feelings of isolation.

The role of the father in managing the practical aspects of funeral arrangements when his wife remains hospitalised may accelerate his grief and significantly influence the father-mother differences in grief scores (Benfield et al. 1978). This study demonstrated differences in grief scores between mothers and fathers, with a higher score achieved by mothers. A suggested explanation is that societal norms discourage fathers from expressing grief. In my practice area I have seen fathers who are concerned for and protective of their partners (McCreight 2004; Rowe et al. 1978) which may reduce available time for them to focus on their own grief. The needs of fathers are best met through support from other bereaved fathers (Samuelsson et al. 2001). Experience of loss appears to be a prerequisite for support or sharing with someone who has viewed the loss through a similar lens.

A further characteristic stated by Benfield et al. (1978) is that parental grief was not influenced by the birth weight, duration of life, and extent of parent contact, previous perinatal loss, parent age or distance from the hospital of birth to the regional centre. The most significant aspects adversely affecting parent grieving were attitudes and behaviour of family, friends and health care professionals.

2.13 Creating Memories

Memories provide parents with valuable and painful reminders of their dead child. Their acquisition is important in order to establish a “durable” biography and a continuing bond through the integration of the memory of their child into their ongoing lives (Walter 1999; Riches & Dawson, 1998; Lewis 1976). In addition, Riches & Dawson, (1998) suggest photographs enable parents to relive significant events and provide a resource to enable them to construct a public post bereavement self. Samuelsson et al. (2001) suggest that the power of artefacts as symbolic representation of the dead child was experienced as priceless by the fathers.

Of particular importance to my research study was the taking of photographs which provide concrete evidence that their child existed and confirmed their parental role. This is particularly crucial in perinatal and neonatal death where contact with the baby may be limited to the parents and the HCPs. In my practice area photos, hand and foot prints are taken and placed in a special booklet. There is a feeling, that by doing so HCPs are giving the parents a tangible memory (Walter 1999; Riches & Dawson 1998; Lewis 1976; Samuelsson 2001). It also serves to help HCPs find meaning in their own actions. In my experience, parents are content to accept the photos and prints, though not every parent will explicitly confirm this. However, there are exceptions, some parents feel it is strange practice to take photos of the dead baby and they may refuse to accept the pictures. Such pictures are stored in the baby’s notes to be accessed at a later date should the parents desire them. Practice suggests that there is a lack of consensus about parents’ response to the taking of pictures.

Perinatal loss requires acknowledgement and the time and space to grieve. Perinatal death is a painful experience for any parent however, for those parents who lose one twin the grief is complicated by the need to grieve for one baby and to celebrate the life of the other. The emotions of joy and sorrow are divergent, the effect of joy is affirmative and energising while sadness drains the energy levels and requires different emotional energy.

The next section considers the literature related to death of a twin and provides a rationale for the research study.

2.14 Perinatal loss in the context of twin loss

Death of a twin is a significant and important aspect of perinatal loss. It is estimated that 15% of twins grow up as singletons and few studies have reported how bereaved multiple birth mothers cope with their bereavement (Swanson et al. 2002; Hall 1996) and suggest that although multiple pregnancies comprise 12% of all pregnancies, only 2% survive as twins to term as many are lost through early miscarriage or as the vanishing twin syndrome. Higher mortality is due in part to twin-to-twin transfusion syndrome (TTTS). TTTS is a recognised midtrimester complication of twin pregnancy occurring in 15% of monochorionic gestations (NICE 2006). If untreated the mortality rate exceeds 90% with significant neurological morbidity in 30-50% of surviving twins (NICE 2006).

Perinatal loss is therefore a significant outcome of twin pregnancy. Parents are often encouraged to forget the dead baby and celebrate the surviving infant (Bryan 1999a; Read et al. 1997). This important point has a relevance to my study as it raises questions as to how parents experience the lack of recognition of their loss. It causes me to consider as to the lens through which this loss is viewed and question the perception that the surviving twin mitigates the sense of loss and grief. More importantly it raises the issue as to how little is known about how parents would like to be cared for. Bryan (1995) suggests that the unqualified sympathy offered to parents who have lost both twins contrast sharply with that offered to parents who have lost one twin. Parents who have lost one twin are treated differently to parents who have lost a singleton. Yet both sets of parents have lost a child, both have experienced a most unwelcome tragedy, both experience a most significant bereavement. Parents who have lost one of their higher multiples but have at least one surviving child often receive little sympathy even though the death of the child is deeply felt and the repercussions of that loss may be as serious as the loss of a singleton and often more complex (Bryan 1998; 2002). The experience of

unacknowledged loss by others is described by Doka (1989) as “disenfranchised grief” which leads both to a lack of permission to grieve and may intensify grief.

Loss is perceived through a different lens, we may describe this as a medical lens where HCPs experience difficulty in acknowledging this loss and may choose to either ignore or even forget what has happened (Bourne 1968). A misguided remark such as “how lucky you are to have one baby” can make parents feel guilty (Bryan 1995). Thus the behaviour of others through action or inaction impacts on the parent’s experience and may exacerbate their sense of loss. Their loss is compounded by the lack of support from HCPs from whom a parent might reasonably expect understanding, support and guidance. What is apparent is the failure to insert ourselves into the world of the bereaved parent.

2.15 Identifying a gap in the literature

The next section considers the research on twin loss. Studies related to twin loss are considered.

2.15.1 Studies related to grief in multi-fetal death

There is a paucity of literature related to this important area of practice. A total of twelve studies were retrieved. Of these, one was conducted in the 1970s, five were conducted in the 1980s, three in the 1990s and three in the first decade of this century. I have reviewed the studies under the following headings, quantitative studies, qualitative studies and qualitative and quantitative studies. The latter group relate to studies which had a component of both quantitative and qualitative methods.

2.16 Quantitative studies

Quantitative studies also referred to as using the scientific approach use deductive reasoning. Mechanisms are used to control the study and the empirical evidence is rooted in objective reality. The aim is to understand reality in broadest terms therefore the applicability of the findings to other than those who participated in the study referred to as generalisability is a widely used criterion for assessing the quality of the findings (Polit & Beck 2004).

2.16.1 Analysis of parental bereavement

Wilson et al. (1982) in a small study, using a quantitative approach (questionnaire) looked at parental bereavement in eight families who had lost a singleton and eight families who had lost a twin (the term family was used throughout however, the questionnaire was completed by the parents). The mean gestational age of the babies in both groups was 31 weeks. Data were collected at a mean time of 15 months following their loss. There was no significant difference between the parents who had lost a twin and those who had lost a singleton. However, the response of professional carers, family and friends often ignored or downplayed the death of the twin. For parents the presence of the surviving twin did not lessen their grief and mothers continued to think about their twin. This is a very small sample and therefore the use of statistics is questionable which raises a question regarding the reliability of the study. My study seeks to address two aspects of the findings from the parents' perspective; the experience of their loss and advice parents may have for HCPs.

2.16.2 Parental response to perinatal death

Wilson et al (1985), using quantitative methods, studied depression and social interaction of mothers and fathers following perinatal loss. Data were collected using a three-part questionnaire. Part 1 asked parents to recall how they felt during the first six weeks following their baby's death. Part 2 contained many of the same questions and asked parents to give their present emotional response. Embedded in each of these two sections was a 20-item Depression Symptom Inventory (DSI) adapted from the Center of Epidemiological Studies Depression Scale. Part 3 of the questionnaire contained open-ended questions pertaining to care issues and specific reactions to the death. The study group consisted of husband and wife pairs, those who lost a singleton (n = 12) and lost a twin (n= 6). The population was white, middle class, rural urban adults. The mean time (post loss) of completion of questionnaire was 25 months and ranged from six to sixty months. The response to the loss varied between mothers and fathers. Depression and social interaction are features of perinatal loss and differ among mothers and fathers. The differences are most apparent in the six weeks following the death and are not substantially different whether the loss was a stillbirth, singleton or twin death. Mothers

presented with more depressive symptoms in the first six weeks and have a need for others to talk about their baby. At 25 months the differences becomes less evident with those fathers exhibiting depressive symptoms and having an increased need for social interaction. Most mothers and fathers in the sample agreed that their marriage had grown strong. However, this does not hold true for those fathers who had more depressive symptoms and increasing needs for social interaction. Maternal depression had no correlation with perceptions of marital strength. This study highlights the difference between the grieving pattern of mothers and fathers. The findings suggest that following loss, greater concern may be expressed towards mothers as compared to fathers. I feel this is a natural response as the mother has had an intimate relationship with her baby from the time of conception. For fathers also the relationship begins prior to birth, technology facilitates the beginning of a relationship, albeit a virtual one. This study serves to raise our awareness about the needs of fathers, and HCPs should consider how best to support fathers in their own grief.

All mothers continued to think how life would be had both twins lived, while all but one of the mothers but, only one of the fathers thought of about their dead twin when looking at the survivor. For this group of parents the imagined life may be likened to the shadow of the dead twin, while suggesting that for mothers it may be impossible to separate both babies. The shadow also serves as a constant reminder to their loss. My study would seek to address the question of how mothers manage their continuing relationship with the dead twin. The use of open-ended questions suggest the data is enriched by the capturing the personal experience of parents which are not accessible using a quantitative approach.

2.17 How support can be improved

The findings from Bryan (1986) in a small quantitative study (n=14) comprised of twin (n= 12), triplet (n=2) sought to understand how support for parents can be improved. Data were collected through a semi-structured questionnaire with a section containing open ended questions. The use of open ended questions is inconsistent with quantitative research and the author does not provide an explanation as to the rationale for its use.

Open ended questions included the following: early and late problems encountered by the mother; the support received and how it might be improved; reaction of other people to the death; mothers' relationship with the survivor; the reaction of the surviving child to the loss of his twin. The questionnaire was sent through TAMBA to 14 mothers who were known to have lost a twin or triplet. The findings suggest a lack of understanding of this loss and therefore a lack of appropriate support. The results highlight problems encountered by parents; difficulty in distinguishing the survivor from the dead baby; lack of substantive memories gave rise to doubting the existence of a second baby. All mothers continued to think of their twin; felt their loss was underestimated; six experienced resentment towards the survivor. The study identifies the need not to underestimate the grief for the baby who has been lost.

2.18 Grief in multi-fetal death

Sainsbury (1988) examined 120 letters and interviews from families predominantly of higher order multiples pregnancies, who had experienced either partial or total loss of their pregnancy. Additional information was gained from interviews with obstetricians and social workers and the author's personal experience of loss. A similarity exists in the working through of the grief response between parents who have lost a singleton and those who have lost a twin. However, for parents who have lost a twin there is a differences in the intensity and length of grief. The grief pattern following multifetal death follows a pattern of opposing emotions which reported that nearly all mothers experienced feelings of ambivalence. A birth death experience occurs which is unique in its conflicting effects and its ability to lead to feelings of guilt about experiencing the grieving process. The mother may feel that she should overlook her loss and be grateful for the surviving twin. She may feel pressurised to act in a way that is incompatible to her true feelings. The space for grieving is lessened due to the responsibility of caring for the surviving twin. This may mean grieving is deferred, to be carried out at a later date. The impact of the deferring if it occurs is as yet unknown. These roles may be reinforced by professionals who urge the mother to bond with and care for the surviving twin. How to refer to the surviving twin remains a challenge to mothers. The findings are consistent with Bryan's (1986) findings and calls for special recognition for this loss. Complexity of

feelings contributes to isolation as does a lack of understanding of their own feelings and the parent's difficulty in discussing them with anyone. This insight is based on letters and I suggest my study would enable a deeper understanding of parent's conscious experience of their loss.

2.19 Guidance after twin or singleton death

de Kleine et al. (1995) adopted a quantitative approach, data were collected using questionnaire. The study involved parents who had lost a twin (n= 72) and parents who had lost a singleton (n= 70). Parents were selected from the medical records of five level three neonatal units, death had occurred 0.5 – 3.5 years earlier. Each couple (except one twin) was closely matched for time of death. The study identified twin parents as having less social support; lack of support organisations to address the specific needs of the bereaved. Parents of twins were advised more often to adopt a positive attitude; fewer twin than singleton parents discussed their loss with their GP. de Kleine argues that the differences between twin and singleton perceptions of care were not significant however they were to the twin parents' disadvantage. This study sought to address how available support for bereaved parents was experienced. The findings raise the issue as to how bereaved parents of twins would wish to shape the service to meet their needs. These findings are pertinent to my study and suggest understanding the parents' perspective requires a qualitative approach seeking their lived experience.

2.20 Grief following death of a newborn twin as compared to a singleton

Cuisiner et al. (1996) in a quantitative study sought to compare the grief of parents who had lost a twin to that of parents who had lost a singleton. Grief was measured using a short 33 item version of The Perinatal Grief Scale (PGS). The PGS contains 33 items developed to measure perinatal loss, bereavement and grief. Its 33 items are categorised in three subscales of eleven statements each. These factors are Active Grief (normal grief), Difficulty Coping (withdrawing from activities and people, indicating more severe depression), and Despair (potentially serious and long-lasting grief). The PGS was standardised (Potvin et al. 1989) on mothers who had experienced a singleton perinatal

death, defined in their study as fetal death after 28 weeks or a neonatal death within 28 days of birth. They stated that the scale could be useful in assessing the severity and depth of grief in those who have become bereaved earlier or later or for other losses. In addition the Dutch version of the Symptom Checklist (SCL-90) was incorporated into the study. The SCL is an accepted validated and sound mental health questionnaire. The comparison between parents who had lost a newborn twin (n= 72) compared to parents who had lost a singleton (n= 70) showed no difference in grief reactions. Mothers showed more grief than fathers. The study recommends medical records are marked to indicate the child was one of twins. The findings from this study provide a rationale for equal bereavement support for bereaved parents irrespective of singleton or twin. The approach to care differs from that suggested by de Kleine et al. (1995) who suggest bereaved parents of twins have specific needs. The findings do not help me in my care of these parents; it fails to tell me how I might care for them. A gap exists to inform practice from the emotional, relational and temporal experience of parents.

2.21 Findings of qualitative studies

Qualitative research or naturalistic enquiry seeks to understand the issue of human complexity by exploring it directly. Emphasis is placed on understanding the human experience as it is lived through and careful collection and analysis of qualitative data that are narrative and subjective (Polit & Beck 2004).

2.21.1 Follow-up following perinatal death

In a follow up study on 26 mothers (including five mothers of a surviving twin) who had experienced a perinatal death Rowe et al. (1978) conducted a telephone interview (10 - 22 months post loss). An open-ended interview was conducted to answer set questions. Six out of the 26 mothers exhibited a morbid grief reaction; the only factor found associated with the morbid reaction was the presence of a new infant in the home or a surviving twin. The source of support for mothers in these studies was husbands, family and friends. Religious beliefs were also a support, while for others a return to work helped to focus their minds on other things rather than their loss. A notable exception to the support was health care professionals, with the exception of one mother who sought counselling. For these parents information was paramount, seven of the 26 mothers were satisfied with

the information they had received. While support may be sought from outside the health care setting, communication is central to ensuring parents understand, and by understanding they may begin the journey of adjusting to their loss. This study suggests grieving is complicated by the surviving twin.

2.21.2 Adjustment following premature singleton versus a twin or triplet infant death

A study by Netzer & Arad (1999) sought an understanding of adjustment patterns in eighteen families who had lost a singleton premature infant and families who had lost one of a multiple birth cohort. An in-depth personal interview was conducted with 18 families between 1-4 years following death. The study group comprised singleton death (n= 9), one surviving twin (n=4) one surviving triplet (n=3) and two surviving triplets (n=2). This is a small sample size and not a homogenous group however as a qualitative study it seeks to identify influential variables common to loss. The study was conducted among a Jewish population. An important consideration is the fact that the Jewish tradition does not recognise the death of a newborn as a normal death. No significant difference was found between the maternal and paternal level of adjustment between both groups. The gestational age, maternal bonding during hospitalisation, and presence of the parents at the time of death was significantly associated with parental adjustment. The authors state the need for ongoing support as society does not recognise the need for consolation or compassion for these families. The findings from this study are congruent with Bryan (1986), de Kleine et al. (1995) and Sainsbury (1988) in the need for special recognition of this loss.

2.21.3 Mothers experience of professional care

The focus on mothers' experience is explored by Lundqvist et al. (2002) in a qualitative study of 16 mothers' (n=5 mothers of twins) experience of professional care when their newborn dies. The study sought to examine and illuminate the mothers' experiences and perceptions of care. The analysis employed was described as a Gadamerian hermeneutic phenomenological method. This method drew on the work of van Manen (1990) and sought interpretation of the experience, followed by the development of themes by asking the question "*what do mothers want others to know about their experiences?*"

Agreement of themes was reached through each author reading the themes and comparing them to the original text. Themes were validated by a sample of the mothers. The actions and behaviours of professionals resulted in the mothers feeling empowered or powerless. All mothers experienced both these states. Feelings of empowerment arose from mothers being treated with respect. This was characterised by experiencing empathy, where health care professionals demonstrated a sympathetic insight of the mothers' feelings and exhibited a warm and human approach. Such professionals were keenly aware of each mother's unexpressed needs and resultant care was individualised. In contrast feelings of powerlessness were experienced where mothers received competent and professional care without humane treatment. This is an important study in highlighting the impact of HCPs behaviour on the bereaved. The study illustrates that the perspective of the HCP differs from the perspective of the bereaved.

It is the bereaved we care for and it is the understanding of their perspective which is required to guide practice. It is this gap in the literature which calls out to be addressed. HCPs require research that will inform and enhance practice from a user perspective (Goodare & Lockward 1999). By uncovering and understanding the experience of parents HCPs would be in a position to provide care that meets parents' individual requirements, serve to empower them during a period of greatest need and at a time of vulnerability.

2.22 Findings of studies using qualitative and quantitative methods

The combination of qualitative and quantitative methods may address the weaknesses of both methods. For example, the use of tight controls in quantitative studies may fail to capture situational context. This aspect may be redressed by the integration of qualitative methods (Polit & Beck 2004).

2.22.1 How mothers cope with the death of a twin or higher multiple

Swanson et al (2002) utilised both quantitative and qualitative methods in her study group (n=71) and found higher levels of grief among mothers who had lost a twin as compared to a singleton. The Beck Depression Inventory -11 (BDI-11) was utilised to measure depression. This is a valid and reliable tool used to measure depression. It takes 10

minutes to self-administer and its 21 items provides a total depression score with each item rated. Depression scores categories are 0-3 = Minimal; 3-13 = Mild; 14- 19 = Moderate; 29-63 = Severe. In common with the above study they also used The Perinatal Grief Scale (PGS). Parents were asked to complete the BDI-11 two weeks before the interview and the PGS to retrospectively rate their emotions at the time of their loss. The qualitative interview consisted of three parts: an opening question “Please tell me your story?” followed by stimulus questions. The stimulus questions were developed from twin loss literature or from themes raised by the first ten mothers interviewed. The third part called for responses to a series of items ranging from “spiritual beliefs”, “acceptance”, the “quality of counselling received following the death of the twin” and “the ability to deal positively” with the father of their twins.

Following the interview the parents were invited to join a focus group to share the study results, to check out the findings and meet other bereaved parents. The mothers ranged in age from 24 to 71 years. Details of 66 of the 71 participants were available on the Western Australian Twin Child Health (WATCH). Some of the mothers not on WATCH were uncertain of the time and causes of death. The average time between death and interview was 11.8 years (range 2.5 months- 41 years). The findings show that mothers experienced greater grief when compared to mothers who had lost a singleton. This finding is different from that of Cuisiner (1996) and may be due to the recruitment approach (Swanson 2002). Cuisiner recruited from clinical and hospital settings while Swanson (2002) recruited from a population based twin register. An additional factor was the bereaved in Cuisiner’s study were between six months and three and a half years post loss. Swanson’s range was two months to forty one years. Also the PGS scores were not reported by Cuisiner and therefore comparison is not possible. The findings from the qualitative approach reported what parents found as most helpful: presence of surviving children; family support; support from partner; spiritual support. Parents also experienced both a denial of their loss and lack of support from partners and HCPs. In addition parents made recommendation for coping with their loss: finding support from others and support organisations; grieve actively and personally; seek meaning through spirituality; seek help, both medical and psychological and avail of sympathetic listeners. The study

identified a need for a sensitive approach by HCPs and the wider community in helping parents through their grief.

This is an important study and raises questions pertaining to support organisations and the role of HCPs in supporting parents. The study confirms the complexity of this loss and lack of understanding not least by HCPs.

2.22.2 How couples cope with the death of a twin

A further study by Swanson et al. (2009) utilised the Beck Depression Inventory II, Perinatal grief scale, and unstructured interviews with some structured queries. The study involved (n=52) couples who had experienced the death of a twin or higher multiple with one survivor of that birth. Both parents found the death of their twin a most dreadful experience but, fathers unlike mothers were not encouraged to grieve. Furthermore fathers believed they should be able to cope irrespective of their grief. There was an increase in spiritual belief. Grieving mothers and those suffering from depression sought solace in spiritual support. Levels of depression did not vary on whether the twin died earlier or later. The findings raise the issue of how societal values influence the experience rather than the personal experience of the bereaved influencing the societal response.

2.23 Identifiable gap in current practice knowledge

The review of the literature provides an insight into the complexity of perinatal loss. It suggests that parents who have experienced the death of a twin receive less support than parents who have lost a singleton. Higher levels of grief are experienced following twin loss and fathers are not encouraged to grieve. As I reflect on the current knowledge base I consider how it has failed to shape practice in my clinical area. I therefore suggest that the missing research is that which provides the experience of loss from the parents' perspective. I suggest a different lens is needed to understand the lived experience of the bereaved parent. This lens would argue for the need of a phenomenological study that enables the HCP to enter into the world of the parent and understand that lived

experience. Such understanding has I believe an important contribution to make to the care of these parents.

2.24 Summary

The literature review has explored bereavement theories from the psychoanalytic to ‘Continuing Bonds’. Perinatal loss was considered. Studies on twin loss were scrutinized. Findings provide evidence of parental response and depth of grief as measured. They also provide some guidance of the care of the bereaved parent in relation to creating memories. The available evidence does not enable the practitioner to ‘feel’ how this loss is experienced. The phenomenon death of a twin is as yet to be discovered. The literature review reveals a need for a phenomenological study that can provide the knowledge regarding the experience of the phenomenon death of a twin and its meaning from the parents who are involved. The study would also seek to capture how parents experience society’s response to their loss. Such knowledge I believe would truly enable practice to reflect the needs of the bereaved parents.

CHAPTER 3: METHODOLOGY, METHODS & DATA ANALYSIS

3.1 Introduction

The previous chapter presented my decision making process regarding the timing and method searching the literature. The literature considered important to the research study was reviewed. The review presented the theoretical basis of grief and the shift towards a new understanding. Perinatal loss was considered prior to discussion on twin loss. The review presented a rationale for a phenomenological study. The previous chapter therefore formed the preparatory work for the methodology and methods and data collection. This chapter provides an account of the decision making process taken in the generation of knowledge. This chapter begins by addressing my world view and that of myself as a phenomenologist, followed by the integration of my world view into my research. Epistemological and methodological and methods positions are then considered. The significance of death of a twin as viewed by the researcher and six presuppositions are presented. This is followed by the individual phenomenological reflection (IPR) which makes explicit the researcher's pre-understanding in relation to the death of a twin. This section enables the reader to enter the world in which the research is situated and is followed by the research design. Finally, data analysis, issues of rigour, position of the researcher and ethical considerations are addressed.

3.2 The choice of methodology

Science is described by the Oxford English dictionary as the systematic study of the structure and behaviour of the physical and natural world through observation and experiment. This narrow definition does not lend itself to the study and understanding of lived experience. Dilthey (1961:109) states "*The working model of the natural sciences is constituted by the concepts of a causal order in a physical world and their particular methodology consists of procedures for discovering it*". White (1938:369) suggests science is pre-eminently a way of dealing with experience, "*The word may be*

appropriately used as a verb: one sciences, i.e. deals with experience according to certain assumptions and with certain techniques". Thus science demonstrates a connectedness between the researcher and the discovery of knowledge.

White (1938:372) suggests "*we must view science as a way of behaving, as a way of interpreting reality, rather than as an entity in itself, as a segment of that reality*". When considering my methodology I gave thought to the pursuit of knowledge of the world of the bereaved parent through a systematic approach. I recognised that the knowledge I wished to access lay in the lived experience of the bereaved parents. Accessing this knowledge required me to employ an approach that would enable me to hear, see and experience that reality from the perspective of the bereaved parents. In the words of Moran (2000:4) I sought phenomenology as "*the attempt to get to the truth of matters, to describe the phenomena in the broadest sense as whatever appears in the manner in which it appears*". This phenomenological study is embedded within Husserlian philosophy. In keeping with Husserl (Moran 2000) I have listened to the parents in my study as they provided concrete descriptions of their experience within the natural attitude. The descriptions provided by the parents are what they have been present to or conscious of (Giorgi 2000; Colaizzi 1978). As I analyse the facts for their meaning my concern for the factual veracity is irrelevant (Giorgi 2000). The epistemological claim that I make is for the situation as meant and intended by the parent thus, I as researcher am adhering to Husserl's (1900/1901) precept of "returning to things themselves". I can therefore understand the phenomenon in a meaningful way (Colaizzi 1978).

3.3 My world view and myself as a phenomenologist

The formulation of my research question in its final form underpins my journey in becoming a novice researcher. This journey has deepened my self-knowledge, stimulated my curiosity and developed my level of theoretical knowledge. The skills and enrichment are not isolated to research; rather they permeate all aspects of my life. The development and answering of the research question suggest varying approaches to qualitative research and different personal perspectives, values and beliefs, and feelings about the world and

how it should be studied and understood (Denzin & Lincoln 2003). Phenomenology is a philosophic attitude and a research approach. It's most fundamental premise is that the most basic human truths are accessible only through inner subjectivity (Thorne 1991) and the person is integral to the environment (Burns & Grove 1999). Phenomenology is a descriptive and interpretative form of qualitative research that seeks to study phenomena that are perceived or experienced (Flood 2010) and has provided a methodological structure for an increasing number of nursing studies (Crotty 1996). As a phenomenologist my decision making in relation to my research was a desire to engage with people in exploring an issue that related to my practice area of neonatal nursing. While the initial development of the question began as an intellectual curiosity (Janesick 2003), a fuller understanding evolved over time which challenged me as a practitioner. The challenge related to the fact that I was caring for bereaved parents of a twin without understanding what this loss meant to the parents. As I began my journey I became aware that the answer to my question was held by the very people who were living the experience and therefore an understanding of their lived experience would enable me as a practitioner to situate myself in their world. I envisaged that "understanding" as informing my practice to provide appropriate and timely care for these bereaved parents.

Leonard (1989) states researchers are required to have a fundamental concern for ontology. This suggests to me that I must make explicit how I view the world, what can be known and how I as researcher can discover what I believe can be known (Crossan 2004). Thus my decision-making sets the research in a particular paradigm and enables the reader to ascertain the credibility of the results based on the decisions made, both at the beginning and during the research process. In my engagement with parents I identify with Denzin & Lincoln (2003:13) as seeking

"the socially constructed nature of reality, the intimate nature of reality, the immediate nature of the relationship between the researcher and what is being studied, and the situational constraints that shape the enquiry".

I begin with a short vignette to introduce the reader to my view of the world and ontological position.

The parents had held and talked to their daughter, I helped put her back in her incubator and they said their goodbyes. As they left the nursery they stated they would not visit the next day as they were going to attend the funeral of her twin sister. The day would be their last opportunity to spend time with her.

At the time I was struck by their actions and their decision not to visit. Perhaps it was something to do with giving the deceased time and space or the difficulty to move from an intense period of mourning to parenting the surviving twin. Due to my lack of knowledge and insight I did not know what they were thinking. I imagined their grief and feelings of loss; and their decision not to visit may have been a difficult one. This couple appeared close with the male protective of his partner, I therefore wondered if they would cope similarly or differently with their grief. I was also aware of my lack of knowledge and how this impacted on my reality as a caring professional. This memory brought into sharp focus my view of reality and enabled the recognition of multiple realities shaped by such influences as experience, emotions, perceptions, behaviour and culture. Each reality is valuable in itself, none is considered more valuable than another. At that time I had a curiosity about the parents' reality; it would be many years before I returned to seek to understand it. However, when I did return to the question my focus remained as a curiosity to understand what it means for the parent to lose a twin. Understanding my reality as distinct from the parents' was the first part of the research process and enabled me to progress. Creswell (1998) speaks of knowledge being within the meaning people make of it, thus meaning is contextualised (Nowotny 2001).

3.4 Integration of my world view into my research

My personal knowledge of the world and specifically my role as practitioner has been acquired through study, experience, socialisation, social change, culture; mine and others, in addition to values and beliefs. My knowledge is of a dynamic nature, changing, developing and expanding. Knowledge then is not a separate entity; it is closely related to

the self. In the words of Carper (1992:220) *“One does not know about the self; one simply strives to know the self”*.

I bring myself and my view of reality to the relationship with another, a relationship of reciprocity. It is this reciprocity which gives me insight into the lived world of the other. Polanyi (1962) describes this as a passionate participation in the art of knowing, influenced by human values (Bronowski 1956). My view of reality is one view and has been constructed by various influences specific to me. There are other realities whose construction will vary from mine. I acknowledge that there is an element of construction, however I believe that construction is based on a consciousness of lived experience. It is the parents’ construction of their experience that interests me. My engagement with the parent has a resonance with Carper, (1992: 220)

“the kind of knowing that promotes wholeness and integrity in the personal encounter, the achievement of engagement rather than detachment; and it denies the manipulative impersonal orientation”.

As a phenomenological researcher my world view recognises different realities and different ways of knowing. The next section considers the generation of knowledge through phenomenology.

3.5 Epistemology

The central question of epistemology includes the nature and origin of knowledge, the scope of knowledge and the reliability of claims to knowledge (Flew & Priest 2002). The epistemological contribution to research is essentially theoretical (Carter & Little 2007) and influences methodology, implementation of method, form, voice and representation in the method. Therefore epistemology seeks congruence through all aspects of the research process. Discovery of knowledge cannot be achieved by empirical-analytical sciences but by sharing common meaning (van Manen 1990) as opposed to arguing a point. Epistemology also has an ethical component; this may be considered as what constitutes trustworthy knowledge. The epistemology of

phenomenology focuses on revealing meaning through a careful description of the ‘things themselves’ (Moran 2000).

Epistemology comes from the Greek word *epistēmē* (knowledge) and *logos* (reason), epistemology is the theory of knowledge (Flew & Priest 2002). Its central questions include the origin of knowledge; the place of experience in generating knowledge and the place of reason in doing so. Knowledge is therefore generated from the parents’ reality; constructed between the parents and researcher; analysed by an approach congruent with the underpinning philosophy. The resultant knowledge has its roots firmly in the domain of the raw data.

The nature of knowledge cannot be understood by the eyes

Lucretius (De Rerum Natura: Book 4:385)

This quote engages me and has caused me to consider a situation whereby I have responded to what I have seen, only upon reflection, to become aware that what I saw was my view of reality and not the reality of those I deemed to help. When the bereaved parent visit their surviving twin, I can see they may look sad, they may be anxious about the survivor, have a major concern that the same fate awaits the survivor and therefore may exhibit over anxious behaviour or avoidance of attachment behaviours. In seeing the parent I have begun to bring my own perspective as to the reason for their sadness.

However, the knowledge of what they are experiencing and how that experience affects them eludes me. While their appearance and presentation of themselves provide me with some information I cannot know the reality of their loss. I have a perspective of their loss and how it affects them; a perspective has been gained from my being an experienced practitioner. I recognise my view of reality differs from that of the parent who is living the experience and a different way knowing. However, it is the only reality I have knowledge of. I therefore ask myself the question “what constitutes knowledge of the death of a twin?” Knowledge provides the answer to what is known about the experience,

how it is lived through, how it impacts upon the parent. I do not have the answers to these questions therefore I do not have the knowledge. To understand the meaning of experience I need to ask those who are living it. The lived experience constitutes “the knowledge”. This knowledge cannot be known by the eyes, rather it is the engagement with the consciousness of those that live or have lived the experience that uncovers the knowledge.

“To know is to think what is: knowledge is a certain relationship- of conformity, of resemblance, of sufficient- between the mind and the world, between the subject and the object”

Compte-Sponville (2004:46)

There are different ways of engaging the mind with the world and these different ways result in the generation of different types of knowledge. They broadly fall into two discrete approaches; qualitative and quantitative. In qualitative research, ‘being’ is central, to knowledge generation, it is a way of making the world visible (Denzin & Lincoln 2005). Quantitative research, often referred to as the scientific method considers knowledge as separate from ‘being’. Quantitative research is primarily designed to test hypothesis, seeks comparisons, establish relationships (Morse & Field 1996). The focus is on a specific area and it is studied under controlled conditions uncontaminated by human perspectives, the facts speak for themselves. The approach is described by Sharrock & Ash (2002:221)

“Science in the modern world is generally thought to be ‘objective’ with science writing a matter of simple fact, unadorned and uncomplicated by rhetoric”.

The separation of the researcher from the research is central. Grix (2004:117) identifies three basic phases to quantitative research: *“finding variable for concepts, operationalising them in the study and measuring them.”*

It is argued by Pope & Mays (1995) that qualitative research has a long history in social sciences and deserves to be a fundamental element in health service research. The argument is not to consider one method as superior to another rather it is to seek a most appropriate epistemological approach to my research. As researcher I have the responsibility to choose a method that is the most appropriate and can be justified for the study (Silverman 2005). I am not concerned with a specific aspect of the parents' experience, for example measuring levels of grief under specific conditions rather I am concerned with the lived experience that is the conscious response to the death of a twin. This may certainly include grief, however grief is expressed from consciousness of the parent's lived experience. I am concerned with the nature of experience and consider that to be complex. This complexity is reflected in Creswell (1998:15)

“Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views to informants, and conducts the study in a natural setting”.

Qualitative research is defined as an approach whereby the researcher studies things in their natural environment attempting to make sense of, or interpret them and the meaning that people bring to them (Denzin & Lincoln 2003). Qualitative research addresses the “why” and “how” questions with the focus on exploring phenomenon. It is by its nature dynamic, and it's the dynamic nature that facilitates the uncovering of knowledge through the engagement between researcher and participant. Such knowledge is a co-construction between the researcher and the participant. Alvesson and Skölberg (2000) describe this process as power sharing in constructing meaning. I see this construction as an engagement of consciousness. I enter this engagement with an awareness and openness. I accept my view may influence the questions I ask. I also accept that there may be a reversal of roles and the participant may ask me questions. I am mindful that parents may present data that challenge my views. The interactive nature of qualitative research continues through its reading. I therefore recognise and acknowledge the presence of multiple realities and in the words of Philips (1990) I am seeking ‘warranted assertibility’. Therefore I am required to produce evidence that is valid for the existence

of the phenomena and congruent with the paradigm perspective employed to generate knowledge within the study (Forbes et al.1999). Validity builds on the coherence and accuracy in reasoning of analysis and findings.

I recognise that I come to the research as an experienced practitioner with both practical and experiential knowledge (Reason & Rowan 1981). When I care for the bereaved mother, I know she is bereaved because that fact is recorded in her surviving twin's notes. When I speak to her I am mindful that she is a grieving mother while also the mother of a surviving twin. I know she is sometimes upset as she is reduced to tears while sitting with or holding her baby. I know she has had a funeral for her dead baby because she has told me. I have some knowledge about this mother and I have formed a perspective on her loss.

However, I do not have empirical knowledge of how she feels, how she experiences her loss and the meaning of her reality. I therefore find myself at a disadvantage which means I am unable to engage with the bereaved on a human understanding level. Therefore my choice of methodology is made on the basis that to understand the bereaved parent I need a methodology which will allow me to approach and access the perspectives of participants who have experienced the death of a twin as they live that experience. White (1938: 369) states that there are two ways of understanding experience one is art the other is science. He suggests their purpose is one *"to render experience intelligible, i.e., to assist man to adjust to his environment in order that he may live"*. Making experience intelligible requires order to be discovered and in a deep sense to be created (Bronowski 1978). I am drawn to the description of science by White (1938: 374) as *"Sciencing must adapt itself to the structure of reality: its tools must be so shaped and its techniques so ordered as to grasp reality effectively and render it intelligible, if not controllable to us"*. Phenomenology is the chosen methodology to gain understanding. Phenomenology facilitates the search for the most invariable parts of that experience as it is located within a context (Araújo Sadala & de Camargo Ferreira 2002).

3.6 The theoretical perspective

The theoretical perspective supports the philosophical position and provides a context for the process involved and a basis for its logic and reason (Flood 2010). There are two main phenomenological approaches descriptive (eidetic) and interpretative (hermeneutic) (Moran 2000). They differ in how findings are generated and used to enhance professional knowledge (Cohen & Omery 1994). The next section considers phenomenology and presents the rationale for my choice of descriptive phenomenology.

3.7 Phenomenology

Phenomenology is a philosophical movement which originated from the Germanic school of thought. There are three main philosophical positions held by Edmund Husserl, Martin Heidegger and Hans-Georg Gadamer. Husserl is attributed to being the father of phenomenology which was first written about in *Logical Investigations* published in 1900/1901. Phenomenology is the study of human experience and the way things present themselves to us in and through experience (Sokolowski 2000). Phenomenology is concerned with the central role of meaning in experience and described by Husserl as the essence of consciousness. It includes acts of consciousness, perceptions and imagination. Phenomenology is a reflective study of consciousness from the first person point of view. Heidegger, a pupil of Husserl developed phenomenology as interpretive and expounded in *Being and Time*. Heidegger's phenomenology concerned the human being making sense of being in the world. Gadamer's study of phenomenology has as its basis language and how language provides our understanding of being in the world (Moran 2000). In France it was developed in the realm of existential phenomenology by Jean-Paul Sartre in his publication *Being and Nothingness*. While Maurice Merleau-Ponty (1964; 1962) developed a phenomenology of perception. Phenomenology has continued as one of the major philosophical traditions over the past century in Europe and to a lesser extent in North America, (Sokolowski 2000). In North America it is a method used extensively in nursing research (Parse 2003; Benner 1994). It is important to note differentiations between what is termed European phenomenology and North American phenomenology. The former is concerned with objectivity that is it elucidates what people experience

while the latter is concerned with the subjective experience of the people it studies (Crotty 1996). Phenomenology in the words of Moran (2000:4) seeks to return to our experience as it is immediately given to us.

“Phenomenology is best understood as a radical, anti-traditional style of philosophising which emphasises the attempt to get to the truth of matters, to describe phenomenon, in the broadest sense as whatever appears in the manner in which it appear, that is as it manifests itself to consciousness, to the experiencer”.

The major European philosophers in the phenomenological movement are presented in Table 3.1

Table 3.1 – Major philosophers in the phenomenological movement

<i>Philosopher</i>	<i>Major contribution</i>	<i>Major works</i>	<i>Issues addressed</i>
<p>Edmund Husserl 1859-1938 Background in mathematics</p>	<p>Descriptive phenomenology Developed intentionality Believed phenomenology was a method of doing philosophy</p>	<p>Logical Investigations 1900/1901</p>	<p>Pure phenomenology Epistemological questions related to acts of consciousness Ontological questions about what it means to be in the world</p>
<p>Martin Heidegger 1889-1976 Background in theology</p>	<p>Interpretive phenomenology</p>	<p>Being and Time 1927</p>	<p>Existential phenomenology Epistemological questions related to acts of consciousness Ontological questions about what it means to be in the world</p>
<p>Hans-Georg Gadamer 1900-2002</p>	<p>Existential phenomenology Hermeneutics</p>	<p>Truth and Method, 1960</p>	<p>Existential phenomenology Epistemological questions related to acts of consciousness Ontological questions about what it means to be in the world</p>

3.7.1 Being a phenomenologist

I situate myself with phenomenology as bringing along with empathy to the research study, openness, a recognition of the unknown and yet to be discovered knowledge and being present to others. I acknowledge my presuppositions and set them aside to better understand the lived experience as shared by the parents in the study.

As a phenomenologist my research study was concerned with understanding the lived experience of the bereaved parent as they lived the loss of their twin. People live their life in a way that is unique to them and with varying degrees of self-consciousness (Johns 1998). A major event such as the death of a twin can heighten levels of self-consciousness. Dilthey (1985:223) suggests that lived experience is an awareness of life without thinking about it.

“lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of the lived experience is there-for-me because I have reflexive awareness of it, because I possess it immediately as belonging to me in some sense. Only in thought does it become objective”.

Dilthey (1985) has identified pre-reflective consciousness of life as it is lived and a reflective consciousness as the experience is reflected upon. Consciousness therefore has a pre-reflective aspect as one is living through the experience and a reflective aspect as one reflects on the experience. The research interview serves to illustrate the iterative nature of pre-reflective and reflective self-consciousness in both the researcher and the participant. The participant in sharing the experience of the death of their twin is in the reflective mode, while I as researcher am living through the experience and am in the pre-reflective mode. I suggest that the parent may also have experience of the pre-reflective mode during interview. This was evident in the interview with Participant 7. As she was relating her experience she stopped and stated that *“this is the first time I have sat down and talked about the death of my twin”*. This appears to me to have a similarity with Schön’s reflection-in-action (Schön 1987). Following this observation the participant returned to the interview in the reflective self-conscious mode. Following the interview I adopted a reflective mode as I wrote field notes. The reflective mode continued in the

process of analysis. Thus reflection as “consciousness of” becomes the key to making sense of human experience.

3.7.2 Being a phenomenologist within the Husserlian tradition

Phenomenology began by Husserl, has been taken by other philosophers and interpreted resulting in many versions. Common to all is the concept of intentionality or the act of consciousness. Husserl came to philosophy from a mathematical background.

Mathematics and philosophy have enjoyed a long history. Pythagoras, a pre-Socratic philosopher was also a gifted mathematician while Descartes invented the graph and the whole subject of analytic geometry (Magee 1998). Husserl’s ground breaking work broke the mould of the previous three hundred years and drew inspiration from the philosopher Aristotle. Aristotle was the first philosopher to insist on the importance of systematic empirical enquiry (Stangroom 2006). Aristotle’s main concern described by Sharrock & Ash (2002:131) is *“to investigate the ‘theory of being as being and of what ‘to be’ means but not in a piecemeal way as others had done before him”*. In a similar vein Husserl challenged the philosophical belief held by Descartes of the two separate entities of mind and body. Husserl unified mind and body through his concept of ‘intentionality’.

Consciousness is something we live through and provides a sense of self as we live through it, it is through consciousness that we live as in see, feel, think. The essence of consciousness consists of various experiences; those concerned with the senses, touching, seeing, feeling, judging, desiring and the states such as happiness sadness, joy; activities such as walking, moving and willing. These are some of the conscious experiences of life.

Every act of consciousness is a consciousness of something, as in perception I perceive, in imagination I imagine, in judgement I judge. This property of consciousness, its being of or about something is what Husserl calls intentionality (Smith 2007). Thus I can say an experience is intentional or directed towards some object. Husserl investigates the

structure of consciousness that makes it possible to understand an empirical world (Holstein and Gubrium 2005).

‘Intentionality’ is described by Husserl as meaning consciousness is always conscious of something i.e. directed toward an object. As I look through the window I see or am visually conscious of a cherry blossom. My act of consciousness, my visual experience is a consciousness of that tree. Every mental act is directed towards something. Husserl states that the act has a special property of being directed towards its object; the act itself is intentional or directed. This intentionality has a specific structure as I will illustrate in the following manner: my act of seeing a parent entering the nursery “is an event in my mind, in my stream of consciousness” (Act). The parent I see is very different; I see a parent presenting a particular countenance, dressed in jeans and t-shirt (parent as content of the act). Something very different from the act of seeing and the content of the act of seeing, a certain idea or concept or precept of the person, Husserl calls this idea ‘noema’ (Moran 2000).

While the act of seeing the parent transpires over a minute or two, the noema is not a temporal entity. For the same noema or idea can be entertained in different acts or experiences at different times. I may bring the noema arising from the experience described above to the relationship with the parent. In the process of engaging with the parent I experience many noema. Such noema may inform my developing relationship and shape my response; this layering of noema formulates a comprehensive meaning of the wholeness (Moustakes 1994). I now become aware of the self-conscious method which occurs in phenomenology. When I reflect on the lived experience of engaging with the parent I become conscious of the richness of data in phenomenology. Being sensitive to this data enables me to bring sensitivity to my relationship with parents and their baby. As a phenomenologist I am fully immersed in the study which has caused me to reflect on how I may influence the study and findings. To prevent the researcher influencing what is perceived; Husserl developed a sequence of steps in order to understand the essential features under investigation. These included the suspension of the natural attitude and adoption of the phenomenological attitude. We live our life in the natural

attitude as we go about our daily life. As researcher I am required to suspend the natural attitude and bring my attention to the pure essences of consciousness (Moran 2000). In practical terms this means that I as researcher set aside my assumptions about the world and move into the phenomenological attitude. The act of adopting the phenomenological attitude is termed bracketing and its significance is described by Moran (2000:11)

“scientific, philosophical, cultural and everyday assumptions had to be put aside – not so much to be negated as to be put out of court”.

I liken bracketing to the role of a jury who are asked to consider the evidence and only the evidence before them. The concept of putting aside our prejudgements, biases and preconceptions is described by Husserl as the *Epoche*, a Greek word meaning to stay away or abstain (Moustakas 1994). This abstaining or ‘bracketing’ my reality when engaging with the parent is challenging for the novice researcher however, what helps me is the recognition that my focus is the parents’ reality and that reality is different to mine. My recognition that the parent’s reality is shaped by the self, culture, values and beliefs which are different from my own help me in this challenge. I see the *Epoche* as both an experience in deriving new knowledge but also an experience in itself (Moustakas 1994)

During re-listening to interviews I have employed what Moustakas (1994:89) describes as reflective-meditation.

“letting the preconceptions and prejudgements enter consciousness and leave freely, being just as receptive to them as I am to unbiased looking and seeing. The meditative procedure is repeated until I experience an internal sense of closure”

By using this approach I arrived at a time where I was receptive to the spoken word, it engages me without the distraction of other thoughts. Therefore I was more receptive to the presence of and appearance of the phenomenon. I accept that I found this immersion in grief difficult at times and sought approaches to lessen the emotional impact. This awareness was an important part of reflexivity during the process (Munhall 2007)

enables the reader to judge the validity of the research findings (Kahn 1993). In qualitative enquiry, the researcher builds a complex, holistic picture based on methodologies to explore a social or human problem (Creswell 1998).

3.7.3 Being a phenomenologist within the Heideggerian tradition

Husserl and Heidegger were recognised as two great thinkers in philosophy from the last century (Sokolowski 2000). Heidegger came to philosophy from a theological background. The fundamental difference between Heidegger and Husserl is described by Moran (2000:228)

“Whereas Husserl made cognition (Erkenntnis) the main connection between humans and the world, Heidegger influenced by Augustine and Scheler, saw that humans are primarily caught up in living their lives, wrapped up in moods and emotional commitment, in cares and worries, falling into temptation, projecting themselves into possibilities, seeking to make themselves whole”.

Heidegger dropped Husserl’s term of intentionality for that of *Dasein* (Moran 2000). *Dasein* becomes a practical way of being-in-the-world. Heidegger interpreted Husserl’s phenomenology and extended to ‘What is the meaning of being?’ Heidegger therefore moved from Husserl’s phenomenology of description to a phenomenology of interpretation. Heidegger encountered hermeneutics as a branch of theological interpretation during his period in the seminary. Heidegger understands hermeneutics as the manner in which human existence is interpretive. Life is lived through interpretation, in encounters with others and interpreting what has already been interpreted; an example of this latter is the editorial in the daily paper or the presence of new HCPs in my clinical area.

“Interpretation is carried out primordially not in a theoretical statement but in an action of circumspective concern- laying aside the unsuitable tool, or exchanging it, “without

wasting words". From the fact that words are absent it may not be concluded that that interpretation is absent".

Being And Time §33; (1962:157)

Heidegger's phenomenology is a means of engaging with and connecting to the world. While Husserl's phenomenology is concerned with description, Heidegger's is concerned with interpretation. Interpretation requires understanding. For example I interpret the snow as indicating low temperatures and dress appropriately when I am building a snowman with the children.

As researcher the way forward is to gain a description of the lived experience of the bereaved parents before I seek to put an interpretation on that experience. In my study I am concerned with the lived experience that is constituted through the parents acts of consciousness (Moran & Mooney 2002). The focus is to describe rather than to interpret.

3.7.4 Being a phenomenologist within the Gadamerian tradition

Gadamer developed phenomenology in the field of hermeneutics. The focus on consciousness and experience is central to hermeneutics (Moustakas 1994) and understanding is gained through interpretation. Gadamer (1976: xii) states "*Its field of application is comprised of all those situations in which we encounter meanings that are not immediately understandable but require interpretive effort. Hermeneutics has to do with bridging the gap between the familiar world in which we stand and the strange meaning that resists assimilation into the horizons of our world*".

Gadamer, a pupil of Heidegger's brings an interpretation of hermeneutics to phenomenology. He does this through language and language is viewed in its widest sense. Moran, (2000:270)

"It means that full understanding, which in his view is an event, is brought about only because of language and in language. Language is where our understanding, our mode of being in the world, comes to realisation".

The aim of enquiry guided by Gadamerian hermeneutics is to understand through the fusion of horizons (that of the researcher and the participant). Language and its interpretation are the medium of communication and language is central to understanding. Interpretations are possible because as Koch (1994) states a dialogue takes place between the researcher and the text or between the reader and the text. There is an acknowledgement that the researcher and the reader may take different interpretations due to their own preconceptions. Therefore researchers using hermeneutics would serve the reader well by introducing their reasons for the study. Thus the reader is enabled to follow the researchers' interpretation whilst finding their own.

Heidegger's and Gadamer's branch of phenomenology is concerned with *being-in-the-world*, interpretation is implicit and is central to understanding the self in relation to the world. In contrast Husserl's phenomenology remains focused on description as a means of understanding the phenomenon. I would argue that understanding consciousness is a necessary prerequisite for being-in-the-world. We must consciously understand before we can interpret and that understanding is gained from the description of the lived experience of those parents who have experienced death of a twin. Within the spirit of Husserl's phenomenology I have sought to investigate the phenomena of the experience of the death of a twin by going back to the phenomena itself, which means seeking the consciousness of those parents who are living through this loss. The phenomenon is uncovered through intentionality. The object of my research is to begin with a description of the phenomena as a way to do philosophy. In the words of Giorgi (1985:1)

“The purpose of the method is to do justice to the lived aspects of human phenomena, and to do so, one first has to know someone actually experienced what has been lived. This means that a description becomes necessary when it is possible to get one”.

I take this stance as I feel the phenomenon is in the parents' lived experience, and I aim to present un-interpreted, in Husserl's slogan “back to the things themselves”. I see my

role as giving voice to those facts, in describing the phenomenon of loss of a twin. I agree with Sokolowski (2000:8)

“The core doctrine of phenomenology is the teaching that every act of consciousness we perform, every experience that we have, is intentional: it is essentially “consciousness of” or an “experience of something or other”.

The importance of this phenomenological investigation is to seek the phenomenon “death of a twin” with intentionality. I am therefore concerned with the structures of intentionality, perception, imagination, evaluation volition, and time and space and experiences of other people. My concern is to focus on how perceptions, thoughts, emotions and actions of the bereaved parents are directed towards the world (Smith, 2007). From a philosophical viewpoint it is the discovery of essences which makes this investigation important. It is the phenomenology that will inform health care professionals who care for those parents who have experienced the death of a twin.

The next section considers the philosophical underpinnings of my approach taken. I present the discussion that centres on the use of phenomenology in nursing research and the criticisms that nurse researchers have failed to adhere to the fundamental principles when utilising Husserlian phenomenology.

3. 8 Philosophical Underpinnings

Phenomenology is a philosophy rather than a scientific research method. Phenomenology has through philosophical commentators and philosophical minded social scientists become a way of doing phenomenology (Paley 1997). There are a number of schools of phenomenology, Moran (2000) states that while they share similarities they also have distinct approaches and different approaches to data analysis. Sokolowski (2000) suggests there are as many phenomenologies as there as phenomenologists while Caelli (2000) has identified eighteen different forms. Nurse researchers have been drawn to phenomenology to the extent that it has become a dominant philosophy that guides knowledge generation in nursing (Norlyk & Harder 2010).

Phenomenological research undertaken by nurse researchers came under serious attack in the late 1990s (Crotty 1996; Paley 1997). Their criticism was that nurse researchers disregarded the fundamental principles and misunderstood key concepts. Understanding key concepts requires the researcher to access the original writings of Husserl. Crotty (1996) following a review of thirty nursing research papers asserts that European phenomenology has been misinterpreted and a less critical approach has been adopted in the nursing literature. It is worthy of note that the papers referred to by Crotty are mainly American in origin. Silverman (1987:6) defends this position and in his writing suggest that American philosophers are not concerned with “*problems that require analysis, dissection, and argument. Their interest is more with the description of a phenomenon, topic, structure, or cultural production through elucidation, elaboration, and demonstrations of difference from related domains*”. While Crotty (1996) acknowledges that nurses are doing phenomenology he refers to their approach as new phenomenology. He argues that it is not European phenomenology and therefore requires a label to identify it from European phenomenology. The central core to this disagreement is that those whose research is steeped in subjectivism cannot be called phenomenology. European phenomenology seeks the objective reality of things themselves (Spiegelberg 1982). It therefore seeks to examine the objective reality of subjective experience (Willis 1996). If there is no object independent of the subject, if the object has collapsed into the subject, phenomenology by mere fact of definition is impossible (Vallack 2002). Therefore researchers who are steeped in subjectivism cannot be called phenomenologist or certainly not within Husserlian phenomenology.

Silverman (1987) states that American phenomenology is more concerned with understanding than with objective examination of the description. Thus he suggests that the directions taken and the approach to conducting research are divergent from European phenomenology. Hamilton (1994) suggest it is not nursing that has changed the way phenomenology is done in America rather it is the way in which American phenomenology has changed and adapted the European phenomenology. The effect has been the emergence of a phenomenology that is less exact but more meaningful to those

who look to philosophy for an understanding of human experience (Silverman, 1987). It would appear that this change has occurred without noting or acknowledging its newness. While European phenomenology seeks the objective reality of the subjective experience American phenomenology seeks the subjective experience. The core of American phenomenology is to understand the subjective experiences of the person as they engage with the phenomenon rather than focus on the more objective reality of the nature of the phenomena itself (Caelli 2000). Understanding the meaning of their patient's experience may enable practitioners to support and provide appropriate care (LeVasseur 2003). While Crotty (1996) argues the case for a new phenomenology Paley (1997) states American phenomenology bears little resemblance to its European roots and therefore its legitimacy as phenomenology. Paley's criticism is that nurse researchers have misunderstood the concepts of 'bracketing', 'reduction' and 'essence' and their results therefore bear little resemblance to the original phenomenology. He suggest that nurse researchers instead of accessing Husserl's work adopted a second hand approach to Husserl's use of 'bracketing', 'essence' and 'things themselves'. Paley identifies three tiers in phenomenology, the important philosophical commentators such as Speilgeberg, Merleau-Ponty and Riccou and how they relate to the study, the second tier refers to philosophically minded scientists, Giorgi, Natanson, van Manen who are responsible for bringing Husserl to sociological thought. The final tier is nurse researchers who have adopted phenomenology in their writings. Included in this list is Parse (1981), Oiler (1982) Omery (1983) Reeder (1987). Phenomenological nursing research refers to Husserl or Heidegger as a way of justifying the technical conceptual resources they employ. Lawlor (1998) argues that nurses are required to invent methodology and design that are currently lacking in textbooks while Koch (1995) suggest that nursing research has focused on 'method' and techniques rather than the underlying philosophical underpinnings. While Koch (1995) argues that concern for the philosophical assumptions that underlie a 'method' and whether they are consistent with the researchers own view, is a necessary starting point of any research. Where this is absent the resultant research bears little resemblance to the original phenomenology espoused by Husserl.

3.8.1 Bracketing

The object of 'bracketing' is to suspend the natural attitude that is the attitude we bring to everyday living. The technique of bracketing has been described as an attempt to hold prior knowledge about the phenomena under study in abeyance in order to perceive it more clearly (Powers & Knapp 1995). Bracketing described by Husserl (1931) implied that prior knowledge could be suspended and set aside so that fresh impressions could be formed about phenomena without interference of these interpretive influences.

Bracketing is used extensively in nursing research (Denzin & Lincoln, 1988). It is appropriated to all phenomenological research regardless of the philosophical framework (Walters 1995). The technique of bracketing remains perplexing and its use controversial when employed in existential or hermeneutic phenomenology (LeVasseur 2003). My experience of bracketing changed during this study. The use of bracketing was a conscious act however I became aware that during data collection and analysis the work of bracketing appeared less onerous. I felt this was due to the data which was new and different to what I had read in the literature. I suggest this experience enabled fresh impressions about the phenomena without the intrusion of previous influences.

Phenomenology as discussed by Husserl sought a return to the world of experience which he sees as the starting point of all science. Husserl sought the description of a phenomenon by focusing on the very things as they manifest themselves. Phenomenology emerged at the end of the 19th century to solve simultaneously a crisis in philosophy, a crisis in the human sciences and a pure and simple crisis in the sciences, where positivism was unable to answer the questions being asked of human sciences (Merleau-Ponty 1962). Positivism was described by Dilthey (1978:18) as "*the preference for a method which interprets mental and historical reality from the standpoint of the study of the natural-external world*". Husserl's response to positivism was a proposal to try to integrate the world of science and the life world. I understand Husserl to mean (Moran 2000: 108) "*by going back to the things themselves Husserl means we cannot be satisfied with employing concepts whose evidential basis has not been properly identified by being brought back to their original sources in intuition*". Husserl links phenomenon to the subject, there is only a phenomenon when there is a subject who experiences the

phenomenon. Thus Husserl focused on the world of experience and that the world is experienced by a subject. The resultant phenomenological analysis results in the explication of the phenomenon as it relates to experience. Therefore all knowledge is rooted in and can be related to experience. Such a view may be contrasted with the scientific approach which hold that there is a world having prior to existence to the world of causality and the relationship between things that scientists aim to describe (Hart, 1998). The resultant knowledge is described by Francis (1986) as abstraction and idealizations about the world in which we live and have little to do with the properties of the things we experience in everyday life. The phenomenological analysis as espoused by Husserl sought descriptions; he was not interested with causation. He was interested in the essential features of a thing so that it could be recognised as such.

Rolfe (2006) argues that what is usually referred to as Husserlian phenomenology by nurse researchers is grounded in several assumptions more usually associated with (post) positivism such the idea that our subjective views could be bracketed out, a belief in *'essential truths about reality'* and the ability *'to confront data in pure form'* (Polit & Hungler 1997). Rolfe holds the view that if not a positivist, Husserl certainly took a 'scientific' approach to the psychology of perception in a similar vein to the early psychology experiments of William James (personal communication). My view is that Husserl's phenomenology has commonalities with positivism that is it seeks the analysis of objective experience of the subject. Is Husserl a positivist? Husserl may be considered a positivist in terms of letting the experience of other people speak out "back to the things themselves". However, I hold that Husserl is not a positivist in that the phenomenon arising from the objective experience maintains a link with the experience as lived as opposed to measurement and abstraction.

Husserl is central to the phenomenological movement which has progressed from Husserl's purely descriptive phenomenology to the development of interpretive phenomenology espoused by Heidegger, Gadamer and Smith. It is within Husserl's phenomenology that my study sits most comfortably. Husserlian phenomenology is now an established and well respected methodology in nursing research and rightly described

as qualitative research (Rolfe 2006). Within Husserl's phenomenology lived experience is a tool to access the description of phenomena in their primordial or original form that is in their everyday physical activity (Husserl 1931). There is little understanding of the lived experience of death of a twin. I therefore suggest what is needed is a rich description of this phenomenon. I also suggest that without description it is difficult to make an interpretation.

3.8.2 Insider/ outsider research

Reflexivity was important throughout the research process; from writing the proposal, through data collection and analysis and writing the exhaustive description. My position as researcher had to be negotiated throughout the process. Through bracketing and in writing the individual phenomenological reflection I examined and made explicit my assumptions. Negotiating the position of the researcher requires thought about insider/ outsider and the implications and advantages of one position over the other (Witcher 2010). As a researcher undertaking this study I also had a role as nurse within the area I was investigating. This placed me as an insider. Indeed I also experienced insider role with the participants. My experience as the mother of a preterm infant resulted in insider status when parents described their experience of having a baby cared for on the NNU. The experience of occupying both roles within the research experience was challenging to me however I also feel it was a positive aspect of the study. Indeed the experience of parents validated my own experience as a mother and similar issues were present e.g. the dependency on the HCP. It is commonly assumed that being an insider can result in a more authentic voice (Merriam et al. 2001) while factors such as gender, age, colour may also impact (Bishop 2005).

As an insider I understood how to gain access (Kidd 1992; Pugh et al. 2000) and employed the use of gatekeepers who themselves were interested and supportive of the study. Of serious concern to me was the fear of isolation resulting from concern and anxiety that colleagues had regarding the perspective of parents. I therefore provided feedback on progress and preliminary results. Interviews were undertaken away from the

clinical area. This was important as it afforded time and space to process negative and challenging comments about professional care.

Being an insider enabled me to answer questions from my colleagues as the study progressed thereby allaying their anxiety and proving a stimulus for thoughtful care. I utilised my supervisory team and my counsellor support to explore areas that challenged me and provided a safe environment to examine my assumptions (Bonner & Tolhurst, 2002). This was of greatest value when discussing issues of anger towards professional colleagues. Parents were also aware of my insider status as evidence of one parent's comment "you are a nurse yourself" before raising a critical opinion of nursing practice.

An advantage was that I knew very little about the experience of death of a twin. This I experienced as an advantage as it enabled me to see and hear the newness of the experience. I was entrusted with very personal information which was affirming of my roles as researcher. As an outsider I was challenged in aspects of professional care. This was uncomfortable and also a stimulus to action. The experience made me realise the degree to which the experience of death of a twin is as yet poorly understood and highlighted to me what matters to parents. I saw my role as outsider as being advantageous to the participants. I presented openness to the relationship (Bonner & Tolhurst 2002). My approach enabled me to develop a relationship with the participants as someone they could talk to. A very important aspect was the fact that their experience was valuable and valued by myself as researcher. As a phenomenologist a reflective approach was taken to ensure the voice of the parents was heard thereby ensuring credibility (Swisher 1999). During interviews I was very aware of my occupying both insider and outsider status. This position highlight to me that the positions are not discrete, rather a movement occurred as the study progressed. This change in position is articulated by Narayan (1993:671) who suggest that the researcher's concern should be directed towards the recognition of "the shifting identification amid a field of interpreting communities and power relations". Thus, all researchers move along a number of axes depending on time, location, participants and topics (Mercer 2006) and it is unrealistic to classify oneself as true or absolute insider or outsider (Hayano 1979). I have become

aware that a high level of reflexivity is demanded of the researcher to remain alert and how identity can impact on the research process (Northway, 2002). Such recognition is an integral aspect of credibility of the research process.

The next section presents the definitions of the individual empirical reflection and the empirical phenomenological reflection and their importance to Husserlian phenomenology.

3.8.3 Individual phenomenological reflection (IPR)

The individual phenomenological is an important aspect of phenomenology within the Husserlian tradition. The individual phenomenological reflection (IPR) makes explicit the researcher's pre-understanding in relation to the death of a twin. I viewed the IPR as a means of bracketing knowledge and assumptions about death of a twin in addition to informing the reader about my presuppositions about the phenomena. The IPR seeks to engage the reader and locate the event in a time and place where the phenomenon has been experienced and therefore to suggest that there exist a phenomenon of 'death of a twin'. The IPR contributes towards the credibility of the study.

3.8.4 Empirical phenomenological reflection (EPR)

In keeping with Husserl's phenomenology I sought the essence of the phenomenon death of a twin. I utilised Colaizzi (1978) approach to analysis who describes the essence as having an essential structure. That structure is made explicit in the EPR. That is what is essential for and constitutive of the phenomenon 'death of a twin'. Thus the invariant elements of the lived experience of death of a twin are identified and from the fundamental structure. The meanings that are not necessary to the identity of the phenomenon are not included in the fundamental structure (Kleiman 2004).

3.9 Rationale for choice of Husserl's phenomenology

The first stage in this phenomenological study is to make explicit my own experience of the death of a twin. I present six presuppositions which serve to bracket my previous experience and knowledge, bracketing is a prerequisite to the phenomenological approach

within Husserlian tradition. This is followed by the individual phenomenological reflection (IPR) and represents my interest in the phenomenon. It tells my story and it orientates the reader to the phenomenon as I have experienced it.

3.10 Significance of the phenomenon as understood by the researcher

The significance of describing the death of a twin was based on six presuppositions and on intuition (intuition in Husserl's terms refers to the evidence of consciousness) from my experience as a nurse and mother. The first presupposition is that death of a twin is a public and complex event. Public due to the environment in which it occurs. Complexity is due to many reasons: the involvement of the MDT when a baby dies on the neonatal unit; the surviving twin remains and serves as a reminder of loss; the expectation that birth is associated with life and not death; the expectation of modern medicine to support life and ensure the survival of preterm infants.

The second presupposition is that of attachment which has been cut short for one baby. While attachment has been cut short for one, there is the desire that this attachment should have continued to develop. Therefore there is both the loss of attachment and the resultant desire. Both factors increase the pain of separation and loss.

The third presupposition is that death of a baby is a painful experience. It is painful because the very fact of survival brings with it hope of a continuing life. This hope grows with every passing hour. It is painful because a life has ended so very soon after birth. To assimilate birth and death within a very short time period is painful. Different emotions are experienced for birth and death. Birth is a time of joy and celebration. Death is final and is difficult to cope with and accompanied by sadness.

The fourth presupposition is that the parents experience a changed life. A stark contrast exists between the last day spent with their dead baby and their return to care for her twin sister or brother. Life continues, in the grieving for one baby and the parenting of the other.

The fifth presupposition is that death leaves a survivor. The survivor enables the parents to continue their parenting role. All the love and care, attention and expectations are now focused on one baby rather than two. However, the survivor serves to remind the parents of their loss.

The previous five presuppositions outlined above make explicit my current consciousness of the phenomena death of a twin. These presuppositions are based on Husserl's concept of intentionality. The sixth and final presupposition is intuition. We are always conscious of something and that something is referred to as the 'object'. Intentionality is the first stage in the development of knowledge. Knowledge requires evidence. For Husserl, intuition provides the evidence of experience. Husserl recognises three types of intuition or evident experience: sensory perception; eidetic or essential insight and phenomenological reflection. I as the researcher engage with parents through the senses and through an intuitive reflective process transforms what is first seen intuitively (Moustakas 1994). As I consider particular phenomena, there emerges a pattern, a similarity, an essence. This essence permeates a particular phenomenon and is expressed through them. This process is known as eidetic description and intuiting of particular phenomena provides the essences (Crotty 1996).

3.11 Individual Phenomenological Reflection

The purpose of the individual phenomenological reflection (IPR) is to expose the phenomenon death of a twin both existentially and phenomenologically in an introductory way. This reflection is the first part of the phenomenological research where the researcher makes contact with the phenomenon, the thing, by returning to the thing (Husserl, 1956). This phase and its fit with philosophy is explained by Spiegelberg 1982:109

“Analysis of meaning and opinions, whether of common sense or of more sophisticated positions, is not the prime objective of philosophy. Instead what philosophy must begin with are the phenomena and problems themselves; all study of theories, however

significant must take second place. The only proper way to evaluate the fittingness of such an approach is by examining its fruits in one's own actual insights"

The IPR and subsequent words were my own actual insights as a means to return to the thing of interest in a pure and yet a-theoretical way. The IPR used a method of thinking to contact, to elucidate in the words of Colaizzi (1987) to interrogate consciousness of the phenomenon. It is only the beginning of phenomenology, however it serves to unpack the presuppositions and expose what is about to be investigated.

The IPR seeks to inform the reader of my presuppositions about the phenomena derived through imaginative presence (the reader's) using phenomenological thinking. The IPR seeks to engage the reader and locate the event in a time and place where the phenomenon has been experienced and therefore to suggest that there exists a phenomenon of 'death of a twin'.

The nursery, one of two, was a typical intensive care environment, providing intensive care for six babies. Mostly all beds were occupied, parents and HCPs worked together to care for the babies. A system of open visiting was in place and parents were present for long or short periods. Mainly the mothers were there in the day time, in the evening the fathers came after work. Parents would sit beside their baby, talk to, sing or read. Often these stories were ones parents had enjoyed during their own childhood. Sometimes the mother would just sit, at other times she would make entries in her diary. She would converse with the nurse, these conversations varied, influenced by the mother and nurse but mostly the mother talked about her baby. The nurse talked to the mother about her baby's progress and on occasions to the mother's delight uncovered some new aspect of her baby's personality.

The nurses strived to keep noise and light to a minimum so as to promote an environment conducive to the growth and development of the sick baby, though their efforts were at times compromised by the unpredictable nature of intensive care. Parents enjoyed cuddles with their baby, for most parents this was a much anticipated and enjoyable time.

However, at times their baby dropped their heart rate or oxygen levels, during holding. Such experiences were stressful for the parents as they felt responsible and were on subsequent occasions sometimes reluctant to have their baby out.

I arrived on duty from a day off and took over the care of twins born at 27 weeks gestation. The twins Alice and Jennifer were almost one week old and were progressing well when I last cared for them. On receiving report I was shocked to hear that Alice had become very unwell. The consultant had spoken to the parents the previous evening, stating Alice had had severe intraventricular haemorrhage in addition to overwhelming sepsis. Two days ago I had left her as a lively pink baby.

As I received handover, my mind was active as I thought of the parents and how they might be feeling. I thought about the parent's attachment to their babies. How attached do parents become when their baby is cared for in an intensive care environment?

Attachment seemed very important to me as I contemplated the fact that Alice might die. In pregnancy mother and baby are one; following delivery and admission to the NNU the HCPs presence separates the mother from the intimacy she enjoyed with her baby during pregnancy. I reflected on the fact that there had been such little time for the parents to become attached and care for Alice. Did they feel they had missed opportunities, had HCPs always helped and facilitated Mum and Dad's contact with Alice? What did it mean to have to face death so early in life at a time when parents were beginning to know their baby?

My first concern was for Alice and to ensure she was comfortable and not in pain. She was no longer pink in colour but, pale with a distended and shiny abdomen, almost green in colour. She was receiving maximum ventilation and cardiovascular support. Her comfort and pain free state was maintained by a morphine infusion. Her peripherals were slightly oedematous and cool in spite of the high ambient incubator temperature. She lay on her back, nested within a soft boundary and attached to her ventilatory support. I opened the incubator door, greeted Alice and cupped her head in my hand as is my usual

practice. Alice lay still, I talked to her and then fleetingly she opened her eyes. Alice looked very sick and appeared to have little energy for any conversation.

Having settled Alice I went to speak with parents. As I walked down the corridor I wondered what I would say to them. I had difficulty in adjusting to Alice's changed appearance I pondered how the parents might be assimilating and adjusting to the changed appearance of their daughter and her prognosis. I reflected that another person was involved. Her sister Jennifer was to become a surviving twin. Jennifer was going to lose the person she had shared life with for the first 27 weeks of her life. Will memories of this time always be present to the parents and how will they be able to separate this sad time from their desire to love and parent Jennifer? I wondered at the term 'survivor', what has she survived? Will she be treated more carefully, will people acknowledge her sister or will people tell the parents "you are lucky, you have got one baby" I did not think these parents were lucky.

3.11.1 Preparation for death

The parents were distressed; they had slept fitfully and for short periods. Mum said "I can't believe it, I thought I was dreaming until I woke up and then realised I was living a nightmare". Mum and Dad had always associated new babies with life, had never seen death or indeed within their family and friends had not known a dead baby. I thought I must prepare them. What does it mean to prepare someone for the death of their child? I accepted that I could prepare them for the practical aspects of her death, for the support that they might need, for the memories they could create. I did not feel I could prepare them for the death. Do I prepare parents for something that I can only imagine? I reflected on my previous experience as a mother of a premature baby. I found the presence of the HCPs both comforting and at times a barrier between myself and my baby. My desire for privacy was overwhelming. Parenting in the NNU is lived out in a very public environment. These memories were helpful in my preparation to care for these parents. I thought about the important things as I saw them, and in my previous experience was found helpful by other parents. However, I was also mindful that each

parent is different and I could only imagine but really I did not know what it felt like to live their experience.

Mum and Dad said “we would like Alice to be baptised and could you arrange it?” I contacted my friend and colleague the hospital chaplain who was attached to the NNU and was familiar with death. I also knew she had sensitivity to parents as her eldest daughter died as a baby, I knew she would say the right thing. What was the right thing to say to parents whose baby is going to die today? How do we know and when do we say it? There were no guidelines as to what to say or when. Was my chaplain friend guided by the parents and did her openness to them ensure that her response was the right one? The nursery quietened during the ceremony and the parents were joined by nurses who had cared for Alice. Other parents who were present stayed with their babies. I remembered too the baptism of my own baby ‘just in case’. Alice’s baptism was a preparation for certain death.

This day would be given to making Alice comfortable and supporting her parents while not forgetting Jennifer. At the end of the shift I would go home and realised that for the parents they would enter a changed world. A world of grief lived partly in the NNU environment, a world of caring and nurturing Jennifer their surviving twin, no longer the parents of twins. As these thoughts passed through my mind and were noted, I became aware of an ordering of my thoughts and the need to make this experience as memorable as possible. In making death as memorable as possible I was thinking about a good death. A good death that the parents would have whatever time they needed to say goodbye and the privacy to do so.

The parents spent some time with Jennifer and Alice. We talked about Alice; I wanted to help parents to know that Alice was a strong girl with a big personality in spite of her weight of 1100grms. I recounted the things she liked; being talked to, being held and her response. As we discussed her development over the past week there were occasional smiles from mum and dad. Memories of happier times were revisited. The HCPs who had cared for Alice came to speak with the parents and provide support. The parents became

aware of how Alice had touched the lives of so many people. I thought this would be an important memory for them.

3.11.2 Acknowledgement of a life / Creating memories

Death though a certainty for all is unpredictable as to its timing. What does it mean to be told this is the last day of your baby's life? What did the parents think about this final day; the last hours and the last minutes and the last seconds of her life? How did they want to plan for this time? This thought was important to me as it focused on what I imagined the day might be like for the parents. Was this the end of a dream of a normal family life? The joy of having twins would end today. How would they remember this day? Memories were created in the form of hand and foot prints and photos were taken. A photo was taken of Alice and Jennifer together with their parents. These memories were put together in a special envelope. As I put these together I thought about what might be the meaning of the memories for the parents. Do they need memories and if yes have we created the right kind of memories? Are memories important, is there a possibility they might ever forget this painful experience? Have I created memories to make me feel better? An important aspect of my care was to give some tangible memories to the parents.

3.11.3 Death

Mum asked to hold her baby while she was still breathing, though really the ventilator was breathing for her. Mum and Dad said "can you stay with us; we have never seen death before?" I thought of the parents that the first experience of death should have been the death of their child, their baby, a twin. This was not a rehearsal and I would not be able to return and make good any errors or omissions. Alice had lived for such a short life, and yet for her parents she had assumed a personality, she had engendered many emotions in her mum and dad as they held her, cared for her and experienced sadness when they had to leave her in the care of the HCPs. They were grateful for this care and knew she would not survive without it. They were also aware that the HCPs were a physical presence between them and their baby. On this last day I wanted to reduce my physical presence and ensure space, time and privacy for the last hours and minutes with

their daughter. The parents wanted a time of quiet before the removal of the endotracheal tube.

As I spoke to the parents about the practical aspects of withdrawing of care and removing the tube I was aware of the finality of this event. What did the death of Alice mean to her parents, and how it might affect her sister Jennifer? As Mum held Alice, I removed her breathing tube. For the first time Mum sees her baby's face without tubes. She held her in her arms tightly yet tenderly. Alice continues to breathe for some minutes, her colour becomes darker, and her lips are now a light shade of blue. Her breathing becomes less frequent and develops into gasps. She gasps a last time and is silent. Alice is dead in her mother's arms. Mum asked "Is she dead?" I listened for her heartbeat and it was silent. Dead, there is such finality in that word. Dead; taking all Mum and Dad's hopes and dreams for her and her anticipated shared life with her sister. Dead, adjusting to a life of no longer parents of twins, how do parents manage this suddenly changed landscape? As Alice took her last gasp the tension in her mothers' shoulder eases and she relaxes and her tears flow. Dad embraces mum as she holds their dead twin.

3.11.4 Saying goodbye and continuing life

The nursery was quiet; a late evening quietness after the busyness of the day was complete. Today the space previously occupied by Alice was empty. Jennifer lay in her incubator under the glare and heat of the phototherapy lights. Mum and dad sat with her for hours and took turns talking to and gently touching their surviving twin. So very recently they had taken turns in visiting her and her sister, now the focus of both parents' love and attention was the survivor.

As the parents left the nursery on the evening before Alice's funeral they stood in the nursery door as we said our goodbyes. Dad said "we will not visit tomorrow as it is the day of Alice's funeral, and we want to spend the day with her". What did spending the last day with Alice mean? Having spent that time did it mean that they would be able to return and care for Jennifer? How would they remember Alice? How would they like me

as a nurse to care for them as parents who had lost one twin? Did they wish for me to speak about Alice and ensure that she was remembered by all the HCPs? Did caring for the parents and Jennifer mean ‘moving on’ and ensuring they had the parenting skills to care for Jennifer? Where would Alice feature in her sister’s life? How would ‘moving on’ affect her sister?

These were the questions that went through my mind as I reflected on the changed life for this family. They are questions that have stayed with me and their presence cause a disturbance in my caring for parents who have lost a twin. These questions formed the basis for my research question “*How do parents experience the death of a twin in the neonatal period?*”

3.12 Research Design

3.12.1 Ethical committee approval

Ethical permission for the study was obtained from the Research Ethics and Governance Committee of the Faculty of Health and Social Science (FREGC). FREGC Application Number: 08/26. Ethical permission was obtained from The National Research Ethics Service (NRES) Research Ethics Committee REC reference number: 08/H0803/111 (Appendix 2). Amendment to include death of a twin in the perinatal period, REC reference 08/H0803/111, Amendment number: 1 (Appendix 2; Appendix 2A).

3.12.2 Sensitivity

Due to the sensitive nature of the research study I considered the possibility that the sharing of their experience might cause upset or distress to the participants. I therefore put in place six counselling sessions for all parents who were invited to participate in the study. The counselling was provided by the MBF and financed by the charity, *First Touch* at St. George’s.

3.12.3 Participant information

An participant information pack containing letter of invitation (Appendix 3), participation information sheet (Appendix 4) and consent form (Appendix 5) was sent to each

participant. The information related to the purpose of the study, the requirement of two interviews and the provision of counselling.

3.12.4 Notifying general practitioners

A letter was sent to the participants' GP (Appendix 6) informing him that his patient had agreed to participate in the study. A copy of the information sheet (Appendix 4) for parents was enclosed. The GP was invited to make contact if they wished for further information regarding the study. None of the GPs made contact with me.

3.12.5 Support for the researcher

Qualitative research is an increasingly important method of developing nursing knowledge (Hewitt 2007). However, the potential for sensitive or difficult subjects to be raised is inevitable (Johnson & Mcleod 2003). Researchers have experienced emotional risks because of the sensitivity of the subject area being researched (Sampson et al. 2008) and experienced vulnerability (Robley 1995). It was anticipated that listening to the lived experience of the bereaved parents would be stressful. To be overburdened with the emotional load would be counterproductive to both interviewing, the research study and to my work in practice. A support system with a colleague qualified in counselling was set in place with the provision of both regular and ad hoc meetings as required. This was particularly important during listening, transcribing and the analysis stage.

3.12.6 Interviews

In keeping with Husserl's phenomenology I was interested in discovering meanings of phenomena from lived experience (Kleiman 2004). In-depth face-to-face interviews were chosen as the most appropriate means of investigating the parents lived experience, (Kvale 1996). Interview prompt questions are presented in Appendix 7. The participants were asked to tell me about the experience of their loss which required an expression of their thoughts about the phenomenon (Forrest 1999). Seven participants were invited to be interviewed in their own home or a private room in the hospital. One parent asked requested a telephone interview as she wished to avoid being seen in an upset state. Interviews were arranged at a mutually agreeable time. The details of the interviews are presented in Table 3.2.

Table 3.2 Interview details

Participant	1st inter- view	Length of 1st interview Hr/min/secs	2nd inter- view	Length of 2nd interview Hr/min/secs	Place of interview
1. Charlotte	25/09/08	1.45.13	05.06.09	25.24	Own home
2. Dennis	16/10/08	1.58.23	14.07.09	1.26.09	Hospital
3. Cathy	16/10/08	1.04.19	14.07.09	44.47	Hospital
4. Tricia	09/10/08	1.14.45	07.08.09	1.1.24	Own home - telephone
5. Chloe	12/11/08	1.10.16	10.02.10	1.30.0	Own home
6. Carol	15/01/09	1.49.25	08/01/10	1.28.18	Own home
7. Alice	09/02/09	1.56	09.11.10	41.54	Own home

The first interview was transcribed, anonymised and analysed. Second interviews were primarily to present my understanding from the analysis. My aim was to ensure that the voice of the parents be heard and that my analysis was true to their experience. This was confirmed by the respondent's comment that I had accurately captured their experience of death of their twin. The second interview was listened to but not transcribed, however in addition to the above confirmation of finding the second interview provided an insight into the temporal impact on grief. The sense of loss remained, the dead twin was remembered, and the use of the baby box (memorabilia related to the dead twin) enabled sharing the biography of the dead twin with the survivor. Detailed medical notes pertaining to the circumstances of the death of the twin were acquired in preparation for sharing the history of death with the survivor at an appropriate date. In addition, ashes were still retained and the search for the perfect place was no nearer being found. Indeed there was an acknowledgement that the perfect place may never be found and confirmed for these parents the difficulty in separation. One parent intended to manage this separation by stating she intended to use half of her baby's ashes to make a piece of jewellery that she could wear continuously. Her decision to use half her baby's ashes was an insurance against losing the jewel. Her husband felt this was a very morbid action. For

another mother the dead twin was remembered by her and her children when visiting an Italian city and lighting candles in a church they visited. Another mother related how she from time to time metaphorically took the baby box from under her bed so as to be with her dead baby. Candles were lit in remembrance of the dead twin on their birthday. The second interview confirmed the continuing bond with the dead twin and the activities to ensure his/ her presence in the ongoing lives of the parent and the surviving twin. I also considered the second interview to have brought a degree of comfort to the parents. Their experience was validated in the research and that experience was shared by others in the study. Parents were interested in other parents' response to their loss. The second interview afforded an opportunity to acknowledge the depth of their loss, for sharing the findings and thereby reducing their sense of isolation.

3.12.7 Timing of interviews

The first interview took place at a minimum of six months following the death. This lapse of time recognised that parents needed time to be adjust to their loss This was an important aspect of timing as the interview had the potential to be distressing to parents (Parkes,1995). These interviews lasted between one hour and four minutes and one hour and fifty eight minutes. The interviews were taped, transcribed and analysed. The second interview planned for six months later was delayed, (Table 3.2). Delay was due to the volume of work involved in analysis and the practical necessity to avoid scheduling interviews during birthdays and school holidays. The second interview with Participant 7 was further delayed due to hospitalisation of the surviving twin and subsequent health needs, and the avoidance of birthday and Christmas.

3.12.8 Selection of the sample

Sampling issues are an important factor to ensure congruence with the method (Corben 1999). In keeping with phenomenology a purposive sample of seven parents (Appendix 7) was drawn from those parents who had experienced the death of a twin during pregnancy and in the neonatal period (Morse 1991). This is in keeping with the requirement to include only those who have experience of the phenomenon (Baillie 1996). The sample therefore encompassed a broad variation, thus allowing for the

establishment of a meaningful relationship between the sample and the wider population (Mason 2002). The gatekeepers were consultants and the counsellor on the Neonatal Unit. They approached parents initially and introduced my research. The consultant spoke to the parents at the time of an outpatient's appointment or phoned parents directly. The consultants spoke to me prior to talking to parents to ascertain whether the parent was suitable for inclusion. In this way I was able to gain a broad perspective of experience. TAMBA acted as gatekeeper for the support organisations.

The bereaved parent is vulnerable and often emotionally upset (Parkes 1995). Parents require time to consider the research, to reflect on the written information and to have a follow-up conversation where questions can be answered and issues clarified. I agree with Parkes (1995:176) *interviews are conducted so as to minimise distress and maximise accuracy of information*. I did not wish to cause distress to the participants and therefore did not approach parents until six months had elapsed following their loss. I feel that lapse of time was crucial for although all parents were upset at times during the interview, none wished to stop. For one parent the interview was the first occasion when she had sat down and spoke about her loss. Miles & Huberman (1994) provides a comprehensive approach to sampling. While my approach was a purposive sample this was extended to criterion sampling to achieve maximum variation. Thus the sample represented parents who experienced the loss of a twin during pregnancy, at time of delivery and in the post natal period. The inclusion and inclusion criteria is set out below.

3.12.9 Inclusion Criteria

- Parents who had experienced the death of a twin in the perinatal/ neonatal period
- Parents who were six months post the loss of their baby
- Parents who could read, hear and speak English

3.12.10 Exclusion criteria

- Parents who had experienced multifetal death unrelated to twins
- Parents, who did not hear, read or speak English. This was justified on the basis that the presence of an interpreter had the potential to influence the interview

3.12.11 Funding for counselling

Approaching this charity posed an ethical dilemma for me as I am a trustee. Following a presentation to the committee I received funding. This was on the basis that one of the aims of the charity is to support parent welfare and my study fell within this remit.

3.11.12 Credibility

The issue of validity is of fundamental importance for enquiry in any research paradigm (Reason & Rowan 1981). I have found the various terms used to clarify the validity of my study confusing. Validity is based on the positivist assumptions regarding instrumentation, reductionism and objectivity (Yonge & Stewin 1988). Generalisability, reliability and validity have reached the status of scientific holy trinity (Kvale 1996; Tobin & Begley 2004) and expounded by all true believers in science. Quantitative research arises from a different philosophical basis, employs different methodology and methods. Therefore, to apply those concepts commonly used to evaluate quantitative research to qualitative research is inappropriate. The application of these concepts have fallen out of favour (Kvale 1996) and have been replaced by other terms, such as credibility, transferability, dependability and confirmability (Lincoln & Guba 1985). I have chosen the term credibility as a useful and appropriate tool to evaluate the truthfulness of my study.

3.13 Credibility of findings

There is a close relationship between dependability and credibility (Lincoln & Guba 1985). Valid knowledge is a matter of relationship, and validity is enhanced if we can say we know (Reason & Rowan 1981). The challenge is therefore to answer the question how do I know the truth that has been uncovered with the participants? I am drawn to the words of Sandelowski (1993:1) who suggest the focus remains with the research and the evidence is “*evocative, true-to-life and meaningful portraits of human experience*”. I suggest that I have achieved credibility in my findings by taking the analysis from the first interview back to the parents for their consideration. The findings were validated by

each parent. In addition, in the last interview with participant 7 (Alice), I sought validation of the empirical phenomenological reflection (EPR). Credibility was achieved by the participant affirming the identification of her experience within the EPR. Thus, I had achieved an understanding described by Reason & Rowan (1981:245)

“One cannot understand any psychological state without the capacity to experience it, not any social situation unless one can get into the ‘world-taken-for-granted’ perspective of those involved; yet at the same time as ‘getting into’ the experience, the researcher needs to be able to maintain a perspective on it.”

A second and important aspect of credibility is an established audit trail (Lincoln & Guba 1985). An audit trail (Appendix 9) enables the reader to follow the flow of the research and while not necessarily agreeing with the conclusions, they can see where the conclusion came from. In addition, the audit trail provides evidence of decisions made and remade therefore the keeping of a reflective journal provides the evidence of the decision making process. Appendix 10 provides excerpts from my reflective journal.

3.14 Method of data analysis

The challenge is to achieve congruency between the approach to analysis and the methodology used. Methods of analysis have been produced by Colaizzi (1978; 1973), Giorgi, (1985), and van Kaam (1969) from The Duquesne School of phenomenology based on the philosophy of Husserl. These researchers came from a background in psychology and sought to redress the balance of experimental methods used in psychological research by accessing experience through description as opposed to its measurement. While they are all concerned with producing a description of the phenomenon, it is only Colaizzi who calls for validation of the results by returning to study participants. van Kaam (1969) situates his phenomenology within hermeneutics, interpretive phenomenology and has its basis in the writings of Heidegger. The approach by van Kaam does not fit with my philosophical basis which is Husserl’s descriptive phenomenology. I will therefore address the approach to analysis taken by Giorgi and

Colaizzi who situate themselves within the descriptive phenomenology of Husserl in order to provide the rationale for my choice of descriptive analysis.

Giorgi (1985:1) in his approach to phenomenology seeks

“to do justice to the lived aspects of human phenomena, and to do so, one first has to get to know how someone actually experienced what has been lived. This means the description becomes necessary when it is possible to get one”.

Giorgi (1985) holds that in qualitative analysis descriptions can provide insight of a value equal to quantitative approaches. He is concerned with going beyond description to that of meaning. Both Giorgi and Colaizzi take a similar approach to analysis to arrive at a description of the phenomenon. Giorgi’s approach to analysis stops at a description albeit a description based on a detailed analysis. However, I wish to go beyond description and identify the essential structure of the phenomenon of the study. I am therefore seeking congruence between the philosophical basis of my research and the method of analysis.

A phenomenological researcher is required not just to provide a description of the experience but also a fundamental structure of the phenomenon (Colaizzi, 1978). The process of analysis as conducted in this study is set out in Table 3.2

Table 3.3 Stages of Analysis (next page)

Stage	Process
Stage 1	<p style="text-align: center;">Individual phenomenological reflection on the death of a twin</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Source of data is researcher alone</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Method of analysis</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Phenomenological reflection</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Discovers fundamental structure (as understood by the researcher)</p>
Stage 2	<p style="text-align: center;">Written descriptions (transcripts)</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Steps 1-4 of analysis</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Read all transcripts to acquire a feel for them (each transcript)</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Significant statements (each transcript)</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Formulate meanings (each transcript)</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Form clusters of themes (each transcript)</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Obtains fundamental description (each transcript)</p>
Stage 3	<p style="text-align: center;">Combine clusters of themes from each transcript</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Reflection on the data to obtain what is fundamental to the subject's description</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Fundamental description (FD) captures that which is fundamental in the description of 'death of a twin' or explicit appearance of a phenomenon 'Death of a twin'</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Return to participants and integrate any new information</p>
Stage 4	<p style="text-align: center;">Taking data processed form Stage 3</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Reflection on the major themes in order to explicate them</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Fundamental structure (FS) refers to the essence of a phenomenon 'death of a twin' as it is revealed by explication</p>

Colaizzi sets out a clear argument for objective description of experience and the importance of this approach. By understanding objectivity we can come to understand experience. Experience that remains with the person is part of their personhood. This objectivity is essential to me as researcher. Colaizzi (1978:52) suggest to be objective is to *“express what stands before him, whatever may be the phenomena that he is present to; objectivity is fidelity to the phenomena. It is a refusal to tell the phenomena what it is, but a respectful silence to what the phenomena speaks of itself”*.

It is the acknowledgement of and the ability to acknowledge my experience as objective that enables me to research the objective experience of others. I am enabled to recognise the objective experience of others by first recognising my own experience as objective. This I have accomplished in the IPR. Colaizzi (1978:52) describes objectivity as a requirement to *“recognise and affirm both my own experience and the experience of others. Simply stated, experience is there, for all of us, and it cannot be objectively eliminated”*.

Equally others experience is out in the world as they engage in and with it. I experience my existence as it thrusts itself in the world. Colaizzi holds that our experience and our existence is closely bound and cannot be separated. He holds that to deny my experience is to deny my existence.

Colaizzi (1978) states that *“no single method or procedure but only methods and procedures of description”*. The challenge then is to describe the experience. Colaizzi devised procedural steps for analysing written protocols in a systematic approach (Colaizzi 1978:59-62)

1. Read all the protocols to *acquire a feeling for them, a making sense of them.*
2. *Extract significant statements* that relate to the phenomenon.
3. *Formulate meanings* from the significant statements.
4. Form *clusters of themes* from the aggregated clusters. Note discrepancies, tolerate ambiguities. Do not exclude data that does not fit.
5. Write *an exhaustive description* of the phenomenon

6. Write a *description of its fundamental structure*
7. Return to subjects and integrate any new data into the description.

Colaizzi's method provides a phenomenological description of the phenomenon. He suggests that the phenomenological methods exist on two distinct levels: the experience of a phenomenon and the phenomenon experienced. He quotes Merleau-Ponty (1962) "*in our experience we can distinguish the fact we are living through something from what it is that we are living through*". Thus consciousness is engaged in a pre-reflective manner as we live through the experience and a reflective manner as consciousness reflects on the content of the experience. Pre-reflective and reflective components will be addressed more fully in chapter 7.

In my study the exhaustive description is the essence of the phenomenon as it is experienced. The exhaustive description is presented within four main themes of this phenomenon as it is experienced. The fundamental structure relates to what is being lived through and is the essence of the phenomenon as it is revealed by explication. The fundamental structure therefore follows on from the description and forms the final part the analysis.

The phenomenon investigated was the experience of seven parents following the death of the twin. The phenomenological analysis of the seven taped interviews was intended to answer the two questions: 1) what is the meaning of the experience of the phenomenon and 2) what is the fundamental structure of the phenomenon. The reader is required to bring their consciousness to the phenomenon investigated. van Manen (1990:13) states that

"when you listen to presentation of a phenomenological nature, you will listen in vain for the punch-line, the latest information, or the big news. As in poetry it is inappropriate to ask for a conclusion or a summary of a phenomenological study. To summarise a poem in order to present the result would destroy the result because the poem itself is the result".

This suggests that the reading of a phenomenological research study does not provide a take away message rather it stimulates us as practitioners to ponder and consider the relevance of the findings in practice. It therefore provides an understanding of the phenomenon and may act as a stimulus to HCPs to consider that understanding in the context of their current practice.

3.15 Summary

This chapter has addressed the nature of reality and my world view and provided a rationale for Husserl's phenomenology. Approaches to phenomenology within nursing research have been discussed. Bracketing my presuppositions has been addressed and through the use of the individual phenomenological reflection the reader has been drawn into the world which is the basis for the research. Consideration is given to what constitutes knowledge in the context of my research. Ethical issues related to the generation of knowledge have been addressed. Finally the method of analysis was presented.

CHAPTER 4: AN ILLUSTRATION OF METHOD OF ANALYSIS

4.1 Introduction

The previous chapter provided the reader with my world view and the rationale for the adoption of descriptive phenomenology. As a phenomenologist I have bracketed my presuppositions as presented in the individual phenomenological reflection. The ethical framework for the study was presented. The chapter ended with a discussion on the adopted method of analysis. This chapter serves to introduce the reader to the management of the data and stages (though not all) of the analysis process. The purpose of this chapter is to illustrate the stages of analysis in progressive manner. The management of the data is first considered. This is followed by four stages of analysis. The first stage is the immersion in the raw data. The second stage is the identification of significant statements; these are statements that are directly related to the phenomenon. The third stage involves moving beyond significant statements to formulating meanings. The formulations must discover and illuminate those hidden meanings in the contexts and horizons of the investigated phenomenon which are announced in the original transcript. The fourth stage presented is the exhaustive description; the exhaustive description captures what is fundamental to the experience of death of a twin.

4.2 Management of the data

The following stages were completed in the management and analysis of the data. The first stage of data analysis involved immersion in the raw data. The purpose of immersion is to get a feel for and make sense of the data. This was achieved by listening to each interview five times. Immersion was further enhanced by transcribing the interview and reading the transcript. Once transcribed each line of the transcript was numbered. Appendix 11 provides an example of a transcript and Appendix 12 provides examples of field notes taken during interview. The purpose of line numbering was to facilitate the location of selected text and enable the reader to cross check. Also the participant's

response is sequentially numbered in bold. The use of bold type for the participant's pseudonym enables the reader to identify the flow of the interview.

4.3 Managing transcript: numbering and flow of interview

This section presents the reader with the illustrated approach to management of the transcript. The interview was transcribed and each line was numbered. The first 156 lines from participant 1 Charlotte's interview are presented. The flow of the interview is made obvious with the use of bold font to identify the participant.

(Starts - next page)

1 Mary Charlotte, can I ask you to tell me a little bit about the events that led up to the
2 death of Isla

3 **No. 1 Charlotte** Mmm, okay, so well I found out I was pregnant in about Jul2003,
4 around ahm then and so do you want me to go in detail about everything

5 Mary However and whatever you would like to share

6 **No.2 Charlotte** Ok, so we went for a scan at our local hospital we, and ahm well I
7 already had a miscarriage a few months early, very early miscarriage, so they already
8 had that information so when we went in the stenographer was very to ensure that I
9 was okay and ah, and she very quickly said I can hear a heartbeat and then asked me if I
10 had been feeling very sick and whether there had been twins in the family and said that
11 we were expecting twin and we were shocked, surprised, excited but then in the next
12 breath she said she was concerned 'cause one of the babies was much smaller.

13 Mary And what gestation were you at this time?

14 **No.3 Charlotte** This was about 13- 14 weeks, so ahm she was concerned
15 that one of the babies was a bit smaller and mentioned a condition called twin to twin,
16 which we didn't know anything about at that point and explained that sometimes
17 when the large baby has all the nutrients and the smaller baby doesn't get any.
18 So she said we needed to wait to see a consultant, so we, so I was very upset obviously,
19 and we had to wait in the waiting room with everyone else (Charlotte laughs- not a happy
20 laugh) and that wasn't good and they eventually came in and took us to a quieter room on
21 our own and we waited and eventually, after quite a while the consultant came and to be
22 honest he didn't He didn't sort of ... (Charlotte slows in her speaking) really say
23 anything, he just said yea, well you know you will have to go to St Elsewhere because
24 that is the Regional unit, they would refer us on and we would get an appointment the
25 next day. Ahm, so that was it really, he couldn't really tell us anything, tell us anything at
26 that point, so we came home and Henry my husband looked up twin to twin on the
27 internet and ... basically... the scenarios were... not good, and he was trying to think, to
28 prepare me for that but ... That if it was twin-to- twin we might lose one, or both of the
29 babies. So anyway the next day we went to A.... and we saw the consultant there. He was

30 actually very good and he explained ,explained what he was going to do, was quite a
31 detailed scan and that he wouldn't be able to talk to us while he was doing because he
32 would be looking at the detail. So not to worry if it was all quiet, which was
33 reassuring and then ... and then he would talk to us afterwards. And basically that
34 was what happened. So he did quite a detailed scan, which took quite a while and
35 then he sat down with us and talked us through and he said the babies had separate
36 placentas and different sacs and it wasn't twin to twin so we were obviously relieved
37 about that, but we were obviously concerned because of the size of the smaller baby
38 and he that it could indicate possibly a chromosomal disorder though I don't know he was
39 that ...I am trying to think back, he said it could indicate some difficulties ...but what he
40 thought was going to happen was disappearing twin

41 Mary Vanishing twin

42 **No.4 Charlotte** Yes vanishing twin and ...ahm and ahm so explained that
43 to us and thought that was the most likely scenario. So we were given some time in the
44 relatives' room and take on board that information and then a midwife came in and gave
45 us some information support groups, it was more about bereavement groups generally I
46 think at that time. You know we were to go back in a couple of weeks so we kind of went
47 off thinking that was the most likely outcome and were trying to trying to adjust to, adjust
48 to thinking about and then I just remember sort of a few things happening, which I
49 didn't think were very good. The next day we had a phone call from our local
50 midwife at our local hospital ah, where we had gone for our original scan, she rang us
51 up and she had obviously got information through and I had never met this lady at all,
52 and she rang up and she said you know I understand you had a scan and there are
53 concerns and she said one of the options was for fetal... I can remember the term, but
54 basically it was to terminate one of, the smaller baby. Ahm and talked a lot about the fact
55 that the baby/ babies going to have a lot of disabilities and so on and it was a bit out of
56 keeping with what we had been told the day before, which was basically that they
57 thought the baby would vanish. It just felt, it felt uncomfortable, very
58 impersonal to have that kind of conversation on the phone with someone I had never
59 met, anyway, so then we then waited a couple of weeks going back, the babies were
60 both still there growing and ahm physically the smaller baby was still smaller and

61 was still growing and that, and the consultant said we will just have to carry on and see
62 and at any point if there is any danger to them to each baby, we would have to review
63 things and ...and ... (Charlotte stopped talking)

64 Mary And were you seen at the regional unit

65 **No.5 Charlotte** Yes, they, we were seen at the regional unit and basically
66 they US scan every two weeks and we had appointment and some weeks both the
67 babies were growing and the smaller one always at a lower rate and at other times
68 there was concern about the blood flow ... ahm. At one point at about 20 weeks
69 the consultant said that he thought the smaller baby, we didn't know the sex of the baby,
70 the smaller baby he thought had a heart condition, a hole in the heart so he referred us to
71 specialist centre (SC), so we had an appointment later that day. We get there and they
72 and they did scan again, did quite detailed scans and they said they couldn't find any
73 difficulty with either of the baby's heart although it was hard because of the smaller
74 baby's size, he didn't think there was anything amiss so we were very pleased about that
75 and that was another hurdle we had got over and quite early on the consultant had
76 picked up the baby had exomphalus (abdominal wall defect), which was an indication
77 that maybe the baby had some chromosomal problem, possibly Downs, some other
78 chromosome, so we went down to the hospital and we came back and we continued to
79 have scans and there is another point where we went in at the weekend for steroid
80 injections just in case I went into early labour. We were kind of living for the scanning
81 appointment; everything else kind of was a blur ahm... So... then... it... got to a point
82 about... (Charlotte is speaking slowly) 22 weeks and again the consultant said he was
83 concerned about the smaller baby's heart and so we had another appointment at the SC
84 and we went down there and they said yea there was hole in the heart and talked about
85 the fact that that in itself isn't necessarily a huge problem and they could do surgery and
86 stuff afterwards but it wasn't.. the picture that the baby was small and there were other ,
87 major conditions ... so they suggested that, they didn't suggest anything particular, they
88 said surgery could happen and we needed to discuss it with our consultant, that is really
89 what they said. It was quite later, I remember, quite late in the afternoon and at this point
90 we were whatever. I think there had been ongoing concerns about blood flow to the
91 placenta, so I rang the consultant, I rang the hospital here on my way back for the SC to

92 say what we should do now. The consultant said come now, come now, it was 7 o'clock
93 at night and I am here and we will talk about it. So we did ... he was very clear that if we
94 delivered the babies there was a risk to the larger baby and we should just carry on and
95 the smaller baby would die anyway and (Charlotte is tearful)... sorry. Charlotte
96 composes herself and starts again so, we kind of, prepare for that (tearful)... So we came
97 back and I just stopped work at this point on their advice. I think the consultant and I
98 wasn't concerned about carrying on work, I didn't physically feel unwell and they said
99 and he said stop work and I did. Because of what the consultant said we just, I contacted
100 ahm, the church, and they were able to talk us through ... so anyway we still clinged to a
101 bit of hope

102 Mary And, Charlotte, what gestation were you at this stage?

103 **No.6 Charlotte** I was 33-34 weeks yea anyway we went back for the scan
104 and there was, I think what had happened was there was an appointment at St
105 Elsewhere... Our consultant said that it would be worth getting a paediatric team in so a
106 paediatric surgeon ahm... who could talk to us about what could happen, if the twins we
107 born that, so there were quite a lot of people around that time when I went for the scan,
108 and there was also a stenographer from the local hospital who also there for the day, I
109 suppose doing some kind of training. She remembered me. They scanned The large
110 baby was fine, the little baby had died ahm... We were obviously upset at that time and
111 they They took us to a family room I think they, I can't remember, I think a
112 midwife had offered to stay with us or if we wanted some time on our own and we had
113 some time o our own and it quite a while, it was an hour later at this point I just wanted to
114 go home, so Henry said ... Can we go home? So they said they just wanted us to wait to
115 see the consultant so we saw him and at this point we asked what the sexes of the babies
116 were and we kinda, we decided we wanted to know that at that point when we thought
117 this might happen, so he told us, we lost a little boy and we were having a little girl ahm
118 and he also explained we could go to (sound of child's voice in the background) and he
119 also explained we could go into early labour and gave us some indication of what to do,
120 go into hospital blah, blah. And he said the other option is that the pregnancy could just
121 continue. And that his advise would be to continue the pregnancy for as long as possible
122 to give the other baby the best chance so that was what we had to do really so we ahm

123 we, we, they'd offered us, I think we asked for scans, for reassurance really they said we
124 could have a weekly scan if we wanted it and ahm, I felt I did want that, so ahm, we
125 ended up having weekly scans

126 Mary Were you able to have those locally or did you go to...

127 **No. 7 Charlotte** No, we probably could have done but, we hadn't been very
128 impressed with the local hospital we hadn't been very impressed with it, we really liked
129 the consultant we had and we felt he had been upfront and gave us the information we
130 needed so we decided to stick with him, so there was quite a lot of travelling and we
131 decided to do that. Yea so then it was just a case of getting on with it really and I have to
132 say I didn't feel like seeing anybody ahm.... We just got through it ahm... and there
133 various things that happened which didn't help. We had the experience where the health
134 visitor (HV) rang me up, she wanted to arrange to meet me from the surgery, and she
135 knew I was due to have a baby soon so she rang up, obviously didn't know what
136 happened so I explained what had happened. She was very nice on the phone, for some
137 reason I didn't end up seeing her, she said I would see her colleague so I said could you
138 make sure to let her know about the situation, she said yes she would do that, she knew.
139 And then when I did go to see this HV she had, been told, she hadn't read the notes, she
140 was all bubbly and you know and I said I had spoken to your colleagues and...and I
141 couldn't talk about it very well and she said sorry I have not read your notes and then
142 she did and I couldn't talk about it. She obviously felt very embarrassed, I just felt things
143 like that just needed not have happened and then so... I'd also been told (Charlotte
144 coughs) very early on in the pregnancy that I would have a caesarean section (CS) and
145 they would probably be born around Christmas time, probably wouldn't go much longer
146 that. I think I was due at the beginning of January. So I had it in my mind these two
147 things and ah the consultant said I should try and go to 39 weeks which was actually
148 after Christmas and that was really hard (Charlotte slows in her conversation) and ... I had
149 in my mind it would all be over with really...(pause) so ahm that was a point ahm and
150 he also said I could have the babies naturally if I wanted to but, I felt I couldn't do that,
151 shouldn't do that, so (Charlotte's voice quietens) he went in, they were due on New
152 Year's Eve so we went in the day before and we. Oh a deacon came in who I think we
153 had been in touch with bereavement, midwife bereavement.

4.4 Significant statements

From the transcript I extracted sentences and phrases that directly related to the research study. These extracts are termed **significant statements** (Colaizzi 1978). The significant statements are numbered and are referenced to the original lines in the transcript e.g. No. 1 Lines 5-6 and Lines: 8-14. The following statements relate to the above section of the transcript.

No. 1 Lines: 3-4 Well I found out I was pregnant in about July 2003, **Lines: 6-12** Ok, so we went for a scan at our local hospital we, and ahm well I already had a miscarriage a few months early, very early miscarriage, so they already had that information so when we went in the stenographer was very to ensure that I was okay and ah, and she very quickly said I can hear a heartbeat and then asked me if I had been feeling very sick and whether there had been twins in the family and said that we were expecting twin and we were shocked, surprised, excited but then in the next breath she said she was concerned cos one of the babies was much smaller

No. 2 Lines: 14-17 This was about 13- 14 weeks, she was concerned one of the babies was a bit smaller and mentioned a condition called twin to twin, which we didn't know anything about at that point and explained that sometimes when the large baby has all the nutrients and the smaller baby doesn't get any.

No. 3 Lines: 18-25 We needed to wait to see a consultant, so we, so I was very upset obviously, so we, and we had to wait in the waiting room with everyone else (Clare laughs- not a happy laugh) and that was a bit, that wasn't good, and they eventually came in and took us to a quieter room on our own and we waited and eventually, after quite a while the consultant came a he just said yea, well you know you will have to go to Riverside Hospital because that is where, that is the Regional unit, they would refer us on and we would get an appointment the next day.

No. 4 Lines: 25-29 He couldn't really tell us anything, tell us anything at that point, so we came home and Henry my husband looked up twin to twin on the internet and ... basically... the scenarios were... not good, and he was trying to think, to prepare me for that but, so we kinda ... that if it was twin to twin we might lose one, or both of the babies both of the babies.

No. 5 Lines: 29-33 The next day we saw the consultant, he was actually very good and he explained, explained what he was going to do, was quite a detailed scan and that he wouldn't be able to talk to us while he was doing because he would be looking at the detail. So not to worry if it was all quiet, which was reassuring and then ... and then he would talk to us afterwards.

No. 6 Lines: 35-40 Then he sat down with us and talked us through and he said the babies had separate placentas and different sacs and it wasn't twin to twin so we were obviously relieved about that, but we were obviously concerned because of the size of the smaller baby and he that it could indicate possibly a chromosomal disorder though I don't know he was that... I am trying to think back, he said it could indicate some difficulties ... but what he thought was going to happen was disappearing twin

No. 7 Lines: 42-46 Yes vanishing twin and ... ahm and ahm so explained that to us and thought that was the most likely scenario. So we were given some time in the relatives room and take on board that information and then a midwife came in and gave us some information about ahm... support groups, it was more about bereavement groups generally I think at that time.

No. 8 Lines: 46-57 we were to go back in a couple of weeks so we kind of went off thinking that was the most likely outcome and were trying to trying to adjust to, adjust to thinking about that and ah ahm and then and then I just remember sort of a few things happening, which I didn't think were very good. The next day we had a phone call from our local midwife at our local hospital ah, where we had gone for our original scan, she rang us up and she had obviously got information through from St. Elsewhere and I had

never met this lady at all, and she rang up and she said you know I understand you had a scan and there are concerns and she said one of the options was for fetal ... I can't remember the term, but basically it was to terminate one of, the smaller baby. Ahm and talked a lot about the fact that the baby/ babies going to have a lot of disabilities and so on and it was a bit out of keeping with what we had been told the day before, which was basically that they thought the baby would vanish.

No. 9 Lines: 57-63 It just felt, it just felt, it felt uncomfortable, very impersonal to have that kind of conversation on the phone with someone I had never met, we then waited a couple of weeks before going back, the babies were both still there growing and ahm physically the smaller baby was still smaller and was still growing and that, and the consultant said we will just have to carry on and see and at any point if there is any danger to them to each baby, we would have to review things. **Lines: 65-68** And basically they scan us every two weeks and some weeks both the babies were growing and the smaller one always at a lower rate and at other time there was concern about the blood flow ... ahm.

No. 10 Lines: 68-78 At one point at about 20 weeks the consultant said that he thought the smaller baby, we didn't know the sex of the baby, the smaller baby he thought had a heart condition, a hole in the heart so he referred us to the Specialist hospital, We get there and they and they did scan again, did quite detailed scans and they said they couldn't find any difficulty with either of the baby's heart although it was hard because of the smaller baby's size, he didn't think there was anything amiss so we were very pleased about that and that was another hurdle we had got over and quite early on the consultant had picked up the baby had exomphalus, which was an indication that maybe the baby had, there was a chromosomal ... some chromosomal problem, possibly Downs, some other chromosome. **Lines: 79-81** There is another point where we went in at the weekend for steroid injections just in case I went into early labour, ahm it was We were kind of living for the scanning appointment, everything else kind of was a blur ahm...

No. 11 Lines: 81-89 So... then... it... got to a point about...(Charlotte speaks slowly) 22 weeks and again the consultant said he was concerned about the smaller baby's heart and so we had another appointment at the Specialist hospital and we went down there and they said yea there was hole in the heart and talked about the fact that that in itself isn't necessarily a huge problem and they could do surgery and stuff afterwards but it wasn't... the picture that the baby was small and there were other , major conditions ... so they suggested that, they didn't suggest anything particular, they said surgery could happen and we needed to discuss it with our consultant, that is really what they said.

No. 12 Lines: 89-96 At this point we were thinking it would be better to deliver the babies and have them and deal with whatever. I think there had been ongoing concerns about blood flow to the placenta, so I rang the consultant, I rang the hospital here at St. Elsewhere on my way back to say what should we do now. The consultant said come now, come now, it was 7 o'clock at night and I am here and we will talk about it. So we did... he was very clear that if we delivered the babies there, there was a risk to the larger baby and we should just carry on and the smaller baby would die anyway. So, we kind of, prepared for that (tearful).

No. 13 Lines: 96-101... So we came back and, and I just stopped work at this point on their advice. I think the consultant and I wasn't concerned about carrying on work, I was I didn't physically feel unwell and they said and he said stop work and I did. Because of what the consultant said we just, I contacted ahm, the church, and they were able to talk us through...so anyway we still clinged to a bit of hope

4.5 Formulating meanings

The next stage was to spell out the meaning of each significant statement, known as formulating meanings (Colaizzi 1978) and described as creative insight and involves the leap from what the participants say to what they mean. All meanings arrived at should maintain a link with the original transcript. Formulating meanings should not be constructed as interpreting the data rather it is a process of illuminating those meanings

hidden in the various contexts of the script. As a phenomenological researcher I feel comfortable with this interpretation of Colaizzi's. I see the emphasis on illuminating meaning as having a close link with reflection that is a central element of phenomenology. The numbering of the formulated meanings matches the numbering of the significant statements. This allows the reader to cross reference the origin of the formulated meaning with the significant statement and identify the source in the original transcript.

No. 1 Announcement of twins received with elation quickly followed by concern for one of the twins.

No. 2 Explanation of possible cause was new knowledge to us.

No. 3 Waiting in a public place for the consultant was a difficult experience.

No. 4 Little understanding of condition from consultant, own research helped in preparation for possible outcome of loss

No. 5 Consultant's sensitive approach and explanation reduced our fear.

No. 6 Detailed picture of twin pregnancy; provided reason for poor growth and likely outcome of vanishing twin.

No. 7 Beginning the process of adjusting. Time alone helps to assimilate information and understanding likely outcome.

No. 8 Shock at phone call (first contact) from local midwife, who suggests termination of smaller twin, was at variance with expected outcome of vanishing twin as explained by consultant.

No. 9 The cold contact from the midwife was put aside, the smaller baby continued to grow and the decision was made by the consultant to review in the event of danger to either twin.

No. 10 Close monitoring showed the smaller twin continued to grow at a slower rate but abdominal wall defect present, possible chromosomal abnormality. Scanning dominated pregnancy. Prepared for the possibility of preterm labour

No. 11 Heart anomaly again raised and confirmed at specialist centre, one of problems facing smaller twin, postnatal surgery to be discussed with consultant.

No. 12 A late evening appointment with consultant resulted in plan to continue pregnancy in the knowledge that the smaller twin would die.

No. 13 Stopped work on the advice of the consultant. Sought spiritual support and hoped against the odds.

4.6 Exhaustive description

The third stage in the analysis is the exhaustive description. The exhaustive description presents the parents' experience of death of a twin and reflects the themes that are present in the formulated meanings. It is in the words of Colaizzi (1978:61) *as unequivocal a statement of identification of its fundamental structure as possible*. As a phenomenologist this was a critical point for me in the process of analysis. I took my description back to the participants for their comment in the second interview. I thus sought to compare my description with their experience and validate my findings. I would like to point out that the exhaustive description is incomplete as it based on part of the interview.

4.7 Pregnancy

Announcement of a twin pregnancy was a great source of elation, quickly displaced by concern for one of the twins. Realisation that twin pregnancy was risky. Lack of privacy was experienced while we tried to assimilate the news. The consultant's sensitivity and individualised care reduced fear. An understanding was gained of poor growth with the likely outcome of vanishing twin. The smaller twin continued to grow and review of progress was planned. Scanning appointments dominated the pregnancy, confronted with a suspected heart anomaly and the possibility of a chromosomal abnormality. A heart anomaly was finally confirmed and post natal surgery discussed. A late evening appointment with consultant resulted in plan to continue the pregnancy in the knowledge that the smaller twin would die.

4.8 Confronting death

Death of twin was announced during the scan to inform surgical opinion.

4.9 Delivery

Anticipated delivery by Christmas did not materialise as consultant advised continuation of the pregnancy until 39 weeks, delivered by caesarean section (CS). Information and spiritual support was received prior to delivery.

4.10 Information

Research on the internet provided a basis of information prior to meeting with consultant.

4.11 Journeying with health care professionals (HCP)

The potential for a meaningful relationship with the HCPs was lost due to the distress caused by her failure to read mother's notes and thus presented herself out of context. The consultant determined delivery at a regional hospital.

4.12 Spiritual support

Sought spiritual support and hoped against the odds.

4.13 Summary

This chapter has presented Colaizzi's (1978) method of analysis. The management of the data was addressed and first four stages of analysis were demonstrated for part of one transcript. The significant statements were identified and formulating meanings were achieved. Finally the exhaustive description based on the selected part of the interview was presented.

CHAPTER 5: THE ESSENTIAL ESSENCE OF THE DEATH OF A TWIN

5.1 Introduction.

The previous chapter presented the management of the data and four stages in the process of analysis. A section of one participant's transcript was utilised to guide the reader through those stages of analysis: significant statements, formulated meanings and exhaustive description. The same approach to analysis was taken for all the transcripts. Therefore this chapter is a progressive display of the process of analysis. This chapter presents the exhaustive descriptions of the death of a twin based on all the transcripts. In order to avoid repetition that part of the exhaustive description from Charlotte's transcript (participant 1) is not included.

The chapter is divided into two parts. The first part presents an exhaustive description of the lived experience death of a twin. The exhaustive description comprises that which has been given to consciousness of the participants. Intuition or conscious acts are immediate presentations of experience. Those intuitions have been clarified and reduced through the process of analysis (Colaizzi 1978) to reveal new contents which were not available to ordinary consciousness or even ordinary reflection (Moran 2000). This eidetic seeing is what Husserl called 'essential seeing or 'seeing essence' (Moran 2000). Therefore the findings present the essence of the lived experience, which enables the reader to situate themselves in the experience and the journey of the bereaved parent. The essences I have grouped together to portray the journey of the bereaved as it is lived. The exhaustive description is lengthy and detailed. Quotations are used to illustrate the description from the raw data. These quotes are referenced to the participant and the lines from the transcript are identified e.g. P1: 21-24

The second part of this chapter presents the empirical phenomenological reflection (EPR) which is the essential structure of death of a twin (Colaizzi, 1978). The essential structure is achieved by the use of imaginative variation, which is dwelling with the exhaustive description to elicit what is essential for and constitutive of the phenomenon 'death of a

twin'. Thus the invariant elements of the lived experience of death of a twin are identified and form the fundamental structure. The meanings that are not necessary to the identity of the phenomenon are not included in the fundamental structure (Kleiman 2004).

5.2 Exhaustive Description

The exhaustive description provides the essences which are presented in four parts. These are presented in table 5.1

Table 5.1 The essence of death of a twin

Main themes	Subthemes
1. Experiencing death	Pregnancy Confronting death Information Meaning of death
2. Accompanied by others	Health care professionals Family Friends Other parents Spiritual support
3. Being Alone	Isolation Grief Loss as an unwelcome companion
3. Understanding the loss	A continuing presence of the dead twin Uncovered strengths

5.3 Part I: Experiencing death

Participants remember their twin pregnancy, their joy; they recount events that challenged that joy as well as the events leading up to the death of their baby.

5.3.1 Pregnancy

The participants describe the associated feelings surrounding twin pregnancy, shock, happiness, elation, joy, specialness, an anticipated normal pregnancy, and longed for healthy babies. The awareness of risks did not intrude into their strong and healthy state. They describe events that change enjoyment of the pregnancy to that of concern, while others describe the announcement of death.

Cathy describes her shock at the announcement which abruptly ends her problem-free pregnancy:

I was on the six months when I went for my scan and it was fine, the babies were wonderful and then of course my cervix was very thin so from then a kind of, my world came shattering down (laughs) and ahm... Ben and I were very, very shocked about everything we heard because we thought everything was going to be perfect, you know how people are naïve when it comes to pregnancy so we kind of... ahm ah we went home and I was bed bound, it was very, very scary time because I was terrified that these babies were going to come especially as I had done IVF. P3: 6-13

An understanding of the risks associated with twin pregnancy did not prepare Chloe for the potential experience of losing one of her babies:

When we discovered what kind of twin pregnancy it was we were warned of the risks associated with a monochorionic twin pregnancy but you never really think it is going to be you. So well we listened, we didn't, I dunno I just felt completely confident that this wasn't going to happen to us and we had a scan at 16 weeks and everything was fine, the consultant said 'Well it's a bit early and I'd like to get people back you know just come back and see me in a couple of weeks just to make absolutely sure that they don't have... the twin to twin transfusion' ah we went back and within the two weeks it was I mean

chronic he said very severe and you could see on the screen that it was. So it was just such a shock. P5: 6-14

Carol experienced a normal pregnancy; routine scans did not give cause for concern as she describes her antenatal visit:

Well I'd been in the week before for a scan and they could only find one heartbeat, which didn't actually concern me at the time, I just assumed, they told me that it was quite difficult sometimes to find two. So I went home, then I was due back in for another routine scan the week after. So I went for the scan, again not expecting anything ahm although I hadn't been feeling one hundred percent but you know, you often don't. Ahm and when I get in there, they immediately identified that one of my twins had died ahm which was a total shock to me actually. P6:5-11

Alice recounts her experience of an abrupt end to her pregnancy and the transfer of her twins to a regional unit and a new reality:

Well obviously you know you give birth at 23 weeks to twins you kind of know without anyone having to tell you, that its grim, ahm and having to cope with them being transferred to St. Elsewhere was the first kind of unexpected surprise that I've got experience of the neonatal unit in St. Elsewhere (fictitious) from having Joseph there for 10 weeks so that was the first blow, but they both survived the journey and it kind of once they have survived 24 hours you kind of start to hope, even though you know that that doesn't count for anything, and people were very careful I think the medical team at St. Elsewhere from the moment we got there were very careful to manage your expectations. Which is depressing but I think that that's something that they have to do and I understand that and I needed reminding um actually because otherwise you do start to be unrealistic in terms of your expectations, your hopes for them both P7:10-21

5.3.2 Confronting death

For some participants death is experienced as a sudden event while for others there is a gradual realisation that death awaits, though hope is sustained in the face of expected death.

Dennis describes his expectations, the events of labour and his response on hearing the confirmation of death:

I don't know if you knew that there was some form like a of a sac or whatever that actually was stopping Timothy for coming out and the whole birth took a long time, before he first came, once that a sac broke he then came shortly after that, in the next five minutes. When he did come they took him, put him on the side and ahm there was an Indian lady there, a doctor and she came over and just looked at him and said 'no there's no chance' and I kind of like moved from there, got a little bit queasy and went and went and lay down for a little while. P2: 7- 20

Cathy speaks of her inability to confront death until the delivery of her second twin was completed:

I didn't want the babies to come and obviously they did ahm... ah... when James was born ahm I actually didn't respond to his death at all, when Ben (husband) said to me ahm, ahm, because all the people there were trying to save him P3: 26 -28

She (consultant) did say to me they have tried but it would be cruel to keep him alive so I kind of listened to that I didn't cry I didn't do anything at all and then ahm... Ben was crying and I wondered why am I not crying what is wrong with me you know am I a terrible mother and then I concentrated on getting Joseph out and Joseph came out quickly and I think because of that it was less traumatic for him he, I assumed the steroids worked for him, I am not a doctor so I don't really know how it works but I assume that is what happened and I was so happy when I heard the little squeak you know and then they took him and ahm then when I turned around and saw James' body only then did I realise that, what happened to him. Because it had taken me, you know ahm... yea, I don't know it just didn't almost like it didn't sink in you know what happened until I saw the body. P3: 34- 44

Tricia recounts her experience, her involvement in withdrawal of ventilator support and the contest of emotions:

I had actually ahm...turn off the ventilator, had... the tube pulled out. That experience in itself was probably one of the worst experience, very traumatic, it is ahm... it's... I don't know, you can't explain without having to go through it yourself...its...it's you do want them to go because you know it is obviously better for them not to suffer but you also want to be selfish and you want them here. P4: 14-19

Chloe recounts her experience and feelings around her decision to accept the laser treatment to treat twin-to-twin transfusion and its unintended results:

We went for the laser surgery and ahm well we were told very unusually, and it was very unusual when they put the probe through the wall of my abdomen they went straight through quite a large blood vessel that was there which meant that the sac which they were going to operate through completely filled with blood and they couldn't see. So, after trying for half an hour they gave up. This apparently, never happened to the consultant doing it, ever before, and ahm I trusted him, we kind of got to know him a bit by then and he was very upset about it . P5:25-32 So we waited two weeks and did it again, but because he knew there was going to be quite a lot of blood, the visibility was going to be poor for the cameras, they gave me a spinal and proceeded to pump fluid into the sac whilst filtering it out to try to clear off the fluid ahm and they told me beforehand they expected it to take about half an hour and it was two and a half hours on the table, so she died that day. P5: 33-38

Carol describes her sense of shock:

I couldn't at all come to terms with it, in fact I thought they had made a mistake and I assumed their equipment was faulty or I just wanted a second opinion I couldn't take it in. P6: 12-14

Alice recounts the moment when death became a likely reality rather than a possibility:

You remind yourself that from the moment they came out it was unlikely that they would make it P7:52-53 it's almost one of the downsides of medical advances isn't it, in that it gives you hope, you know you feel that there is a chance and I of course in many parts of the world there would be no hope from the moment they'd come out but you'd kind of almost known that as it was happening and you'd have mourned P7:54-58 Julie did explain there was no rush to make a decision...about him... but it felt like it was clear and I'm grateful to Julie for the fact that she made it quite clear... that she felt we ought to give proper consideration to letting him go and not prolonging it and I'm glad she did that because I don't know how I would have been able to make that decision if she hadn't have been so clear cut. P7: 60-65

5.3.3 Information

Loss is viewed in the context of information. Information facilitates preparation for and adjustment to the situation while also enabling meaningful discussion with the medical team. Parents identified both a lack of information and lack of awareness by HCPs for the need for information. Information was required in the immediate period following death, information regarding possible long term effects of the death on the survivor, details so as to provide an adequate explanation to the survivor at an appropriate time. Failure to read shared information resulted in unnecessary distress for one parent.

Charlotte recounts her search for information and highlight points in her journey where information would have been helpful:

There was no information about TAMBA or about, I was kind of aware that SANDS was around I had no idea about TAMBA so as I say it wasn't until some weeks afterwards I was finding it very difficult and the HV did go off and looked some stuff on the internet and came back and I suppose I could have done that. I wasn't in a state (laughs) so then we got some information through from TAMBA and that was very much emphasising the telling the siblings about what happened so that is what we have done. P1: 296- 300

Charlotte lacked information about the emotional response and how to deal with it:

I think in terms of how you feel ... when you have lost one baby and have another one to look after ... nobody really told us what that would be like... maybe people don't know? But it would have been helpful to find something to say we'd probably going to feel something like this or have days when you feel, you don't want to cry in front of the baby, things like that, it would have been helpful advice P1: 579-584

Dennis views information as essential to meaningful discussion and reducing issues of doubt:

I thought the most important thing while I was there was to know as much as the doctors knew, so I used to read up and keep informed, I didn't really doubt it, so when they actually did tell me something that, I didn't really doubt it. P2: 167-169

Failure to provide explanations as to the meaning of high risk:

The whole time we came in with twins they said high risk, but they never told you why it was high risk or what you might experience, or what could go wrong or things. I think the only knowledge you most probably would get whatever you did researched yourself, and I think that's a shame, cos that's what I think, I think that's what midwives are there for. To, to explain all those things to you, to tell you what could happen and what couldn't happen and its really getting you prepared for this whole journey that you are about to go on. P2: 772-778

Tricia recalls her experience of being deprived of information:

To be honest when I got in the room...obviously I knew what they were gonna say because I had already been told in a manner of speaking ahm... as soon as he said I am sorry I just ran out of the room ahm...I didn't have a chance to speak to him again until ahm...two weeks ago (almost two years later) and that was just the case of David went for his gastric tube to be put in his belly and it happened to be the surgeon who'd done it P4:330-335

Chloe experienced a lack of information regarding care to the survivor. The dead twin continues in the life of the survivor. She identified her need for information that in due course she could use to explain fully to the survivor the nature of her sister's death:

I mean looking back now you know ahm there were things about ahm her condition when she was born so it took quite a long time for her to be able to feed milk because she had green stuff coming out of her bowel which took a couple of weeks for a consultant to say to me 'Oh that's because she was unwell when you were pregnant with her' and nobody kind of explained that to me that that was to do with the twin thing I thought it was just a young baby but apparently not, so it might have been nice ahm and I did say this to one of the doctors that when we first got admitted they said to me 'Right she is a survivor twin and this may come from this and this is the kind of thing we see and we don't know' but because you know it was I just realised now looking back on it I didn't understand lots of things that were going on and nobody kind of said what was individual to her and what was related to the twin problem. P5: 304-314

Carol describes the information that was required immediately after the death:

The third one (counsellor) who I think was in charge of it all, was in fact much more experienced and I found her much more helpful, not in terms of counselling, but in terms of giving me which at that stage is all I wanted, information in fact, she was very helpful with the funeral arrangements and how to deal with all that. P6:68-70

5.3.4 The meaning of death

Death has robbed the parents on many levels, joy and celebration, status as parents of twins, surviving twin of a sibling. For some parents pregnancy continued for some weeks, another was delivered the day following confirmation of death. Understanding extreme prematurity as a cause of death did not make its acceptance easier. For others their participation in the withdrawal of intensive care was a painful experience with lasting consequences.

Carol's describes her experience:

Yes you feel completely robbed I mean you know you're used to opening a bottle of champagne at the birth of your, well I mean you don't do that. P6: 374-375

Carol expands on the meaning of death: *But you know you feel completely robbed of the whole experience. And the joy. I don't think there's anything you can do about that though...cos that's really the way it is isn't it. P6: 377-79*

Carol experienced a changed self:

For the whole of the first year I didn't feel particularly normal I didn't feel like it was me, you know, I couldn't make any big decisions about things I mean I struggled to decide whether I should go back to work actually ahm and I and I did go back to work and I think that, not full time just a couple of days, two or three days and that was again that was quite helpful because that was part of a normalising process. So I think I started to feel a bit more normal then, a bit less, I felt like a bit of a sad person really and I didn't like that, didn't like feeling like that but I'm not sure, I had much control over it at the time....P6:384-391

Cathy finds solace in an early death though mixed emotions are present:

Because we didn't get to know James I think that made it much easier because if James had survived and he died later in hospital, I think that would have been terrible, terrible. Even though it was very sad for us and we mourned, it was like a weird feeling because I was happy to have Joseph and I was terrible sad to have ah not to have James. P3: 49-53

The survivor serves as a constant reminder to Tricia of her loss. Death serves to highlight the depth of her attachment and the disruption to her routine serves as a constant reminder:

I know that there is meant to be someone else with him and because I didn't lose Dominic straight away, he was with me for eight weeks ahm, obviously I grew attached to him...and ... it was always like... I'd see one child in an incubator and then I would go to another nursery to see another baby... there would always be another one... but because there is nobody else there... that is how it reminds... it's like... you know there's something missing ahm... that's the hardest. P4: 72-77

Chloe recounts how death brought anger, a time of waiting and the unexpected delivery of both babies:

I was really sad about that and angry about it... though not angry at the time, angrier now (six months later) I wasn't at the time, at the time I was just distraught. And then after that I kind of limped through another ten weeks, with an amniotic leak at six weeks which was awful, kept thinking I was miscarrying her or I don't know it just went on and on and then finally my waters broke properly at 31 weeks so sort of ten weeks after we'd lost Sophie. And gave birth to both of them, having been told I wouldn't, that the other twin would have reduced down and gone into the placenta, oh no, no, no. P5: 50-57

Death had a sense of unreality for Carol until she sees her dead baby:

It wasn't clear when, really, ahm, or indeed what she died of. I had the caesarean the next day, I had to wait the whole of the next day, in fact, ahm and have the caesarean about six or seven o'clock at night, ahm and then immediately, you know when Elizabeth came out ahm that, I think at that stage, well at that stage when I saw her I suppose you know knew that she had died but again it was almost as if I was expecting them to say 'Oh well yes we have made a mistake'. P6: 28-34

Alice recounts the meaning of death for her, at its centre is the decision making to withdraw care:

It is effectively having you to judge where this possible you know standard of life is going to be something that is going to be acceptable for James and the rest of the family. P7: 1036-1038

You know I don't have any regrets over James I just sometimes beat myself up over the fact whether there was a small minute possibility that had we let him carry on he might slightly he might have had a chance of being okay you know cos I went with the odds I went with the odds and you know I just have and that's one of the things I have come to terms with but it is the only thing that gives me you know a moment everything else I feel we did the right thing and all the medical team did the right thing. P7: 1288-1294

5.4 Part 2: Accompanied by others

Participants were accompanied in their experience by HCPs, family, friends and other parents. The presence of others was experienced positively in terms of empathic support and negatively in terms of lack of acknowledgement of their loss, lack of understanding and support.

5.4.1 Health care professionals

The participants experienced the presence of the HCP along a continuum. Individualised care maintained the focus of care on the parent in terms of professionalism, support and care. Arrogance was experienced as a lack of professionalism, poor levels of knowledge, intrusion and a belief that they (HCPs) could make things better.

Charlotte describes how the care she received fell short of her expected and needed care: *When they come to do your post-natal depression questionnaire and I just thought it ridiculous to do really... how can they tell the difference between being depressed, post natal depression and grieving, really. And so I remember I didn't fill the form in correctly. I thought this is stupid (laughs tearfully) I probably just didn't but I came out as borderline but I should probably have come out as lower than that... and I said that. And she did sort of acknowledge that probably there were other reasons why I was scoring borderline... P1: 344-351 (needed) somebody just to acknowledge that Isla had existed... P1:355*

Charlotte describes the distress caused by HCP (community midwife) not reading communication related to her care and the resultant over optimistic view of the midwife contradicts the concerns expressed by the consultant:

One of the big things about communication was that I would be given a letter from the (word unclear) and there would be... a letter for me and a letter for the GP and there would be a letter for the midwife and I was actually physically given them to people, so I knew they had got to the people they needed to get to I had actually delivered them ahm yet I would go to an appointment and ahm that information wouldn't be there... wouldn't have been read...ahm so... I would find myself having to say to the community midwife,

the consultant said this and they are concerned and I mean her take on it all from the outset was you know people have very small babies and they survive and that was very much her message to me whereas I was getting from the hospital actually there's a lot to be concerned about . P1:634-644

Charlotte associates care out of context as disrespectful:

I think the great thing about notes being read which would have saved a lot of grief, I think it is unnecessary, it is hard to talk about it at the time, feeling emotional and ahm its, it would be helpful if people had read the information. P1:722-724

Dennis describes what was for him, important aspects of care:

From the consultants right down to the cleaners I mean everybody, they all do what they are, more than what they are supposed to do. Ah, everyone one of them does a little bit more. I mean even the cleaner who comes around and cleans the dustbins he always used to say 'hello' and 'how are you doing' and try to find out from you. And the nurses they did everything and more than what they are supposed to do and at times I think they became quite a good family as well. P2: 564-570

Cathy describes her experience of the HCPs as engendering feelings of safety for her baby:

I mean it is just such a miracle... that's what I thought so yea I definitely felt very, very safe with everybody and I trusted everybody I knew that whatever happened... if he did die everybody would have tried their best to keep him alive. P3: 147-151

Cathy describes the effect of receiving photographs of her dead baby and the resultant difficulty in separating the identities of her babies:

When James died they gave me pictures of his... dead fetus and I did find that very strange (laugh) and it did freak me out and I kept on seeing James' face in Joseph's face so when Joseph was born I kept seeing James' face and thinking of my God this is terrible I kept on thinking Joseph is dead every time I looked at him he looked like he was dead I couldn't look at Joseph for a long time. P3: 273-278

Cathy remembers clearly the occasion of her receiving the photos and her reaction:

She (midwife) came in and she was saying goodbye to us and she gave us this little sort of booklet...and inside the booklet were the pictures and she opened it a little bit and I looked away and then she closed it and I never looked at it again and I said to Ben when we got home I really don't want that, I am really upset by that. I don't want to see a picture of my dead child. P3: 290-295

Cathy describes the meaning of being cared for:

They were there for me , I just felt like, I felt so close to them, I really, really did and I felt like ahm, they were even crying with me and that's why I felt so connected to them because I felt they felt my pain, they weren't just ahm there doing their job basically and saying well I am very sorry but it is just one of those things, but they were really wonderful and they were holding me and supporting me in all the ways that I thought that I would have wanted at the time. P3:540-546

Tricia reflects on her experience of care and its resultant effects:

I wasn't very pleased with the way things were handled with Dominic the same night he died as well ahm... so that obviously pushed me away from the support that if I wanted any, I wouldn't have taken it ahm...because it was such a horrible experience.

P4: 236-238

Tricia recalls the unwelcome intrusion of HCPs at the time of her baby's death:

It has, it really has affected me badly, (voice shaky/ trembling) yes it has... it has...I mean when I was holding Dominic waiting for him, because obviously we pulled the tube out and then went into the Quiet Room to hold him while he was going to sleep...and ...my...complaint was...that I wasn't left alone with him...just to let him go. I had people coming in, nurses coming in every 10 minutes... ahm... just checking his heart 'Oh he is not gone yet' his heart is fading 'I'll be back in another 10 minutes. You don't want that, you just want to be left alone, you know he is going to die...die...you just want...just let me hold him in peace. P4: 241-248

Tricia describes what she would have liked at that time:

This is what I would have liked, I would have liked to in the Quiet Room just me, him and Daddy... and then let us hold him and talk to him as he is going to sleep... but we never got that. And I think if I would have got that I would have been a little calmer ahm... and maybe not so anxious at that specific time. P4: 250-254

Tricia speaks of deep pain associated with the intended supportive action of the nurse:

One of the nurses came up to me, put her arm around me and said 'I am so sorry' obviously I hadn't been told anything by then... obviously that gave it away...so when (voice trembling) I got to the room as soon as Mr Oliver opened his mouth I just ran out of the room because I knew the situation before I got in the room. So that was handled diabolically. P4: 263-269

Tricia describes how she wished for normality from the HCPs and reflects on the private nature of her loss:

Let them talk to me normally as if nothing has happened. P4: 283-284
To be honest I don't like being approached about it. Everyone is different... I don't like being approached about it. I would like to talk about when I need to talk about it, I don't like talking about him unless I want to talk about him, because obviously it is a heart breaking situation, it's not something you can talk about as in a normal day to day conversation some people can but I am just one of the people who can't. P4: 286-291

Tricia recalls when her relationship changed with the HCPs:

I personally lost all faith in the hospital... not so much the nurses...ahm...more the...ahm the head of the people really... why didn't they intervene sooner... why...I was treated the way I was treated... people coming in... well one person coming in every 10 minutes P4: 319-322

Tricia speaks of her sadness at what she has lost:

I never got the peace and quiet to hold him... .. and that's wrong... the hospital when it comes to things like that... they need to break away a little bit... just to leave the parent alone... to give them space. P4: 496-498

Tricia remembers how the attitudes and belief of the HCPs are brought to bear on her unique situation and lack of recognition of her distress:

And then once I had calmed down a bit and I'd gone into the nursery to speak to him that's when I was pressured to 'Oh it's gonna be the kindest thing to pull the tube out, you need to let him go now, you don't want him to suffer no more' and I knew that I didn't need to be reminded... I just wanted... they ... need to give you time. That's what it is all about, they just need to give you time to get over the initial shock, which I know you never do... P4: 508-516

Chloe describes her continuing anger towards the HCP while acknowledging his care and his vulnerability:

I am aware that I am angry which I assume will disappear. Angry, with God, if he's there. The consultant... I think he should have looked, I think you know even if the chance was low, he knew it could happen because it had happened to other people before him if not to him and it would have avoided what happened to us and I am angry about that ahm although I respect him hugely and I like him so much. P5: 336- 343

Chloe remembers the care as individualised and the significance attached to that:

I mean everybody was so sensitive at the fetal medicine unit where we were, both of the consultant who I saw were lovely people and the twins' midwives who we got to know quite well were so upset for me as well. I mean they obviously have such a hard time doing that job that is a really tough job to do and you know even on the day we lost Sophie you know they came in and gave us both huge hug and they were really hands on and upset themselves which really helped they didn't just carry on and do it all solemnly and professionally they were actually really warm and felt it themselves and that was helpful to us although it must be awful for them if they are like that all the time, you know

God. But ahm they made us feel like it mattered you know and it genuinely did matter ahm and in fact. P5: 537- 546.

The experience of supportive HCPs is valued by Chloe however; there is a need for someone who fully understands the experience of her loss:

I think had they been cooler we'd have found it harder, whereas we knew it was alright to be upset we knew it was alright to talk to people at length because they made us feel like you know we could phone at any hour and speak to somebody about our concerns and that was great. I think what was missing for me and I said to the consultant afterwards was the chance to speak to somebody who had gone through exactly the same thing as me and that's not a professional thing. P5:565-571

Carol describes her experience of a sequence of three counsellors:

They (HCPs) were very good, they immediately also offered sort of counselling service now that wasn't quite so good, cos the first of the two counsellors that walked in the door, they had about three of them and I saw one pretty immediately after the scan the previous day, and I think it is just a question of ahm what clicks, doesn't it?. But I just didn't immediately find she said the right things to me, but you know, I guess she tried. But the next one we saw was even worse actually she came in she said you know, she was young and didn't have a clue really, to be honest, ahm and she said things that were not well, I mean, they weren't the right things to say, again. Ahm and then they had, in fact, a third one who I think was in charge of it all, was in fact much more experienced and I found her much more helpful, not in terms of counselling, but in terms of giving me which at that stage is all I wanted, information in fact, and she was very helpful with the funeral arrangements, and how to deal with that. P6: 60-71

Carol describes what she requires in a relationship prior to sharing:

You don't know this person (counsellor) at all you've got no relationship of trust, and someone like me, like most people you have to build up a relationship before you can speak to people, certainly about that sort of thing. Ahm, and I didn't want to, actually, so

I think there is a timing issue, what I wanted was just the facts, that's what I wanted and this is, given to me in a fairly objective way. P6:89-94.

Carol clearly remembers what she needed was factual information and not counselling:
I didn't really want anything else, because I wasn't ready to, to talk about anything else, certainly not to them really, as you say, so I just wanted, but the practical information was very important, so for me yes that type of service would be the best actually.

P6: 96-99

Alice describes the effect of not trusting the medical team as one of needing to know everything about the care of her baby:

I can't trust the medical team, I need to know every single thing P7: 301-302, you know you're trying to keep on top of what's going on which of course is completely pointless but it gives you a sense of control a sense that that you might have some say in that's what's kind of going on which again I mean I can see its all completely pointless but it kind of helps. P7:305- 309

Alice shares the importance of trust in the parent-nurse relationship and the peace that comes from being cared for by the 'good' practitioner:

So yes I would say after we lost James I probably became more obsessive about what was wrong with Henry and who was looking after him and whether I felt they could be trusted you're a nurse yourself so it's a delicate subject but you know rightly or wrongly you start to form opinions on the medical team and you know individuals, ahm you know people fall into different categories there were the ones that I didn't like and were good so I was quite happy with those, there were ones that I liked but I thought were a bit flaky, you know you know there were ones that were good and I liked them and wahey when I came in and they were on it was like woohoo! P7: 323-331

Alice identifies the qualities of the 'good' practitioner, to enable her to parent and have confidence in her baby's care:

You got, got your little kind of list and part, part of how you measured them was to what extent they would communicate with me and let me know what was going on and take me seriously. I think it took a while but I think sort of presumably doctors and nurses do the same with parents as we're doing with the medical team and make assessments which may change over time of course but I found that I felt at the end people took me seriously it felt like it did, they would talk things over with me find out if I had an opinion . The relatively junior consultants I know would ask me for my view and if I disagreed would take that seriously and you know the nurses a lot of the nurses were the same and that made a huge difference you know to myself my personal sense of worth and also to my confidence in you know Henry's care. P7: 331-342

Alice recalls her impotence in the presence of poor practice.

There were moments when you know split seconds almost when I felt his care was positively casual and you know you want to kind of scream but again you're busy balancing you know this person might do a the night shift in a week you don't want to upset them but you know those moments were you know were few I should say. P7:342-346

Alice questions her response to counselling. She understands counselling as an incongruity between the understanding of her loss and the offer of help:

Why it's so offensive early on I don't know. P7: 801-802.

It's just some random person that you don't know it's just the last thing you want. P7: 839-840

It's the audacity of this person (counsellor) to think they might be able to offer me any help you know I've lost my son unless they're going to magic him alive again which is beyond their powers then it's kind of like don't . It's almost patronising. P7: 806-810

Alice's describes the importance of giving space to the bereaved:

I think it's almost PC-ness gone mad, I think we're all desperate to do the right thing and make things but you can't make it better at all cos you have to let somebody wallow in self pity and distress and misery. P7: 845-849

Alice describes how counselling at this point would be helpful (2½ years after the death of her baby):

Yeah I think I think I feel like that, my husband doesn't interestingly maybe it's just a bloke thing you know they just kind of get on with it ahm I've thought that quite often it might be a positive thing for me to do... you know just to help put everything in its rightful place and give me a be a bit of peace maybe but I haven't had time ahm what with Henry. P7:758-762

Support from nurses was important for Alice:

I probably got more emotional help and support from unwitting members of the nursing team who would just say something based on their experience and it would actually provide me with quite a lot of comfort even if that hadn't been their intention. P7:824 - 827

Alice describes her appreciation of the division of labour among the HCPs; the sharing of facts by the consultant in a very practical way and the attention to emotional labour by other staff:

Everyone was pretty amazing generally I certainly wouldn't have any criticisms. What I appreciated was the very, is pragmatic the right word, very pragmatic practical realistic approach that people took while holding a box of tissues because you know I don't want a doctor bursting into tears although they may feel like it you know I just need be told the facts and generally I found that's what people did while having the box of tissues ready because clearly the facts you know turn into an emotional outcome for the parents and generally I thought everyone was pretty fab at getting the balance right. P7:950-958

People staying practical and dealing with the logistics and the facts I find quite helpful because it helped me to just keep on top of you know the emotional outburst until I've somewhere private and can do it without cos you know nobody wants to turn into a wreck. P7: 973- 976

5.4.2 Family

The family was experienced as compassionate in terms of practical and psychological support. Partners and family provided both practical and psychological support. This was not universal to all participants. Support from mother-in-law was valued but was experienced as an intrusion. A source of distress was the lack of recognition of the impact of the loss on the mother. A difference in generational response to the loss was experienced. Differences in the experience of the loss between mothers and fathers were present.

Dennis remembers how he and his partner helped each other:

It was difficult at times... having a partner and that...I think we really did help each other. P2:158-160

Dennis describes his perspective on the importance of family support in the presence of his wife's grief:

I mean even Ellen she, she used to say, she had my mum thank goodness who is a really strong person and ah she was experiencing the emotions but she didn't even know what they were. She kept on saying 'I don't even know why I am feeling this. I don't know why I am angry. I don't know why I am – I just can't control myself' and having someone, my mum she had five children who can just sit her down and say 'This is why you are feeling this'.P2: 520-525

Family support is described by Dennis as more valuable because of the emotional bond than that which is available from a HCP:

I mean my sister, my oldest sister she had I think she had post natal depression but she called up Ellen and said 'I went through the same things that you are going through as well. The same feelings, it's natural to be going through those things.' And, just to have a voice, not really having a counsellor or psychiatrist but just someone who you know, I'd say (laughing) just not a counsellor or psychiatrist. Because you can't like, you take a step back when you have people like that talking to you, you know, it's just human nature you shy away from that or you just don't really want to talk to them. P2: 525-531

Cathy describes her emotional ambiguity and conflict, the difficulty of reconciling support from her mother-in-law with her own needs for privacy and space to grieve:

I was so angry with her for being there because I felt she was invading on my space, my space with my husband, my space with Joseph and my space with mourning for my child definitely with her for being there and I wanted her even though I was angry with her I was grateful that she was there she really is a lovely woman and she is very supportive, I know that she sensed that I was very angry. P3:363-367

One evening I think she realised I was going through a really hard time and was resenting her being there but she came and gave me this huge hug and she just said I love you I love you and I know what you are going through and I understand and I am here for you and I really felt it was a wonderful thing that she was there for me because I know that I was ... so angry with Ben as well for how dare you let her be here, she needs to go you know and once we had that talk and she sat down with me and she said if you want to go crazy. If you want to scream and shout and do whatever you want to do, just do it ahm and after we had that talk I did feel a lot better. P3: 370-378

The need for personal space is of critical importance following the loss:

I still wished that she wasn't there, even though she was, was supportive, she was helpful, she did everything, she rearranged our entire flat organised all that she cooked and she cleaned and she and I mean she was she really was fantastic and even after I gave birth, she was wonderful, she looked after me while Ben was sleeping, she was fantastic yea so even though she made me feel so angry I did, I did partly (Mary: recognise) you know half wanted her there and half didn't, it was kind of weird. P3: 378-384

Chloe describes the gap between care and understanding within family support:

You know everybody tries to make you feel better because they love you and they want to look after you but it's not, they don't always say the right thing and ah you know. My sister has got two boys as well and we both wanted a girl and I remember her saying 'Oh God, don't moan at least you've got your daughter' and I remember thinking 'oh you have no idea you know' and ahm she loves me to death and we are very close you know

from her point of view I'm sure that is really what she sees but, it's harder than that.

P5:199-205

Chloe grieves for her dead baby and her parents grieve for her. They too want to make things better for her:

Basically I think because they (parents) are too scared at the prospect of it not being okay for me you know, but sometimes that's not, as I said to Mum several times very bluntly 'Why do I need to hear that now?' I just need you to tell me this is awful and then she would say 'It's awful' (laughs) but they were great, and they have been great all year, saying to me all the time 'We're here if you want to ring up and yell at someone or sob at someone we're here and no, they've been fantastic. P5: 209-215

Chloe describes how the death of Sophie has challenged her relationship with her husband:

I'm angry with my husband as well but I don't think that is to do with the twin thing I think that's to do with the person that he is, I, you know I am angry he didn't come and see the baby with me, for me, to do it for me because I needed to, he only just went to the funeral... because I think he felt he really had to do that ahm because my mum and dad offered to come with me instead and I just thought that was too much and he was really glad he had done afterwards so that was a relief. P5: 361-367

Chloe considers part of the emotional cost of her loss as an impact on her relationship. The differences are recognised and there is agreement to deal with them at a later date:

But I felt I had to be in charge of the whole thing you know I had to organise it even push him to do it I had to you know but you know that's just what he's like and he would be like that in any situation with regard to a bereavement and has been like that since his dad died when he was a teenager and apparently behaved very much like that then. So he's definitely got some issues to deal with about that, which he does know ahm but it hasn't been easy because it shows up the biggest differences between us and sometimes I think he should just do things for me because I need them to be done and you know he definitely felt that his loss was as awful as my loss over the twin whereas I felt it was

definitely worse for me, awful as if was for him, you know I had to have the operations, I had to give birth do it all, so it had to be worse for me but he never recognised that ... and still doesn't really recognise that. He himself was so angry with everybody else for saying 'they're all asking about you nobody's asking about me' and fair enough I mean I'm sure for dads that is a real problem but they were asking about me because I had had months of surgery, recuperation, leaks you know it just went on and on and on and they were asking about me because he couldn't be here because he was working so hard so it was, I did understand but at the same time I ended up saying to him 'But lovely you know, it's alright I know how awful it's been for you but it's been terrible and blah blah blah' and I never felt that he really turned around and did that for me. It kind of, so you know it has been a problem but it's a problem that we have talked about and are aware of it and I wouldn't say it's gone away. P5: 367-386

But we do keep saying to each other, when this is over we really must sort this out [laughs] so it's not like we don't know, we're well aware, but it is there and you know if there is a cross word it comes out very quickly. P5: 388-391

Carol describes the importance of family support as enabling her to focus on the needs of her children:

I had lots of support (family) because I'd put lots of things in place thinking I'd have twins, so I had too much, well in a way too much help, well it was probably better that way than not. Ahm and it meant that I could focus, I actually focused quite heavily on Sophie and Mark my older ones to keep things going for them and Matilda P6: 161-165

Carol describes the impact of the death on her eldest daughter (who was six at the time of their birth):

She was fine really yeah I mean not initially she wouldn't talk about it for the first year or so very much at all in fact after that we could talk about it and she, it did affect her, it affected her cos she was very excited about the possibility of two babies and to come home with one was for her... P6:171-174

Carol speaks of gratitude for support and highlights the generational difference perception of loss:

I mean my parents came to stay, for two weeks really and did you know, and did everything really. P6: 281-282 Except I think there's a bit of a generational thing, with parents in terms of their attitude more to it. Well I don't know but it's a bit this is nature's way a little bit and a little bit of that. P6: 284-286

5.4.3 Friends

The support one mother received from her friends serves to illustrate how support from the mother of twins is both supportive but also demanding on the bereaved mother. This situation resulted in the bereaved mother protecting her friend from the distress the understanding of this loss brings.

Carol describes her friend who has a special insight into her loss:

She knows more than me what it's like because has twins and I don't so I think at the time she was very upset and probably more upset than a lot of my friends because I think she knew, she knew you know and I didn't know and she did what I had lost ahm so yeah she has, she's a very good friend. P6: 210-214

Carol reveals her friends perspective on her loss:

I don't know, I'll never know. P6:219 I suppose it's the flip side of the coin I knew what it was like to lose one she knew what it was like to have twins. P6: 220-222

Carol describes understanding demands a moderation of her grief.

You know she was very supportive but equally she would get more upset because she could imagine so then my concern would be not to upset her. P6:225-227

5.4.4 Other parents

Other parents in the neonatal unit speak from a perspective of knowledge. Their empathy is borne from lived experience.

Alice describes the moment she faced the possibility of the loss of her twins:

I had never known anyone who had lost a baby and ahm although I was telling everybody via text and phone call that I had given birth at 23 weeks and that it was grim and that they would probably both die it wasn't until Joan looked me in the eye and told me that she had lost her first girl a year ago and this was her second attempt and Sian was very ill and I actually suddenly realised and that it really was possible quite almost definitely going to happen, it's kind of weird you know busy telling everybody, acting as if I'd totally accepted the fact that this but I don't think I still actually believed it until you know she said. P7: 275-282

5.4.5 Spiritual support

All parents held a funeral which served as a public acknowledgement of their baby's life. Some parents experienced spiritual support at this time which was experienced as providing healing and a sense of closure.

Spiritual support was continued following Charlotte's discharge from hospital:

Our priest was very supportive, he came and saw us at home, we ahm talked about what we wanted and it was a very short service and we had a burial after P1: 311-313

Dennis describes the spiritual support as a means of saying goodbye and the resultant healing:

I must say the reverend Jo was absolutely amazing. P2:37

I mean Ellen held him and I held him and in the service we said the prayers and that was very nice. P2: 49-50

I just felt that I had experienced, had expressed it to Ellen that going to the crematorium and having to see a small little coffin and that would really be etched in your brain forever, your whole life that most probable would be there. It's not, you don't really want to remember that sort of thing because his life was so short, I mean you don't really want to remember that major part of it ah , you really just want to remember the birth of him, saying goodbye and that' it I don't see no point in reliving it all the time, P:51-57

but at the same time we wanted a little service which is what the Rev Jo offered us ah... at the same time straight after, which was nice, I mean, there again I think he went beyond what he was supposed to do and gave us that little service , we did a little bit of crying there also a little bit more healing you know but I think it was from the first point, from the birth, from that little service I think it was healing thereafter, you know rather than going back and mourning. P2: 58-63.

For Dennis a staged approach to accepting loss was helped by spiritual support:

I think that service with Rev Jo was the beginning after he was born of accepting things there and basically from that you can move on and the second service was more like a healing service P2: 73-76

Cathy describes the spiritual support as important following death and a service recounts her story:

It was really nice because the priest came in straight away and he had a little service for us and then I got to hold James and that was lovely and I really appreciated that and that definitely helped me to move on. P3: 46-48

I am very, very grateful to have Joseph basically, yea and then we also had a service for James as well with the priest and that definitely helped me heal and get over his loss, definitely. P3: 66-68

Cathy found the service helped in saying goodbye:

The last little service for ... for James, ahm I did feel that was definitely our time to say goodbye obviously there were a lot of tears, but there was a lot of joy because we had Joseph and he was doing so well at that time so it was ... I think we definitely did say goodbye in a way that that we felt was good, good for us P3:237- 240

Alice speaks of spiritual support as a means of formal recognition:

My husband and I aren't religious at all but of course when things like that happen it's just about its not that I didn't suddenly start to believe in God in fact quite the opposite

but you do feel like you want some kind of formal acknowledgement of their existence and Denise (sister-in-law) was wonderful because she kind of knows I'm not very godly but loves me anyway bless her and came in with her dog collar on and did just a small naming ceremony for Henry and James this was as soon as we knew, once when we had decided what was happening with James so she came in and did that for both the boys.
P7: 603-610

Alice's expresses her gratitude for her sister-in-law's insight:

Henry was very ill that was obviously playing on my mind obviously in the service itself it was very emotionally draining and ahm Joseph (sibling) I don't think entirely understood what was going on we, Denise had done a great job and organised that all her kids, all Joseph's cousins are a little bit older than Joseph, and all had a big giant daisy to give James so we had something that we could say to Joseph later on because he will have no memory of that day particularly and ahm we just wanted to be able to say to him you know this is what happened and you were part of it and you contributed. P7:629-636

5.5 Part 3: Being alone

Being alone takes the parent to a lonely place where they experience isolation as they live through their grief and assume loss as a companion. It is also a place where parents become intimate with their grief. Grief is personal and is coped with on an individual basis and not readily accessed by others. Or indeed is it desired to be accessed by others.

5.5.1 Isolation

Lack of information enhanced isolation:

There was no information about TAMBA or about SANDS me, I was kind of aware that SANDS, I was kind of aware that SANDS was around I had no idea about TAMBA. P1: 296-298

Charlotte speaks of being further isolated from support organisations by virtue of the fact that her dead baby was a twin:

One of the reasons that I didn't get involved with SANDS is the feeling that I have got a baby P1:909-910

I went to try and get information about the TAMBA support group and there was a SANDS lady there and she was actually saying you they don't get people coming to the meetings for the very reasons that I was saying, she said and she thought if people turned up and they had a surviving baby they .. I think people do perceive that you have got one baby ahm... to me it doesn't lessen it at all. P1: 913-920

Charlotte explains how professional support is both needed and expected:

I can't think it was helpful to just keep everything bottled up really, and people don't ask, I mean friends and things don't ask 'cause they don't want to upset you... so in a way professionals could be the way forward.. I think that is part of their job... I guess... so they might be thinking oh well ...you have friends to talk to, but friends find it very hard. P1: 762-765

Dennis seeks a reduction in isolation through an opportunity to share:

You just need some form of support basis whereby if parents need anybody else to talk to they have it there, it really needs to be like 24 hours because I mean there were times when late at night I wanted somebody to talk to and you don't want to always talk to your other half (laughs) P2: 603-606

The perception that speaking to the counsellor would ease the pain does not hold true for Dennis:

The counsellor, she is a wonderful lady...but...at the same time I know ah the parents find her very difficult to talk to because of how she hasn't really been through all of it is, P2:217-219

Cathy is alone in a reality at variance with that which was anticipated:

When I heard other couples and both their babies survived, I would get very upset about that, when couples come in and I'd say to Ben well how come, why? that's not fair why

can't I have the two babies, you know and I, I used to get very upset, yea when people used to tell me you know we've got twins and they both survived especially when mums used to come in and say that they... that both their twins were 28 weeks or something and I would think Oh my God if only ...P3: 102-108

Chloe experiences a sense of isolation in the well intentioned comments that fail to acknowledge her loss. She acknowledges there isn't a right thing to say:

I think I felt that no one said the right thing, but I don't think anyone could have said the right thing to me, (laughs). Cos everybody said 'At least you've got one' you know 'At least she you know 'Oh life would have been a nightmare with four children under four' all of which were things that I was thinking myself you know, of course, one I would much rather have one daughter than no daughter. P190-194 Ahm so people were only saying things that I was saying to myself to make myself feel better, I still didn't want to hear it from anybody else! I just wanted everybody to say 'you poor thing' and leave it at that. You know everybody tries to make you feel better because they love you and they want to look after you but it's not, they don't always say the right thing and ah you know. P3: 197- 201

Chloe experiences comments from husband's step dad as lack of understanding:

I mean Kevin's step dad just said 'At least you've got one, be grateful, you've got one' and clearly just having no idea what it feels like at all. Yeah but why should he had any idea? But he didn't! P3:224-227

Chloe identified support that would lessen feelings of isolation and normalise her situation:

But I wanted to speak to someone who had lost a twin in the way that I had lost a twin not just someone who had lost a sibling twin a boy and then they had had a girl, I wanted somebody who had to carry an identical twin and then see their baby who would have looked exactly like her and you know I wanted someone who had had the same experience as me and there wasn't anybody. P5:582-586

Carol recounts her experience of different responses to her loss:

It's part of people looking on the positive side of it and ignoring the negative side ahm. I think you know I think when you get out the difficulty is, talking to your friends you kind of feel you know they are going to be upset by it, it depends on the friends I guess, or that they don't have an idea of the experience which again is a kind of problem ahm yeah so those two things make it quite difficult and obviously you can talk about it a bit but to keep talking about it, you can't. Your family is very difficult to talk to again you have a big protection. P6: 451-457

Carol acknowledges the value of family support; however it is the support organisations whose help is most appreciated:

So that's one reason why the TAMBA thing has been very good actually yeah because I think the best people to talk to have been and still are you know the people that have been through it. P6:460-463

Alice describes the loneliness of decision making:

The consultant did explain there was no rush to make a decision ... about him ... but it felt like it was quite clear and I'm grateful to her for the fact that she made it quite clear... that she felt we ought to give proper consideration to letting him go and not prolonging it and I'm glad she did that because I don't know how I would have been able to make the decision if she hadn't have been so clear cut and one of the many things that I struggled with later when I went over it the following 48 hours is that nobody ever really repeated it. I understand people can't tell you what the right decision is I and realise that. It would be nice to have some more reassurance because you feel very lonely making that decision P7:60-69

The depth of loneliness is teased out:

It's all about quality of life isn't it it's just that you never expect to have to do that with a human life you know to make that kind of a call P.7:76-77 and no one can be sure what the right decision is you know so you're left to make it P7:80-81

Alice recounts being so alone:

It was very unbearable and there's nobody to talk to about, and you're not going to a doctor to come and say to you it was still the right thing to have done (blows nose) cos that's not what their job is, (blows nose) but that's kind of almost what you want, you need somebody to tell you that what you know anyway but you need to you need to hear it out loud... because you're not in any condition to ask because you wouldn't get your sentence out ... that was the most unbearable thing. P6: 109-115

The issues of doubts remain for Alice:

There's always that little bit of doubt and because you know the consultants and people weren't able to say to me look he will without doubt 100% be extremely compromised.

P6: 210-212

Alice gives a perspective on lonely decision making:

I kind of don't have any regrets about the decision but that's because I'm in a little bubble where I'm able to convince myself it was totally the right thing to do and because I know that it's no good asking anybody else to tell me that because even another individual another mum you know might have chosen differently certainly the medical team you know all they can say is what they think and they did tell me what they thought and on the back of that we made our decision... and you know you can't ask any more from anybody I mean that is a very sort of lonely thing to have to sort of deal with and I have to explain that to Henry ultimately as well. P7:221- 2

5.5.2 Grieving

The loss is such that support does not meet a need. It is as though grieving begins with an initial state of shock. Grief consumes energies, where those energies are unavailable as in the situation of the survivor requiring intensive care, grief then is delayed. The needs of the survivor and other children in the family take precedence over the mother's need to grieve. The parents acknowledge their depth of grief and feelings of misery. The feelings experienced are those that require understanding rather than medication.

Tricia speaks of her powerful emotional response whose presence isolates her from help and support:

At that particular time you have just lost, lost a twin there is nothing anything anybody can do for you... there is absolutely nothing and not only that you don't always want to accept the help because you just want to left alone. P4: 219-221

For Charlotte there are difficulties in differentiating what is grief and what is part of being a new mother. Protecting the survivor from the outward expression of grief was important:

I think it's hard to know what feelings were you know being a new mum and what was because we were grieving as well. I felt that, particularly in the early days I felt that I was on automatic pilot in a way. And much as you know it was great and lovely having William, I felt very numb and I also felt guilty about feeling happy sort of (tearful as she speaks). It was a real mix, and the other thing was I felt that I didn't want William to see me upset, that was a big thing at the time.P1: 320-326

Grief requires both time and space as Charlotte discovered:

I'd ...been with William all day and tried not to be upset and do all the things I should do so then in the evenings it was quite a difficult time for me and I'd pass William over... (tearful) and I'd cry, there wasn't enough support, nobody talked about it and ahm well there was support, there was support in the family not from professionals... ahm... so it was hard and we just had to get on with it.

P1: 327- 332

Charlotte managed her time to ensure time for Isla while protecting the survivor from the obvious expression of grief:

I'd kind of tried not to think too much about her because I knew it would upset me and I didn't want William to get upset. P1: 335-337

If we took him out for walks often we would go to the cemetery and where we were living you know it was quite feasible to do that.P1: 337-339

It was helpful; yeah it was helpful at that point I think I felt you know that even though it would upset me, but William was often asleep in the pram when we would get there or yeah... he was so little, he wasn't so aware. So that seemed okay P1: 341-344

Charlotte reveals her GPs response to call for help:

I ended up going to my GP about nine ten months after they were born, you know just sort of saying I wasn't coping very well with it. He offered me medication or counselling. And basically I just said I think medication was not the answer for me, so I did go and see a counsellor, and again I only went a few times, I didn't go more than three times but what was the thing about it, wasn't what was talked about I don't think but more having the space to actually sit down with somebody and having to talk about what had happened ... that ...that was quite a useful thing to do P1: 358-366

Charlotte explains the difficulty of living with bereavement:

Before then it was quite hard because on the one hand you want people to ask you about Isla and to acknowledge her and on the other hand you know you will be upset so people didn't for whatever reason ask because they didn't want to upset me. P1: 367-370.

Charlotte speaks of the benefit of counselling:

And I think that's what it was about these counselling sessions is that it got me to a point I suppose where I could talk about it and I got past the upset bit, (laughs) and I know I still get upset now but ahm but I can at some levels obviously we're talking about it in some detail but I can talk about it without getting upset now...usually! (laughs). Not always. P1: 373-377

Charlotte speaks of the importance of acknowledgement:

I think in the long term, for me it would have been more helpful had somebody mentioned Isla and asked me about her, about how I was feeling about losing her or about William and how I was. P1:750-752

The affects of grief is highlighted in a subsequent pregnancy:

I knew that I felt numb at the time, ahm I kind of knew that but having another baby and not having all the other things to deal with brought it home, how different it was. P1:600-602

Charlotte speaks of the need to be invited to the memorial service:

I don't feel I could have initiated ringing someone up and saying could I come, but, if I had been invited ... I would have felt part of that and I would have gone. P1: 842-844

Talking would have helped Dennis:

I mean, and I know, Ellen she said it, her boss as well, if you can give someone else a bit of help to make their time a little bit easier, I mean, definitely I wish I had it then because I mean I might not talk about a lot of things now I think I most probably would have talked about a lot of things then, when your actually experiencing and you're actually going through it. P2: 646-651

Dennis speaks about the private and public person and that coping takes precedence over grief:

You do have trying moments but when you have a twin that passed away and you have a twin that's left you just have to keep on going. Because if you fall apart what's there for him? P2: 654-657

Dennis comments on his experience of seeing other parents who have lost a twin:

We tried to talk to them quite a few of the parents and ah, but they will deal with it in their own way some like I say they had lost twins were very quiet, went completely into themselves but that is also not a good thing, you need to be who you were before you gave birth to your children. P2: 448-452

Dennis found that speaking to others in a similar situation helped to normalise feelings while recognising the impact of loss on the relationship:

You tend to have more problems between each other than dealing with the death to be honest. Because all that does really is create problems and friction between you and

your spouse and that if you kind of know from other spouses and other parents that they had the same problem then you can kind of like work on that not to have that because then you know it's not just you . P2: 415-419

Cathy recounts her experience of the displacement of grief while caring for her sick survivor:

*I think... the way I was feeling at the time I wanted to ... forget it because I was feeling so much pain ...ahm about what happened that because I was dealing so much with Joseph I did want to forget it, I would have preferred it if they didn't say anything at that time
P3: 164-167*

Cathy vividly recalls the meaning of the first cuddle with her dead baby:

I also found it quite difficult to hold him when I did as well I he felt very strange because he felt really warm (Mary yes) (Cathy cries) he felt very warm and (Mary take your time, Cathy) and it was strange to ahm...to.... (crying, as she says) Oh I desperately wanted him to be alive ... I wish, I think when I felt him and he was so warm I wished he had stayed that way P3: 306-310

Cathy speaks of grief eased by the presence of the survivor:

*The last time we went you know to have the last little service for ... for James, ahm I did feel that was definitely our time to say goodbye obviously there were a lot of tears, but there was a lot of joy because we had Joseph and he was doing so well at that time.
P3: 236-239*

Cathy occasionally uses pretence as a means of coping. She finds value in the interview:

Sometimes I like to ... pretend, everything is wonderful (laughs) and just its kind of you know get on with life, I know this is a very stupid thing because obviously we are still ... things in my mind, I actually had a big cry before I got here with my friend...(laughs) I feel very strange coming here today all the memories coming back but, it has actually been very good ahm, I feel actually feel a lot better now that I am talking to you about this really feel better yes I really do because it is all coming out everything that I been

feeling (Mary mmm) all my emotions (Mary mmm) and I really appreciate it actually yes, it is really helping (laughs) it is helpful. P3: 321-329

Cathy speaks of the why her grief differs from her husband's and his influence on her grieving:

Ben... because he didn't carry James, because he didn't carry the babies, I think men feel slightly different than a woman feels so ahm, when I did have ... obviously when everything happened Ben kept saying you know we need to get over this, it's over we have said our goodbyes it's no we don't need to carry on getting upset because it just makes you, you know it's silly and it's too sad and I think because of him saying that, I think I might have held back some of the memories that I probably would have liked to you know but sometimes I think sometimes I would do it privately as well. If he wasn't around I know I would you know crumble up into a little heap and cry and cry and cry about the situation especially in the early, early days you know when nobody was around and I felt that was helpful. Definitely yea because I was grieving on my own and I didn't have someone telling me that's enough now and you don't need to do this getting yourself into a state or what have you. P3: 437-449

Cathy expresses the need for time and space to grieve while caring for her surviving twin. Counselling at this time was seen as invasive of personal space:

I don't think I grieved for a while when I was with Joseph, no, no I held my emotions for a long time and I know a couple of times I would try not to talk about it too much, about James and I know when the psychologist (counsellor) came in and she talked to me about it and I know I was in tears at one stage and that was the first time that I actually talked to her about my experience because every time she came in and she'd ask questions and what have you and I'd shun her off and I wouldn't want her to talk to me and I felt especially that lady, I don't know why, I felt like she was really invading my space, I don't know why. P3: 514-521

Cathy recalls the value of anger as a coping mechanism:

You know I think I was focusing my anger on just anyone, I think whoever was there, I would just focus my anger on, it was almost ...easier than dealing with what I had to deal with, it was easier just to be angry at somebody and it was unfortunately Ben's Mum
yea P3: P3: 45-48

I felt so frustrated by that I wanted to be very angry, I wanted to be angry, angry, angry, I wanted to just hit someone, I was even like scratching my face, doing stupid things like that you know screaming in the pillow, ahm ... and really being angry, angry at anyone I could be angry at, at the time yea it just ...it was just ... it's just an excuse really not to, not have to deal with what I had to deal with at the time so poor old Ben's mum, (laughs). P3: 648-654

Cathy reveals the difficulties of parenting a sick neonate and the additional burden of lack of personal space:

We kept on having to go home to be with Ben's mum and I know I was quite resentful for that as well 'cause I thought I have lost my baby but then and then I can't be with Joseph either, I always have to come home you know, it was Ben's mum what have you and be polite and when you had a long day here at the hospital and then go home and be polite to someone it was very, very difficult (laughs) you just want to explode and go crazy yes.
P3: 412-417

Tricia recounts how the demands of the survivor take precedence over mother's need to grieve:

If my surviving twin had been a well, a well healthy ahm I would have been able to deal with it ...differently, I would have been able to have support around myself, to help me grieve over the child as well as look after the child that has survived as well as grieve after the child that I have lost but, because he is a sick child I have had to shut myself off from the loss and to stay strong for my surviving twin and to carry on with all of his difficulties P4: 36-41:

Tricia speaks of mixed emotions:

There are a lot of mixed emotions ahm... a... surrounding it is not as simple as you have lost a baby and that is it when it comes to twins you have a constant reminder not as if you haven't got a constant reminder if was just a singleton baby but because it is a twin ... there's something missing ahm ... you don't ... you want to celebrate.. You've got to try to be positive for the ... the... surviving twin on his or her birthday as well Christmas but at the same you have got the other emotion of ... of the loss of one ahm. P4: 44-50

Celebrating birthday is anticipated as being difficult:

It is fortunate really ... that his birthday is on bonfires night, the 5th November ... so I have got a means of celebrating for him, P4: 56-58

If it was just a normal calendar day I don't know how I would celebrate I don't know if I would be able to ... to be honest ... not that I mean ... I don't want to be horrible to the surviving twin or anything like that. It is just ... it is just very mixed emotional hard day. P4:61-64

Tricia describes her coping mechanism:

Sweetheart, you've just got to carry ... it is just like groundhog day unfortunately, I know it sounds horrible but you just got to try not to try not think about it ... but... I don't have time to sit down and think about it Because if I was to sit down and think about it I would not get back up... I have got to be strong for David with his sickness ... his difficulties ahm... so I haven't really had time for myself to grieve about him ... but I have noticed that lately I am, it doesn't come out all at once ... the normal grief where you sit down and cry and cry and go through it every single day. I can't do that, I have to shut myself off ... ahm... switch myself off and continue every single day and my body just lets go, gets tearful as and when ... my body slowly releases ...the pain ... slowly not all at once and I know it seems very strange to hear but sometimes it is like it's never happened, it's like I can't accept that its happened. P4:90-100

Tricia reveals the conditions necessary for grieving:

I need time and space because obviously when somebody wants to let themselves go ahm... and grieve properly they let everything out and they just really let rip, because I

can't do that I am really limited ahm ... I am sure it's affecting me worse than if I was to let it all out at once. P3: 668-671

Tricia reveals the affect death had on the relationship with the survivor:

Not long ago after Dominic died I found myself not wanting to go to the hospital, I know that sounds horrible, I didn't want to go to the hospital because as I have said I just lost one baby and because of David's difficulties I was prepared to let him go as well and I didn't want to get myself attached to David thinking that he was going to leave me as well ahm... so it was ... it was quite a weird experience if you get what I mean it was I had to keep myself on the go ... I didn't have a chance to sit down and think about anything I think that is another reason why my body has got used to not thinking about it, being able to shut itself away because that is how I've had to be since the same night he died. P4:207-215

Chloe describes a survival instinct in the face of grief:

It was just the most awful month, I don't think I even really had time to do the grieving thing ahm because I was running between there and here the whole time, trying to make the boys think everything was alright trying to spend as much time as I could with her, it was just, my husband's just started a new business and he was working 90 hour weeks and couldn't take any time off and it was just so busy I think I think the grieving thing came once she had got home and life got back to normal a bit rather than, I felt like when she was still in hospital I felt like it was like kind of emergency and focus on getting through each day doing the right thing for all the kids, trying to balance everything and yeah it was it was very, very, hard, very hard. P5:230-238

Chloe describes the difficulty of and the unknown factor about the period of grief:

The grieving thing its quite hard to do when you've got a young baby and I don't know if that means that it's a longer or shorter process than well I don't know yet because I am still in it

Chloe speaks of how she wishes to accommodate her loss and the difficulty of achieving that state:

It's difficult because I'm so desperate to feel like my old self, I want to be my old self, I want to just get on with life I don't want to forget her, because how could I? But I don't want to think about it every day, I don't want to you know I just want to be happy and I want to be a normal family and I want you know everything to be okay and I can't make it okay and I can't make it go away. P5:636-640

Chloe describes how reality does not meet with her expectations:

I think the more life is returning to normal you know, she's starting to sleep she's become much more of a normal baby I don't have to worry about her day to day because she's not a preemie anymore, you know I don't, I keep expecting to think, to feel better, and I don't feel better. P5:644-647

Family expectations:

But I think you know I'm not sure I've got over it now but I know my family think I should try not to dwell on it and I should try to see the positive in life, which I think is right, rather than the negative, but you know it just doesn't go away, it's just always in the background all the time. P5:650-654

Chloe ponders the future:

But I wonder if it's never going to be okay, because I've got her because now I'm always going to feel like you know 'Ah you should have a sister' all the time. P5:658-660

Chloe reflects on her GPs response experience at variance with medical expectations:

Do you think you've got depression, is everything getting harder, are you feeling blacker and blacker? Well yes, but that doesn't mean I think I have some kind of depression that needs some kind of treatment because I think I am a bit depressed but I think it would be strange if I wasn't, I think it's normal, I don't think it's abnormal. P5:690-694

Chloe looks forward to a dulling of the pain:

In fact I said to somebody the other day, I think when she is one I'll feel like, not that it's over but that it's moving away from the newness a bit more. P5:701-702

Chloe's reveals the difference between her and her husband's grieving:

*I think if I ever turn around and wail or weep at my husband he just looks so like ahhh!
Frozen like oh don't do this, he is just so scared of it. P5: 704-705*

Carol reflects on grief in the first year:

It's just you're not so completely overwhelmed by it, you know the grief I mean it's a process grief isn't it and I think you know I'm reading things subsequently and I fitted that process completely in terms of stages that I went through and ahm until you've sort of worked through it all and you know it is always there it's never, it doesn't go but it lessens and you can accommodate it and you can get on with your life whereas you can't get on with your life really, you do, but you function on a totally sort of automatic pilot. P6:397-403

Carol reflects on the need to live through grief:

Yes, I feel you have to go through it I do. Because I think if you don't go through it then you're blocking the things and it's going to come out at some stage. P6:409-410

Carol reveals that her progress through grief means a return to its beginnings:

I mean you like to think it's a journey and you're continuing forward all the time but I think sometimes you're pulled right back and to be honest it's the minute you start to talk about it and remember it's as raw as it was the day it happened. P6:419-422

Feelings associated with the first encounters with professionals following the death:

And you remember everything everybody said to you, I can still remember virtually everything everybody said and what they said and when they said it and you know. P6: 426-428

I don't have a particularly good memory for other things at all, but that, it's absolutely vivid. P6:430-431

Well I think it's to do with, I don't know what it's to do with, shock that you're in at the time, so how people treat you is incredibly important actually and what they say and how they say it. P6:432-434

Carol speaks of the differences in coping with grief:

I think men and women deal with grief in different ways as well so there's a desire to keep going on with things to keep going on with men, and with women there's a desire to talk about things sort of try and heal it that way so that is very different. P6: 541-544

Carol reflects on her loss:

I think were you to lose a living person who'd lived then you have more memories and you have more joy so there must be I mean I don't know because I haven't done it but I would have thought there must be more sadness too because you know what you've lost I don't necessarily know what I've lost because I haven't had it, so I've lost a potential. I mean it's you know obviously it has affected me hugely. P6:489-494

Carol speaks of the continual confusion between feelings of sadness and negotiating a path between the two:

I keep it separate from Matilda's birthday because you know you want some joy you want some happiness you don't want to feel sad on a day when you should feel happy, this is the continual thing that you have to sort confusion about what you feel, what you should feel because you want to feel happy and glad and ahm but there's sadness as well and they are the two edges of the same spectrum really aren't they it is continually confusing the way you have these two feelings and that's what you have to coping with that is difficult really and that's initially what you feel after the birth, confusion is very difficult ahm. P6:330-337

Carol reflects on the milestone of a year:

Ahm for the whole first year I found difficult you know and ahm after the first anniversary after I got through an anniversary it was easier. P6: 343-344

For Carol, grieving is personal and managed within her own time and space:

Again I think that's why talking to you is different because I haven't, you know I've talked to lots of people and I've relived the experience lots of times but it's always in a different context, and if I'm going through a sort of grief then I've done it by myself.

P6:734-637

Alice describes how time is negotiated for grieving her dead twin:

Most of the time (coughs) most of the time it was about keeping on top of yeah of what was going on with him and the tears for James would just come in the evening generally when I got home but when I was with Henry it was just about Henry and I still feel the same way you know his life is about living really I don't want to waste my life crying about James you know it's not fair on Henry and Joseph for a start. P7:346-351

Alice describes her grief for loss entwined with grief for the surviving twin:

I did spend a lot of time crying early on (cries)... I think ahm... at some point you cross over when I'm probably no longer crying about James but starting to cry about Henry but I wasn't really ever very conscious of when that transition and I suddenly realised that it had done at some point, you know so for a while I would you know almost have nightmares about the evening when we said goodbye to James. P7: 353-358

Alice reflects on the different perspectives and the impact of that:

Well you know I suppose from other people's point of view it happened two and a half years ago they were all fab at the time P7:427-428

So the thing is for those people it happened and they moved on because it didn't actually happen to them whereas it happened to you, you never really move on entirely and you can't expect everyone else to sit around remembering and in fact I've just said to you in my last breath I said I didn't want to be defined as the woman who lost a baby so I can't have it both ways right? P7:432-435

Alice describes her decision not to have ashes:

I wouldn't have had a clue what to do with the ashes it would have just presented to me an absolute emotional trauma that I would have had to have done something significant with them. P7:646-648

But you know James didn't have a life you know he was robbed of that so there were no associated memories, scatter it in Room One, not appropriate so um yeah nothing happened with that and I don't have any regrets it'd probably still be in the bottom of the cupboard somewhere doing my head in cos I'd know it was there and not knowing what to do with it, I suppose if your religious there's an easy answer to those things but because we're not it just feels like another emotional burden that I have to kind of deal with P7:651-657

Alice reveals her feelings about photos:

why I haven't looked at them yeah I've tried a few times. P7:872

I just started to cry and I've chickened out basically. P7: 874

(cries) ... I suppose I'm worried about how I might feel when I look at them (cries) you know I think it's that whole moments of grief you want to remember something positive and of course when you've lost a baby that's very difficult because, we've touched on this, they haven't had a happy life P7: 878-881p2

Alice speaks of the decision to have photos:

You can't smile for the photo can you(cries) something felt very odd and I'm still not entirely sure how I feel about it but equally of course if we didn't have them there these photos we'd have nothing to show he'd ever been here, well his birth certificate. P7:888-891

Alice compares the images of both her babies:

They're put away again like everything, I've looked at all the photos of Henry (surviving twin) that we had you know during his time in the hospital which are pretty unpleasant (blows nose) but James' (dead twin) are just a step too far I think for the time being. P7:926-929

Alice finds difficulty in the image of her 23 week baby:

And you know what 23 week babies are like their skin isn't proper there's nothing about them really and its hard it's kind of weird having such an emotional connection about them cos these things that look really barely like babies they have arms and legs and head but they don't really you know they blatantly aren't ready to be born that's kind of hard because you feel bad for thinking those things. P7:938943

Alice reflects on attendance at the memorial service:

(blows nose) no we haven't done (laughs) you might have guessed we wouldn't, no we haven't. Ah I don't quite know why not, my husband wouldn't go in a million years ahm it's the religious connection, you wouldn't get my husband doing anything that required. P7: 1072-1075

Yeah so we get invited to both and that's appreciated ah I think you know ah I think maybe it would be different if we didn't have Henry I think I would be much keener to cling onto a memory of James and all that that kind of encompassed. P7:1106-1109

Grief and loss are personal:

I'm never going to be the sort of person who has lots of very public displays of you know; remembrance because it is quite a private thing. I mean no one apart from me and my husband and my sister-in-law you know the Vicar met him, amongst my family and friends so you know it is a very personal thing. P7: 1114-1119

Alice compares the different response in herself and her husband:

He doesn't talk about it anymore and obviously at the time he was very emotional and we talked about it about everything at great length. P7:1124-1126

Alice reveals the protective action of her husband and suggests difference in his grieving:

He was very involved those first few months and over losing James and he was he was devastated he's very close to his children ahm but whether he's still thinks about it I suspect probably not you know if you asked him the everyday question I think it could be a 'no' there I may be wrong I've never asked him he would be very careful not

mentioning to me about it if he was because I'm more aware of the fact that I'll sometimes get upset and you know he'll want to protect me, so if he is upset I suspect I'd be the last person he'd probably tell, he wouldn't want to upset me. P7:1130-1137

Alice reflects on whether her loss is greater as compared to loss of a singleton:

No, I wouldn't have thought so, I wouldn't know how you could compare I imagine its much the same, I think I have if anything it might be the opposite it might be less just cos I have Henry like I said he's just amazing to call him a consolation is insulting to him but he kind of was you know he's what got me through the event of losing James you know cos Henry forced me to keep going and of course I'd already got Joseph (older sibling). P7:1151-1156

Alice reflects on the need to work on managing her grief and anticipates changes:

I think it will get easier just like all grief things will get easier and I don't think it's any different in losing a twin it's just that there is a permanent reminder. P7:1219-1221

Alice acknowledges her emotions are close to the surface:

It's just one of those things isn't it I knew that I would wail as soon as we started but I really wanted to see if I could help I'm not sure that I have been a help. P7:1443-1445

5.5.3 Loss as a companion

The death of the twin takes a part of the parent and in its place is a sense of loss. The mother has grown and carried her baby and the death takes part of her. This loss is carried in the changed self, while it changes with time it does not disappear. Parents find ways and means of both recognising and managing it.

Charlotte carries her loss, a loss that is greater than her husband's:

It feels I am the one who ... who seems to be constantly carrying this ... thing... but again... you know... it is probably it is more overt with me than with him (husband), I will It is things like ... I know if I am tired then ahm... I am more likely to think about Isla ... and get upset ... not morbid... more upset easily... and little things will start me off ... well I suppose factors like that don't impact on him in quite the same way

ahm So yes I suppose I do feel ... that I ... more than him I don't know if that is a natural thing. P1:896-903...

Chloe reflects the medical approach to her grief:

And I don't want to be given pills for something that I think is a natural thing that has to be worked through rather than you know I'm not a person who would have got depression in a normal life without anything happening. P5:

Chloe expresses concern for the presence of a continual sadness:

That's what worries me now, that I'm never going to, I'm always going to be you know not obviously sad but there's going to be a sadness nagging at me all the time you know and is that ever going to go away I don't know. Cos it feels different to other losses, when I have been sad because someone else has died, whether it be grandparents or a couple of my friends that I have lost over time or you know that feels awful but it's different to, it's kind of in your mind why you feel like that whereas this is just kind of there. P5: 328-334

Alice speaks of the impossibility of forgetting:

If you want to forget it completely I suppose you're free to do aren't you whereas if I wanted to forget it completely I kind of can't. P7:1206-1208

It's always there yeah I would acknowledge that bit of it, I suppose but that that's not an issue for me I don't think because I would want to try to remember it always anyway its only that I don't want it to screw up things like Henry's birthday you know I mean you know hopefully by the time he's 18 [laughs] I'm going to stop looking miserable [laughs] and the poor lad might actually get to have a laugh on his birthday and you know the onus is on me just to really try isn't it P7:1210-1217

5.6 Part 4: Understanding the loss

Living with the death of a twin has become assimilated into life. It holds a sacred space within the lives of the bereaved parent. The perfect place for the baby is with the mother and therefore separation cannot be achieved. There is an appreciation of the personal growth achieved through this experience of suffering. The experience of death has uncovered areas of personal growth and an appreciation for life's riches.

5.6.1 Presence of the twins

The presence of the dead twin is held close and cannot be separated. Images and tangible memories provide confirmation of their existence. A perfect resting place for the ashes has yet to be found. The presence of the dead twin is also to be found in its surviving twin. Images remain and those images and memories are carried. Some solace is present for those who have lost an identical twin as the image of what they have lost is present.

Charlotte speaks of Isla's presence in family life:

We planted a tree actually because we moved here (family home), that's quite helpful to have you can see that's Isla's tree, it was just another way of remembering her. P1:311-314

We talk about it then and quite often he'll (survivor) go and get his box out and talk about that and ahm he knows that we just say, he says, Isla has gone to Heaven and her body is with Jesus and we say yes...and at certain points he will initiate the conversation more ahm... we probably don't... and obviously if we are in the garden we will say that's Isla's tree and they will come to the cemetery with us. P1:382-387

Charlotte reflects on the reality of having twins:

I'm aware as well that having twins you know wouldn't have been a ball at times (laughs) it would have been hard and I know that and part of me sort of thinks I, its hard having one child rather than having two and I'm under no illusions it would have been very hard and I would have had days where it would have been very difficult to cope but I know I

would rather have had that experience than the one I have had.... So yeah she's certainly there... yeah. P1:548-553

Charlotte values acknowledgment of Isla's anniversary and contrast the difference in response:

My mum and dad do in what is a very obvious way...flowers or something like that ... my brothers and sisters I know acknowledge it but not in such a direct way, they'll ring me up. P1:859-861

Henry's family don't acknowledge ... I find it quite difficult ... I don't really understand it but ... when we lost Isla... his Mum is a twin ah... I thought she would have quite a good understanding but she,... she didn't understand at all and was quite surprised at how I had taken time off work and .. was surprised we had a funeral and things like that... which she didn't say directly to me ... but I ... I ... know that she did... and so ... I suppose I find that... a quite hard to understand.P1:864-869

Charlotte reflects on birthday celebrations:

William's actual birthday ahm we try to make as William's day and... its harder, it's harder to do it, you know it's easy to say it but it's quite hard obviously you have to be...it brings back the sort of memories of as well as it was that day that she was born P1: 410-413 ... we try very much to make it William's day... and er... I still find it very difficult...I certainly find it much worse in November when we have Isla's anniversary but I still find William's birthday quite hard, it feels like going through the motions. P1:414-417

Charlotte reveals the difficulty in seeing William other than as a twin:

I've always got this thing about...you know, William I suppose, I think that what it is that he should kind of feel he should have somebody else with him. P1: 450-452

Milestones bring a reminder and a meaning to what might have been.

I did find it hard and it did make me think about what should have been and... you know... it's hard when you see him going off with other children of the same age, little girls and its hard.P1:479-481

Dennis ponders the act of explaining death to the survivor:

I think, well most probably when he can understand, I think we will tell him and we will just basically say that his brother is in heaven. And ah, at the same time I hope by then that he actually has understood things cos it will make it a little bit easier. Ah I think that's going to be a very important thing for him. P2:691-695

Dennis anticipates the survivor's first birthday as a time for remembering and celebration:

For Thomas' first birthday in December and ah I think what we'll most probably burn a little small candle and then at the beginning of the morning and that will be it I think it will be still quite emotional for Ellen during the holiday, but just try and make it as good as possible. P2:395-399

Dennis speaks of holding the ashes:

We've have still got his ashes, and most probably, I think one day when maybe one day we get a house where we may be living for a long time we may put a tree down and put the ashes on the tree rather than just scatter them. P2:376-379

Dennis tells how life with the survivor contains a space for the dead twin:

I don't really think about it that much. It's really just because I'm focusing so much on Thomas. Ellen the same but I do know that she does think about Timothy every once in a while when circumstances arise. We do take a little bit, once (unclear) we do take a little bit of time out we do have a little bit of a chat about him and then we kinda like just move on from that, but we'll never forget. P2: 576-561

Cathy imagines a life with twins:

I do think I wonder what it would have been like to have him here with Joseph and you know... two boys together and you know yes I do think about that. P3:125-127

Cathy is selective with whom she shares the history of her twins:

I just talk of him as a just one baby, sometimes I don't even tell people my story, sometimes I just say I have a baby and his name is Joseph, because sometimes I don't want to bring all that up, sometimes it is too hurtful P3: 584-586, unless we are talking about something or you know an intense conversation and I feel I can trust them, then I'll bring it up yea. p3: 589-590

Cathy recognises the gift of Joseph:

I used to be angry about them having twins and how come I didn't have twins but now it's not now I don't, now it doesn't affect me anymore because Joseph is in such a good place at the moment no I don't I'm just so, I'm just enjoying him so much you that's that he's such a pleasure it just takes all your problems away I think that's also why he has helped me so much in this whole situation because the way he is what he does for me and the love that I feel for him and I, it just makes everything, all the pain and everything just goes away when you look into his eyes and you just realise how lucky we are to have him.P3: 597-605

Cathy has yet to deal with the ashes:

We haven't had the opportunity to go somewhere really nice where we feel special enough to get rid of, of the , not get rid of [Mary no] of the ahm ashes so we haven't found and we also want to wait until Joseph is a little bit older and we can say this is your brother, we want to tell Joseph about James definitely, we want him to know that you know ... we are going to make out that James was a little hero and he was the one, the one you know who saved Joseph, say something sweet like that and then we'll take Joseph with us. P3:254-260

Happiness for the survivor occupies greater space in Cathy's life:

I think that when I am with Joseph, because he makes me so happy, because he makes me so happy and I love him so much I don't think about James so much ahm... I don't know, you know my friend asked me the same question today ...I think, I think obviously in the back of my mind I will be thinking you know they both would have been here on their first birthday but I think it gets easier as time goes on . P3: 346-351

Tricia explains how she wishes to keep her loss separate:

I don't like talking about him unless I want to talk about him, because obviously it is a heart breaking situation, it's not something you can talk about as in a normal day to day conversation some people can but I am just one of the people that can't. P4:288-291

For Tricia the loss of her baby is closely connected to that of the survivor:

Everything that is going through your head at once, you can't help but be angry, be defensive just want be left alone, just want to come and see your child that you want to see speak to the nurses on how the child is that is surviving and then just do what you have to do on a normal day to day basis as good as you can. P4: 302-306

Tricia speaks of the inability to discuss the death of her baby with her partner:

Sometimes I want to talk about Dominic but I don't want to talk about ... because I don't want to hurt him ... and I am sure he feels the same as well. P4: 629-631

It just put a restriction that he probably wants to talk about Dominic to me, but he's probably frightened of hurting me and the same visa versa it is a very, very delicate situation. P4:632-634

Tricia describes a sense of incompleteness at the time of discharge:

It didn't feel right just leaving with one. It was like I was leaving someone behind ahm... it was ... you knew something was missing, something was, it was a joyful moment because I was going home, but then it wasn't because there were two and now there's was only one. P4:699-704

Chloe reflects on the difficulty of managing her loss:

It's just a classic situation of trying to be happy about something and celebrate something at the same time and that is very difficult to do. It's normally a lot simpler than that if you are grieving you are simply sad but you know I feel like I shouldn't be too sad you know I have got a beautiful daughter she's healthy I could be in so much worse a situation than I am so I just I, everyday I think to myself if I have a down moment, come

on you know, it is very sad but you have three beautiful kids and some people never have any children or they have you know disabled children that hasn't happened to us and however sad it is and it was. P5:281-288

Chloe acknowledges she will deal with the ashes but, not yet:

Ahm but the grieving thing its quite hard to do when you've got a young baby and I don't know if that means that it's a longer or shorter process than well I don't know yet because I am still in it ahm I mean I haven't been able to, I haven't been able to do anything with her ashes I have had to keep them. P5:241-244

Chloe keeps the ashes in her bedroom:

Upstairs in a pot! No they've, the funeral ahm director gave us a nice little urn for her and ahm with her name on it and stuff and ahm I don't know if it's that I feel like I can't let go of her yet or whether it's that no where feels right to put her. P5: 45-248

Acceptance is both difficult and takes time for Chloe:

I don't want to be reminded of it or want to let go of it or what at the moment it's all a bit confused. I know it's happened and I know I have got to accept it but it's quite a hard thing to accept. P5:255-257

Chloe reveals the difficulty of living with the death:

And sometimes I get cross with myself for feeling down about it, and I think you've got so much how can you , you're so lucky, don't feel like that, but then you do feel like that, you can't just push it away you can't make it go away.

P5:669-672

Carol reveals the importance of identical twins:

I find helpful actually, ahm because I do at least, I think its part of the memory thing I do know what she would have looked like. P6: 802-803

Carol recognises the potential of her actions to ensure her dead twin is kept in the present:

I'm always aware of how much you transfer onto your child, you transfer an awful lot don't you, so you know there's part of me that will think, you won't forget sort of thing and there is that. p6:864-867

Carol recognises the event that has ensured her dead twin remains constant:

For the first time she played for a whole evening with twins, she had a wonderful evening, but then you know the next day or the day after it had dawned on her quite what she'd lost. P6:872-874

Carol has maintained the presence of Elizabeth through Matilda:

It's part of her identity and it's part of her story and I feel quite strongly, and I do talk to her more, I have to say, I do talk to Sophie quite a lot about it probably, and Mark, but I probably have talked to Matilda (survivor) the most about it, you know rightly or wrongly, and ahm yes it probably. But you know and again when I read things clearly I think she has spent nine months, or eight months well probably only seven because they were 33 weeks or whatever in the womb with Elizabeth so, she will have had a connection there. P6: 878-884

Carol acknowledges that speaking of her loss to Matilda is perhaps the closest she will get to Elizabeth:

Yes, probably, I guess, yep, yep... It's difficult to know why you do these things isn't it? It's difficult to know whether you do it you know, you hope you do it for Matilda but actually I'm sure inevitably you do it for yourself as well. P6:888-890

Carol speaks about the difficulty of final separation and finding the perfect place:

I still have the ashes, yeah (laughs) is that, have lots of people? P6:576

Yes, yes, well I've always wanted to put them in the garden, ahm, but I've never quite found the right spot for them, so I still have them and I still think you know I think this is part of my unresolved bit, I still feel I should put them somewhere and I'm not quite sure and it sort of needs to be perfect. P6:578-581

I mean the biggest difficulty is thinking that you will move house, and then I thought if I put them in the pot then I would take the pot but then but then it's having the right plant I don't know. P6:607-609

Carol recounts how Elizabeth's presence is kept by her children in family moments and not a family event to remember her anniversary:

We have been on holiday to Italy over the summer, and of course you go to the churches and there's the candles to light, so we had one moment where Matilda, I said to Matilda do you want to light a candle, I didn't say any more than that or I think actually she said 'I want to light a candle' so they all lit candles and then she walked out and I said oh who did you light your candle for and she said for her ahm great grandmother who was 100 who died last year, and I said oh that was a lovely that you did that, and then she said Oh I didn't light it, you know she got quite upset that she hadn't lit it for Elizabeth, and then Sophie whispered to her, it's okay I lit it for Elizabeth! (laughs) P6:936-944

Alice reveals how memories are maintained:

Now you know I think about him you know sometimes unexpectedly sometimes I do on purpose but I try and do it not when the other kids aren't about. P7:495-497

We all have to deal with it in our own ways whatever you sort of feel most comfy with and I don't I don't think I'm busy you know being unhealthy by blocking it all in because I have my little crying session and I let it out you know - yeah cos that's what it comes down to it becomes a practical problem you've got to get on with your life you've got other children that you love dearly you need to move on -if I put it in a box and buried it and never opened it that might be a bit dodgy but putting it in a box and sliding it under your bed and just getting it out once a month for a little private weep that kind of, that's allowed right. P7:463-474

5.6.2 Personal growth

Personal growth has arisen from this loss. Changes have been experienced as the discovery of inner strength and a reaching out to other parents in need of support. In the

second interview Participant 7 related how the experience had enabled her to reach a deeper relationship with the emotional side of her personality.

Charlotte's growth has emerged as a deepening relationship:

I think in some ways it has made us stronger cos I think...that's a positive part of it is that you know we went through... a really difficult time and we got through it... so I think, you know, I think that's a strength if you like. P1:507- 510

Cathy acknowledges the growth arising from her experience:

It is such an incredible lesson that we have learnt as well as just to appreciate life so much, you know to really appreciate life and not to take things for granted P3: 611-613

An appreciation of a closer relationship with her husband: *We definitely became much, much closer because of it, we were so lucky because we, we were warned in advance you know this is very stressful on couples, couples can break up. I think our relationship was quite strong in the beginning so I think that having this happen, you know was very helpful that we were solid already and that stressful situation didn't break us up. P3: 632-737*

Chloe experienced personal growth in terms of a deeper understanding of motherhood:

I would never want them (children) to think for even a second that something had come before them because it wouldn't ever do that for me, you know but, and I used to be such a quite a selfish obsessed person before I had kids you know I was so tired, I must do this, my life is so stressful but you change when you have kids but I'm not sure men change as much as women do, no its been an interesting year for unveiling things that may never have been so obviously unveiled. P5: 470-475

The loss has revealed previously hidden aspects of her character:

I am not sure it has made me stronger I think it's made me realise how strong I am, because I wouldn't have thought I'd have got through this like I have. P5: 477-479

Carol describes the uncovering of potential and greater insight into her relationship with her husband:

I think there are certain events in life that change you more than others and I feel for me it has been a totally life changing event, actually I do. It's not that I'm a different person but I have taken directions and I've its exposed parts of my personality that might otherwise have remained less developed. P6: 982-986

Grief has uncovered in Carol a previously unknown part of herself:

I suppose I am more aware of the parts of myself than I would have been, and you know it's put me in touch with that side of myself which was always there, but it's put me in touch with that side of myself that wants you know do the work for TAMBA.

P6:1001-1004

Carol expresses her own insight into differences in grieving:

I think men and women deal with grief in different ways as well so there's a desire to keep going on with things to keep on going with men, and with women there's a desire to talk about things sort of try and heal it that way so that is very different. P6:541- 544

Alice speaks of the deep impact the experience has left on her:

You never really move on entirely and you can't expect everyone else to sit around remembering and in fact I've just said to you in my last breath I said I don't want to be defined as the woman who lost a baby so I can't have it both ways right? P7: 432- 435

This section ends the exhaustive description. It is a description that represents the intentionality of the lived experience.

The final part of the analysis is as far as possible to identify its essential structure from the exhaustive description. The fundamental structure relates to what is being lived through and is the essence of the phenomenon as it is revealed by explication. The fundamental structure therefore follows on from the description and forms the final part the analysis. I have sought to present an unequivocal a statement of identification

(Colaizzi 1978) of the fundamental structure of 'death of a twin'. I suggest this is a reflective rather than an interpretive process.

5.7 Empirical phenomenological reflection: Discovered fundamental structure of the phenomenon

The experience of loss has a distinct beginning in an end to an anticipated joyful pregnancy. However it is the intentionality of the lived experience following death that is recounted as an ongoing experience of loss from six months to seven years and in all probability beyond.

Death of a twin occurs at a point in time in the perinatal/neonatal period when life can no longer be sustained. It is an event that is preceded by one of the following events; poor growth, failed surgery for TTTS, unexplained reason or active withdrawal of life support. In the latter case it is the physical removal of life support where death of a twin is preceded by rational decision making. It is moral act by parents where life can no longer be sustained by medical care.

Death of a twin is an intuitive consciousness of pain, loss, isolation and grief lived out in a world that fails to understand and acknowledge the impact of this loss. It is an event that is complicated by the lack of time and space to grieve and the contrasting labour of parenting the survivor. The experience is lived through as one of shock at the initial announcement and difficulty in orientating her /him to this reality due to lack of helpful information. Health care professionals in seeking to support parents are compromised by their lack of knowledge and understanding of the parent's perspective.

It is an experience where separation from the dead twin cannot take place. The presence of the dead twin is maintained in memories, images and retention of ashes. Separation is an impossible task and ashes are held as a perfect place has yet to be found suggesting the perfect place is with the parent.

The meaning of death of a twin is an ongoing journey in which parents seek to validate their grief and loss. It is an event whereby the dead twin is a continuing and central part of the lives of the bereaved parent. Parents maintain the dead twin in their lives and the lives of the survivor. Death of a twin is a lived experience where inner and previously hidden strengths are unveiled and life enhancing growth post loss is revealed.

5.8 Summary

This chapter has provided a progressive analysis of the data. The exhaustive description has provided a lens through which the reader can engage with the lived experience of death of a twin. The final part of the analysis is its reduction to a fundamental structure. Through the use of imaginative variation I have looked at the exhaustive description and sought out that which is invariable. That is, I have looked at what is essential to the experience of death of a twin. This is in keeping with Husserl as in the ‘whatness’ of the experience. I suggest there is a phenomenon death of a twin. The essence or essential seeing (Husserl) provides a new and different way of viewing this loss. It is a different lens that brings into sharp focus a new understanding with what we have known. The phenomenon provides a new and different perspective on the loss of a twin. An understanding that death of a twin is an event that continues through the life of the parent. The understanding challenges traditionally held bereavement theories where separation with the dead occurs. The findings provide a new and different perspective on the loss of a twin and are congruent with the concept of *Continuing Bonds*.

CHAPTER 6: DISCUSSION OF THE PHENOMENON

6.1 Introduction

The overall aim of this study was to understand how parents experienced the death of a twin in the perinatal/ neonatal period from their perspective. In order to achieve this aim the following four sub aims were formulated: to identify the factors that influenced or continue to influence the experience; to ascertain the advice that parents would offer health care professionals; to identify factors that helped or hindered the process of bereavement; to identify what follow up care is required by these parents. The focus of the study was on informing my clinical practice to inform care of bereaved parents of a twin. Semi-structured interviews were conducted with the participants. In keeping with Husserl's descriptive phenomenology and using Colaizzi's method of analysis a description of the phenomenon 'death of a twin' was elucidated. The exhaustive description represented the essence of what it is to lose a twin while the fundamental structure was an unambiguous statement of what it lived through. The essential essence or the essential structure of the death of a twin contained four main themes, presented in table 6.1.

Table 6.1 Themes within the essential essence/ structure of death of a twin

Number	Theme
1.	Experiencing Death
2.	Accompanied by Others
3.	Being Alone
4.	Understanding the Loss

The essential structure of the phenomenon has yielded an understanding of the meaning of this phenomenon as it is experienced in contemporary society. Four major themes emerged from this study. **Theme 1 'Experiencing death'** provided the contextual data to the death of the twin, an event for which parents were unprepared. Their sense of joy in

their twin pregnancy stands in stark contrast to the abrupt and unanticipated entry into the world of bereavement. Parents recounted their loss not as an isolated event but, in the context of and fabric of their lives. It is important to integrate this understanding into the care of the bereaved parent. **Theme 2 ‘Accompanied by others’** provided insight into the personal and social world of the grieving parent. HCPs, family, friends and spiritual support play varying roles. The role of the HCP is experienced along a continuum from supportive to intrusive. This theme revealed that parents experienced counselling as intrusive and there was a timing issue. This is a very significant finding and has not been discussed in previous literature. Parents make suggestions as to what they want. A second significant finding related to the value of the non-professional organisations. This theme enhanced knowledge about the value of non-professional support organisations and reflects previous studies. This theme calls for a repositioning of these organisations to be central to the parents’ support system. **Theme 3, ‘Being alone’** provided detailed experience of bereavement as parents relate their experience over time. This theme is significant as the trinity of isolation, grief and loss as a companion provides a new understanding as voiced by the parents. Isolation and grief have been discussed in previous literature. It is important to consider of isolation as a natural and necessary process, in understanding the depth of their grief and an acknowledgement that mothers have lost part of themselves. Thus loss as an unwelcome companion occupies that part of the lost self. **Theme 4, ‘Understanding the loss’** provides insight into the parents experience over time. Parents are enriched by their suffering as previously hidden strengths are uncovered. Their loss is assimilated into life, it is a continual process and as the process unfolds so too does the experience of loss. Thus the experience of loss continues as a contextual loss. It is a theme in which the parents acknowledge their dead twin continues as a presence in their lives and in the lives of their siblings, particularly the surviving twin. The dead twin is held in the ashes, in memorabilia and in a biography to accompany the surviving twin. This is a very significant finding as it describes the sense of loss and how that loss is carried forward in the ongoing lives of the bereaved. The theme provided an understanding of the loss that is not written about in the literature. Furthermore this theme substantiates the theory of Continuing Bond and I suggest extends that understanding.

The essential essence of death of a twin was expressed in terms of spatiality, temporality, corporeality, relationality (Munhall 2007; van Manen 1990). That is the experience had a distinct beginning situating the experience of death within the context of the parent's life. The eloquent voice of the parent is heard as is their desire to shape practice. Parents require care that is empathetic, care which is not mediated by the HCPs assumptions. They require support from those who understand their experience; members of non-professional organisations. Counselling support may be valuable for some parents and this is required some time after the death. Parents experience the intensity and depth of loss in the third theme. The fourth theme illuminates the changed self through suffering and loss. Understanding the loss reflects a sense of growth and accommodation of loss. Parents are changed by this loss, and the dead twin is carried forward in their ongoing lives. Remembering brings the parent back to the time of death with a vividness and clarity that is as clear as the day it happened.

The next stage in the study is to consider what the reader of this phenomenology might do with it, that is how useful is it. The phenomenology tells me that I have a role to play in the care of the bereaved parent of a twin. Caring for the parent who has lost a twin requires sensitivity to the context of their loss, and awareness of the nurses' presence to impact positively on the experience. The phenomenology also tells me of the need to inform and educate not just the HCPs but family, friends and the wider society of the significance of this loss. This phenomenology also tells me the importance of providing a package of care to illuminate the phenomenon for the parent as they begin their journey accompanied by the dead twin.

This chapter will begin by addressing the clinical relevance of the research question to the researcher and the social and cultural context of the research. This will be followed by a discussion of the findings and their implication for practice, theory and training. The final section discusses the methodological issues. This aspect of the discussion is the final thread linking the introduction, the literature review, methodology and methods and findings. It is not the end of the debate rather it is a reflection on the path of sciencing

(White 1938) for practice. As such it is an awareness of what it means to care from the perspective of a researching practitioner.

6.2 Clinical relevance of the research question to the researcher

The research question caused me to address an area of practice in the light of unanswered questions related to the care of the bereaved parent following the death of a twin. There were a number of contributory factors in my practice area of neonatal care. There was no outward expression of grief to differentiate these parents from others who were not bereaved. HCPs avoided speaking to parents about their loss for fear of upsetting them. I colluded in this practice for a number of years until experience enabled me to speak with the parents about their dead twin. I was also aware that there was no specific training provided to help me deal with these bereaved parents. Through reflection I have come to understand my question on a deeper level than mere curiosity and in doing so make explicit my philosophy of care. I hold that for care to be wholly meaningful to the recipient, the carer is required to have an understanding of the values and beliefs which contribute majorly to the lived experience of the recipient. I begin to understand that care must therefore be rooted in the world of the recipient. McCormack (2001) describes this approach as one of authenticity, whereby an appreciation of the individual human being is a prerequisite to particular course of action from a variety of possible options. As a developing practitioner my focus of concern and energies was on the preterm infant and to a lesser degree on the parents. I consider the reason for this focus to be the dependency of the baby and my own inexperience. My deepening knowledge of practice has been achieved through experience, role modelling, education and training resulting in my perspective of the family as a unit to be cared for. I have also recognised that my own experience as the recipient of care has shaped my philosophy. My experience of best care was the capacity of the HCP to be ‘with me’ and engage with me as I presented myself. While the worst care was that where the HCP took a course of action that gave no understanding of my values. This lasting memory has shaped my practice to the extent that I challenge my HCP colleagues who in my view impose their own value system on another. The application of the principle to ‘do no harm’ (Beauchamp & Childress 1994)

requires to be understood in the context of care. That is in situations where we do not know and we do not ask. Not knowing may lead to inaction; however not asking may also lead to action resulting in non-adherence to the principle of nonmaleficence. Questions related to my lack of knowledge led me to exploration of practice and the characteristics of ethical practice. I came to understand more fully where the focus of care needs to be. My discomfort in this area of practice was crystalised in mindfulness of another's values and beliefs as a prerequisite for caring as it facilitates a course of action based on the individual's life experience (McCormack 2001). Mindfulness gave rise to feelings of discomfort regarding my lack of knowledge of the lived experience of the bereaved parents in the context of my caring for them. Those feelings related to a lack of understanding from the perspective of the parent. I believed that by understanding the parent's experience I could provide appropriate care in response to their needs.

6.3 Social and cultural context of the research

This research study was conducted in the context of death of a child being regarded as against the natural order of things in a society where parents are expected to die before their children (Walter 1999). Death may be viewed as unnatural by HCPs (Papadatou 1997) resulting in the unmet need of the bereaved (Neidig & Dalgas-Pelish 1991). Comparatively fewer people experience the death of a child within their own community (Davies 2004), and less support may therefore be available to those who do. It has been recognised since the 1980s that traditional held bereavement theories which have dominated practice over the past century do not reflect the distinctive experience of bereaved parents (Davies 2004). New perspectives based on studies of bereaved parents have provided both new understanding and suggested interventions to support bereaved parents. The new perspectives suggest as in the Victorian era that parents reject the breaking of bonds with the deceased as a means of resolving grief which formed such a central part of traditional models. New theoretical perspectives emphasise the concept of continuing bonds (Klass 1993a, 1993b). Parents obtain solace from those continuing bonds with their dead children (Klass 1999). Remembering and maintaining a connection with their dead children was a healing factor for many (Talbot 2002). While keeping

reminders and talking about their dead children to others in their social world (Rosenblatt 2001) was also a means of staying connected. Failure to find someone to share with results in intense loneliness; self-help groups identified by Klass (1999) provide the means for parents to remember and continue to value their children. It is against this background of evolving perspectives of bereavement theory that the research study was conducted.

6.4 Discussion of the findings

6.4.1 Introduction

Death of a twin is an unusual occurrence. The impact of this loss on the parents has yet to be fully understood. While the finality of death cannot be argued, the circumstance leading up to and the moment of cessation of life are exclusive to each parent. This thesis began by a review of the literature (Chapter 2), the title and a brief summary of the findings are presented in table 6.2

Table 6.2 Summary of findings in the literature.

Author	Title and Findings
Rowe et al.(1978)	Follow-up of families who experience perinatal death Things which helped; return to work and religious beliefs. Parents' need for information.
Wilson et al (1983)	The death of a newborn twin: an analysis of parental bereavement Professionals, family, friends downplayed the death of a twin. Mothers continued to think about the dead twin.
Wilson et al. (1985)	Parental response to perinatal death: Mother father differences Mothers experienced greater depression in the first six weeks. Fathers experienced greater depression at 25 weeks post loss
Bryan (1986)	The death of a newborn twin: How can support for parents be improved? Difficulty in distinguishing survivor from the dead baby, continued to think about the dead baby, lack of substantive memories, loss underestimated

Sainsbury (1988)	<p>Grief in multifetal death</p> <p>Conflicting emotions, how to refer to dead twin and grief may be deferred. Professionals urge parents to bond with the surviving twin</p>
DeKleine et al. (1995)	<p>Guidance after twin and singleton death</p> <p>Less social support, lack of support organisations to address specific needs of parents who have lost a twin.</p>
Cuisiner et al. (1996)	<p>Grief following the loss of a newborn twin compared to a singleton</p> <p>Mothers' grief is greater than fathers. No difference between grief reactions following loss of twin as compared to loss of singleton. Parents have specific needs following the loss of a twin.</p>
Netzer & Arad (1999)	<p>Premature singleton versus a twin or triplet infant death: parental adjustment studied through personal interview</p> <p>No significance difference in maternal and paternal level of adjustment following loss of a singleton as compared to loss of a twin. Parents had need for understanding and support</p>
Swanson et al (2002)	<p>How mothers cope with the death of a twin or higher multiple</p> <p>Mothers experience greater grief following the death of a twin than mothers following loss of a singleton. Most helpful was surviving children, family support and support from partner and spiritual support.</p>
Lundqvist et al. (2002)	<p>Both empowered and powerless: mothers experience of professional care when their newborn dies</p> <p>Need for sensitive support from HCPs. Impact of HCPs to empower parents or make them powerless.</p>
Swanson et al. (2009)	<p>How couples cope with the death of a twin or higher order multiple</p> <p>Death of a twin experienced as a most dreadful experience. Fathers were not encouraged to grieve; fathers believed they should be able to cope. An increase in spiritual belief.</p>

No study had wholly explored the experience from the parents' perspective. The literature review provided evidence of a perspective that was missing in our understanding of what it means to experience the death of a twin in the perinatal/neonatal

period. Aspects of loss have been identified in the literature review and there is significant evidence to suggest knowledge in this area could be expanded through accessing the parents' experience of death of a twin.

The findings from this study formed four major themes. The emergent themes addressed the aims of the research question. The findings have provided a new understanding of the death of a twin by the parents as they live through the experience. This new understanding has uncovered new knowledge in relation to counselling and its timing while repositioning of non-professional organisations is called for. It has unified experience of isolation, grief and loss as a companion to provide an understating of the period of 'being alone'. Furthermore it has substantiated the theory of 'Continuing Bond' with the dead infant and has extended understanding to include the biography of the dead infant is carried forward in the life on the surviving twin.

The findings from this study are important as they enable the voices of the parents to be heard. The findings give a new perspective on the death of a twin. This new perspective does not exist in the literature. The importance of the findings is viewed as follows.

- They give voice to the parents
- They challenge the service of counselling and its timing
- They call for the repositioning of non-professional organisations to provide support
- They substantiate Continuing Bonds
- They advance understanding of Continuing Bond in the context of twin loss
- The provision of a conceptual model enhances understanding of this loss
- The findings have potential to make a significant impact on practice.

The following discussion explores the findings in greater depth and their relation to previous studies is considered. Finally, the themes are considered in the context of their relevance to clinical practice, education and bereavement theory.

6.4.2 Theme 1: Experiencing Death

This theme was revealed when seeking to understand the social and cultural context to the death of a twin. Death of a twin was experienced not as an isolated event. Parents situate the death in a temporal and spatial world. All parents talked of their joy and the excitement associated with the twin pregnancy and such was their confidence that it prevented the intrusion of negative thoughts. There was an expectation that everything will be perfect and *“you never really think it is going to be you”* Participant 6: lines 7-8. That feeling of confidence was not disrupted by a 34 week scan where only one heart beat could be heard

“which didn’t actually concern me at the time” Participant 5: line 7.

In spite of delivery at 23 weeks gestational age parents’ hope grew and increased with every passing day. They needed reminders to help them maintain realistic expectations. This theme also uncovers a perspective on western medicine as parents contrast their reality with mothers in less affluent societies where survival would not have been possible and mourning would have begun at birth. One mother tells of not being able to acknowledge the death of her first twin until her second live twin was safely delivered. The acknowledgement of death became a conscious act once she had seen and held his still warm body. As parents negotiated the difficult path of withdrawing life support treatment they spoke of a tension in their needs *“you do want them to go because you know it is obviously better for them not to suffer but you also want to be selfish and keep them here”*. P4: lines 17-19.

One mother gives substance to the morbidity associated with laser treatment for the TTTS *“two and half hours on the table and she died that day”* Participant 5: lines 37-38

The findings from this study demonstrated the importance of information. Parents identified three discrete areas pertaining to information. The first related to information sharing and the reading of that information among professionals. It fell to the mother to provide the information at a time when she was vulnerable. This aspect of care reflects the fragmented midwifery service where an additional load is placed on the pregnant mother (McCourt & Stevens 2009). The implication for midwifery practice relates to organisation of care and a recognition of the emotional labour associated with pregnancy

and particularly with a high risk pregnancy. The second area related to conversation with the HCPs. Parents wanted detailed information to understand their situation and for future reference to help them explain to the survivor the life and death of their twin. Detailed information included copy of medical notes scans and reports. The need for information is consistent with Rowe et al. (1978) and as means of empowering parents (Lundqvist et al. 2002) and as means of creating a durable biography (Walter 1999; Riches & Dawson 1998; Lewis 1976). Parents received practical information about funeral arrangements (Forrest et al. 1981). There was a third area of information needs which were unmet and this related to that which would help parents make sense of the *“when you have lost one baby and have another one to look after... nobody really told us what that would be like...maybe people don't know”*. It was in this area that information was lacking in both written form and access to someone who had a similar experience and could therefore illuminate the journey for the bereaved parent. The role of non-professional organisations is central to the care of these parents where there is lack of understanding and loss is underestimated (Bryan 1986) lack of social support (de Kleine et al. 1995) and need for support and acknowledgement (Netzer & Arad 1999). Non-professional organisations by virtue of their being staffed by people who themselves have experience the death of a twin are in a position to provide empathetic support. The support organisation of choice is TAMBA as it is dedicated to the support of parents who have lost a twin.

There is strong evidence from previous studies and from the findings from this theme for a coordinated approach to care. Parents require clear communication and practical information regarding funeral arrangements. They also require and detailed information which may include medical notes and scans, the purpose of which is to understand and create a durable biography for the surviving twin. Parents also require written information about the emotional journey following the death of their twin. It is this area of practice that requires addressing.

The findings tell of the meaning of death, the feelings of being robbed of the joy of celebration, status as parents of twins. Understanding extreme prematurity as the cause of death did not make it easier nor did it lessen the grief (Kennell 1970). Parents tell of the impact of decision making on withdrawal of care and its lasting legacy. Participating in

withdrawal of care was experienced as making a judgement on someone else's quality of life. The decision is made in the context of the family and is one of the things the parent has to come to terms with. Coming to terms is a slow process taking years and the acknowledgement that it continues and will be revisited when full explanation is given to the survivor about the circumstances of surrounding death.

The contextual data serves to embed the loss in the fabric of the parent's life. This is an important aspect as it requires sensitivity on the part of the HCP to the circumstances of loss. Parents face bewilderment following their loss and need to make sense of their changed world. Parents experience shock (Kubler-Ross 1969) and 'not feeling normal'. Importantly this 'not feeling normal' was not referred to as depression (Wilson, 1985). Parents experienced not wanting to see anyone; this has a resonance with a sense of isolation which will be discussed later in more detail.

Parents experience death as difficult to cope with (Callister 2006; Davies, 2004). The findings support the experience a complexity of emotions (Sainsbury 1988) and the resultant struggle to understand what is happening. This then provides understanding of the parents experience at this point in their loss. Parents have been robbed of the joy and celebration. However, the experience of being robbed has yet to be lived through. This theme therefore provides what may be described as the first and preparatory stage in understanding death of a twin.

6.4.3 Theme 2: Accompanied by others

This theme emerged as the parents described their experience of living their loss in a social world. This was a very revealing theme as parents described what was important and valuable to them. The findings provide a unique insight into how the parents experience HCPs and how resulting events impact on parents experience. The theme illustrated what parents valued HCPs as "being there for me" and "I felt they felt my pain" they "weren't just doing their job". Other care suggested the actions of the HCPs took precedence over the mother's needs this is consistent with disempowerment as described by (Lundqvist 2002). The significance of this experience pushed the mother away from support which she might have otherwise availed of. Receiving of pictures of

her very immature infant was experienced as traumatic. This finding challenges the notion that photos (Sands 2007; Riches & Dawson 1998; Bryan 1986) are acceptable to all parents. This is an important finding to guide practice and HCPs should therefore be guided by discussion with the parent and draw on the knowledge that many but not all parents find this practice helpful. The findings caution against a blanket application of policies and procedures (Mchaffie 2001). It is important to note that while one mother understood parents reaction she advised the taking of pictures as at a later date parents may come to wish they had them. The photos may be the only tangible evidence of their baby.

This theme provides significant new knowledge in relation to counselling. The very personal nature of the loss and the need to understand the loss makes it difficult to share. Parents expressed a strong reaction towards counsellors. There was an expressed need for a relationship of trust prior to sharing in addition to a timing issue. Parents want HCPs to know and understand that following the death they are vulnerable. In this vulnerable state parents seek to protect themselves. The offer of counselling at this point is viewed as audacious and the offer is perceived as an endeavour to make things better. This is a very significant finding from the study. Previous studies (Parkes 1965; Lindemann 1944) suggest counselling can reduce psychiatric and psychosomatic disorders following bereavement. It is important to note that Lindemann sought to emancipate the bereaved from the deceased. Swanson (2009) suggests all parents should be offered counselling. Evidence suggests that newly bereaved find difficulty in accepting counselling (Forrest et al. 1981). The experience of parents from the study provides evidence as to why counselling is unacceptable in the immediate period following the loss and there is a timing issue.

The reasons given by the parents relate to the requirement of a relationship of trust and not wanting to share with a stranger. There is also the additional aspect that has emerged related to the need to be 'left alone' which is eloquently expressed.

“At that particular time you have just lost, lost a twin there is nothing anybody can do for you... there is absolutely nothing and not only that you don't always want to accept the help because you just want to be left alone” Participant 4: lines 219-221

This being ‘left alone’ suggests a respect for the parent’s loss and an acknowledgement that they need to become acquainted with the loss and its meaning before they can share. Thus the parent becomes a major informant of care and counselling support may be viewed as part of available support at a time when parent desire it as opposed to a common assumption that parent will benefit from its provision. In caring it is the ‘being there for me’ which is important rather than what HCPs can offer from a list of services. It is important that this finding is integrated into the care of the bereaved parent.

This theme highlighted the difference in grieving between the mothers and fathers. The one father in the study spoke of having the difficulty of coping with his partner’s grief, though they provided mutual support. The literature suggests that men and women grieve differently and it is acknowledged that mothers’ grief was greater than their partners (Cuisiner et al.1996). Failure of the husband to acknowledge this was a source of discord and ill feeling. The concern by others for the mother’s welfare was acknowledged by one mother as a real problem for dads. Both parents have lost an infant yet a disproportionate amount of care may be extended to the mothers as compared to the father. One mother acknowledged that her husband would not initiate a conversation about their dead twin as a means of protecting her, while another mother stated that her husband did not speak about their dead twin. The making of the ashes into a piece of jewellery was perceived as morbid and may explain that it is the mothers who have greater difficulty than the fathers in separating from the dead twin. Swanson (2009) suggests fathers are not encouraged to grieve. These findings suggest that the situation is complex and the mothers in this study desired support from their partners. The findings suggest that some fathers may be unable to support their partner.

This theme gives insight into the response by family members

“My sister has got two boys as well and we both wanted a girl and I remember her saying ‘Oh God, don’t moan at least you’ve got your daughter’ and I remember thinking ‘oh you have no idea you know’ and ahm she loves me to death and we are very close you know, from her point of view I’m sure that is really what she sees, but it is harder than that”. Participant 5: lines 201-205.

The theme supported the evidence that family wish to make things better but they don’t say the right thing (Wilson 1982) and suggests little has changed in the intervening years. One mother in the second interview contrasted the support she and her husband received following the death of their twin with that received by her sister-in-law following the death of her singleton. The latter received more support and from a larger number of family members. This lack of recognition was difficult to accept for both herself and her husband. The impact on her six year old daughter was recounted by one mother who stated that her daughter was excited by the prospect of twins. Her response to the death of her sibling was marked by her refusal to speak of the twins for one year. The mother had not explored the reason for this however, following the second interview she volunteered that she may do so. While practical support was valued, one mother experienced the presence of a family with ambiguity and led to internal conflict. That conflict demanded energy at a time when she was both grieving her dead twin and parenting the surviving twin. While the family support was present for all families the experience of loss in the context of friendship was different. There is a limited period within which the bereaved parent shared with friends. The bereaved employed a different perspective when sharing with friends and questioned how long it is acceptable to discuss their loss. Friendships with mothers of twins pose a particular problem as the mother of twins has a greater appreciation than other of what the bereaved has lost. While this might appear to be a valuable support to the bereaved mother, the reality is the friend becomes upset. Thus the bereaved mother seeks to protect her friend by not speaking of her loss.

Spiritual belief and spiritual support has been reported (Swanson 2002; Swanson 2009) as valuable. This theme confirms the value of spiritual support to some though not all of the bereaved parents. For those not overly religious the funeral served as a formal

acknowledgement of the twin's existence. Furthermore the funeral served as a means of involving siblings in order to be able to say at a later date 'this is how you were involved'. This aspect is the first instance where the biography of the dead twin in being held by the parents as an active event in the ongoing life of the survivor. In this theme the parent's voice tell how they experience death within the context of their life. They experienced death as a movement from pregnancy to a world of loss and that loss is also experienced in the presence of others. In **Accompanied by others** parents tell of the impact of others on their experience of loss. Parents move from being accompanied by others to being alone.

6.4.4 Theme 3: Being alone

This theme gives insight into the experience and meaning of loss for the parents. Parents speak of a sense of isolation, that isolation presents itself for a number of reasons. Parents have lost their infant and something of themselves; the lack of understanding serves to isolate these parents. There is another dimension experienced by the mothers and that is the intimacy of the relationship with their unborn child which exacerbates the sense of isolation. Their grief enters deeply into their psyche giving rise to a profound sense of loss. This loss becomes an unwelcome companion and sits within. It occupies a space for thoughts, memories and potential of the dead infant. This theme provides an in-depth insight into the parents' grief. The voice of the parents speaks eloquently and allows us to understand their loss.

In this theme parents are beginning to gain their own understanding of their loss. Parents speak of isolation by lack of information of support groups, of isolation by friends who do not speak and acknowledge their loss. Parents are denied permission to speak with resultant denial of their loss. Isolation is accentuated by seeing others twins. Parents speak of acknowledging the surviving twin while failing to acknowledge the loss of the other. People do not say the right things 'at least you've got one' are a not unfamiliar response to loss. This theme confirms that loss is underestimated (Wilson, 1982; DeKleine et al. 1995). Loss was experienced as underestimated and parents find themselves protecting their family and friends by not mentioning their loss. Parents are

also isolated by the fact of having to make a decision on withdrawal of life support and the legacy of an element of doubt. Parents voice the responsibility of that lonely decision and in providing an explanation to the surviving twin at an appropriate time.

This theme gives an insight into the parents' perspective and meaning of grief. It is a grief that is deep and personal and gives a different perspective of grief than that which is available in the literature. It is a grief that requires time and space, a grief that parents must become intimately acquainted with. It is a lonely journey and marks a period where the life of their twin is replaced by loss as a companion. It is a grief that is required to be managed within the demands of family life. The theme confirms the literature on the differences between how men and women grieve. The need to be alone is acknowledged by parents, that time and space serves to know their grief. It is only in their knowing their grief can parents share.

Parents tell of the contextual management of their loss. Time and space is negotiated for grieving. For one mother the presence of her mother-in-law was helpful from a practical sense however, that value was negated by the mothers need for personal space. Visits to the cemetery coincide with the survivor's sleeping pattern. This avoids the baby seeing his mother upset. Time is negotiated with their partner at the end of the day. Time is taken to think about and 'be with' the dead twin, while time is also taken to look through the memorabilia. The power of clothes (Sverakova 2009:215) has been likened "*to gatekeepers for feelings on the path back to living, even living with pain*". For another parent she wants to forget about it she knows 'this is silly' but she yearns for normality and she uses pretence as a means of coping.

The theme gives an understanding of grieving in the presence of the surviving twin in the neonatal unit. Those parents are concerned for the surviving twin and when present in the NNU their energies are focused on the health care needs. Parents manage their grief by not wanting to talk about it. It is not the sort of everyday conversation and the parents wish to be treated as normal. They wish to talk about their loss at a time of their own volition. This theme also sheds light on the impact on grieving of continuing morbidity

of the surviving twin. On-going care and periods of hospitalisation reduce space and time for grieving. Deferred grieving (Sainsbury 1988) was evident in one parent at two years' post loss she acknowledged she still needed to grieve. The need for time and space to grieve is confirmed by her plan to access time when her surviving twin is 'well enough' to be left with a family member. In the meantime her time is severely rationed for grieving.

This theme confirms the difference between how mothers and fathers grieve. The mothers thought about their dead twin and that twin occupied much space (Bryan 1986; Wilson 1982). One mother described the difference as men keep going while women need to talk and sort things out. The one father in the study felt they needed to move on after the funeral service, not forget but they needed to focus on the survivor. I believe fathers may be concerned for the health of their partners when they see the depth of their loss. They are concerned for their partner and also concerned that if grief becomes too great the surviving twin will not have a mother capable of parenting. This is an area that requires further research. The response of the father to his partner 'you need to get over' this underpins the difference. The response may also reflect the inability to deal with the raw expression of grief. A further concern may be the important role of caring for the survivor. The concern may be if the mother becomes so engulfed in her own grief she may be unable to care for the surviving twin. Not all parents spoke to each other about their grief. The perceptions of the mothers ranged from an understanding that her husband thinks about his dead infant but will not initiate a conversation because it will upset his partner. Another mother volunteered she did not know if her still thinks about his dead infant, though she suspects perhaps not. The father in the study said he thought about his dead infant and would never forget him. Evidence suggests that mothers experience greater grief than fathers (Cuisiner et al 1996) and that mothers experience a unique grief (Callister 2006). The findings both support the evidence and provide an explanation. The fact that mothers carry their babies is attributable to the difference in grieving. The voice of the parents tells us that there is not one uniform response when grieving the dead twin. This is an important finding as it underpins the need for an individual approach and laying aside our assumptions and acknowledgement that parent

may grieve differently. While support may be sought within families the loss may be too great for partners to support each other. One mother whose surviving twin spent a month in the NNU stated she didn't have time to do the 'grieving thing' and wondered if that made the process of grief longer.

This theme give a different perspective on depression associated with loss of a twin (Wilson et al. 1985). The state of not feeling normal for the first year was lived through by one mother. For two other mothers this feeling brought them to their GP. Neither mother wished for medication for something they saw as a normal reaction to their loss. One availed of three counselling sessions; the other 'wallowed in her misery'. This finding is significant as it challenges HCPs how to view loss. In contemporary society medication is readily available to make things better and to dull the pain. These mothers are stating they wish this process to be recognised as normal. Time is viewed as moving away from the newness. This theme challenges assumptions that grieving is a process that is completed or that it is possible to separate from the dead (Freud 1917). It is a journey in which the bereaved is moving forward but in remembering and talking about it is as raw as the day it happened.

The sense of loss is deep and impacts on the bereaved parents. Loss is carried and assimilated into life. Parents learn to recognise triggers such as tiredness that exacerbates the sense of loss. This loss is recognised as different from others. It is also a loss that is daunting; expressed as a concern that it will always be there. While no parent considered their loss to be greater than the loss of a singleton, one parent suggested that a parent could forget a singleton loss as there wasn't the constant reminder of a singleton.

6.4.5 Theme 4: Understanding the loss

This theme provides significant new insight into the death of a twin. Over time parents have moved from '**experiencing death**' to '**accompanied by others**' to '**being alone**' and they come to an '**understanding the loss**'. The need to remember and maintain the presence of the dead twin in ongoing life is an essential part of understanding the loss. Loss is therefore understood as a continuing attachment and relationship with the dead

baby. The five parents who had had a cremation all have retained the ashes. Time does not lessen the need to hold on as revealed one parent who was six years post loss at the first interview.

“Well she’s in our bedroom at the moment in a suitcase. (line 598) I keep thinking I must do something and every year I think that but it doesn’t seem quite right” Participant 6: lines 600-601. Nothing had changed between the first and second interview. The surviving twin serves as a link to the dead twin and therefore may provide an ongoing support to the bereaved parent. The bond is nurtured to ensure the continuing presence of the dead twin within the fabric of the family life. The dead twin is remembered in the family garden *“You can see that’s Isla’s tree, it was just another way of remembering her”*. Participant 3: lines 315-316

The baby box is a means for one mother to nurture the relationship between the survivor and his dead sister dead twin is part of the survivor’s identity

“Quite often he’ll (survivor) go and get his box out and talk about that and ahm he knows that we just say, he says, Isla has gone to heaven”. Participant 3:line 385-386

The mother holds the dead twin in conversation with her siblings, though a greater emphasis is placed on talking to her survivor. *“It’s part of her identity and its part of her story and I feel quite strongly, and I do talk to her more, I have to say, I do talk to Sophie quite a lot about it probably, and Mark, but I probably have talked to Matilda (survivor) the most about it”* Participant 6:lines878-880

A life is imagined with both twins *“I do think I wonder what it would have been like to have him here with Joseph, two boys together and you know yes I do think about that”*. Participant 3: lines 125-127

“Now you know I think about him sometimes unexpectedly sometimes I do on purpose but I try and do it not when the other kids are about”. Participant 7: lines 495-497

For two parents they had lost an identical twin and they gained some comfort in knowing what the dead infant would have looked like. Understanding the loss may be seen within the context of a continuing bond (Klass 1996) with the dead twin. Time, energy and emotion are invested in maintaining the dead twin within the fabric of continuing life of the bereaved parent and the life of the family. This theme has uncovered previously hidden strength, there is acknowledgment that this experience of loss has enabled parents

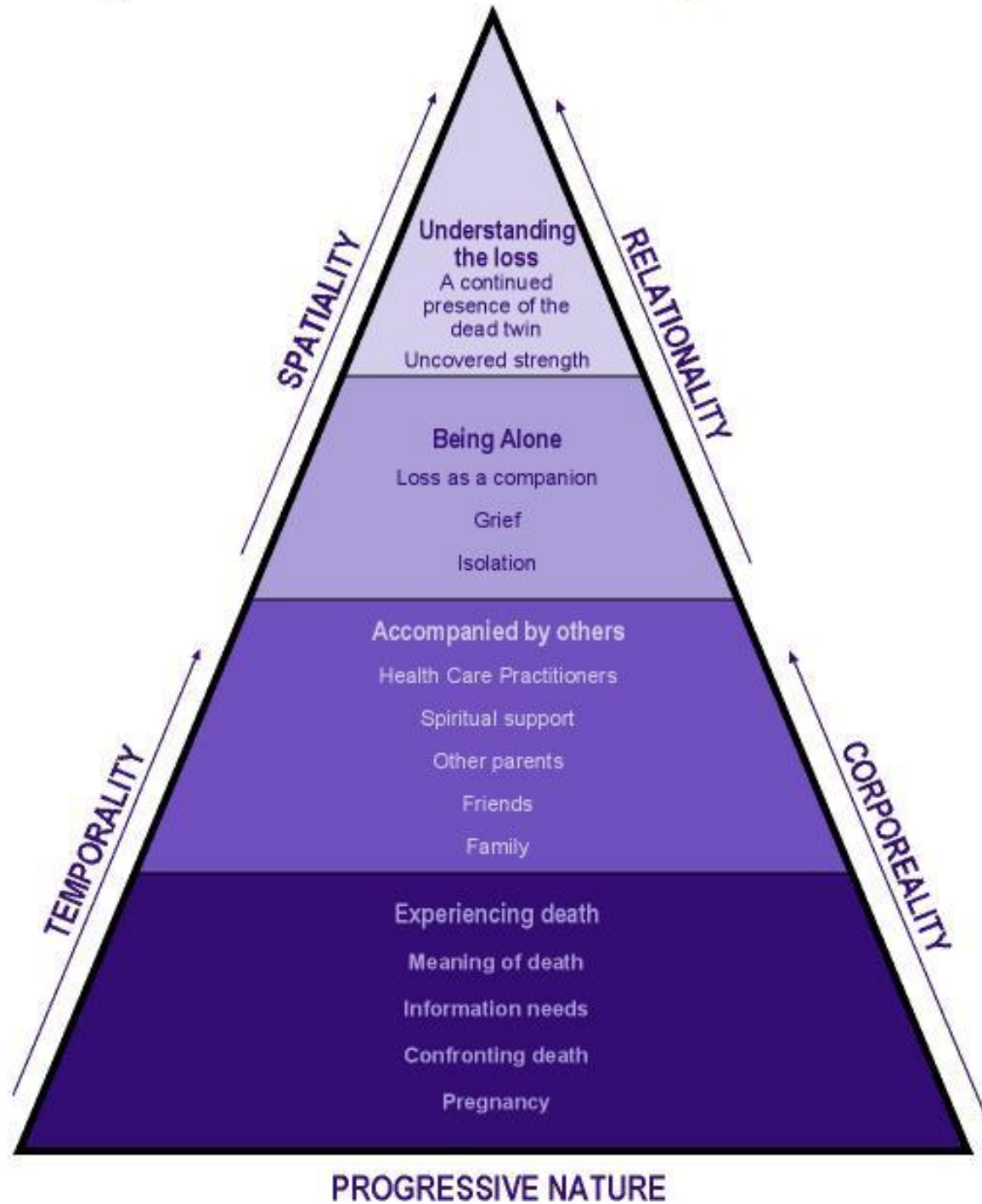
to get in touch at a deeper level with their emotional self. The experience has surprised parents that in spite of their grief and suffering they can and do put their family needs before their own. Parents have also reached out to others as a result of their pain and suffering.

The themes from this study provide a new perspective on parents' experience following the death of a twin. That experience speaks of a loss that is deep and lasting, a loss that maintains the dead twin within the ongoing life of the parents, the surviving twin and the fabric of the family. These findings allow HCPs to enter into the experience of the parents and respond on a human-to-human level.

Understanding of the essence of death of a twin is represented in a conceptual framework (6.3 Conceptual framework for understanding the death of a twin) The framework represents the progressive nature of this loss. The progressive nature of the loss was evident in the interviews, the experience of contextualising the loss, following by the parents becoming aware of others response to their loss and their own bodily response and emerging towards an understating of their loss. Parents become aware that people do not understand their loss. It is the experience of *Being Alone* that parents come to understand their loss. The depth of grief is unexpected and the feeling of isolation is difficult to bear. As the parents emerge from *Being Alone* they come to understand that they will never forget their dead infant, rather they recognise that the dead infant holds a place within their ongoing life, the life of the family and the life of the survivor. It is the experience and its progressive nature which is made explicit in the conceptual model. It is a model that allows the reader to move with the bereaved as they accommodate their loss. It is a model that invites the reader to see this loss not as an event but as a loss that is expressed in the four worlds of temporeality, spatiality, corporality and relationality (Munhall, 2007; van Manen 1990). I wish to make clear that although the apex of the pyramid is closed this represents my understanding at this point in the parents' experience. It does not represent an end to the parents' experience of their loss. Indeed the retention of the ashes suggests a continuing journey with the dead twin. It is a journey that has yet to be uncovered.

Table 6.3 Conceptual framework

Conceptual Framework for understanding 'Death of a Twin'



6.5 Contribution to practice knowledge

This research explored the lived experience of parents following the death of a twin in the perinatal/neonatal period. The focus of the study was to understand the parents experience and to use that knowledge to inform future clinical practice in this area of care. As a neonatal nurse caring for bereaved parents of a twin I was keen to understand the lived experience of parents and whether and how practice might be changed as a result. Caring for the bereaved is a central aspect of practice. The findings confirmed a new understanding not previously written in the literature. That new understanding is considered in the context of contribution to practice.

The findings from this study are important primarily because they have given voice to the parent. This is a different voice and a different perspective that that in existing literature. It is a voice that speaks of lack of understanding of their loss. It is loss for which they are unprepared and their experience of that loss is of a progressive nature. It is I suggest that by understanding the progressive nature that HCPs may best support this group of parents. Parents ask that their loss is recognised and HCPs are in a position to do this and help educate the wider family of the need to do so. Parents have identified that it is not the HCPs but non-professional organisations who are best placed to help them. The provision of contact numbers and named contacts should be available for the bereaved parent. Attention to the role of the organisation is important, and the findings suggest that it is TAMBA which is best suited to the needs of the bereaved. These findings go beyond the neonatal environment and provide guidance as to the need for well trained and empathic midwives. The findings also inform the timing of counselling. This is a very important aspect of the findings and calls for a thoughtful provision of services. Unlike the mothers in the study the one father voiced his opinion that he would have found it beneficial to have had someone to speak to in the immediate period following the loss. Further research is needed in this area to confirm whether this view is consistent with other bereaved fathers. The findings have highlighted the differences in how men and women grieve. This is very important in order to help parents understand how each may cope differently and may therefore not be able to provide desired support to each other. In response to the findings the following may be considered as good practice guidelines.

- Clear communication, the provision of factual information
- Acknowledgement of loss
- Identification of the surviving twins medical notes
- Named contact and phone number of TAMBA support
- The provision of a follow-up counselling appointment at between six and twelve months, this to be reviewed if the parent deems the timing to be is inappropriate
- Information leaflet for parents to prepare them for the emotional journey they are beginning. This should include a section to explain that men and women grieve differently
- Invitation to memorial service

6.6 Contribution to bereavement theory

Understanding the grieving process has been informed by the psychoanalytic model (Freud, 1917) which required separation from the dead. Where separation from the dead was not achieved grief was diagnosed as pathological (Lindemann 1944). This view was challenged during the last decades of the 20th century and there emerged a different way of understanding bereavement and the expression of grief. That understanding emerged from the voice of the bereaved and is reflected in a continuing bond with the dead (Klass 1996; Neimeyer 2001). The findings from his study are important as they substantiate the theory of Continuing Bonds following bereavement. This aspect of continuing bonds in relation to twin loss has not been written about in the literature. Indeed the findings make explicit how this bond is maintained and retention of the ashes speaks powerfully of the actions taken to maintain that bond. Furthermore, the biography of the dead twin is created as a means for remembering and sharing with the survivor the history of their dead sibling. It is important to note that the parent cultivates the Continuing Bond with the survivor through the use of the baby box, memorabilia and medical notes. The contextual data surrounding the death is gathered and provides a reference to the death twin. Finally the parent speaks to the surviving twin at greater length about the loss of their sibling twin that with other children in the family. Parents are initially concerned that they may forget the dead twin but as time passes they are reassured they will not. Substantiating Continuing Bonds is a very important aspect of the findings and serves to

provide guidance to HCPs in caring for parents. The limitations of relinquishing emotional ties and progress towards recovery have been recognised in the literature (Attig 1996; Neimeyer 1998). HCPs can reassure parents that the concern that they might forget their dead twin is ill founded, rather they will find their own individual way of maintaining the bond with their dead twin. Parents may receive some comfort in knowing that it is normal to wish to maintain the dead twin within the fabric of their life and that of the family and that it is normal to do so. Informing both parents about retention of the ashes may enable them to feel comfortable in their quest for a suitable resting place. That there is no urgency about this matter is an important consideration.

6.7 Contribution to education and training

The findings from this study have relevance to all HCPs caring for the bereaved parents. The findings therefore need to be incorporated into in-house training for nursing and medical staff. The training should also form part of the orientation for all groups of staff. I see simulation training as offering a valuable opportunity to enable HCPs to learn within a safe environment so as to be appropriately deal with and support bereaved parents.

6.8 Methodological discussion

6.8.1 Introduction

The methodological discussion addresses the decision regarding my choice of phenomenology to address the research question. This is followed by a discussion on the generation of knowledge to answer my research question. What constitutes knowledge in the context of my research question is considered. The resultant knowledge is considered in both the answering of the research question and in facilitating a thought responding action in other HCPs. This section ends with consideration as to the rigour of the findings. The strength of the Husserl's phenomenology is considered. The application requires a phenomenology of interpretation.

6.8.2 Uncovering knowledge through phenomenology

As I reflect on the parents' lived experience I am drawn to the words of Dilthey (1978:110) "*The standpoint of life allows things to appear as what they are "for us" (für uns) in actual lived experience rather than hastily introducing conditions and constructs to account for the purported grounds and causes of such appearances. In contrast to both physics and metaphysics, the standpoint of life demands the fullest possible viewing and description of experience prior to formulation of models, schema and hypotheses*".

Dilthey suggests that lived experience provides the most complete description and it is this description that is fundamental to understanding. It is I believe necessary for the understanding of what it means to be human.

My research study provides knowledge from a different perspective. It is a perspective that is embedded not in the natural sciences described by Parse (2001:2) "*methodologies have a causal ontology and elicit quantitative data from observable data to confirm or reject causal relationships*" My study sought knowledge through understanding however, it also sought to achieve this knowledge through a no less rigorous path than that employed by the natural sciences. Sciencing, described by White (1938) is coming to know and understand the meaning of phenomenon of concern to a discipline. This opens up the possibility and appropriateness of different approaches to knowing and understanding. I therefore turn to phenomenology as a means of uncovering meaning of the lived experience of parents following the death of a twin.

I would like to draw the reader's attention to Moran (2000:4) who suggests phenomenology "*is best understood as a radical, anti-traditional approach which emphasises the attempt to get to the truth of matters, to describe the phenomena, in the broadest sense as whatever appears in the manner in which it appears*". At this point I can see that there is a gap between phenomenology as a philosophy and phenomenology as a means of understanding phenomena. Giorgi (2000) and Colaizzi, (1978) are helpful in bridging what initially appears to be an insurmountable gap as I will illustrate in the following. The findings from my research study were arrived at following engagement

with a phenomenological philosophy operationalised at the level of nursing practice (Giorgi, 2000) through Colaizzi's (1978) approach to research.

This meaning is achieved through addressing each description and recognising specific meanings that differ from other descriptions. The specific meanings are raised to a more general level in the exhaustive description. The essences within the exhaustive description are taken to give form to the fundamental structure of the phenomenon 'death of a twin'. I have demonstrated the use of phenomenological methods of description, reduction and the search for higher order essences that are typical of the contexts. I can therefore lay claim to a method based on Husserlian viewpoint. I also claim that the knowledge is true to the parents as evidenced by direct quotes to support the essences.

Having established the truth and veracity of the findings I would like to draw the reader's attention to the fact that this knowledge seeks to inform HCPs in practice. The research study has not sought to measure or quantify loss or aspects of loss. It has sought through a scientific approach to provide descriptions of what that loss means to the parent. It provides a rich description that I believe engages the HCP on both an intellectual and affective level. In understanding the phenomenon I am enabled to question my practice and my approach to caring for this group of bereaved parents. The meaning speaks to me as a practitioner in the context of care on a human-to-human neonatal practitioner. The meaning also speaks of how phenomenology has illuminated the experience of death of a twin in the perinatal/ neonatal period. That illumination is in contrast to research into grief levels, Netzer & Arad (1999); Wilson et al. (1982; 1985) have compared how parents cope with the loss of a multiple as compared to loss of a singleton. As a practitioner I am engaged on a human-to-human level and I seek knowledge that will enhance that engagement. In my research approach I have given due consideration to an approach that has provided knowledge of the lived experience rather than comparison of grief levels. It is this knowledge that demands a response from the HCP to care for the bereaved parents from the perspective of their reality rather than the imposition of their own (HCPs) values. The approach to the study of human phenomena differs in an ontological and therefore an epistemological and methodological approach. The findings

from such enquiries are also different. They differ because science is portrayed as an exact science. I ask the reader to consider quantifying grief. How grief might be appropriately quantified? Once quantified it is now evaluated against the medical model which seeks to treat grief. Yet grief is a normal response to loss. That response is mediated by the person, circumstance, support, culture and background. Therefore the response may be expected to be varied in intensity and length. Nevertheless it is not uncommon in research to measure grief (Wilson et al, 1982: 1985; White et al. 1984; Cuisiner et al 1996). I argue that quantifying grief does not provide 'thick description' or richness of data from which to inform my practice on a human-to-human level. I as a practitioner want to understand the parents' experience, that understanding helps shape my practice, in a way that is different from knowing the quantification of grief, even if that was truly possible.

The phenomenological approach used in this study has caused me to reflect on knowledge for practice and the methodology we use to gain this knowledge. In my introduction I set out my presuppositions regarding death of a twin. I would draw the reader's notice to the richness of data in the exhaustive description. The approach that I have taken as a qualitative researcher has provided a deep understanding of what it means to experience the death of a twin.

As I reflect on the phenomenological approach I have undertaken I am conscious of the cost this method has made on my emotional reserves. It was a cost that had I known I might not have embarked on this study. When challenged by my supervisor I had cause to reflect on the meaning of a caring practitioner. I view caring as a willingness to enter into the world of the parent I care for, to listen to and seek to understand their needs and in my understanding, to respond appropriate. I feel it is this realisation that give meaning to the aim of the Professional Doctorate programme to develop 'researching professionals'. The findings from this study may help HCPs towards an attitude of openness and enable the provision of care that is appropriate to the need of the bereaved parent.

The discussion has focused on three areas. In the discussion on findings in context of existing knowledge I have demonstrated how the findings both support areas of existing knowledge and the discovery of new knowledge which provides a new understanding of the experience 'death of a twin'. The knowledge of the parent's reality demands a response to care that is patient centred and individualised. I have also addressed how that new knowledge may be shared and disseminated. In the final part of the discussion I have made explicit how this new knowledge has been gained through a phenomenological approach. The next section addresses issues of rigour in the research study.

6.8.3 Rigour of the findings

The achievement of rigour in a research study is addressed through adherence to concepts of validity, reliability and generalisability (Priest 1997), while Denzin & Lincoln (2003) consider the issue of whether they are believable. An audit trial is advocated by Mays & Pope (1995) and Sandelowski (1993). There are additional concerns about rigour in phenomenological research. As my research study is situated within a Husserlian philosophy and therefore the uncovering of the essences of death of a twin are unique to the participants of the study therefore the issue of transferability is limited. Rather the question to be asked is does the richness of description reflect the data? (Stephenson & Corben 1997). The issue of rigour resulted in my seeking considerations specific to phenomenology. Munhall (2007) suggests a specific approach of *One P, Ten Rs* to evaluate phenomenological research for rigour and merit. These are presented in Table 6.4 to evaluate rigour. The P refers to the *Phenomenological Nod* (i.e. nodding in agreement when reading or listening to the study findings).

Table 6.4 To evaluate Rigour

Resonancy	The interpretation of the meaning of experience is familiar, sounds correct, “ <i>resonates</i> ” with past experiences
Reasonableness	All activities of the study, including the interpretation of the meaning of all experience, sound “reasonable”
Representativeness	The findings represent the many dimensions of the lived experience; this is evident because of the multiple data sources examined (I understand this to refer to participants)
Recognisability	The reader becomes more aware of an experience by recognizing some aspects of that experience, which leads to the next criterion
Raised consciousness	The reader focuses on and gains understanding of experience, a new insight not thought of before
Readability	Writing should be concrete, readable, interesting, and understandable
Relevance	Research findings “should bring us close to our humanness, increase our consciousness, enable understanding, give us possible interpretation, offer us possible meaning, and guide us in our lives, personally and professionally
Revelations	As the reader gains a deeper understanding, “ behind or underneath what is revealed to us, we have considered what is being concealed or what wishes to be concealed”
Responsibility	Ethical considerations are evident, including process consent, sensitivity to content of conversations, and authentic representations of meaning
Richness	A full embodied, multifaceted, multilayered, thoughtful, sensitive, impassioned description of human experience
Responsiveness	People are moved to rethink preconceptions or act in some way in response to the study

It is to the reader that the above Rs are directed. The descriptions of the phenomenon has made evident in the exhaustive description and the fundamental structure meet the criteria as specified by Munhall (2007) with the exception of “Revelations”. I wish to acknowledge that I feel a discomfort with this criterion as I am unable to grasp its meaning and therefore cannot seek to address it. While this is an extensive list, its detail focuses consciousness on the meaning of a phenomenological study. Therefore criteria extend and deepen my understanding of what it means to conduct a phenomenological research study.

The phenomenological approach has sought to develop scholarship in practice. This has been achieved through the elucidation of the phenomenon death of a twin. The phenomenon has extracted the essential essences of the phenomenon rather than a description of the experience. I therefore suggest that this phenomenological has less in common with researchers who are concerned with description of experience (Crotty 1996). The result is to help stimulate a thoughtful action in response to the findings. The reader is challenged to a personal response, a response that is mediated by the richness of the description.

6.8.4 Strengths and limitations of the study

This research study was of a sensitive nature and I had concerns for the care of the parents’ emotional health. I see the opportunity of the study to give voice to the parents as the major strength of the study. Parents spoke openly and freely and the fact that they were happy to participate in a second interview was encouraging to me as researcher. Two parents voiced their appreciation of the opportunity to share their experience. Another participant asked how the findings were to be made known. I see this question as an important strength as the participant anticipated the findings would be made known to the HCP team. The second interview also enabled the participants to hear of others experience. The study therefore validated the parents experience and I believe reduced their isolation.

A strength of the study was the inclusion of parents who had experienced the loss of a twin during pregnancy, at the time of delivery and in the postnatal period. The findings

therefore capture a wide range of experience. Consistency within the findings supports the opinion that there is a similarity of emotional experience irrespective of when the loss occurred. The findings are therefore relevant to antenatal, intra partum and postnatal care.

The study was appropriately limited to a small sample size. Within the sample of seven participants only one father was represented. There was consistency with the mothers with regard to many areas and this is valuable. A greater representation of fathers would have enabled me to understand more fully the meaning of their loss and enabled a direct comparison between mothers and fathers. The limited data does suggest a difference but there is much that is as yet unknown. While acknowledging this limitation I would suggest the impact of under representation has highlighted an area for further research that would have as its focus understanding the meaning of death of a twin from a father's perspective.

Another limitation was the fact that all the participants were Caucasian including two non Europeans. My area of practice serves a multi-ethnic population and this population was not represented. This is an area to be addressed in future research. A further area of exploration relates to experience of family members whose response impacts on the bereaved parents. Therefore an area for exploration would be the lived experience of family members including sibling and grandparents.

A further strength relates to the new understanding uncovered. The findings raise further questions in relation to our understanding the meaning of death of a twin in the perinatal / neonatal period. The findings show that the meaning of the lived experience is complex. I have sought to capture this complexity in a small group of parents. This suggests that loss is lasting, the length of which is as yet unknown and indeed cannot be known. The findings serve to highlight the need for a longitudinal study.

A further strength relates to the use of phenomenology. The use of phenomenology enables a full understanding of the death of a twin. As a phenomenologist the study has highlighted to me the challenge of researching. The findings raised issues about the

nature of the loss and how it may impact upon the survivor. The study did not seek to address this area, however the findings suggest this is an area that would benefit from further research.

6.9 Summary

This chapter has addressed the relevance of the research question to practice and situated the research study within the current cultural and social context. The findings provide a new understanding of death of a twin. The conceptual model reflects this new understanding within a phenomenological framework. The findings were considered in the light of existing literature and their relevance to inform practice. The methodological issues pertaining to the study were then addressed. Finally the findings were considered in the context of informing practice. Finally the strengths and limitations of the study were considered.

CHAPTER 7: REFLECTION ON THE RESEARCH PROCESS

7.1 Introduction

The previous chapter addressed the findings of the study in the context of what was previously known about ‘death of a twin’. The findings add to the existing body of knowledge and provide a lens through which to view the experience of loss and how that experience is lived. Practice is therefore informed by knowledge which has been generated through scholarship in practice. This chapter provides a reflective account of the process of completing the research study. I identify my reflection with Boyd and Fales (1983: 101) *“as the process of creating and clarifying the meaning of experience in terms of self in both relation to self and the world. The outcome of this process is changed perceptual perspectives”*. This chapter presents a reflection that represents the research process as context bound and constructed by context (Freshwater 1998; 2005). This chapter addresses scholarship in practice, a defence of the methodology, bracketing, informing transforming practice, user involvement and finally dissemination of findings.

7.2 Scholarship and the professional doctorate

The completion of this Doctorate in Nursing was an all consuming experience. It was an experience that impacted on time available for family and friends and social life. It was also an experience that was enriched through sharing the experience with supportive colleagues from other disciplines. Finally, it was an experience that brought an awareness of scholarship in practice (Rolfe 2009; Rolfe & Davies 2009; Rolfe & Gardner 2005). It is the final aspect of the experience that I wish to address in this chapter.

The practice of nursing has been impacted on by a number of factors which has resulted in the trend towards academia. The Royal College of nursing (RCN) provides scholarships and awards to practitioners for study and to focus on areas of practice. In the UK the entry of nursing to higher education has resulted in an enormous growth of

nursing professors (Kitson 2006). The key role of university education as outlined by Sir Ron Dearing in the UK Report Higher Education in the Learning Society (Department of Education and Employment 1997) focuses on four areas. The first relates to the acquisition of knowledge and skills for employment, the second sought to equip students with the problem-solving skills, reflection and decision making. The third point refers to the generation of new knowledge, the final point addresses safeguarding the transmission of society's values through art, art, literature, science and cultural activity. Thus scholarship is seen as a central support and is characterised by Kitson (2006) as an understanding of the existing body of knowledge, the ability to integrate and synthesise, the ability to communicate effectively, cogently and coherently and concisely through the written word and orally, the ability to think logically and clearly and present a balanced argument. Nurses as practitioners are therefore in a position to contribute to the profession's knowledge base in areas of propositional or scientific knowledge, professional craft and personal knowledge amplified by critical reflection on professionals and life experiences (Rolfe & Davies 2009; Higgs & Titchen 2001; Doncaster & Thorne 2000).

The professional doctorate in nursing affords the means to advance professional practice outside of academia (Green & Powell 2005) and has arisen due to the limitations of the traditional PhD qualification for practice. The UK is among countries that have developed the professional doctorates in response to perceived gaps in doctoral education (Park 2007). The emphasis of the professional doctorate is to develop 'researching professionals' as opposed to the emphasis on 'professional researchers' within the traditional PhD (Bourner et al. 2001). Thus research is informed by real world problems in professional practice (Park 2007). The RCUK (2001) set out the standards expected of research students. These skills pertain to acquisition of research skills and techniques, an understanding of the research environment, accomplish research management, realise personal effectiveness, demonstrate clarity of communication in a variety of setting and to different audiences, develop networking and manage career development. One of the core themes of doctoral graduates is the "ability to see oneself as a scholar-citizen who will connect his or her expertise to the needs of society" (Nyquist 2002). Their

development is therefore essential to the survival of the profession in the current political climate (Morley & Petty 2010). Indeed McKenna (2005: 245) argues that *“with new technologies, faster patient throughput, more community care, new diseases being discovered and old ones coming back- more than ever before we require a cadre of nurse scholars educated to doctoral level”*.

I therefore suggest that the Professional doctorate has enabled me to explore a very important issue in practice. Prior to this research study my practice was guided by a practical approach to the care of the bereaved parent. I suggest there existed a phenomenon death of a twin and this study has provided a new understating of that phenomenon. It is an understanding that is presented in the conceptual framework and has its basis in the lived experience of the bereaved parents. This conceptual framework reflects the phenomenological basis in terms of worlds of existence of temporality, spatiality, corporeality and relationality (van Manen 1990). At this point in time the study has provided a framework within which to plan care. There may be other evidence that will inform and develop this framework. It is envisaged that the positive aspects of a change in local policy may be extended to extend to influence national policy in the care of the bereaved parent. I believe the findings from this study have the potential to do so.

I endorse McKenna’s statement and I end this section with a quote from Vanstone (1982: 35) who describes the state of dependence as entering into passion *“he becomes one who is done to, is treated: he becomes the object of the decisions of care and treatment of others”*. I suggest this quote calls us as HCPs to seek to be mindful of and open so that we may more fully understand the human condition of the bereaved parent who is living through the phenomenon ‘death of a twin’

7.3 Phenomenology

In keeping with the philosophy of the professional doctorate the research question arose from a real world problem (Green & Powell, 2005). The research question acknowledges the fact that we do not know how parents experience their loss. Indeed the question tells

me that is only the parents who can provide this knowledge. Uncovering this knowledge drew me to phenomenology as a methodology suited to gain an insight into the essence or structure of lived experience (Rose 1995). The nature of inquiry is to seek for truth and understanding from the perspective of those who are being studied and is especially useful when a phenomenon of interest has been poorly defined or lacks conceptualisation (Polit & Hungler 1999). It does so by providing a different perspective, it is a perspective from those who have lived the experience.

Semi-structured interviews reflected co-operative researcher-participant relationship and open dialogue in order to fully appreciate the participant's experience of their loss (Knaak, 1984). This approach to data collection allowed the researcher entrance to the participants' world and access to their lived experience (Polit & Hungler, 1999). This research study was appropriate to this research methodology as its focus was centred on life experience of the participants (Streubert & Carpenter 1999). The study may be viewed as 'sensitive' due to the potential for intrusion into the participant's private world (Lee & Renzetti 1993). This was an important aspect of the study as 'sensitive' issues may preclude research into important areas of practice. Recognition of this issue was addressed through the provision of counselling support for all the participants.

The strength of the findings as evidenced in Chapter 5 validates the use of phenomenology. It does so by providing insight into the lived experience of the death of a twin and provides a different lens to view this loss. The findings add to the existing body of knowledge and in doing so redress the balance between the quantification of grief and the lived experience. The findings provide HCPs with knowledge to influence care. The resultant care takes on board what it means to experience the death of a twin. The research methodology has addressed a real life problem and done justice to the participants about knowledge for practice.

7.4 Reflexivity

Qualitative research by its very nature suggests my role is not passive but, rather an active reflexive one. Qualitative research should involve self-critical scrutiny by the researcher, or active reflexivity (Mason 2002). Reflexivity requires me to recognise that I

am part of what is produced and my presence and influence must be acknowledged. Carolan (2003) refers to self scrutiny and critical analysis while Mason (2002) suggests the role of reflexivity requires the researcher to show a sensitivity to a range of interpretations and voices in your data, and a willingness to critique and question your own as well. I feel I am immersed in a messiness of research, at this point I find it difficult to see resolution though I anticipate this will happen. If I fail to acknowledge or indeed keep the messiness in focus I may in the words of Reason & Rowan (1981:244) *“forget the part that we play as knowers, and are unable to see that which we are unawaresly contributing”*.

I have brought to this research my experience as a practitioner, yet that experience did not equip me to deal with the immersion in the study. There were times when my identity became so closely entangled with that of the grieving parent. Reflexivity is therefore a recognition and an acceptance and is described by Soros (1995:67)

“Essentially, it has to do with the role of the thinking participant, and the relationship between his thinking and the events in which he participates”. I believe that a thinking participant is in a very difficult position, because he is trying to understand a situation in which he is one of the actors”.

The resultant knowledge does not purport to be a pure or perfect meaning rather it is the meaning for these specific group of parents at this particular time. Acknowledging my active participation contributes to the credibility (Lincoln & Guba 1985). By acknowledging my own experience, I gained an awareness of its possible influence.

7.5 Bracketing

As I consider my role as researcher I am mindful that this role entails my being the instrument (Kvale 1996) in understanding how the world of the participant is experienced. In seeking to understand I aimed not to influence that understanding by my own knowledge and experience. Bracketing is a fundamental principle of Husserlian phenomenology. Bracketing is essential so as not to influence the data collection or to impose my understanding on the data (Crotty 1996, 1998: Polit & Beck 2004). A further

consideration of bracketing and its effectiveness is the degree to which it affects the trustworthiness of the study and analysis. Bracketing is not limited in its influence to shaping the data collection but also to the trustworthiness and rigour (Hamil & Sinclair 2010). I believe this is an important point as the impositions of a method on Husserlian phenomenology require safeguards to ensure researchers remain mindful of its fundamental principles. Bracketing enabled me to hold in abeyance my knowledge and previous experience (Priest 1997). Thus the setting out of my presupposition in Chapter 3 allows the reader to access the subjective world of the researcher. The individual phenomenological reflection sought further to engage the reader through their imagination and to situate my suppositions in the existential world of the bereaved parent.

I came to understand that I too was a participant (Munhall 2007) in this process. I use the term participant to denote my relationship in data collection. I understood my role to be that of the active listener and being an active listener required a readiness on my part to hear the experience of the bereaved parent. The process of becoming participant uncovered previously hidden meaning for me as I came to understand the appeal of Husserl's descriptive phenomenology. Completion of the thesis is secondary to self-discovery (McCormack 2001). The first 'bath' of my own premature daughter was 'taken' from me as a result of an assumption by a HCP that I would prefer a clean baby when I came to visit rather than having to bath her myself. This memory has remained with me and I continue to experience the event as a personal loss and to highlight how another's' perception can negatively influence our experience. I have come to understand this event as instrumental in undertaking a phenomenological study. I knew the HCP in question wanted to help and care for me. My experience told me that she did this from her perspective of my needs and her interpretation of them. This has raised a fundamental issue for me as to what knowledge HCPs need for practice and how this knowledge may be accessed and generated in order to inform care provision from the perspective of those who are receiving it. I believe the HCP would have acted differently had she been aware of the meaning to me of being able to give my daughter her first bath. Suppositions can therefore alter our view and bring bias into practice and equally into the research process. McCormack (2001) suggests it is not enough to 'do no harm' as the application of this

principle does not inform the nurse what ‘harm’ means. He advocates knowledge of another’s authentic values through understanding each patient as an individual human being. Thus the completion of the professional doctorate has also been a process of self-discovery (McCormack 2001).

Bracketing was facilitated by the uniqueness of each participant’s experience, the richness of the data and different understandings (Beech 1999; Parahoo 1997).

Bracketing is a near impossible action, however I have sought to do it to the greatest extent I can possibly do. Clearing our assumptions from prior knowledge and experience is described by Munhall (2007) as a “perspective of unknowing” in which the researcher listens with the “third” ear free to the extent possible of any prejudice or bias. This sense of unknowing of another’s experience is critical to the evolution of understanding meaning of others (Munhall 2007). I therefore come with a curiosity that may be likened to a childlike curiosity about the existence of the world of the bereaved parent. This approach enabled me to stand in my own world and acknowledge that I did not know the subjective world of the participant. In bracketing we become curious (LeVasseur 2003), I can identify with the concept of curiosity as it fits comfortably with bracketing. Curiosity is an easily understood concept that complements and should not replace bracketing. It is not enough to be curious. Bracketing enables us to set aside, to put in abeyance and that essential preparatory action results in a curiosity about the experience I am about to hear in the interview.

However, I suggest bracketing does not present such a problem as the researcher enters into the lived experience of the bereaved parent. I suggest this reflects the self-conscious method essential to phenomenology. I describe it as follows. I enter the interview in the pre-reflective mode that is I live through the experience as the parent shares the intentionality of their experience. It is through repeated listening to the interview and reading the transcript that I enter reflective self-consciousness.

Reflection and therefore self-conscious method is fundamental to phenomenological research. Reflection is employed in the individual phenomenological reflection (IPR)

where as researcher I have produced my own descriptive data solely from myself (Colaizzi, 1978). Reflection is also employed in the process of analysis that is moving from the raw data to the essence of the death of a twin. I concur with Colaizzi (1978:30) that without reflection the researcher “*would simply confront it, (the data) never reducing it, organising it or interpreting it, because all such activities would demand at least some reflection*”.

Thus I have become aware of the meaning of the natural attitude and the meaning of as Giorgi (2000:6) describes the “*phenomenological attitude is adopted precisely in order to understand the natural attitude better than it can understand itself*”.

7.6 Informing / Transforming practice

As a phenomenological researcher I can see how the process of completing this research study has informed a new perspective.

As an experienced practitioner my practice was influenced by the stages of grief (Kubler-Ross 1969) attachment theory (Bowlby 1982). The bereavement training that I received focused on stages of grief and bereavement was a process to be completed. The practice of not talking about the dead twin was common. Avoidance was utilised as a means of “protecting” the bereaved parent, however avoidance may be utilised by HCPs to protect themselves (Bourne 1968). A contributory factor to the lack of care was the fact that little research existed pertaining to perinatal loss (Forrest 1999) and only a partial understanding of this (Bourne & Lewis 1991) and therefore there was little to guide practice. In my practice area parents held and touched their baby (Benfield et al. 1978). While mentioning of the dead twin was uncommon HCPs did create memories for the parents (Riches & Dawson 1998). Practice was very much based on the practical aspects of care. Parents’ emotional needs were less well cared for. I believe this to be due to the fact that that information was lacking. The literature enlarged my understanding of the death of a twin, those which utilised a quantitative approach sought to measure grief (Rowe et al. 1978). Qualitative studies suggested that there was a lack of understanding

of the bereaved parents' grief and less support available to them. Two important studies Swanson et al. (2002) identified the need for sensitive care by HCP and support from the wider community while Swanson et al. (2009) found both mothers and fathers experienced the death of their twin as a most dreadful experience. Fathers unlike mothers were not encouraged to grieve and fathers believed they should be able to cope. Spiritual support was important to grieving mothers and to those who were depressed.

The process of completing this research study has been one of transformation. I identify two aspects one in relation to myself as practitioner and the second in relation to the value and the implementation of the research findings. The first relates to self-discovery (McCormack 2001). I now understand caring as being open to the other which means sharing in their experience in the case of the research study sharing in the grief and loss. However, understanding from this new perspective relates not just to research but encompasses all aspects of caring. I am mindful that there is an emotional investment by the HCP in caring. I see the importance of continuing clinical supervision as a means of redressing this aspect of caring in order for the focus of caring whether in research or practice to remain with the participant/ patient.

The second aspect relates to the findings which add to the existing body of research on death of a twin. The findings contribute to understanding of death from qualitative studies (Swanson et al. 2002; 2009). The findings also fall within the theoretical understanding of *Continuing Bonds* (Klass 1996). The findings have also highlighted the important role of non-professional organisations in the provision of support and information. The findings suggest that the loss is ongoing and therefore all HCPs that bereaved parents come in contact with need to be aware of the lived experience. I see this research study as a beginning and greater understanding to be gained through further research.

7.7 User perspective

User perspective was central to this research study as a means of enhancing quality and relevance to needs of service users (RCN 2007; 2010; DH 2005a, 2005b, 2007a, 2007b, 2009, Goodare & Lockward (1999)). User involvement is essential to the health and

wealth of society (RCN, 2007), enabling service must meet the emotional and social needs of parents (DH 2007a). Research which integrates the needs and views of the users is likely to improve practice (Department of Health 2000; Wykes, 2002).

7.8 Dissemination

The findings from this research study are important to the participants, to those caring for the bereaved parents of twins, to non-professional organisations and to the academic community. They are important as a means of validating the experience of death of a twin and of stimulating discussion of care in the clinical area.

A summary of the findings have been provided to the participants of the study. Non-professional organisations are central to the provision of support for these bereaved parents. Ongoing contact has been maintained with TAMBA and MBF. A summary of findings have been provided to both organisations.

The findings which were presented at a joint clinical governance meeting of obstetric and neonatal services have influenced the practice of one neonatal consultant. Based on the findings the consultant offered the bereaved mother of a twin counselling support at a six month appointment. She informed me that the mother accepted and said that prior to that she was unable to talk about her experience. A further experience of sharing the findings with newly bereaved parents of a twin elicited a response that it validated their experience and made what they were feeling 'normal'. I acknowledge that these two instances occurred at local level however, I suggest they demonstrate how the findings have the potential to influence practice and do justice to the participants in the study. Work is in progress with the design of a sticker to identify maternal notes and those of the survivor and therefore heighten awareness among HCPs. Parental input is accessed to help in this process. In addition a formal approach to follow up is being put in place; this includes an appointment with the counsellor at a time of six months post loss and contact details of TAMBA support. An information leaflet based on the findings of the study is

being prepared for bereaved parents of a twin. Contact with TAMBA coordinator is in progress with the aim to share the findings widely.

The process of sharing with the academic community has begun with poster presentation and oral presentations at international conference.

7.9 Summary

This chapter details my journey as a novice phenomenological researcher. When reflecting on the research process I have come to understand that I have accessed the experience of the bereaved parent in the natural attitude, while I as researcher have adopted the phenomenological attitude in order to describe the essence of their experience. The self-consciousness as experienced has enabled both mindfulness of my role as participant and instrument. As instrument I have sought to illustrate the mode of bracketing required both at the outset and as a continuing feature of the research process. The process of completing this thesis has proved both enriching from a personal and professional perspective with an increased openness to others and their experience. I have identified the value of the findings and their dissemination.

CHAPTER 8: CONCLUSION

8.1 Introduction

The aim of this research study has been to understand how parents experience the death of a twin in the perinatal/neonatal period. A purposive sample of seven parents was recruited; six mothers and one father. Recruitment was from my own practice area of neonatal care and TAMBA. The length of time since death ranged from six months to six years. The parents shared their experience with me in a semi-structured interview. A follow-up interview was undertaken. Parents were invited to comment on the findings from the first interview. Any new material was subsequently included.

Data analysis followed procedural steps devised by Colaizzi (1978) which uncovered the essences of the experience; these were presented in an exhaustive description from which the fundamental structure of the phenomenon “death of a twin in the perinatal period” was formulated. The findings were considered in the context of existing literature.

8.2 Impact of the research study

The discovery of the phenomenon death of a twin provides the reader with an understanding of the nature of the parents’ reality. The discovery of the phenomenon which is located in the lived experience of the parents is considered. This phenomenon stands in contrast to the literature that has informed our practice. The illumination of the phenomenon has the potential to liberate the bereaved parents from the restrictions of a lens that is unrepresentative of their experience. The next stage of bringing this new understanding to a wider audience has begun through the process of dissemination at conferences. I will also seek publication of both the findings and the value of a phenomenological research approach used in what is considered a sensitive topic.

8.3 Philosophical basis

The philosophical basis and the methodology underpinning the research study may stimulate interest in the approach to research that has as its basis human-to-human interaction. The resultant discovery seeks to elucidate the meaning of the lived experience as it is given to consciousness. The reader is invited and challenged to respond to this knowledge which is rooted in reality (Crotty, 1996). I believe it calls for human interaction based on requirement of the HCP to situate her/ /himself within the world of the bereaved. It also provides the language with which the HCPs can engage with and communicate with the bereaved. It therefore enables the HCP to access the private world of the bereaved parent.

8.4 Contribution to practice

The contribution to practice has been to establish the existence of the phenomena death of a twin. The phenomenon exists in the temporal-spatial-corporeal-relational world of the bereaved. It is a phenomenon that is influenced by the personal circumstances of the loss, societal response and the impossibility of separating from the dead baby. Separation is impossible for the baby is part of the mother, and the natural place for a baby to be is with his mother. Loss of a baby means the loss of a future, that loss remains and is revisited in the milestones and development of the survivor. It is a loss that cries out for recognition. While the focus of my study is in neonates the findings may stimulate other professionals to consider their role in the provision of healthcare and support to these parents.

8.5 Contribution to knowledge

The contribution of knowledge of the study is to show that there is a phenomenon ‘death of a twin. That contribution may be viewed as elucidating the lived experience. That elucidation enables the HCP to question their practice in the light of new knowledge. In addition the findings have resulted in a shift in my own paradigm. This shift causes me to question my approach to the bereaved parent and my starting point is seeking to engage with the bereaved parent while leaving my own presuppositions aside. I have come to realise I cannot know another’s reality until it is revealed to me.

8.6 The process of completing the study

The process of conducting research into the lived experience of parents proved emotionally demanding. I came to understand the pre-reflective self-consciousness and reflective self-consciousness through the interview and analysis. Reflective self-consciousness enabled me to be mindful of the emotional burden as a phenomenological researcher. Others were also engaged within this self-conscious method of phenomenology. I became mindful of my supervisors who adopted a reflective self-consciousness as I related my experience of the emotional demands. I consider this aspect of the supervision as 'being with' the researcher. To illustrate this point there was a time following six months of analysis where my supervisors advised me to step back from the data and begin writing the methodology. At that point I felt I was living the parents' grief and this aspect of the research process was understood by my supervisory team.

As I lived through the data collection and analysis I became aware of tension between self-preservation and self as researcher. This was evident to me in my reluctance to return for a second interview. The second interview was delayed due to the volume of data and data analysis. I was conscious that I did not wish to enter a-fresh the bereaved world of the parents. This concerned me from a personal and ethical standpoint. I was challenged to consider whether I could complete this research study or indeed whether I had the qualities and capabilities to do so. I discussed my concerns with my counsellor support which enabled me to complete the second interviews. All interviews went well and the parents were interested to hear about the findings. I came to understand the second interview as cathartic for myself as researcher. My experience has demonstrated how the research process unfolds and in spite of being well prepared there may be unanticipated challenges to the researcher. From my experience as a phenomenological researcher I would advocate a period of time is factored in to provide a 'space' to both accommodate the emotions and progress with the study.

As researcher I had a responsibility to the participant and a requirement to complete the Professional Doctorate within a specific time frame. Achieving the balance between these

two factors require a robust support system that is accessible locally to the researcher and through the supervisory team. An integral part of the process is an attitude of openness and sensitivity by the researcher to changes. A further area for consideration is the role of the supervisory team. They also lived through the phenomenological research and were exposed to my emotional rawness at times of supervision. I found it most helpful to check my behaviour with a trusted friend. I see this as an important aspect of undertaking sensitive research.

8.7 Limitations and strengths of the study

If I were to repeat this study I would do two things differently. Firstly I would seek multi-ethnic representation and secondly include greater representation of fathers. Both these factors would address the limitations of the study as I see them. I see the strength of the study as that of giving voice to the bereaved parents.

8.8 Application to nursing and midwifery curriculum

It is a voice that challenges our assumptions and calls for a response from HCPs. A further strength is the voice of the father and the mothers' reference to their partner's response to the death of a twin. Further research is required to understand the fathers' reality. Such a study would expand the findings from this research study.

8.9 Dissemination of findings

The dissemination of the findings of this study is important in order to bring the parents experience following the death of a twin to a wider audience. A summary of presentations are in Appendix 14. The findings are also important as they substantiate the theory of Continuing Bond following bereavement. Finally the findings are important for their potential to impact on practice. In order to reach a wide audience the strategy employed has been local, national and international.

8.9.1 Local Impact

The findings have been shared with both medical and nursing staff. The response has been positive and staff are open to change in practice. In order to implement the findings I have set up a working party with the lead consultant and the counsellor. This has resulted in a planned package of care. The first stage is the design of stickers to identify the survivor and medical notes. The provision of an information leaflet for parents explaining about the emotional journey they are beginning. The provision of contact with a named member from TAMBA and the TAMBA information booklet. Parents will receive a six-month follow-up appointment with the counsellor. This appointment will be valid for two years and parents will be made aware that they can access that appointment earlier if they desire. Since I conducted this study I have spoken to parents who have experienced the death of a twin, they have expressed a desire that the dead twin should be acknowledged and spoken of. They also appreciated the use of a sticker as some staff are not aware that their baby was a surviving twin. The views of TAMBA and the MBF have been taken into account and both organisations are supportive of these measures.

The findings will also be shared at a London based educational group incorporating three teaching hospitals. Thus there is an opportunity to share the development of an innovative package of care for the bereaved parents of a twin.

Presentation has been achieved at joint neonatal and obstetric clinical governance meeting. This event provided an opportunity to share findings with midwifery and obstetric staff. The resultant discussion challenged assumptions regarding the care of the bereaved parent.

8.9.2 National Impact

I have presented the findings at the National Neonatal Study Day at St. George's Hospital in 2009. I aim to build on reaching a wider audience at national level and have made tentative enquiries about a possible feature on BBC Radio 4's "Women's Hour." This would involve TAMBA, a participant from the study group and myself. I am in the process of completing a grant application to BLISS to facilitate from research findings to

practice. This would involve a package of care as described above to be available nationally.

8.9.3 International Impact

Interim findings were presented as a poster presentation at ESPNIC conference in 2009. The findings from the study were presented in an oral presentation at the EAPS conference in 2010. This provided an opportunity to share research findings to an international audience.

8.9.4 Publications

I have been invited to write an article on withdrawal of intensive care from the parents' perspective by the journal "Early Human Development". This will provide an opportunity to introduce the findings of my research to a wider audience. Date of submission is July 2011. I plan to write two papers to bring the findings to a wider audience and to share the methodological approach.

8.9.5 Future research

The findings from this study have provided insight into the lived experience of parents following the death of a twin. It is a life changing experience and it is shared in order that the reader may reflect on practice. The findings have given rise to further questions pertaining to this loss. They are as follows:

- The lived experience of fathers following the death of a twin.
- The lived experience of the surviving twin
- The lived experience of others siblings within the family.

Finally, while this study has provided new knowledge of the death of a twin it acts as a stimulus to question how this group of parents will progress through the next ten years. During that time the surviving g twin will have reached a number of milestones and some of the survivors will be in High School. A follow-up study of this group of parents would I suggest give a fuller picture of the meaning of the death of a twin.

8.10 Knowledge development

The findings from this study have given a voice to parents. It is a voice that is different to that found in the literature. It is a voice that calls for HCPs to set aside their assumptions and enter into the care of the bereaved in an empathic manner. The findings have led to knowledge development, the impact of which has the potential to improve care for the bereaved beyond the confines of the neo-natal unit.

8.11 Conclusion

At the heart of this research study is the explication of the experience of parents following the death of a twin in the perinatal/neonatal period. The research shows that there is a phenomenon death of a twin. Health care professionals are invited to read and respond to this phenomenon. The phenomenon raises issues regarding the need for training and education for all HCPs involved in the care of the bereaved parent of a twin. Part of that care requires the HCP to engage with non professional organisations which are in a position to provide support to the bereaved parent. Finally the research study raises the issues of the need to understand another's reality in order to care on a human-to-human level.

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APPENDIX 1

Victorian influences: Cultural and sociological response to death

The response to death in the Victorian era provides background bereavement theory. In this section I consider the lived experience of the bereaved in the Victorian period. This is followed by the response to loss of life in the World Wars and the changing response to loss in peacetime. I will demonstrate that the response to loss has undergone changes and those changes are partly attributable to societal activities. The response to loss at the beginning of the 21st century share many commonalities with that of Victorian era. I have chosen to start from the Victorian era as it was a period where efforts were not focused on addressing either the quality or the quantity of grief (De Vita-Raeburn , 2004). It also reflected practice within peacetime and therefore I believe has a resonance with society today. Prior to World War 1 Victorian the widow and widower wore their loss literally and metaphorically speaking (DeVita Raeburn, 2004). Mourning clothes, lockets containing locks of hair were outward evidence of a broken heart resulting from loss of a loved one (Neimyer, 2001). A further contributory factor was the held view of romanticism which demanded a love that would persist beyond the grave. Therefore, a cessation of grief would be considered a betrayal to the beloved (Stroebe et al 1992).

Queen Victoria epitomizes this tradition of mourning, following the death of her husband Prince Albert she retired to the Isle of Wight and lived out her days never shedding her black mourning clothes. Lived experience varied and was dependent upon one's place in society and availability of leisure. Time was available to upper and upper-middle classes who could absent themselves from social life for a period of time (Walter, 1999). Their lived experience of bereavement stands in contrasts with that of the working widow who could not afford a lengthy period of mourning. She needed to concentrate on the care of her children and find a replacement husband as soon as possible. Thus, her period of mourning was foreshortened by her needs and those of her dependents. While the length of mourning varied the public display of mourning and the identification of the bereaved

through dress was a feature of all. That public display informed others and therefore mediated an appropriate response.

Influence of the Great War

The Great War 1914 -1918 the resulted in the loss of millions of lives across Europe and the deprivation of the British nation of a generation of its youth. This loss of life impacted particularly on the lived experience of women whereby irrespective of social class they had to work to support the war effort. Women worked in the munitions factories, on the land and staffed the field hospitals. Their lived experience delivered a blow to Victorian romanticism and the independence achieved from the war effort contributed to a more individual grief rather than grief that was socially prescribed. This move was characterized by Cannadine (1981) as a reaction against the morbid practice of “living” with the dead. For many this change may have been experienced as one of liberation as society no longer mandated strict behaviour in relation to the dead and bereaved. At this point we begin to see the lived experience of the individual take precedence over societal views. The effect was to shift the focus from an obsession with the dead to how death is experienced by the living. However, not all in society appeared to wish to focus on how death is experienced by the living. A different perspective is seen from the soldiers engaged in war.

The sociological context

The first two generations of the last century were exposed to death on a massive scale. Death was experienced by the troops and the civilian population. The dead in war were buried where they fell, whether in friendly or enemy territory (www.ww2cemeteries.co.uk/). The dead from those wars are acknowledged and remembered in war cemeteries throughout Europe. A national service of remembrance is held each November. Representatives of the crown, political parties, past and current serving members of the armed forces attend this service in addition to members of. Remembering the dead is an important part of life (Walter, 1999; Seale, 1998). Following the Wars energies were focused on the essential rebuilding of the country. Indulgence in the celebration of death and living with the memory of the dead was not possible or a

priority. All members of society colluded in forgetting, it is poetry Sasson (1983:138) that provides a glimpse into the world of war, the experience of which soldiers returning from battle choose not to share the awfulness of their experience.

*“He asks me to contribute my small quota
Of reminiscence. What can I unbury?
Seven years have crowded past me since I wrote a
Word on war that left me far from merry.
And in those seven years I have erected
A barrier, that my soul might be protected
Against the invading ghosts of what I saw
In years when Murder wore the mask of law”*

The lived experience of those who had experienced the effect of war was to forget and not speak about the pain, loss and horrors they had seen. The impact of forgetting is not known, nor indeed how this forgetting might have impacted on the families of returned soldiers. What is now obvious is the difference in the lived experience of both society and soldiers in war.

A century later, war is conducted in a different manner and the loss of life bears no comparison to early wars. Nor indeed does the response to loss of life. No longer are soldiers left to rest where they fall. Their bodies are returned to their families for burial. Their return is marked by a mostly silent and respectful witness paid by the residents of Wootton Bassett. What began as the response of a village has enlarged to symbolically represent the solidarity of the whole nation. Indeed, Wootton Bassett is to be the first town in more than 100 years to receive the title of "Royal" in recognition of its efforts to honour the UK's war dead. It is interesting to me that an army who is expected to fight and die for their country has elicited such a response. The response may be partly due to the fact that two generations have enjoyed peacetime. Furthermore, increasing use of unmanned aerial vehicle (UAVs) protect the very people who are sent to fight. Despite detailed preparation for war less developed countries such as Afghanistan can and do inflict the pain of loss on families in Britain. The response to the loss of life is visible and represents a very public response of modern society. It is a response by a community and

that represents the nation's response to the loss of life. What has emerged is the lived experience of a society involved in war, it is both collective and personal.

I view the last century as a period of change whereby societal control has been lessened and the lived experience of the individual is recognized and valued. That lived experience has a resonance with the public expression of grief. I believe this public expression is possible because many families share the experience of loss, while others contemplate the possibility of death.

Provision of healthcare

Increasing economic growth and peace time have impacted on the lived experience of the second two generations of the 20th century. One of the effects has been to as in Victorian time focus inwardly. A major difference is that leisure is more available to all rather than the few. Increased leisure time means more time is available to grieve. Social factors such as the formation of the welfare state, the inception of the NHS contributed to an improved standard of living and access to free health care. Better education has enabled people to question and articulate their needs with resultant self-help groups. Some self-help groups e.g. Stillbirth and Neonatal Death Society (SANDS) have gained national recognition and provide a medium through which the lived experience of the voice of the bereaved can be heard. This is a different voice than that heard through scholarship and research. It is a very important voice. It is a voice that informs and challenges as it articulates experience and the meaning that experience has for people and as it is lived by the people. The effect of this voice and its influence on bereavement theory will be considered more fully in the literature review.

From a historical and sociological perspective we can see how the response to loss has changed. It is therefore appropriate to explore bereavement theory and how it has reflected the individual and personal response to loss. The evolution of bereavement theory has occurred against a backdrop of major changes in society.

- The First and Second World Wars
- The development of a multicultural society.

- The inception of the Welfare state and the formation of the National Health Service.
- The secularization of society, the reduction in the power / role of the church, the move from burial to cremation.
- The increasing power of the state. (Walter, 1999)

Following massive loss of life in World War 1 a different response was called for. Neimeyer (2001) suggests the need to maintain detachment, restraint and distance from grief became one's patriotic duty. The Second World War resulted in a significant number of deaths among the civilian population. A similar response was demanded. The country needed to recover after the War and energies were invested in rebuilding both the country and the economy. The formation of the Welfare state and the inception of the National Health Service, which provided care free at the point of delivery, may have helped to refocus energies. I would like to draw the reader's attention to the fact that while detachment from the dead was required the practice of remembering the dead became official. The National Service of Remembrance commemorates those who died in the First World War. It was extended to focus on the death from both Wars. In 1980, it was further extended to commemorate all those who had suffered or died in conflict and in the service of country and those who mourn them. The outpouring of grief following the death of Diana, Princess of Wales raises the question not as to whether there was a public change in the expression of grief but demonstrates the extent of that change. The televising of her funeral resulted in record viewing figures both nationally and worldwide not previously seen. The tributes of flowers laid in Kensington gardens and the burial route of 80 miles lined by people suggest a very personal and public response to her death. This outward expression of grief shares a commonality with Victorian expression of grief.

Therefore at the beginning of the 21st century bereavement, grief and mourning has an established place in society. I suggest that the response to bereavement has almost come circle. The findings from the study highlight the presence and significance of the memorabilia retained by the bereaved parents. This practice has a resonance with the lockets retained by the bereaved in the Victorian era and maintaining as does maintaining the life of the bereaved in the ongoing life of the bereaved.

Appendix 2 Research Ethical Approval Form

Appendix 2 A National Research Ethics Service Approval Form: Amendment



National Research Ethics Service

Wandsworth Research Ethics Committee

South London REC Office (1)
Room 1.14
1st Floor, Jenner Wing
St Georges University of London
Cranmer Terrace
Tooting, London
SW17 0RE

Telephone: 0208 725 1558
Facsimile: 0208 725 1980

1st August 2008

Miss Mary Goggin
Practice Educator
St. George's Healthcare NHS Trust
Neonatal Intensive Care Unit
1st Floor Lanesborough Wing
St. George's Hospital, London
SW17 0QT

Dear Miss Goggin,

Full title of study: How do parents experience the death of a twin in the neonatal period? Version 1.0
REC reference number: 08/H0803/111

Thank you for your letter of 25 July 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 25 July 2008. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.6	02 May 2008
Investigator CV		29 June 2008
Protocol	1.1	01 July 2008
Covering Letter		23 May 2008
Summary/Synopsis		
Letter from Sponsor		27 May 2008
Interview Schedules/Topic Guides		
Letter of invitation to participant	1.0	
GP/Consultant Information Sheets	1.1	01 July 2008
Participant Information Sheet	1.1	01 July 2008
Participant Consent Form	1.1	01 July 2008
Response to Request for Further Information		25 July 2008
Letter from Multiple Foundation and letter from The Friends of the Neonatal Unit to cover the cost of counselling		29 May 2007
letter from funder		24 July 2007
C.V (student research)		29 May 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0803/111	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely


PP **Professor George Hall**
Vice-Chair

Email: recwand@stgeorges.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting*
 "After ethical review – guidance for researchers"

Copy to: *Ms Jane Ingles*
 Edyta Dillon, St Georges University of London



National Research Ethics Service
Wandsworth Research Ethics Committee

South London REC Office (1)
Room 1.14, Jenner Wing
St Georges University of London
Cranmer Terrace
Tooting, London
SW17 0RE

Tel: 0208 725 1558
Fax: 0208 725 1980

11 December 2008

Miss Mar/Goggin
Practice Educator
St. George's Healthcare NHS Trust
Neonatal Intensive Care Unit
1st Floor Lanesborough Wing
St. George's Hospital, London
SW17 0QT

Dear Mary

Study title: How do parents experience the death of a twin in the neonatal period? Version 1.0
REC reference: 08/H0803/111
Amendment number: 1
Amendment date: 01 December 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 11 December 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	1.2	01 December 2008
Participant Information Sheet	1.2	01 December 2008
Participant Consent Form	1.2	01 December 2008
Letter of invitation to participant	1.1	01 December 2008
GP/Consultant Information Sheets	1.2	01 December 2008
Covering Letter		05 December 2008
Notice of Substantial Amendment (non-CTIMPs)	3.1	01 December 2008

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0803/111:	Please quote this number on all correspondence
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Yours sincerely



Adam Parsons
Committee Co-ordinator

E-mail: recwand@stgeorges.nhs.uk

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: *University of Brighton*

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Appendix 3 Letter of Invitation to Participants

Dear

I would be grateful if you could spare time to read this letter and the enclosed information. My name is Mary Goggin and I work as a nurse on the Neonatal Unit at St. George’s Hospital, London.

I am writing to ask for your help in a research study that I am doing for a Professional Doctorate Degree in Nursing from the University of Brighton. The study is looking at the experience of parents following the death of a twin in the neonatal period.

The enclosed information tells you about the purpose of the study and what happens if you take part. Please take time to read it carefully. You need to understand why the research is being done. Your participation will only happen with your prior informed consent.

Take time to decide whether or not you wish to take part. The information is yours to keep. If you decide to take part, will you complete the attached form with your details and return to me in the stamped addressed envelope.

If you have any queries about the study please call me on 020 8725 1934. Or you can email me at mary.goggin@stgeorges.nhs.uk or write to me at Neonatal Unit, St. George’s Hospital, London SW17 0QT.

Thank you in anticipation for your help.

Yours sincerely

Mary Goggin

Version 1. April 2008

Your Contact Details

Name:

Address.....
.....
.....

If you would like me to contact you by phone or email address, please complete the following:

Telephone no.....
Email address

Appendix 4 Participant Information Sheet

Participant information sheet- Version 1.1 July 2008

Project Title: How do parents experience the death of a twin in the neonatal period?

You are being invited to take part in a research study. Before you decide to participate, it is important to understand why this research is being undertaken and what it will involve. Please take time to read this information carefully, you may wish to discuss it with others in order to help you make a decision. If you would like more information about the study, or if something is unclear, feel free to ask me. This study forms the basis of my Professional Doctorate in Nursing undertaken at the University of Brighton. During the study I will be supported and supervised by Dr. Jackie Bentley.

What is the purpose of the study?

The purpose of the study is to seek to understand your experience of being a parent following the death of a twin. It is important for health care professionals to understand your experience so they can provide the appropriate care that is required at this difficult time. I am interested in the experience of mothers and fathers; however there is no requirement for both parents to take part.

Do I have to take part?

Your participation is entirely voluntary. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. You may withdraw at any time during the study. In the event of your withdrawal I would like to use the data already collected however you do not have to agree to this. If this is the case your data will be destroyed and not used in the study.

What happens to me if I take part?

I will interview you twice, the second interview will take place six months following the first interview. Taping of interview is not a requirement to participating. If you decide you do not wish the interview to be taped, you may still take part in the study. Interviews will take place in your own home or in a private room in St George's hospital if you prefer.

What will happen at the interview?

I will ask you to share with me how you have experienced the loss of your twin. I shall then explore the issues you raise. This will help me to get a clearer picture and to understand your personal experience. I will also ask you about advice you might give to health care professionals caring for bereaved parents and what follow up care would you recommend following the discharge of your surviving twin. If you, at any time, find the interview upsetting we can stop the interview. I am the only researcher involved in this study and I will maintain confidentiality in the following ways: I will tape the interviews as we talk; tapes will be stored in a locked cabinet.

Your personal details will be kept separate from the tapes; transcripts of your interview will not carry your personal details. I may wish to use quotations from your interview when writing up the findings of the study and in publications. These will be anonymous and will not identify you in any way.

What are the possible disadvantages and risks of taking part?

Discussing the death of your twin may evoke unexpected emotions relating to your loss. You may need extra support; during the study or after taking part. Counselling will be available, free of charge. This is provided by the Multiple Births Foundation (MBF). A total of 6 sessions is available for you. All parents, who have been invited, to participate in the study, will be offered counselling.

What are the possible benefits of taking part?

The information I gather might help improve future care of parents in the future who are experiencing the death of a twin. You may find it helpful to have your feelings acknowledged and documented. You may also benefit from sharing your experience and having someone to listen who is not a relative or friend.

What happens when the research study stops?

Following analysis of the data I will send you a copy of the findings. The findings will be shared locally within St. George's hospital and within the Neonatal Network and nationally at conferences and through publication. The findings will also be shared with the Twins and Multiple Births Association (TAMBA) and the Multiple Births Foundation (MBF).

What if there is a problem?

Complaints should be directed to my supervisor, Dr. Jackie Bentley. Her contact details are included below.

Will my taking part in the study be kept confidential?

Participant's identity will be anonymised by assigning a code to the transcripts which will be stored separately. Only the researcher will have access to this data, which will be stored in a locked cabinet. Your data will be kept for a maximum of three years until the completion of my professional doctorate. Data will be handled, stored and destroyed in accordance with the Data Protection Act (DPA, 1998). As a nurse I have responsibility to report any concerns that I might have about the safety of the surviving twin. Under such circumstances confidentiality would not be maintained.

Who has reviewed the study?

Wandsworth Local Research Ethics Committee and the University of Brighton have reviewed the project. You will be given a copy of this information sheet to keep for your own reference throughout the study.

I would like to thank you for reading this information.

Appendix 5 Consent Form

CONSENT FORM

Please initial box

- 1. I agree to take part in this research study which is “How do parents experience the death of a twin in the neonatal period?”.

- 2. I confirm that I have read and understood the information sheet, Version 1.1 I have had the study explained to me, and understand the procedures fully.

- 3. The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.

- 4. I understand I will be required to answer questions about my experience.

- 5. I agree to the interview being taped.

- 6. I do not agree to the interview being taped

- 7. I understand that any confidential information will be seen only by the researcher and will not be revealed to anyone else.

- 8. I agree to anonymised quotes being used in publications

- 9. I understand that I am free to withdraw from the investigation at any time.

- 10. I agree to my GP being informed of my participation in the study.

For the specific purpose of this study six counselling sessions are available for you. This will be provided by The Multiple Births Foundation.

Name (please print)
.....

Signed.....

Date

Name of Researcher: Mary Goggin, Practice Educator, Neonatal Unit, St. George's Hospital

Name of Supervisor: Dr. Jackie Bentley, University of Brighton

Version 1.1 July 2008

Appendix 6 Letter to General Practitioner

Dear

My name is Mary Goggin and I work as a nurse on the Neonatal Unit at St. George's Hospital, London.

I am undertaking a research study looking at the experience of parents following the death of a twin in the neonatal period. This study forms part of a Professional Doctorate Degree in Nursing from the University of Brighton.

(Name of parent) has consented to participate in the study. I enclose the participant information leaflet to keep you informed.

Please contact me if you have concerns about (name of parent) involvement in the study.

If you have any queries about the study please call me on 020 8725 1934. Or you can email me at mary.goggin@stgeorges.nhs.uk or write to me at Neonatal Unit, St. George's Hospital, London SW17 0QT.

Yours sincerely

Mary Goggin

Version 1.1 July 2008

Appendix Interview prompt Questions

The questions that the study will attempt to answer are the following:

1. What is the impact and significance of the death of their twin infant on the parents?
2. What are the factors that influence their experience following the death of their infant twin?
3. What advice do parents have for health care professionals in caring for them in the immediate, medium and long term period following the death of their infant twin?
4. What factors have helped or hindered the process of bereavement?

Appendix 8 Demographics of Participants

Participant	Baby	Time of interview
1. Charlotte - second pregnancy, first pregnancy ended with early miscarriage. Excited by twin pregnancy Married	Baby died in utero at 31 weeks gestation. Pregnancy continued until term with delivery of both babies by caesarean section Survivor: healthy boy	Four years following death of twin
2. Dennis - first pregnancy by IVF, much wished for babies. Normal delivery at 24 weeks gestation Married	Twin 1 died at time of delivery, following unsuccessful resuscitation Survivor: discharged aged 5½ months from the neonatal unit (NNU).	Six months following death of twin
3. Cathy - first pregnancy by IVF, much wished for babies. Normal delivery at 24 weeks gestation Married	Twin died at time of delivery, following unsuccessful resuscitation Survivor: discharged aged 5½ months from the neonatal unit (NNU)	Six months following death of twin
4. Tricia - fourth pregnancy. Delivered at 28 weeks gestation Supportive partner	Twin admitted to the NNU Twin 1 died at eight weeks of age following an episode of necrotising enterocolitis resulting in the decision to withdraw treatment	Six months following death of twin
5. Chloe -third pregnancy Normal delivery of both babies at 34 weeks gestation Married	Laser ablation for twin-to-twin transfusion resulting in haemorrhage into amniotic sac and death of twin at 22weeks. Expected vanishing twin.. Survivor spent first four weeks in the NNU.	Six months following death of twin
6. Carol - Third pregnancy Married	Twin died in utero at 34 confirmed at scan. Delivered by caesarean section within the following 24 hours	Seven years following death of twin
7. Alice - Second pregnancy Delivered at 23 weeks gestation Married	Twin died at eight days of age following withdrawal of treatment	2½ years following death of twin

Appendix 9 Audit Trail of Data Collection and Analysis

Audit trail classification	File Types	Evidence
Recruitment to the study	Letter of invitation Participant information Consent form	Signed consent form
Raw data	Taped interviews Field notes	Dialogue Description of death of a twin Descriptions of events Feelings Characteristics of environment
Data reduction and analysis	Listening to interview X 5 times Transcription of interviews Significant statements Formulated meanings Exhaustive description Fundamental structure of the phenomenon “death of a twin” Confirmation	Transcripts Main themes Subthemes Supervisory checking of analysis Second interview to confirm analysis
Data reconstruction and synthesis	Connecting findings to existing literature	New understanding Chapter 6 of thesis
Process notes	Methodological decisions Rationale for choice of phenomenology Filed notes Reflective log	Chapter 3 of thesis Prolonged engagement with study Appendix 11 Appendix 9 Supervisory notes and dates Reflective log
Intentions and deposition	Proposal Goals and objectives Intended methodology Relevant literature	Written document Reference list Self evaluation Individual phenomenological reflection Reflection on process Ch.7

Instrument development	Interview questions	First and second drafts Final draft
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Adapted from Edward S. Harpen (1983) In: Lincoln, Y.S. & Guba, E.G. (1985)
Naturalistic Inquiry. Newbury Park, CA: Sage Publications

Appendix Example of reflective log generated from interviews to analysis

Self as instrument

Qualitative research recognises the presence of the researcher as integral to the research process. Setting aside presuppositions (Ch.3.9) regarding the phenomenon as articulated in Chapter 1 is a prerequisite for the researcher following a transcendental phenomenological researcher (Moustakas, 1994). Being integral means one is drawn into all aspects of the process; the ontological reflecting ontological, epistemological and methodological as addressed on Chapter 3. Being drawn in means one affects and is affected by the process, indeed this is evident in the analysis as it is the researcher who justifies the approach to analysis as in Chapter 5. The immersion of the researcher requires a passion (Janesick, 2003) to engage with people to communicate and to understand. The researcher thus becomes the ‘backbone’ of the study. Immersion in qualitative research therefore became for me a discourse on the personal and its meaning for the individual participant. Thus the study sought *“the socially constructed nature of reality, the intimate nature of the relationship between the researcher and what is being studied, and the situational constraints that shape the inquiry”*

Denzin & Lincoln, 2003 page 13

Living qualitative research requires an understanding of its flexible nature. Throughout the process actions are taken that were not initially anticipated e.g. expansion of the study to include perinatal death, a decision which strengthened the study. Unanticipated effects (the emotional load, the volume of data) on the researcher from the data delayed the second interview again this was unforeseen.

Considering how to analyse the mountains of data was a challenge for me. How to do justice to the data and how to maintain the ‘voice’ of the participants in the emerging descriptions? Maintaining the ‘voice’ of the participants was an ethical issue for me and influenced my approach to analysis. I was also reluctant to interpret as this had the potential as I saw it to lose the participant’s voice. It was this latter need that resulted in my decision to utilise Colaizzi’s (1973;1978) approach to phenomenological analysis. I considered Giorgi’s (1985) method of analysis which shares many similarities with Colaizzi with one major exception. Colaizzi (1973) suggests returning the findings to the participants in order to ensure they are a true representation of the experience. This served two purposes that of validating the findings with the participant, and an opportunity to uncover new material and also to share the findings with the participants. This was important to me as researcher and to the participants as I was giving voice to their experience.

The individual phenomenological reflection (IPR) (Ch.3.10) was based on my own perceptions of the loss; the empirical phenomenological reflection (EPR) (Ch5.7) was based on the parents’ own experience and is therefore different. Colaizzi maintains that the IPR may be considered pre-reflective while the EPR discloses meaning. As Colaizzi

argue they complement each other. The importance of the different insights acquired in the process of employing the two methods should not be overestimated. This implies that the endeavour to establish the fundamental structure of any phenomenon must be pursued by both a strictly reflective and empirical method.

Challenges of sensitive data

As I began interviewing the parents I was mindful that I am seeking to uncover the experience of parents in the presence of their grief, while I as researcher am experiencing grief in the process of uncovering their experience. I had no means of knowing how the interview would affect me or indeed what aspects of my life, professional and personal might be challenged by the encounter. The first interview gave life to what I had written and provided some insight into its meaning. Until I uncovered its full meaning, I could not hope to do justice to the data. I was challenged in fundamental beliefs about myself, my role as a nurse, how I viewed my colleagues, my relationship with others and my capabilities as a novice researcher. I have come to understand my role in a way that is different from how I had written about it in assignments. That understanding has been achieved through experience and its interrogation. This interrogation has resonance with 'bracketing' as described by Husserl (Smith, 2007). The resultant understanding has enabled the separation of me from the parents' grief and in so doing I am in a position to look objectively at the data. This is an ongoing journey.

Supervisory meeting 15/07/09

Beginning to understand how my approach to analysis fits with Husserl's phenomenology. I begin to see pre-understanding and post understanding. I would later see these are the pre-reflective and reflective modes. Pre-reflective mode when one is living through an experience. Reflective mode when one has reflected on what is present to consciousness. The emotionality of the research is strong. This needs to be captured as that others may learn from it.

The emotional load

The nature of qualitative involves a close partnership between researcher and participant. Rager (2005) speaks of the impact on the researcher of conducting emotionally charged research. He suggests there is a paucity of information and a need for change in this area. Gilbert (2001) contrasts this lack of attention to the researcher with the requirement to put in place support for participants; a support that recognises the emotional load and protects them from the negative impact. Failure to address these issues results in the researcher being totally unprepared for the level of emotional engagement.

Taking my difficulty of the intrusion of research into life to my counselling support I was challenged to identify why I was doing this study which involved sadness. What had triggered my need? I found this question very difficult to answer. Yes, I wanted to improve practice but, that seemed to be a superficial answer to her question. I have looked at my motivation for working with neonates, changing my role from staff nurse to sister to educator, always with the focus on the baby and family. With a history in midwifery I have come to see the sojourn of the neonate and family in the neonatal unit as having similarities with labour. Albeit, a long drawn out labour. I see myself as being

in attendance to baby and the parents until the day when their baby is delivered into their sole care. I am aware the actions of the health care professional can impact positively or negatively and parents may be reluctant to inform us when our actions have a negative impact. I also wish to acknowledge that my first baby was born prematurely at 28 weeks gestation in the pre surfactant and pre steroid era. I experienced a roller-coaster of emotions when faced with each new problem and her possible death. Perhaps one of the most difficult aspects was being dependent on others for her care. That experience has shaped my practice in terms of caring for parents of accepting how they are and how they choose to present themselves and a curiosity that helps me to understand them. This acknowledgement has enabled me to recognise the reason I have undertaken this study is to seek a deeper understanding of these parents, to give voice to the parents in order to improve practice. I have also come to understand the importance of emotions in this process. Rew, Bechtel & Sapp (1993) suggest their essential role as

“The inherent value of human beings and their intersubjective experience underscore the significance of the use of self-as-instrument in qualitative inquiry. No other entity could fully capture the multidimensionality and intricacy of the human experience”

The point being made is that we are relational beings. Therefore, when researching on something that is close to the person it is both inevitable and necessary to be emotionally involved. I believe the issue is not so much the involvement; rather it is the recognition and management of this involvement so as to do justice to the data and maintain self protection. For the reader it is being able to identify with the researcher and how they came to take decisions and arrive at their findings. The reader also has the right to take his or her interpretations from the process. I have come to recognise that compassion fatigue, compassion stress and secondary traumatic stress as the unwelcome effects of working with suffering people (Figley 1999). Addressing these issues is an ongoing process.

The effects of interviewing, transcribing and re-listening to the interview resulted in what I describe as a heaviness of spirit. The conception of heaviness of spirit occurred at the time of transcribing the first interview. It remained my companion for months sometimes leaving but, always returning. In addition to this I also experienced the intrusion of my research into my working day: I describe this as the intrusion of the parents experience into my consciousness. For example I could be talking, teaching or caring for a patient and something related to the research would come into my mind. The effect of this experience was disruptive and I had to work very hard to stay focused on the activity I was engaged in. I did not understand why this was happening. I can also see this experience as mirroring the parents’ experience of managing their grief while parenting the surviving twin. At this point I began to question myself and my capability as a developing researcher and to understand myself. I identified with Maykut & Morehouse (1994:26)

“It is the ability to be with others that distinguishes the qualitative researcher. When a person indwells in a situation, he or she is with the person, i.e., the qualitative researcher is experiencing the world in a similar way with the participant”

I understand the effect of being with others as one of authenticity, where I as researcher can speak with rather than for the parent. I did not perceive these experiences as negative, rather I was challenged to understand them and why they were occurring and the effects they were having on me. In addition these experiences increased my sensitivity to others in my practice and personal life. I was moving towards a deepening understanding of the human condition.

This was experienced as a period of isolation distressing period however, on reflection I have come to understand this process as a necessary part of phenomenology. Moustakas (1994:25) describes this as “*withdrawing completely into myself, while seeking to acquire knowledge of science through concentrated studies of experience and the reflective powers of the self*” .

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I feel I am making good progress with analysis. However, the challenge is to link Husserl’s phenomenology to Colaizzi (1978) method of analysis in order to achieve the essential structure of the phenomenon. Themes agreed, though the term (theme) does not fit comfortable with Husserl’s philosophy. The term essences are better suited and are viewed as intentionality fulfilled through intuition. Continue the reflection to capture the emotional journey reflecting the emotionally sad and taxing aspect of this study.

Role of emotions

The emotional aspect of the research took me by surprise in spite of the preparation prior to undertaking the first interview. While I expected that at times I would be upset, sad and tearful I was not prepared for the rawness of emotion and the strength of feeling. Rawness that was very present in parents whose baby had died five and six years previously. In February 2009 having completed six interviews and the analysis of three, I felt I was living the parent’s grief. The exposure to parents’ grief was emotionally demanding and also made me very sad. My emotional state at that time is reflected in the following:

*“Sometimes sad is very big.
It is everywhere. All over me.”*

Michael Rosen, 2004

However, sadness did not always dominate. I enjoyed a sense of achievement upon completion of each interview. However, there was another aspect and this related to one of humility, that I had been invited in to share in the very personal journey of each parent. The interviews resulted in the sharing of very personal experiences. There was an element of elation in the knowledge that I was building rich data. This acknowledgement was important as a means of retaining a focus of giving voice to these parents. In supervision in February, in response to being asked how are you I **replied I said I am not sure, I am scared and do not know where I am.** As soon as I said this I

remembered being taken by surprise and actually realised that is how I felt. Thus began in earnest an attempt to both acknowledge and make explicit the emotional impact of the research. At this time I was experiencing a heaviness of spirit, yet I functioned well at work, maintained family life, enjoyed a social life and yet there was this heaviness of spirit that I could not explain. I also carried the parents' experience with me on a continual basis; it was difficult to stop it intruding. My supervision team suggested stepping back and focusing on the writing the methodology chapter. This advice was welcome and gave me time to consider the

“Maintenance of personal and professional support networks, attention to self-care and life enjoyment activities and the maintenance of realistic goals, limits, and boundaries regarding interactions with clients”.

Pickett, et al 1994, page 250

A week of skiing provided a welcome break following which I returned refreshed. The writing of my role as researcher allowed me to articulate my thoughts and consign them to paper and begin to look at them objectively. The result helped in separating myself from the parents' grief.

The meaning of the research process and its influence on my perspective as a practitioner

When reflecting on the emotional load I articulated to my supervisor that had I known what was involved, I probably would not have embarked on this study. This resulted in a very helpful discussion and gave me a deeper understanding of my professional role. By avoiding this type of research I as a practitioner close myself to the experience of parents and those for whom I care. Such closure challenged my own perceptions of a caring practitioner within the context of evidence based practice. The meaning of good research is captured by Rosenblatt 2001:24

“The only way to do good qualitative research is to step outside of yourself and pay attention with your eyes, ears, heart and mind to what others have to say”.

The research has highlighted for me that it is difficult if not impossible to divorce research from practice. Indeed it may be unethical to do so. The experience has also made me more fully aware of the impact of the journey of the Professional Doctorate. I agree with Newman 1999 cited in Picard, 2002

“Nursing is caring in the human health experience, where nurses form partnerships to support growth and transformation. When nurses engage in dialogue with full presence, they embody this theoretical perspective and create space for the story of meaning to unfold in deeper ways”.

Appendix 11 Example of Transcript

Participant 3: Transcript

Mary So Cathy, to start would you like to tell me as little or start by telling me either how you are or how the experience or where and again start wherever you wish to start in your story

No.2 Cathy Alright, ok, well I'll start from the beginning ahm, ahm, basically my obviously my 24, 23. how many weeks was I ... well I was on the 6 months when I went for my scan and it was fine, the babies were wonderful but then of course my cervix was very thin so from then from then a kind of , my world came shattering down (laughs) and ahm... Ben and I were very, very shocked about everything we heard because we thought everything was going to be perfect (Mary mmm) you know how people are naive when it comes to pregnancy so we kind of ... ahm ah we went home and I was bed bound, it was very, very scary time because I was terrified that these babies were going to come especially as I had done IVF so it was, it was you know ahm ...ahm Ben and I were desperate for these children and to have this while thing taken away from us, I mean it was traumatic for us so we did our best and you know and Ben rearranged the whole flat so I was in the bed in the lounge and whatever and eventually you know, you know holding thumbs because time was going on and nothing was happening and we were really thinking we are going to make it but, unfortunately we didn't and I had a you know a show and we went to the hospital and then and kind of from then ahm.. when they said to me when they , they had to give me the steroids perhaps it might only work for one because you have got twins, then in my mind I realised that perhaps only one would survive or none at all because I realised if they came when they did it was not good at all and I know Ben was kind of ahm ... he was all happy about it , he was don't worry about it , I don't think he realised , he just thought the babies were going to come you know they might be a little bit premature, and I don't think he realised so I was terrified for them to come and definitely I didn't want the babies to come and obviously they did ahm... ah ... when James was born ahm I actually didn't respond to his death at all, when Ben said to me ahm, ahm, because all the people there and they were trying to save him Mary and how many weeks were you when you delivered?

No. 3 Cathy 24 weeks and 4 days Joseph was 24 weeks and 4 days yeah when they were born. So ahm obviously he died form extreme prematurity .James, and they did say to me Debbie, the lady is that her name?

Mary Yes

No. 4 Cathy she did say to me they have tried but it would be cruel to keep him alive so I was kind of listened to that and I didn't cry I didn't do anything at all and then ahm... Ben was crying and I wondered why am I not crying what is wrong with me you know am I a terrible mother and then I concentrated on getting Joseph out and Joseph came out quite quickly and I think because of that it was less traumatic for him he, I assumed the steroids worked for him, I am not a doctor so I don't really know how it works but I assume that that is what happened and I was so happy when I heard the little squeak you know and then they took and ahm then when I turned around and saw James' body only then did I realise that what him off had happened. Because it had taken me, you know ahm ... yea, I don't know it just didn't, almost like it didn't sink in you know to me what happened until I saw the body of course I was very, very upset crying and

what have you. Of course I was very worried about Joseph as well thinking you know I am going to lose both of them and you know and then it was really nice because the priest came in straight away and he had a little service for us and then I got to hold James and that was lovely and I really appreciated that and that definitely helped me to move on and to and also because we didn't get to know James I think that made it so much easier because if James had survived and he had died later on in the hospital, I think that would have been terrible, terrible even though it was very sad for us and we mourned you know ahm, ahm, it was like a weird feeling because I was so happy to have Joseph and I was terribly sad to have ah not have James as well and I also expected James to be the survivor because in my tummy he's always been kind of always been active and Joseph had always been very quiet so always in my mind I thought James was the one who would survive you know, against all odds Joseph was the one, yes and I think I was just so grateful to have one baby so ahm you know I moved on and everything was up and down, my emotions were all over the place and especially because I had Ben's mum at our house ahm and I found it so difficult to mourn because I couldn't let go while she was there because I felt like I had to be polite around her and you know and I felt like I was going through all these crazy emotions and loss of my baby and then may be losing my other child and I felt like I couldn't really I felt like exploding you know and I felt like I couldn't and you know Ben's mum was there and ahm... every once in a while when Ben and I would go off and I would really cry and go crazy and you know obviously you go through the PN depression so I was ... doing all stupid things and laughs... and ahm but ahm I think that, I am very, very grateful to have Joseph basically, yea and then we also had a service for James as well with the priest and that definitely helped me heal and get over his loss, definitely and I think it is Fr. Steven?

Mary Yes, yes

No. 5 Cathy He dealt with that and every day well whenever he could he would come over and visit us, how we were, see how Joseph was doing and yea and because I had to cling on hope that Joseph would be okay basically and he was and he did and then I know that when I came home I was very, very sad, I know that, eventually after those 5 1/2 months when eventually I did go home, I was very sad about not having the twin with me, yea

Mary Did you have a space of time at home when Ben's mum went home did you have that space before Joseph went home, Cathy.

No. 6 Cathy His mum wasn't there the whole time, she'd left after, she was there for I think a month, a month so she wasn't there for too long but when she did go, and yes I know that I was always on the phone to my family I was always crying but I find the positive as well I am not really I try not to be negative so I try not to dwell on what has happened with James because ahm as far as I am concerned it is terrible thing that happened, it is part of nature as well and something that's not you can't control basically and if, and if it is not meant to be obviously that's what its meant to be, he was obviously not meant be here for a reason, obviously it would have been terrible complications and something terribly wrong with him and it would be so much stress on Ben and I ahm you know if we had 2 babies you know in the same kind of situation so ahm that was probably a good thing that he wasn't there to suffer any more than he needed to.

Mary And was James well until the time you went into labour

No. 7 Cathy Yes, they were both fantastic both of them there was nothing wrong with them, except during labour I know that, he kept on that something happening in the passage he kept on getting, going backwards and forwards and I think because I hadn't gone to any classes I didn't have a clue what I was doing I didn't know how to push or when to push that's why it took a long time for them to come out, I think well probably because they are premature too it takes longer I But I think that ah... I really struggled, struggled to get them out, yea

Mary Mmm, and what was ... it like having Joseph on the Unit and coming in and visiting him, did you feel, you should have had, you should have been coming in to visit 2 babies

No.8 Cathy ...ahm no it didn't ...no because ... actually no you are right .. I remember it, it actually I was very upset when I heard and I do remember now , when I heard other couples and both their babies survived, I would get very upset about that, when couples come in and I'd say to Ben well how come, why? that's not fair why can't I have the 2 babies, you know and I, I used to get very upset, yea when people used to tell me you know we've got twins and they both survived especially when mums used to come in and say that they... that both their twins were 28 weeks or something and I would think Oh my God if only and I'd also blame myself sometimes for having the babies so early, I used to blame my job, because I had a very stressful job, I used to look after a special needs child, and I used to take him to the special needs school and teach him there and used to be involved with the other special needs children, its kind of a full on job, from 7am until ah... 'til 6 in the evening no sorry 8 'til half past six in the evening (Mary it's a long day) really long, full on and I was really running around and I always felt I was stupid because I should have looked after myself more, I should have rested more when I had the opportunity and I should have really taken advantage of other (one word, can't make out) that I was pregnant but because I'm a, I'm a yes sir no sir 3 bags full type of person so I'll always do what they tell me to do to please everyone (Laughs) so it was a bit silly that I did that, I really should have rested more I think and then maybe they would've both, both have been here, yea, yea, that is something that I did think about but, I don't think about it anymore, because I have Joseph home with me now and I have you know, have grieved for James ... and that sort of thing

Mary And do you think about James

No. 9 Cathy Yes I do, when ... when I look at it ... we've got a little candle a candle ... with the ...with a little butterfly on it and in the lounge and I do look at it every once in a while and yes and I, I do think I wonder what it would have been like to have him here with Joseph and you know... two boys together and you know yes I do think about that and I think that why Ben and I are trying for a baby now, because we also you know we... we desperately wanted 2 you know, we, from the very beginning when we found out we were having 2 it was so wonderful so we, we definitely want another one for Joseph.

Mary And how were you cared for ... I suppose in terms of, you as a new mum with a premature baby but also you as a new mum was grieving for a twin... who you had lost and James had died, so you had two roles ... so how were you cared for ... or how did you experience the care on the neonatal unit or from the staff here

No. 10 Cathy What... I thought they were very, very supportive, very supportive, because I felt, immediately felt safe and I felt... it was a stupid thing, but I felt like

everyone here was ... were angels from heaven because I never experienced anything like this before I never ... known about such prematurity and all that kind of thing, I thought I was on my own with this so when I came in and saw all these people, you know looking after Joseph I was, I was just ... I, I really, really felt like everyone was angels to me from God and God ... had put this place for you know (Mary mmm) he'd, he'd basically I felt God had brought us here for a purpose like because this is one of the best neonatal units in London. Where I come from you don't have this type of thing in ---- at all if your baby is born at 24 weeks it will definitely die, even if your baby is born at 26 or 28 weeks you know they just leave the baby so and you kind of go home with it and if it passes away, that is unfortunate, they don't have the facilities that they do here so for us to be here when you know ... I mean it is just such a miracle... that's what I thought so yea I definitely felt very, very safe with everybody and I trusted everybody so much because I felt that everybody did... I knew whatever happened to James because of the way I saw everyone look after him, I knew that whatever happened ... if he did die everybody would have tried their best to keep him alive, that's what how I felt so I did feel very safe yea, yea, definitely felt very safe

Mary And staff, either medical or nursing staff, did they talk about James?

No.11 Cathy ... Ahm... no... (Mary right) no... I don't think, not that I remember ... they would always focus on Joseph yea,

Mary Would you have

No 12 Cathy actually the psychologist ahm (Mary Jane, the counsellor) Jane? (Mary Helen, was Helen there?) not Helen, (Mary Jane Browne? The counsellor) Jane the counsellor with the glasses, kind of short hair yea. Yea, she ahm... she would talk about. you know James and that but you know ahm ... no not that I can remember, I can't really recall

Mary And is that something that at the time or sine you thought it might have been nice to talk about James?

No.13 Cathy I think... the way I was feeling at the time I wanted to ... forget it because I was feeling so much pain ...ahm about what happened that because I was dealing so much with Joseph -identifying need for time to grieve, while caring for sick twin the time and space was not available]

I did want to forget it, I would have preferred it if they didn't say anything at that time

Mary Mmm

No. 14 Cathy but I know that some of the other mums I would talk about it you know in the lounge we would talk about our experiences losing [Mary, yea] this, you know, losing one you know, ahm...but no I kind of preferred it that way...

Mary And Cathy this is a difficult question, what was the difference ... for you in talking to other parents who might have lost a twin and in talking to staff

No. 15 Cathy I think because I felt ahm... that they knew exactly what I was going through because they'd experienced the same kind of ... trauma ... or what, what have you that's why I felt they knew exactly what I was experiencing... that's how I.. felt ... yea and also the mums as well, when we went in to talk to the mums, the mums would come up to me when we first got here, and they could see we were terrified, didn't know what was going on, they were so kind of blasé about what was happening oh n o you'll go through this and through that and that and we were thinking what is going on why are talking like this and making it ...such like it is not really a big deal that your

child has a hole in the heart or something and ah...ahm I think... ahm...I don't know, I don't know it just seemed easier... to talk to the parents yea, because it just seemed like they ...

Mary knew?

No. 16 Cathy Knew, knew what we were going through yea, yea

Mary And you talked about ... the things they mentioned you might go through, was that... did that in a way serve as an education as to what you might expect

No.17 Cathy Sorry, say that again

Mary When you talked to parent and they said you might expect this ,you might expect this, did that help you ...in terms oh is that what I am going to go through of ... I am going to go through or I suppose was it helpful or...

No.18 Cathy Definitely helpful, yes it was because, it, it just made ... you know why (Mary Mmm) its because other people were going through the same thing as us, so it didn't make you feel alone, that's also another reason why we chatted to the parents so much, we felt like yea, we weren't alone and we had other people to support us ahm and ah it definitely opened our eyes to the reality of what was going on yes. [Mary mmm] ahm... ahm... yea it was very helpful indeed yes.

Mary And I am interested in... if the staff had said you are likely to experience this and this . perhaps not identical but in a similar way to the parents, how would you ...

Cathy I think...you know... I think it, it ...I think it would have been helpful yes, because some situations ahm...we would go in and see Joseph and ... say for instance he had a collapsed lung ... you know how that's quite common with premature babies and then yea for instance he would have that and then I would be quite frightened by it, I was frightened by it by the things that were unfamiliar to me and I think may be perhaps the staff were so used to that kind of thing happening to them, to the babies so for them it is quite normal, normal thing but when you come as a parent and you have no clue of what's going on, I think it definitely, I mean it would have helped me definitely, for them to say, you know, but, I'm sue they did though, I know the staff did tell us yea but it just felt easier to talk to the parents than it did to the staff, I don't know why it just did yea,

Mary And how, you have mentioned about ...ahm when James was born and you had a service and the priest came for you was the spiritual support important

No. 20 Cathy Yes, yea, most definitely ... ahm it was, because it just it just... it felt like he was being looked after and protected by God and yea and by yea and the reverend's prayers and whoever came along and was praying, I mean everybody was praying for Joseph and I felt that that helped him, I, I yea, I really did feel that really, really helped him so much that I ... I am obviously a Christian and I do believe that he is definitely a miracle (laughs) without a doubt but I also, I also know that the people here, the staff here do the most incredible job I have ever, ever seen, I mean I respect everybody here so much for everything that they do really, really respect everyone [a gentle laugh]

Mary Thank you, and for James did you have a funeral service for him

No. 21 Cathy Yea, we did, we did ... but we did have one ... but what the priest did...is he actually, I don't know why we did this , Ben wanted ... wanted to do this because, I think because he said we were going through so much at the time that he didn't want to have more, more emotions so he asked the priest if he could have the little

service at the ... at the ...ahm you know ... have the cremation ... at the crematorium and then asked if we could collect the ashes and have a service with the reverend in the church with the you know

Mary with James

No.22 Cathy With James, basically... yea so that's what we did ,yea, I think because we, yea, like I said we had been through so much already we felt like we'd felt like it was too painful to go through that all over again.

Mary And as you look back does that feel ...comfortable?

No.23 Cathy Yes, it does, because when ahm... the last time we went you know to have the last little service for ... for James, ahm I did feel that was definitely our time to say goodbye obviously there were a lot of tears, but there was a lot of joy because we had Joseph and he was doing so well at that time so it was ...

I think we definitely did say goodbye in a way that that we felt was good, good for us

Mary And where did you put his ashes?

No. 24 Cathy We have them in our house, because we are waiting 'til Joseph is a bit bigger and then we're going to take them to the seaside and ... and... get rid of them there

Mary So James is with you

No. 25 Cathy He is with us (laughs)- a happy laugh

Mary Can I ask where you keep him?

No. 26 Cathy ... (Loud laughter lasting 11 seconds) we keep him... in the cupboard... in Joseph's bedroom [laughter continues]...I know it sounds bizarre actually , because it makes, it sounds bizarre because it makes, maybe makes you think we want James to be in the bedroom [Mary yes] but actually that's quite strange that it is in the bedroom... with Joseph [Mary I knew someone who kept her mother in the living room... for some time] more laughter

No 26 Cathy Oh dear... its not because , its because we haven't had the opportunity to go somewhere really nice where we feel special enough to get rid of, of the , not get rid of [Mary no] of the ahm ashes so we haven't found and we also want to wait until Joseph is a little bit older and we can say this is your brother, we want to tell Joseph bout James definitely, we want him to know that you know ... we are going to make out that James was a little hero and he was the one, the one you know who saved Joseph, say something sweet like that and then we'll take we want to take Joseph with us to ahm yea, (laughter) it is quite strange now that I said it

Mary No, no...

No. 27 Cathy I'll tell Ben to move them into the kitchen or something

Mary Well Joseph is very comfortable with having James in his bedroom

No.28 Cathy Yes, I suppose so, yes I suppose so (more laughter) oh dear

Mary You don't want in the back of a cupboard in the kitchen

No. 29 Cathy Laughs... sounds a bit strange, now that I have said that.

Mary No...as I said, a friend of mine (Cathy yes) she kept her mother under the television (more laughter form both of us) so you know, just her presence

No. 30 Cathy It is not on purpose, its is not on purpose, I actually forgot, I actually forget that they are there to be honest so you know one thing I did find very strange was ... I don't know if they do this for all the parents or if they asked me I am not sure whether they did not or what happened but I know that when James died they

game me pictures of his ... dead fetus and I did find that very strange ... short little laugh [Mary right okay, right] and it did freak me out, [Mary right, right] and I kept on seeing James' face in Joseph' face so when Joseph was born I kept on seeing James' face and thinking oh my God this is terrible I kept on thinking Joseph looks dead every time I looked at him he looked like he was dead and I couldn't look at Joseph for a long time And then also when I looked at Joseph ... I know it sounds a terrible but he used to really scare me the way he looked and I used to think why cannot I why can't he be just a normal child why , why, why are we being put through this why (Mary Mmm) I want to love my child I want to protect him ... you know ... nurture him and protect him and I can't and

And it was Yea, I used to look at him and really be quite scared about his experience

Mary Right...

No. 31 Cathy the way he was, yea

Mary So when... the photograph of James, was he dressed?

No. 32 Cathy He ...he... I can't remember because I have never looked at it properly ... when one of the ladies came into our room after this had all happened and we were still in hospital you know in the special parents room when a twin dies, she came in and she was saying goodbye to us and she gave us this little [Mary sort of booklet]... and inside the booklet were the pictures and she opened it a little bit and I looked away and then she closed it and then I never looked at it again and I said to Ben when we got home I really don't want that I am really upset by that (Mary yes) I don't want to see you know, I don't want to see a picture of my dead child you know... I don't know what Ben did with them (Mary yea) I am not too sure what he did with those photos, I never really asked him.

Mary and do you think there may come a time where you think, maybe I might want them

No. 33 Cathy No, definitely not no I would really not like to see a photo of my a dead baby, no definitely not, no

Mary So would you like to have been asked or somebody to say we have taken pictures or shall we take pictures some pictures of James [Cathy yes] or permission to take

No 34 Cathy I definitely would have said no, yes, yes because I, I just felt there was very scary looking for me [Mary right] yea he was very strange looking kind of something black, very strange colour you know... I also found it quite difficult to hold him when I did as well I he felt very strange because he felt really warm [Mary yes] Cathy cries he felt very warm and [Mary take your time, Cathy] and it was strange to to ahm...to.... Crying as she says Oh I desperately wanted him to be alive ... I wish, I I think when I felt him and he was so warm I wished he had stayed that way ...laughs...cries...I wish that he had stayed that way.

Mary So it was difficult to take on board the fact that he was dead because he was still so warm

No 35 Cathy Yes, yes, yes and then because he looked so strange that is whenever I saw Joseph I would see him in Joseph, yea

Mary Yes

No. 36 Cathy But, I just didn't realise that it still something? This way

Mary But he is still your baby and you have grown him and carried him, you know he is always going to be (I have moved from my researcher role to caring role) an important part of you

No. 37 Cathy Yes, he is ...I think sometimes I like to ... pretend, everything is wonderful (laughs) and just its kind of you know get on with life, I know this is a very stupid thing because obviously we are still ... things in my mind, I actually had a big cry before I got here with my friend ----(laughs) I feel very strange coming here today all the memories coming back but, it has actually been very good ahm, I feel actually feel a lot better now that I am talking to you about this really feel better yes I really do because it is all coming out everything that I been feeling (Mary mmm) all my emotions (Mary mmm) and I really appreciate it actually yes, it is really helping (laughs) it is helpful

Mary I am so, so pleased, yea

No. 38 Cathy Thank you

Mary And how do you remember James, when you remember him, how do you remember him?

No. 39 Cathy I remember him in my tummy and I remember his, specifically sitting in Starbucks sitting with the little boy I look after and he was just kicking about you know ... wonderful to sit there and feel him in my tummy. I didn't really get to enjoy my pregnancy too much because I was quite, really busy in my job, I didn't really get the chance to just kind of chill out and feel the babies and what have you. I'd feel them kick once in a while but yea, it was really wonderful, I remember you know, ahm James was really quiet, so every kick [Mary yes] every once in awhile I remember yea, he would kick , kicking about and you know he was always so active you know always kicking he was always the one that we were able to feel mostly when, when Ben and I would feel my stomach yea we were always saying that is going to be the feisty one you know [laughs]

Mary And Cathy looking ahead how are you going to celebrate James and Joseph's birthday or do you think that is ... do you look forward and think I suppose

No. 40 Cathy Well you know people keep on asking me that. I, I think that when I am with Joseph, because he makes me so happy, because he makes me so happy and I love him so much I don't think about James so much ahm... I don't know, you know my friend asked me the same question today ...I think, I think obviously in the back of my mind I will be thinking you know they both would have been here on their first birthday but I think it gets easier as time goes on .. you know ... and ... the better Joseph does... I mean we are so thrilled [Mary yes] that I think yea... it won't be too difficult I don't think I don't think I will be very upset, I don't think I will be crying thinking oh my God I wish James was here [Mary yes] because I know that, that there is nothing I can do about it, he has gone and I have accepted that you know [Mary yes] and I need to move on and I need to focus on my life with Joseph, that's is how I am feeling at the moment

Mary Just something I want to go back to, in the first month when you had Ben's mum staying with you ahm...and from what you said that seemed to have taken some of your personal space away... did you during that time, have time, put time aside or need time totally for James

No. 41 Cathy I do wish I had yes, I definitely do wish I had, because I was so angry, I was so angry with her for being there because I felt she was invading on my space, my space with my husband, my space with Joseph and my space with mourning for my child definitely with her for being there and I wanted her even though I was angry with her I was grateful that she was there she really is a lovely woman and she is very supportive, I know that she sensed that I was very angry and whatever and she kept on phoning her daughters and finding out from them you know because they'd experienced having children and what have you and they were just giving her advice and what have you and then she would come in and even when I was so angry with her and I the one evening I think she realised I was going through a really hard time and was resenting her being there but she came and gave me this huge hug and she just said I love you I love you and I know what you are going through and I understand and I am here for you and I really felt it was a wonderful thing that she was there for me because I know that I was ... so angry with Ben as well for how dare you let her be here, she needs to go you know and once we had that talk and she sat down with me and she said if you want to go crazy. If you want to scream and shout and do whatever you want to do, just do it ahm and after we had that talk I did feel a lot better I still wished that she wasn't there, even though she was, was supportive, she was helpful, she did everything, she rearranged our entire flat organised all that she cooked and she cleaned and she and I mean she was she really was fantastic and even after I gave birth, she was wonderful, she looked after me while Ben was sleeping, she was fantastic yea so even though she made me feel so angry I did, I did partly (Mary recognise) you know half wanted her there and half didn't, it was kind of weird

Mary And when she

No.42 Cathy A weird thing...

Mary But understandable

No. 43 Cathy Yea, yea

Mary because you yea...

No. 44 Cathy I think my mum and dad were also kind of felt angry that she was there as well you know

Mary And if it had been your mum would that have been different

No.45 Cathy No I still wouldn't have wanted ...anyone to be there, felt like I needed to get to... get through that on my own, I just needed to be myself, you know I feel that when my family are there I can't really be myself, so much its weird, I mean it sounds strange, but I really can't, I feel like... fake when I am with my family, I really can't really be myself

Mary is that because you are in the role of daughter rather than in your own role as mother, an established role?

No. 46 Cathy Yes, yes I think so

Mary And when Ben's mum went ... where you able then to do your grieving or had the effect of that month elapsing, that time gone, things had moved on

No. 47 Cathy I think I had moved on I think, I don't think that ahm... I think because we had had the ahm ceremony with ... now was it after she went or before, I can't remember now ahm... but I ... I can't remember if we had the service when she was here or when she was gone, it was either after she'd gone or just before she left ahm, but I felt it was like it was ... you know...it was very strange because while Joseph was

in hospital too, Ben would often not let me hold him because certain situation when I held him things went wrong and he kept on saying it was because it was because I was holding him and I shouldn't be holding him and ah I was angry, really angry with Ben's mum because she was there so much and we always had to come home to her in the evenings and just wanted to spend the whole day here as much time as I can and we kept on having to go home to be with Ben's mum and I know I was quite resentful for that as well 'cause I thought I have lost my baby but then and then I can't be with Joseph either, I always have to come home you know, it was Ben's mum what have you and be polite and when you had a long day here at the hospital and then go home and be polite to someone it was very, very difficult [laughs] you just want to explode and go crazy yes.

Mary When you held Joseph you said sometimes things changed

No. 48 Cathy Yes, yes would often go wrong... when I held him, one time when I held him and I think he had ahm ... secretions [Mary mmm] and they got stuck and everything dropped heart rate and everything and they had to reintubate him and I was very frightened and I thought I was going to lose him ahm... ahm... and after that happened a couple of times when I held him he would go back, go backwards and Ben kept on , was convinced it was because I was holding him [laughs]

Mary And what did you think?

No. 49 Cathy I was so angry with him, I was angry with him, I said how dare you do this, you can't prevent me from holding him he is my child and I have to hold him in order for him to become well again you know because he needs your physical contact, that type of thing we used to fight about that all the time, about him, yea taking that , I felt he was taking it away from me that privilege you know

Mary In terms of grieving, what are things that helped you most, I think you talked about your presence of Craig's mum, not just her presence but the fact that you had two roles, your role here as mum and you had to go home and behave in a certain role ... so that seemed to have taken away some of your space were there other things that stopped you or hindered you from grieving?

No. 50 Cathy Ahm... mmm. I think I would say that and .another thing was ahm... Ben ... Ben... because he didn't carry James, because he didn't carry the babies, I think men feel slightly different than a woman feels so when ahm when I did have ... obviously when everything happened Ben kept saying you know we need to get over this, its over we have said our good byes its no we don't need to carry on getting upset because it just makes you, you know it's silly and it's too sad and I think ahm... I think.... in that, in that because of him saying that, I think I might have held back some of the memories that I probably would have liked to you know but sometimes I think sometimes I would do it privately as well. If he wasn't around I know I would you know crumble up into a little heap and cry ad cry and cry about , about the situation especially in the early, early days you know when nobody was around and I felt that was helpful. Definitely yea because I was grieving on my own and I didn't have someone telling me that's enough now and you don't need to do this getting yourself into a state or what have you.

Mary So having a space is important?

No. 51 Cathy Definitely having that space , and also found that being here at the hospital, it was difficult because when Joseph was born I can't remember who it was said congratulations and I thought how can they say congratulations because you know

but to them it was normal baby that was being born but for me it wasn't a baby it was a fetus and it wasn't supposed to be born and I was yeah , I know that I was , I thought why is she saying that for everyone who works here, these are babies, and basically they are real and they are alive you know and so yea when they said congratulations I was quite surprised and I thought I had to kind of think about it for a while and think well I actually had a baby you know and I suppose it is, it is supposed to be a happy time, yea but it wasn't really , no

Mary Quite a long journey?

No. 52 Cathy Yes

Mary A long journey, so the things that might have hindered you were very close to home, close to you,

No. 53 Cathy Yes, yes

Mary What about professionals?

No.54 Cathy Yes, you know ahm... I think that ...[pause] how can I say mmm, I think having the support of everybody here, you know what they made it... What was the question again, what did you say ?

Mary I was just thinking about

No. 55 Cathy of the support of the staff

Mary yes, in terms of just thinking about the things that may have hindered you, when you talked about the lack of space, the presence of others , needing your own space and my question was coming a little bit closer to the Unit , whether, what might have hindered the lack of space

No. 56 Cathy I think there was, especially when ahm... oh I am sorry I am having a having a brain freeze ... ahm.... I am having a frozen moment in my head

Mary I suppose think about it might the actions of some professionals good and helpful and other professionals was helpful ... in terms of your care as a mother who was grieving

No.57 Cathy I don't know, all of a sudden I can't think of anything to say, I feel a bit strange in my head, I don't know why. It is almost as if I can't understand your questions, I don't know why I am feeling a bit strange at the moment, silly [at this point I am thinking something unexpected is happening, have I triggered something in Cathy's memory, that she has perhaps suppressed or is she experiencing some thoughts that have taken her by surprise and she needs time to order them. As we sit, Cathy is quiet, alert, her demeanour hasn't changed, she looks thoughtful, there are no signs of distress in her appearance and she is composed. I am reassured by this however, as a researcher I wish to continue the interview, as a professional I am concerned not to cause distress, as I ask. As I reflect on this situation I am aware the professional role is more comfortable, the researcher role at this point is uncomfortable and this I feel is due to the unknown of what may emerge or indeed will I be capable of dealing with the situation]

Mary Is it warm enough or cool enough in here?

No. 58 Cathy Yes, its fine

Mary Ok

No. 59 Cathy Let me just gather my thoughts and just Think about it

Mary And if you want to stop, please just say... you don't have to carry on

No. 60 Cathy No, no I do want to carry on, I just need a moment to gather my thoughts and think about what you have, are asking me because when you were asking me I was kind of going blank and forgetting what you were saying

Mary That's ok

No. 61 Cathy Something like a brain freeze, you know like when you are pregnant and you have those frozen moments and you think what on earth did you say...

Mary Or when you are very tired, you are listening and your mind is concentrating on something else, did they say something that I should answer.

No. 62 Cathy Having a frozen moment, yes [both laugh] Ok yes, now you were saying that with regard to the staff if they were hindering any mourning that I was having, well when we used to come here I think because I was kind of concentrating on Joseph so much I didn't really, didn't really ahm.....oh I am having that moment again, I don't know why I am doing this , it is so stupid ...

Mary Did you want to keep the time , when you came to the Unit to keep the time for Joseph? [As I read this I wonder why I did not ask Cathy if talking about his time was difficult or too painful for]

No. 63. Cathy You mean instead of grieving? I don't think I grieved for a while when I was with Joseph, no, no I held my emotions for a long time because and I know a couple of times I would try not to talk about it too much, about James and I know when the psychologist came in and she talked to me about it and I know I was in tears at one stage and that was the first time that I actually talked to her about my experience No 63c. because every time she came in and she'd ask questions and what have you and I'd shun her off and I wouldn't want her to talk to me and I felt especially that lady, I don't know why, I felt like she was really invading my space, I don't know why, but I think maybe because maybe because she'd just started and she was feeling a little uncomfortable about her position and how and how she could approach the parents, I think, I think I felt her awkwardness around us and she would try and talk to us try and give us help you know help and what have you, but I did feel when she would ask me questions I would maybe get yea a little bit defensive or say everything is fine I'm fine yes and then she would go off ahm and then obviously when we got used to each other and she felt a little bit more relaxed around us I think it was a little e bit easier, yea , everybody else, yea, everybody else was ... was, was fine, was good, we could talk, we felt we could talk to, to the staff, and things they were always so friendly , they were very supportive yea, very supportive

Mary And would you have advice for professionals, you mention about taking a photograph of James, that wasn't helpful at all, so for you that would be something that

No. 64 Cathy No

Mary And if you had been asked it sounds as you would have said no thank you

No. 65 Cathy yes, yes

Mary is there any other advice because James died on delivery suite, after the death?

No. 67 Cathy You know, you know what I thought, I thought they were just really wonderful, they gave me so much support no I have nothing to say because ahm.. you know they were there for me, I just felt like, I felt so close to them, I really, really did and I felt like ahm, they were even crying with me and that's why I felt so connected to them because I felt they felt my pain, they weren't just ahm there doing their job basically and saying well I am very sorry but it is just one of those things one of these

things and you have to you know what have what you, what have you, but they were really wonderful and they were holding me and supporting me in all the way that I thought, [Mary that you would have wanted] that I would have wanted at the time yea, definitely, definitely I felt like everybody was just and also during the labour and what have ahm I know that the midwives were with me they were just wonderful when the when I wanted to give up and I didn't want to carry on anymore they just gave me so much confidence and support yea, I don't that there was anything that they could have done that was better yea, yea, laughs

Mary And coming back to hospital, because Joseph has come back to hospital and I imagine he has also come back for outpatients appointments, how has that been?

No. 68 Cathy That's horrible, its really horrible having to come back, because I, we thought, we just thought that when we got home, its was just, no what happened was before we got home he had that ear check and they said he couldn't hear 30% from one ear and whatever % in the other and yea he had to have those hearing aids so for us we were so happy about him coming home and as soon as we heard about that we were devastated because we thought oh this is not going to end this is going to continue, there's going to be problem after problem after problem, and then when we got home it was very difficult for us to come to terms with the fact we thought he was going to be like this forever, he was going to have to wear this hearing aid forever, but he doesn't because we went to the doctor and he doesn't need hearing aids anymore obviously fluid or something (Mary yes) that was blocking but now it is all out so he is 100% fine so when we did come back we found it very difficult we said to ourselves this is what our lives is going to be like for the next how ever long 'til Joseph gets better and it was difficult to come back because I almost felt like having said good bye to the hospital you in my little world that's never coming back ... laughs, you know, it was going to be perfect and then we did come back it was a bit of a shock to the system, a bit of a reality check yea, definitely [For Cathy and Ben discharge did not bring separation and independence, the dashing of this expectation is painful as in the anticipated life of the hearing impaired child, yet the tie to the hospital also provides a reality check]

Mary And in terms of the HV, she comes in to see you?[Cathy yes] and does she talk to you about ...ahm [Jane ? reference to the neonatal community team] oh right no a Jane and Vicky, but do you have a HV as well

No. 68 Cathy We have a HV as well but she doesn't often come,[Mary she doesn't come and talk to you] no not all, she, think been once yea, she doesn't come I don't know why may be she knows we have other people to support us thinks that she doesn't need to but I don't even remember her name to be honest [laughs]

Mary She hasn't made a big impression

No. 69 Cathy No, not really

Mary She may do later

No. 70 Cathy May be, Yes

Mary And would you want Joseph to be referred always as a twin? Is that something?

No. 71 Cathy No, actually I don't ever say that no I don't know I just say Joseph I just talk of him as a just one baby, sometimes I don't even tell people my story, sometimes I just say I have a baby and his name is Joseph, because sometimes I don't want to bring all that up, sometimes it is too hurtful, I just like to say it is sometimes easier maybe when I am talking in conversation with someone you know I just say oh

no his name is Joseph you know but I don't often , unless it is very, you know, unless I unless we are talking about something s or you know an intense conversation and I feel I can trust them, then I'll bring it up yea I don't really I don't , I stopped saying it after a while actually, after not so long after it happened ahm, that I had a baby , because I found , I almost felt I was also like, I didn't want people to feel sorry for me as well because I didn't yea, I didn't want to make out as if I was looking for attention or something if I kept on saying it or you know morbid or something you know oh I lost one you know so I kind of stopped saying it, after a while its [a gentle laugh, more a loud smile] but I mean I yea, I do ahm...its not something you talk about to.

Mary And when you see twins Cathy how does that, does that effect you?

No. 72 Cathy It used to affect me, quite badly yes I used to be I used to be angry about them having twins and how come I didn't have twins but now its not now I don't, now it doesn't affect me anymore because Joseph is in such a good place at the moment no I don't I'm just so, I'm just enjoying him so much you that's that he's such a pleasure it just takes all your problems away I think that's also why he has helped me so much in this whole situation because the way he is what he does for me and the love that I feel for him and I , it just makes everything, all the pain and everything just goes away when you look into his eyes and you just realise how lucky we are to have him.

Mary So he gives a perspective on the reality

No. 73 Cathy Yes, it definitely, definitely yea, he definitely makes it all worthwhile and everything that we have been through definitely makes , I mean it just makes everything just so wonderful that he's home even though we've been through so much you know we are so grateful for what we have been through because it is such an incredible lesson that we've learnt as well just to appreciate life so much, you know to really appreciate life and not to take things for granted and yea and when you have a baby like that, like Joseph you know, you realise you know how incredible it is that he's here yea, you know, yea, yea, we are definitely so, we are very, very happy yes

[Lessons learnt form this painful loss: acknowledging experience, appreciation of life, incredibility of survival, home at last, joy. As I read through this text I am drawn to think about how the media portray the premature infant, medicine, technology which perhaps cultivates unrealistic expectations]

Mary Ahm... and a How has it affected your relationship with Ben?

No. 74 Cathy Yea, yea, you know actually it is very strange in the beginning I hated everyone, you know I was going through the postnatal depression and I was really yea, I was really angry with everyone, and angry with him as well and then after a while we, we just fought a lot when Ben's mum was there we fought all the time and I was always angry with him 'cause I felt like he ahm he wasn't really understanding what I was going through as a mother because his feelings were different as a father than it is to a mother, you know ahm and I felt he didn't understand me and all these things were quite frustrating in the beginning but after Ben's mothers left it was really wonderful because all of a sudden we kind of became so close and instead of screaming and shouting at each other we actually found that we got closer than we had ever been in our relationship, our, our we were always supporting each other because we understood what each other was going through, so when he was having a bad day you know I would like help him and when I was having a bad day he would help me.

But it wasn't always wonderful of course we would you know have our arguments what have you because its difficult, very difficult as you know having a premature baby ahm.. so it wasn't always wonderful but we yea we definitely became much, much closer because of it we were so lucky because we were always warned in advance you know this is very stressful on couples, couples can break up because of this and we just yea, has I think because our relationship was quite strong in the beginning so I think that having this happen, you know was very helpful that we were solid already and that stressful situation didn't break us up.

Mary Well we know having a premature baby is stressful, then having a premature baby and then, a bereavement on top of that is quite a lot to cope with.

No. 75 Cathy yea, but Ben is very, very ah strong, so I feel very protective, very protected when he is around , you know he protects me , I feel protected and I feel safe so yea, he is a very good husband yes, laughs.

Mary And, I think this probably my last questions ahm, you talked about the presence of Ben's mother and how angry you felt, when you look back, was that time of being angry was that useful?

No 76 Cathy You know I think that,...was focusing my anger on just anyone, I think whoever was there, I would just focus my anger on, it was almost ...easier than dealing with what I had to deal with, it was easier just to be angry at somebody and it was unfortunately Ben's Mum yea but I, I, there were times when I tried to ahm... when I was in the room and I felt so angry and I felt like I couldn't be angry and I felt so frustrated by that I wanted to be very angry, I wanted to be angry, angry, angry, I wanted to just hit someone, I was even like scratching my face, doing stupid things like that you know screaming in the pillow, ahm ... and really being angry, angry at anyone I could be angry at, at the time yea it just ...it was just ... its just an excuse really not to, not have to deal with what I had to deal with at the time so poor old Ben's mum, (laughs).

Mary I get the feeling although it was her presence wasn't always welcome, not that she wasn't welcome but her presence wasn't welcome but it seems to me it served a purpose

No. 77 Cathy Yes, I am glad, as I said I am glad that she was there because she was very, very supportive yea I am very glad that she was there. So even though I said that I wished she wasn't there I do in a way, I am glad that she was ...yea

Mary And what is your relationship like now

No. 78 Cathy I am very close to her yea, close to her, I am closer to her than I am to my own mother because as my step mom, because even though I love her very much she has been wonder but I do feel closer to Ben's mum than I do to my own step mom.

Mary And has that always been so or what effect has this experience

No. 79 Cathy I think what she has seen with me and Ben and what you know, what she's dealt with, with me, because she's, she's been there through, ahm ... through ah she's been there for me you know a lot in my life, in situations that I have been through, stressful situations very big support for me yea and I do feel very, I do feel very close to her

Mary And do you feel angry with her now?

No. 80 Cathy No, no not at all, grateful , I do feel grateful to have her yea, I love her, we are very close, we always send text messages to each other ' I love you so much' 'miss you' and what have you yea it is just like a daughter, because she has always told me from the beginning that she felt like I was a daughter to her and she always made me

feel welcome... in her home... always, always and I think because of that she just made me feel safe, I think and loved I think yea laughs gently.

Mary That is a really positive note to end on [Cathy laughs, a gentle laugh, and I join in her laughter]

No 81. Cathy Good, It's a pleasure, sorry about my kind of brain freeze laughs, I hope I have made sense

Mary You have made an enormous amount of sense, thank you so, so much

No. 82 Cathy It's a pleasure, an absolute pleasure.

Appendix 12 Example of field notes taken during interview

APPENDIX 11 Example of field notes taken during interview

Interview 1 Charlotte

25th September 2008

I had thought about and planned for this first interview. I had practiced my interview skills with the counsellor. I began my immediate preparation for this first interview during the train journey. I set aside time to focus on bracketing previous experience and knowledge. Bracketing is an essential aspect of phenomenology (Moran, 2000) while the view held by Alvesson and Scholdberg (2000) as setting aside the real world. My approach has a resonance with the view held by Hallett (1995) who describes bracketing as one of mental reasoning as opposed to a paper exercise. The approach I took was the use of a stillness exercise. This enabled me to put aside other thoughts and bring my mind to the work of the interview. The late September morning was bright and sunny and I took this as a good omen.

I arrived at Charlotte's home to find it no response to my knock on the door. A hint of anxiety presented itself. I checked my notes and the email I had received from Charlotte confirming the date and time. There was nothing to do but wait. In ten minutes Charlotte, her husband and their son returned from the school run. We introduced ourselves and commented on the beautiful morning and surrounding landscape. Charlotte told me that I could walk through the fields into town to catch my train after the interview. I looked forward to that. Charlotte's husband looked after their son so that Charlotte would not be interrupted during the interview.

We settled ourselves and I checked my tape recorder was working. Charlotte asked me how many parents I had intended to interview and what I hoped to achieve. I answered that she was the first participant and that I would interview between six and ten parents. She was also interested in the response I received from TAMBA. This conversation was valuable as it enabled Charlotte to have her questions answered and the conversation helped me to understand Charlotte's very interest in the experience of other parents. This aspect of her needing to know was encouraging to me as a researcher as it confirmed that for Charlotte there was a need for better service and support.

Charlotte had many tearful moments during the interview, her tears were deeply moving and the accompanying silence spoke as eloquently as her words. In my preparation I had pondered how I might respond to tears from the participant. In the event my tears flowed in response to the experience as it was shared. Tears neither felt inappropriate or intrusive but, they served as a response to Charlotte's experience.

I was struck by how few questions I asked. Once Charlotte began to speak her experience flowed freely. Pre interview preoccupations with questions / concerns were unfounded. At various points towards the end I was aware of the fact that I may have asked leading questions. As I reflected on this aspect of the interview I realised that what was required was to ask for comment. My preoccupation with remembering what was said was not a problem.

I was also struck by the 'ordinariness' of the aspect of professionals not reading the patients' notes and letters on communication prior to engaging with the parent. As I listened I felt I was 'with' Charlotte. I liken this 'being with' as reflecting both

engagement with the parent and a phenomenological approach of being immersed in the experience.

During the course of the interview Charlotte raised the issues of her desire to attend a memorial service but her inability to contact her local hospital. She needed an invitation. As I listened to her need I offered to make contact on her behalf. I was aware that I had moved from the role of researcher to that of professional carer. The opportunity to provide the information also served as a means of meet this parent's need.

As I returned to the train station I reflected on the information I had received. I was struck by the depth and complexity of this loss. The thread that ran through this mother's experience was pain, grief, loss, remembering, a mother's love. There was a daily challenge of managing parenting and grieving. The impact of professionals which was described as the follows: the good; the poor; the unprofessional. This mother highlighted how her grief differed from her husband's. Hers was more overt and its impact was greater than that of her husband's. Expectations of family were required to be managed: parents; siblings; in-laws. The lack of understanding from her mother-in-law who herself was a twin was a deep cause of distress. As I reflected on what I experienced from this interview I was mindful that this loss is deeply personal, that partners, family and HCPs impact on that loss. This first interview informed me of what it meant to a parent to live this loss.

Interview 4 Tricia

9th October 2008

Tricia was known to me as I had cared for her twins during their stay on the NNU in which I worked. We had spoken by phone and she "would prefer telephone conversations, not wishing to show my emotions" I was conscious that this might be a very different experience from face to face interviews as I would not have the non verbal feedback and facial expressions to inform the interview. That lack of information raised my mindfulness of silences and how I might deal with them. I prepared by using a stillness exercise and phoned Tricia at the agreed time. A brief conversation ensued and Tricia asked me to call back in thirty minutes as she had workmen in the house at that time. Once the interview began I was again struck by the fact that Tricia, like the previous three parents spoke freely. The lack of non verbal cues did not appear to be problematic except in one area. This related to the fact that I was unable to tolerate long silences. However, as the interview progressed I became aware of my interrupting silences. This lessened as the interview progressed as I became mindful that silence was part of the interview.

I had written "during the interview Tricia spoke freely, openly, at times qualifying what she was about to say 'I am not sure I should say this' and then continued. I was struck by how few questions I asked yet in the telling of her experience she answered my questions". This interview had a resonance with Interview 1 (Charlotte) of the need for time and space to grieve. This space and time will not be available until her surviving twin is older. The intentionality (consciousness) of her experience challenged my views on grieving as Tricia relates "haven't grieved, can't grieve properly, goes to your subconscious". For more than two years this mother has not grieved, I become aware of the personal nature of grief and how personal circumstance and the morbidity of the surviving twin reduces time and space to grieve. I am now mindful of the lack of service

provision for this grieving mother and how the findings from this research study may help shape a pathway for the care of the bereaved following the death of a twin.

Interview 7 Alice

9th February 2009

Having had a number of phone calls with Alice, I feel I know her. I had cared for her and her surviving twin however; the research interview would be a different from previous interactions and conducted in her home. I have some anxiety about the interview; this anxiety was similar to the others. As with previous interview I prepared myself by bracketing the knowledge from previous interviews. This was not such an enormous task as I had anticipated. I believe this to be so due to the fact that each parents experience was different though there were shared commonalities. The differences enabled me to anticipate the experience as personal and unique. This approach was helpful in enabling me to bracket previous knowledge and experience. As for previous interviews I did a stillness exercise. I found this valuable in enabling me to enter into the relationship with the parent.

It was good to see Alice and she introduced me to her mother who had arrived to care for her surviving twin during the interview. Alice brought me up to date on her son's progress, his medical problems, his need to be fed through a gastrostomy tube and his weekly physiotherapy routine. The conversation gave me an insight into her family life and the impact of morbidity of her surviving twin. Alice's mother had made us tea, the lighted fire provided a feeling of welcome and the presence of children's toys gave a feeling of normal family life. Alice asked questions about how many parents I had interviewed, she was interested to know what the findings would reveal. Alice began to story after looking for and saying she needed tissues. I had brought a supply.

As I began the interview with Alice I was mentally focusing on her responses and intentionality. Therefore her consciousness of pain, grief, decision making, decision making about withdrawal of treatment and living with the decision made of managing the emotional energy for grieving and the emotional energy for parenting. As I completed the interview I was mindful of my development as a phenomenological researcher.

Alice cried throughout the interview and more than any other parent I had interviewed. I had come to expect tears and accept them as part of the experience of interviewing. I had also come to understand them as an expression of grief and they were an important aspect of the interview. As in all interviews I was affected by those tears and it did not feel uncomfortable or intrusive to share in them. Alice shared easily with few questions asked. At the end of the interview Alice said she could talk for hours, that in spite of her tears she enjoyed it.

Yet again I was struck by the complexity of this loss. As Alice's twins were born at 23 weeks gestation she was aware of the risks of death yet that did not prepare her for the event or lessen her grief. As I reflected on the experience of the interview I was very conscious of the physical and emotional demands of this loss.

Appendix 13 Summary of Findings to Participants

Study Title: How do parents experience the death of a twin in the neonatal period? A phenomenological study, of seven parents.

“It’s difficult because I’m so desperate to feel like my old self. I want to be my old self. I want to get on with my life; I don’t want to forget her, because how could I? But I don’t want to think about it every day. I don’t want to, you know, I just want to be happy and I want to be a normal family and I want, you know, everything to be okay and I can’t make it okay and I can’t make it go away”.

Introduction

This phenomenological study sought to provide a description of the death of a twin in the neonatal/ perinatal period. This serves to provide insight into how the parents experienced the death of a twin. The findings may help Health Care Professionals (HCPs) to provide care that is appropriate and responsive to the individual needs of the bereaved parent.

The study group were seven parents, six mothers and one father. The parents were interviewed on two occasions. The interview was transcribed prior to analysis. The first and main in-depth interview took place between six months and six years following the death. The second interview was to ensure that analysis was true to the parents’ experience. New material from the second interview was integrated into the findings. The second interview planned for six months following the first was delayed due to the volume of data to be analysed.

Findings from the study

The findings present the parents’ experience as painful and lasting, and the feelings of loss have become an unwelcome companion. The grief following this loss is poorly understood by others and therefore support is not available, with resultant feelings of isolation experienced by the bereaved parent. Their dead twin is maintained as a continuing presence in the lives of the parents and fabric of the family. HCPs are in a position to take the lead while non professional organisations such as Twins and Multiple Births Association (TAMBA) are crucial to the support of these bereaved parents. Professional support may also help. The journey following the death of a twin has uncovered, for the parents, previously hidden strengths.

Fourteen themes were identified which were condensed into four main themes. These are presented in Table 1.

Table 1 Main themes and subthemes from the study

Main themes	Subthemes
1. Experiencing death	Pregnancy Confronting death Information Meaning of death
2. Accompanied by others	Health care professionals Family Friends Other parents Spiritual support
3. Being Alone	Isolation Grieving Loss as an unwelcome companion
4. Understanding the Loss	A continuing presence of the dead twin Uncovered strengths

Part 1: Experiencing death

1.1 Pregnancy

The parents experienced their twin pregnancy as a time of joy and described associated feelings of shock, happiness, elation, specialness, an anticipated normal pregnancy, and longed for healthy babies. The awareness of risks did not intrude into their strong and healthy state. They recounted their experience of events that challenged that joy. Some parents described events that changed enjoyment of pregnancy to that of concern, while others describe the announcement of death in pregnancy; others described death at time of delivery and others described the decision to withdraw life support.

1.2 Confronting death

Death was confronted at various stages and in a variety of settings:

- As a sudden event in an otherwise uncomplicated twin pregnancy
- Following laser treatment for twin-to-twin transfusion syndrome
- Due to poor growth
- Extreme prematurity
- Following the decision to withdraw life support treatment
- Overwhelming sepsis

In all situations parents were shocked and unprepared for the death. For two mothers there was the added difficulty of continuing their pregnancy for up to a further ten weeks. Another mother delivered her twins the day following confirmation of death of one twin.

1.3 Information

Parents identified the need for practical information about funeral arrangements and registration of the death. Parents asked for information to help them understand the emotional journey they were beginning, how to deal with their emotions and what was considered 'normal'. Parents identified a lack of awareness by HCPs for the need for this information "*maybe they don't know*". Parents also required information which related to events in pregnancy and cause of death. This information would be used at a later date to provide an explanation to the survivor about the history of his/her twin.

Those parents whose surviving twin was cared for in the neonatal unit had additional needs for information. They needed to know "*as much as the doctors*". They required a level of knowledge that would enable meaningful dialogue with the HCP caring for their surviving twin. The provision of information by the HCPs was equated with the giving of "*respect*" to the parent.

For one parent lack of professional knowledge was a cause of unnecessary distress. The distress was worsened by behaviour of the HCP in not reading shared information and not reading the mother's notes.

1.4 Meaning of death

Death has robbed the parents on many levels: joy; celebration; status as parents of twins and the surviving twin of a sibling. "*You feel completely robbed of the whole experience, and the joy. I don't think there's anything you can do about that though...cos that's really the way it is, isn't it*".

For some parents pregnancy continued for some weeks, another was delivered the day following confirmation of death. Extreme prematurity did not make its acceptance easier. "*I was happy to have Joseph and I was terrible sad not to have James*". For others their participation in the withdrawal of intensive care was a painful experience with lasting consequences.

Part 2 Accompanied by others

2.1 Health care professionals

Parents experienced inconsistencies in care. Parents valued individualised care which maintained the focus of care on the parent in terms of empathetic support in addition to professionalism. Arrogance was experienced. Some parents experienced a lack of professionalism: poor levels of knowledge; intrusion; and a belief that they (HCPs) could make things better. The presence of counselling support in the immediate period following the death of the twin was seen as unwelcome and an intrusion into the very personal nature of the loss. **Parents needed time and space to both grieve and come to understand and own their loss. The provision of counselling between six and twelve months may be an appropriate time.**

2.2 Family

Family support was experienced mainly as compassionate in terms of practical and psychological support *“You know everybody tries to make you feel better because they love you and they want to look after you but it’s not, they don’t always say the right thing”*. The constant presence of a family member, while providing valuable practical support, was seen as an intrusion as it reduced the mother’s space to grieve. Lack of understanding was evident in a generational response *“this is nature’s way”*. For another mother *“I mean Kevin’s step dad just said ‘at least you’ve got one, be grateful, you’ve got one’ and clearly just having no idea what it feels like at all”*.

2.3 Partners

Differences in the experience of the loss between mothers and fathers were present. Mothers experienced a deep sense of loss; this sense is attributed to the intimacy of the relationship between the mother and her unborn baby and may partly account for the difference between the men and women. Men are concerned for their partners to move on and return to their pre-loss state. There is also a concern to remain strong for the survivor. As time passed some of the mothers did not discuss the death of their twin with their partners, while others did. This may reflect a difference in approach to grieving. The difference in approach to grieving may result in partners being unable to support each other.

2.4 Friends

Friends are valuable but may have unrealistic expectations of the bereaved mother. The problem with friends is that they get upset and don’t have an idea of the experience. In addition, parents can speak to friends for a limited period about their loss and friends *“don’t ask because they don’t want to upset you”*. Friends who themselves are mothers of twins understand the loss. This understanding does not necessarily result in support to the bereaved mother. The bereaved mother seeks to protect them from the distress this understanding brings. Contact with mothers of twins serves as a reminder of loss.

2.5 Other parents

Other parents in the neonatal unit at the same time did provide support, speaking from a perspective of knowledge. *“I was telling everybody via text and phone call that I had given birth at 23 weeks and that it was grim and that they would probably both die it wasn’t until Joan looked me in the eye and told me that she had lost her first girl a year ago and this was her second attempt and Sian was very ill and I suddenly realised that it really was possible almost definitely going to happen”* Their empathy is borne from lived experience.

2.6 Spiritual support

Spiritual support provided a public acknowledgement of their baby’s death and the parent’s loss. *“I think that service with Rev. Jo was the beginning, after he was born, of accepting things and basically from that you can move on and the second service was more like a healing service”* Spiritual support was experienced as providing healing and a sense of closure. The funeral was an important public acknowledgement. For

nonbeliever there was a strong desire for a public acknowledgement *“I didn’t suddenly start to believe in God, in fact quite the opposite, but you feel like you want some kind of formal acknowledgement of their existence”*.

Part 3 Being Alone

3.1 Isolation

Parents are isolated due to the depth of their grief and the lack of understanding and lack of support. That lack of understanding was characterised by the fact that *“people look on the positive side and ignore the negative side”*. Lack of information increased isolation *“there was no information about TAMBA or about SANDS”*. The decision to withdraw care is viewed as one of extreme loneliness’ *“it was very unbearable and there’s nobody to talk to about, (the experience) and you’re not going to get a doctor to come and say to you it was still the right thing to have done cos that’s not what their job is but that’s kind of almost what you want”*. Talking about the loss within the family was limited for one parent; this was due to protecting the members of the family. Grief is personal and is coped with on an individual basis and not readily accessed by others. Or indeed desired to be accessed by others.

3.2 Grieving

The loss is so severe that support is ineffectual and there is a desire to be alone”*when you have just lost, lost a twin there is nothing anything anybody can do for you... there is absolutely nothing and not only that you don’t always want to accept the help because you just want to be left alone”*.

Time for grieving has to be negotiated within the demands of family life. The needs of the survivor and other children in the family take precedence over the mother’s need to grieve. Managing the emotions of joy and grief required the bereaved parents not to think about their dead twin.

Grief is to be lived, to be miserable is part of the experience which requires understanding rather than medication. Mothers and fathers grieve differently. The mothers acknowledge their depth of grief and feelings of misery. Mothers experienced their partners not talking about the dead twin as sparing them grief. The one father in the study sought to focus on the surviving twin *“we lost one, then we really had to focus on the one baby we did have”*. Focusing on the survivor was seen as *“giving you time to heal”*.

Grief consumes energies. Where those energies are unavailable as in the situation of the survivor requiring intensive care, grief then is delayed. The delay in grief results in the assumption that grief is completed when in fact grief may not as yet occurred. The presence of the surviving twin may lead people to view the loss as lessened.

3.3 Loss as an unwelcome companion

The death of the twin takes from the parent their sense of self and their role as a parent. The mother has grown and carried the baby and its death takes part of her. There is a

longing to be “*her old self*”. The presence of loss “*is always there*”. The lasting sense of loss and sadness is of concern to parents and that loss as an unwelcome companion will not leave and there is a concern “*there’s going to be a sadness nagging at me all the time, you know, and is that ever going to go away?*”

Part 4 Understanding the loss

Parents assimilate the death of their twin into their lives. This is an important aspect of the death. The dead twin is held within the ongoing life of the parents and family. Previously unknown strengths have been uncovered as a result of the death.

4.1 A continuing presence of the dead twin

Both twins occupy different spaces and require different energies. The presence of the dead twin is held close, images and tangible memories provide confirmation of their existence. Birthdays and Christmas are difficult times for most of the parents, particularly the first birthday. Milestones such as starting school serve as a reminder that there should be someone else, thoughts turn to “*wonder what it would be like to have him here with Joseph and you know... two boys together*”. Parents who have retained the ashes of their dead baby have yet to find a perfect resting place. This is an ongoing search yet to be satisfied. There is no urgency to accomplish this task. Some solace is present for those who have lost an identical twin as the image of child they have lost is present in the survivor. “*I find it helpful actually, because I do know what she would have looked like*”. The presence of the dead twin is maintained within the fabric of the family in various ways and in the ongoing life of the survivor who is made aware of his/ her dead sibling.

4.2 Uncovered strengths Personal growth

Personal growth has arisen from this loss. Changes have been experienced as the discovery of inner strength and a reaching out to other parents in need of support. There is also an appreciation of life’s riches.

5. How may the findings shape practice?

The findings provide health care professionals (HCPs) with a different lens through which to view the death of a twin in the neonatal period. The findings speak of the very personal and heart-breaking loss as experienced by the parents. The findings also tell of the continuation of loss in the life of the bereaved parent. Communicating the findings to a wider audience is essential in order to improve practice and ensure bereaved parents of a twin receive care that is appropriate to their individual needs.

5. Recommendations for practice

Four areas have been identified for improvement of service to the bereaved parents of a twin. These relate to: the provision of information; support; training needs of HCPs; identification of medical notes.

5.1 Information

Information is crucial for these bereaved parents in order for them to arrange registration of death and funeral arrangements. This is required in the immediate period following death. is essential in the immediate period following the death. Information is also required to provide some understanding of the emotional journey, grief and loss. This would serve to acknowledge their loss and validate their experience.

5.2 Support

The findings suggest the most appropriate support is that which is provided by those who have experienced the death of a twin. Non-professional support organisations such as TAMBA are best suited to supporting parents. Raising the profile nationally of these organisations is essential. HCPs caring for these parents should provide a named contact prior to discharge. In addition, the bereaved parent should also have the opportunity for counselling support at a period of between six and twelve months. Each parent should be provided with a named counsellor, contact details. The parent decides the timig of this support.

5.3 Education and training of health care professionals

Understanding the experience of loss of a twin from the perspective of the parent provides the HCP with insight as to how that loss is experienced. Training and educating of all HCP involved in the care of parents is essential to ensure the provision of care is appropriate and responsive to the individual parent's needs.

5.4 Identification of medical notes

The medical notes of the mother and surviving twin should be identified by a sticker denoting one surviving twin.

Acknowledgements

I wish to thank the parents who participated in this study. I wish to acknowledge their generosity and time in sharing their experience. I felt and continue to feel privileged to have been given access to a very private and personal part of their lives.

I also wish to acknowledge my supervisors Dr Huguetta Comersamy and Dr Jackie Bentley, University of Brighton. They have supported, challenged and cared for me during the many ups and downs of completing this thesis.

Appendix 14 Thank you Letter to Participants

Dear

I am writing to thank you for participating in my research study “How do parents experience death of a twin in the neonatal period? Thank you for giving of your time and your generosity in sharing your very personal experience. I have felt privileged to share in your experience and for that I thank you most sincerely.

The purpose of the study was to seek to understand your experience following the death of a twin. It is important for health care professionals to understand your experience so they can provide the appropriate care that is required at this difficult time.

The findings will help to shape practice and improve the care of bereaved parents following the death of a twin. I have begun the process of sharing the findings to a wider audience. In my own area of practice the provision of counselling at a six month follow-up appointment is now offered to parents. I include a summary of presentations related to the study. I will keep you updated regarding any publication related to the research.

If you have any questions about the study or the findings please do not hesitate to contact me.

Thank you again for your contribution to this important study.

Yours sincerely

Mary Goggin

Appendix 15 Summary of Presentations Relating to this Study

Presentation of work in progress, Brighton, 2006

Presentation of work in progress, Brighton, 2007

Presentation of work in progress, Brighton, 2008

Presentation of work in progress, Brighton, 2009

Presentation to South West London Neonatal Network Board, 2009

Poster presentation at ESPNIC Conference, Verona, 2009

South London Research in Child Health (RiCH) meeting, May 2010

Poster presentation at the International Nurses' Day event at St. George's Hospital, London 2010

Presentation at the National Neonatal Study Day, St. George's Hospital, London 2010

Oral presentation at the European Society of Paediatrics Societies (EAPS) Conference, Copenhagen, 2010

Presentation at joint Obstetric and Neonatal Clinical Governance meeting, St. St. George's Hospital, London, November 2010