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Caring for families experiencing perinatal loss: What do students need to know?

A thesis submitted in fulfilment of the requirements of
University of West London,
for the award of Doctor of Health Sciences

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Abstract

Background

Perinatal loss and bereavement care is an area that significantly impacts families and the health professionals caring for them. The care provided can make an enormous difference to families experiencing perinatal loss, so it is imperative that midwives and health professionals are trained adequately. There is inconsistency and lack of equity in the education provision for this and in turn the care that families receive.

Aim

This research aimed to assess the existing provision of bereavement training for student midwives and create a proficiency framework which comprehensively includes all aspects of knowledge required and to inform the training that is required and discuss how this can be incorporated into the 3 year BSc (Hons) Midwifery course. This research was undertaken involving three phases.

Method

Phase 1

Phase one used an online survey to assess what is already provided in relation to perinatal loss teaching but at a high level. This included the number of hours dedicated to the subject and who provided the training.

Phase 2

Phase two utilised the Delphi technique to create a comprehensive Perinatal Loss Proficiency Framework (PLPF). This was created through the input from experts in the field with extensive expertise and experience.

Phase 3

Phase three then explored the implementation of this and the teaching and learning strategies which should be employed. The participants were 2nd and 3rd year student midwives using nominal group technique (NGT).

Data Analysis

Phase 1

Survey analysis was carried out using the survey tool giving statistical analysis. This was further supported through opportunity for free text responses to give further context.

Phase 2

The data from the Delphi technique came from open ended questions and required thematic analysis carried out using Braun and Clarke (2006) six phase model.

Phase 3

Nominal Group Techniques is a consensus technique which facilitated analysis of the data and allowed consensus to be reached within the group discussion.

Findings

Phase 1

There is very little time allocated to bereavement training for student midwives and provision varies greatly nationally. This variance was across who facilitated the sessions, when they were delivered, and the time allocated to this provision.

Phase 2

The resultant four themes were practical clinical skills; emotional and spiritual support; communication; paperwork. These themes were populated with competencies created from the data contained within the thematic analysis. The inclusion of practical clinical skills incorporated many aspects of care not yet included in existing training provision. This created the Perinatal Loss Proficiency Framework (PLPF).

Phase 3

The participants allocated various elements to either practice or university as the most appropriate learning environment. All themes had elements allocated to both learning environments so aligning with the way midwifery education is delivered. They also proposed a three year training programme using the PLPF as a structure for this.

Conclusions

There is inconsistency and lack of equity in the education provision for this and in turn the care that families receive. The PLPF can be tailored to suit differing specialities as discussed, but for midwifery the full framework is applicable. Midwives will meet women and families at all gestations suffering all losses so need to have the skills to care for them. It is essential that there is widespread dissemination of these findings and support for implementation. Through this there can be a more standardised approach to perinatal loss in education and in practice nationally and internationally. This is essential in order to support the nurses,

midwives and other health professionals providing the care and improve care for the families receiving it.

Recommendations for Practice

- There needs to be greater consistency of training provision for healthcare professionals providing care for families experiencing perinatal loss which can be facilitated by implementation of the findings from this research.
- The Perinatal Loss Proficiency Framework (PLPF) should be incorporated into all pre-registration midwifery courses.
- The PLPF should be amended for use in specialities i.e. gynaecology and incorporated into pre-registration nursing courses using applicable content. This can also support inter-professional learning.
- The PLPF should be used to create a post graduate module on perinatal loss; this should be created in conjunction with charities within the field of perinatal loss in order to gain accreditation. This can provide a basis and requirement for Bereavement Specialist Midwife qualification.

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Chapter One: Introduction.

1.1 Introduction

The National Health Service (NHS) established in 1948 was an historic moment in the development of a comprehensive service funded by taxation that is freely available to all in their time of need (Bevan, 1948). The NHS has evolved immensely since its inception and covers birth to death from maternity services to care of the elderly and end of life care, mental health services and many more (NHS, 2021). Over the last year, 2020-2021 the NHS as a whole has seen one of its greatest challenges due to the covid pandemic. Whilst the pandemic has undoubtedly affected medical wards and stretched intensive care resources it has also influenced the delivery of maternity care. The way in which midwives deliver care, partners being allowed to be present at the birth and many more aspects have changed beyond recognition. The role of the midwife in supporting the parents from booking through to the postnatal period has never been more challenging or more important.

1.2 Why are midwives needed?

Midwives have an essential role in the provision of maternity care. In the UK midwifery is a protected function; this means that it is only a midwife or a registered medical practitioner who can attend a woman in childbirth and it is actually a criminal offence for anyone else to fulfil this role (NMC, 2021a). The numbers of births per year in 2019 was 615,557 (ONS, 2021); the number of midwives in practice is recorded on the Nursing and Midwifery Council (NMC) register went from 34,554 in 2017 to 39,070 in 2021 (NMC, 2021b) which equates to one midwife for every 16 pregnant women and their families. Some of these midwives will be in non-clinical roles such as education or managerial roles such as Head of Midwifery so not all midwives are in clinical practice giving hands on care. Of the births counted per year not all will end with the happy arrival of a live, healthy baby. The most up to date statistics show that 6 per 1000 births will result in the baby being still born or a neonatal death (ONS, 2020). This translates to approximately 4,300 babies per year. This number does not include any perinatal loss at less than 24 weeks gestation, or any termination of pregnancy for fetal abnormality (ToPfA) so the actual number of families experiencing perinatal loss is higher than this. Please see section 1.6 for full definitions of these terms.

These families who are experiencing perinatal loss will receive care from a number of midwives in the antenatal, intrapartum, and postnatal episodes of care. For example if a woman is in a labour ward to deliver, the duration of this may continue over three or more shift changes. This means that each family experiencing perinatal loss may have care provided by several midwives during the intrapartum period (in labour); this is only one part of their care. Antenatal and postnatal care may be provided by different midwives also. If each family was cared for by four midwives (though this can be more) the total number of midwives involved in care for all families would equate to 17,200 midwives. If you then add the numbers of families not included in this number as discussed it is clear to see that 20-30,000 midwives or more could be involved in their care which is 51-76% of the midwives who are registered with the NMC and practice in the UK. This demonstrates the need for all midwives to be competent in delivering care to families experiencing perinatal loss.

1.3 Midwifery Education

Midwifery education is something that has changed and evolved over the years. In the 1980's and 90's it was the norm that midwifery followed on after nursing training which then led to the establishment of a diploma in midwifery from 1996. This was awarded by higher education institutions and allowed the development of a theoretical framework to underpin the content and structure of the course (Fraser, Murphy, Worth-Butler, 1997). This was a critical development in midwifery education that allowed for the development within the curricula of a focus on critical thinking and the inclusion of evidence based content which would support the midwife as an autonomous practitioner. As education moved into university this has also provided a basis for competition between universities to attract students to their courses. This is often based on league tables and results from student satisfaction surveys such as the National Student Survey (NSS) which can be used to promote a particular HEI as a better choice than others (Briscoe and Clark, 2018).

The funding for education has also evolved and changed over the years. As places were funded by the Strategic Health Authority this allowed them to avoid the annual tuition fees for university. However, this changed with the decommissioning of student bursaries in 2017 after which student midwives paid fees but could also access the student loan system (Briscoe and Clark, 2018). In 2020 Learning Support Fund was established (NHS Business Services Authority, 2020) which allowed access to funds for healthcare students that were not repayable; it remains to be

seen whether this will affect the recruitment to the midwifery courses in a positive way.

The Nursing and Midwifery Council (2019) standards for education stipulate that the training must comprise of 50% theory and 50% practice placement and be at least 3 years duration. The emphasis on learning in practice is evidenced by the document used in practice for which midwives supervising students sign off proficiencies as students achieve these, enabling continuous learning and assessment within practice. This can help bridge the theory practice gap (Saifan, AbuRuz, Masa'deh, 2015), as theory learnt in the university setting is then applied in the real world practice setting. The value of this 'on the job' training is well established though there is more to discuss around the theory practice gap which will be addressed in Chapter 2 section 2.4.5 and Chapter 5 section 5.4. It can be more challenging for students to gain experience in areas such as perinatal loss and bereavement care for a variety of reasons which will be discussed further in Chapter 2 section 2.5.2 and Chapter 5 section 5.3.1.

1.4 Policies affecting practice

The Health and Social Care Act (2012) established the need for the NHS to ensure there was modernisation within the services offered, acknowledging the need for improvement and an emphasis on a greater voice for patients. In March 2015 the then Chief Executive of NHS England, Simon Stevens announced that there would be a major review of maternity services. The resultant report was Better Births (2016) which found that maternal and perinatal outcomes had improved from 2003-2013 (the date range reviewed) there was still the opportunity to further improve safety and quality of care. This led to, amongst other recommendations, the increased emphasis on the inclusion of the woman and her family in their care decisions and that care for each woman should be led by a small team of midwives who would provide continuity of carer and whom the woman can get to know. This is to support the development of mutual trust and ensure the woman's decisions re her care are respected.

As this review was taking place and being written there was also the Morecombe Bay investigation (Kirkup, 2015) which was established by the Secretary of State for Health investigating serious incidents at University Hospitals of Morecombe Bay NHS Foundation Trust between 2004-2013. The report highlights failures at every level including clinical competence of staff and investigatory procedures and oversight of

serious events. Even after this report there are still ongoing issues around safety which is demonstrated through the Ockenden review into Shrewsbury and Telford NHS Trust. The first report published in December 2020 (Ockenden, 2020) covers 250 case reviews; there were 1,486 cases in total reviewed for the final report (Ockenden, 2022). Similar findings in report one highlights the lack of clinical competence and also the processes by which serious incidents were investigated, reported and how the family voice was, or in most cases, was not heard. These reports would support that there is a need for a change in how maternity services are delivered and oversight of these from a senior level needs to be transparent and appropriate. It also highlights the fact that there are many bereaved parents who are not receiving the care they need or should have at the time when they have the greatest need.

Since the Morecombe Bay Investigation Report in 2015 into baby deaths and the publication of Better Births in 2016 the Maternity Transformation Programme has facilitated the co-working of the NHS and its partners to implement the vision of better and safer care for all. This includes a national ambition to reduce the rates of stillbirth, neonatal mortality, maternal mortality and brain injury by 50% by 2025; the overall perinatal mortality rate between 2010- 2018 has fallen by 15.1% which is a positive indicator that changes in practice are having the effect of improving care and outcomes (NHS England and NHS Improvement (NHSE and I), 2020). However, there is still much improvement required to reduce rates further to achieve the national ambition of reduction by 50%. This also highlights that whilst this is good news, there are still a significant number of families who are experiencing perinatal loss and need bereavement care after the loss of their baby. It is the midwife who is the lead carer for families at this point (NMC, 2019) and so must have the knowledge, skills and ability to provide the care required and involve the multidisciplinary team as appropriate.

There are many initiatives with the aim to reduce the rate of perinatal mortality. These initiatives are aimed at improving care to reduce the incidence if perinatal loss. This does not cover the care of those who will sadly still suffer perinatal loss and need bereavement care throughout this. Therefore there needs to be further research regarding the care when families do experience perinatal loss.

1.5 Why is perinatal bereavement care in midwifery education needed?

Pregnancy and childbirth are seen as a time of joy and happiness as the pregnancy usually results in the birth of a healthy baby. This is not always the case as statistics from 2021 have shown that 13 babies die before, during or soon after their birth every day in the United Kingdom (UK) (SANDS, 2021). This does not encompass the total number of pregnancies that end in an unexpected loss and perinatal bereavement for the families as these statistics only include stillbirth and neonatal death. The neonatal mortality rate has stayed the same since 2017 as reported in 2019. It is noted that the increase in live births under 24 weeks completed gestation may be a contributing factor in this as babies born at earlier gestations have less chance of survival (SANDS, 2021). The Office for National Statistics has published data for stillbirths from January to September 2020 which shows the stillbirth rate has decreased from 4 per 1000 to total births to 3.8 per 1000 totals births (RCOG, 2020). Whilst this is a very small change, this rate is from the time period in which the covid pandemic was prevalent. It is positive that there has not been an increase at this time when services are stretched, and that student midwives training has continued during this time.

To put the concept of perinatal loss and bereavement into perspective it is key to review the statistics regarding perinatal mortality. This illustrates the prevalence of perinatal loss and the need for the healthcare professionals, including midwives, to be suitably qualified and trained to care for families when they experience loss. The statistics available for the UK are obtained from the Office for National Statistics and detailed in Figure 1 below.

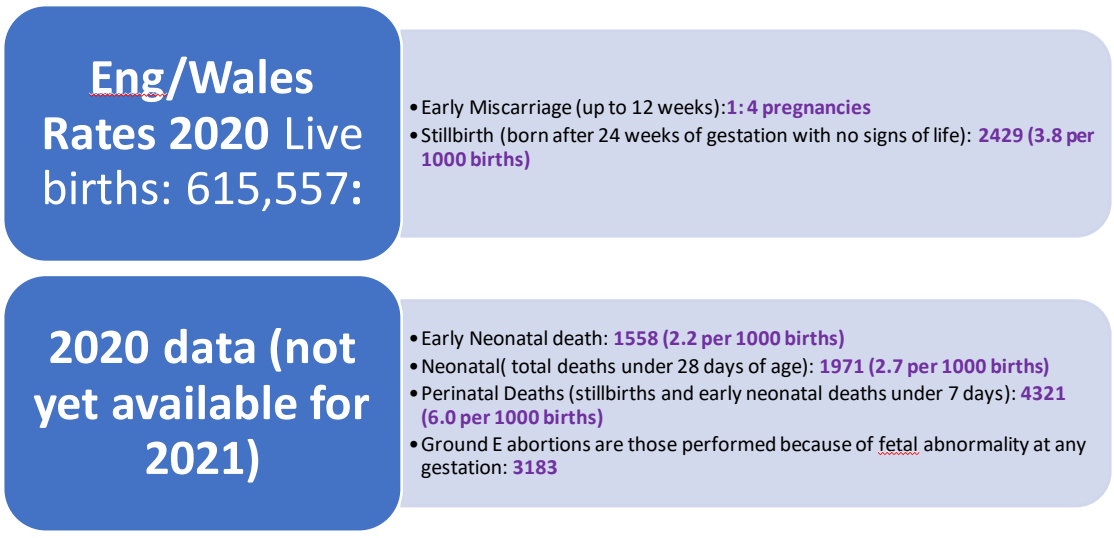

Figure 1.1: Perinatal Loss Statistics ONS (2022)

1.6 Perinatal loss definitions

These statistics show that 1 in every 250 babies born in the UK is stillborn, which is defined as an intrauterine death after 24 weeks gestation by the Stillbirth Definition Act (1992). These losses are reported to an organisation called Mothers and Babies-Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK). A baby which is stillborn over 24 weeks gestation and a baby born alive who then dies within the first 28 days of life at any gestation must be registered with the Registrar and a birth, death or stillbirth certificate issued (Birth and Deaths Registration Act, 1953) and the loss is reported to MBRRACE. A baby lost between 22-23+6 weeks of gestation is reported to MBRRACE as a late fetal loss. There are still many more babies lost which are not recorded in this way as they have died at less than 22 weeks gestation. This can be a spontaneous loss or termination of a wanted pregnancy due to fetal abnormality (ToPFA) being diagnosed. It is worth noting that ToPFA can be conducted at a later gestation though the majority will take place before 24 weeks. These losses are not registered as detailed above but still have a devastating impact on the families involved (Read, Stewart, Cartwright et al, 2003; Modiba, 2008; SANDS 2016).

The definitions of perinatal mortality vary between countries due to the differing legal definitions of this term. The World Health Organisation (WHO) (2020) define perinatal mortality as the death of a fetus from 22 completed weeks gestation to the neonate up to 7 days old. In the UK, MBRRACE-UK uses the term perinatal mortality to include stillbirths from 24 weeks gestation to neonatal death of a baby born at any gestation who lives for any period of time but dies within 4 weeks of age. There are other texts that propose perinatal mortality covers pregnancy loss from the time pregnancy is confirmed (Pauli 1999). Fenstermacher and Hupcey (2013) completed a systematic literature review on the concept of perinatal bereavement. The final data set included 143 articles and was reviewed using the principle based concept analysis. They found that there are few explicit definitions and a great deal of inconsistency in the conceptual meaning. The lack of clarity and definition means that it is difficult to translate research findings and make comparisons between studies to provide evidence for and support the translation of research findings into practice. All education in maternity care must be evidence based and this lack of clarity can make the standardisation of both curriculum content and application of standardised care for all problematic.

1.7 Evidence Based Practice

Evidence based practice has a long history within healthcare (Lipscomb, 2015) and implementation comes with challenges. Gould (2010) discusses the development of evidence based guidelines within a social work context in that there was a dominance of quantitative research and marginalisation of qualitative approaches. This could mean a great deal of rich data and varying perspectives are not included in the development of practice guidelines which leaves gaps in knowledge. The issue around what actually counts as evidence and how it is used in practice has been present for some time and continues now (Rycroft-Malone, Seers, Titchen et al, 2003). Using evidence is increasingly relied upon for making decisions and care planning and this emphasis on what constitutes good or bad evidence is included in midwives' education from the start (Spencer and Yuill, 2018).

The scope of this thesis is intended to be inclusive and will address unexpected loss from early pregnancy (miscarriage) through to later fetal losses and neonatal death (Flenady and Wilson, 2008) and also loss through termination of a planned pregnancy for fetal abnormalities. This loss is felt as intensely as any other unexpected or unplanned loss and can have lasting psychological consequences (Lafarge, Mitchell, Breeze et al, 2017). A study by Kersting, Kroker, Steinhard et al (2007) found that compared with women experiencing spontaneous losses, those who experienced ToPFA were significantly more stressed at 14 days, 6 months, and 14 months. The fact that they had to make a decision not to continue with the pregnancy may have been a factor in long term mental health sequelae as well as a lack of aftercare (Lafarge, Mitchell, and Fox, 2013). Perinatal loss at any gestation is a loss of the future and what it could have been and can be felt as keenly no matter what the gestation (Robinson, Baker and Nackerud, 1999).

1.8 Bereavement Care

Whilst in recent years there has been a real focus on prevention of perinatal loss the bereavement care required has not had such scrutiny or spotlight. Historically it has been noted that the potential effects of pregnancy loss and death of a baby has long been overlooked by clinicians and researchers alike (Speckhard, 1997). Indeed, this was written 22 years ago, and care has improved to a degree since then. However, it could also be argued that the evidence is still that the significance and reality of bereavement experienced through perinatal loss is not yet fully appreciated and there is still much scope for further improvement. Hughes and Goodall (2013) note

that the care received by families at the time of bereavement can have a significant and lasting impact on them. This can be positive or negative depending on the care provided including the experience and how that care is perceived by the parents at that time. Part of the recommendations are that staff be given the time for education around perinatal bereavement so that care can be delivered that will not exacerbate the grief and distress the families experience (Ravaldi, Levi, Angeli, 2018). It is proposed that staff who are well prepared and provided with support and training will in turn provide the care that will support and benefit the families in their care, not make the situation worse (Siasskos, Jackson, Gleeson et al, 2017). Doherty, Cullen and Casey et al (2018) have also identified that the education for student midwives around bereavement is to date inconsistent and insufficient.

1.8.1 Bereavement Specialist Midwife

There are specialist roles within midwifery, the scope of which have increased as the women requiring care become more complex (Better Births,2016). One such role that has evolved is the Bereavement Specialist Midwife (BSM). The BSM is a practitioner with a special interest in perinatal bereavement who can support both staff and parents. In a review of the support available for loss in early and late pregnancy, one of the key findings was that there needs to be better recognition of the bereavement midwife role. Trusts are now beginning to value these specialised posts and whilst they do not exist in every Trust, they are becoming more commonplace (NHS Improving Quality, 2014). In the last national audit conducted only 62% of NHS Trusts have a bereavement midwife in post in clinical practice and 13% of these had not had specialist bereavement care training (SANDS, 2016). Of these Trusts 56% had no mandatory bereavement care training. An audit into the provision of bereavement care in neonatal units found 83% had a bereavement lead (SANDS, 2018) audit. However, only 14% of these bereavement leads have dedicated time in their workplan to provide support and 23% have not received any bereavement care training. It was also found that only 12% of units have mandatory bereavement care training. This means that 88% of Trusts in this audit do not have any consistent, mandatory provision of training in bereavement care for their staff. It is recommended that bereavement training is mandatory, but this does not stipulate what this training should include and so there can be a wide variation in the content of any training provision. The result of this will be that the majority of staff are not supported to provide adequate, evidence based bereavement care to the parents whom evidence has shown overwhelmingly need it.

The position of BSMs within each Trust is also something that is still not consistent or equitable. This can be from the banding of the positions i.e. some are band 6, others band 8, which can be related to the importance placed on the role. Equally the scope of practice and responsibilities of the BSM vary immensely between Trusts and this contributes to the inequalities in the training for midwives and care provision nationally as previously discussed. A national framework and recognised qualification or training structure is required to support the standardisation of this role and including the responsibilities of the BSM, and the structure of the service provided. This research will create a proficiency framework which can inform practice and provide this consistency to training that is required to support a more consistent approach to bereavement care, which in turn would result in less variations in the care experienced by bereaved parents.

Not every Trust has a bereavement midwife and equally not all Trusts give equitable time and resources to the role. It is not necessarily the bereavement midwife but can be any midwife on duty who is caring for these families at the time of perinatal loss from diagnosis through to birth births and follow up. Indeed in most cases it will be a midwife other than the bereavement midwife whose role may include advice, follow up but not the clinical care at the time of births. It has been identified that many midwives feel under prepared for caring for families experiencing perinatal loss and this can have a detrimental effect on the care families receive (Hughes and Goodall, 2013). It is essential that student midwives reach the point of registration with a base level of proficiency in perinatal loss care for both them and the families in their care. As soon as they qualify, they may be the midwife who is caring for the family who is experiencing the perinatal loss. Students can shy away from these experiences if they feel underprepared to deal with them; this will have an impact on their preparedness for caring for families with perinatal loss as a qualified midwife. Experience and exposure for students to caring for families experiencing loss is essential for preparation to provide care in these situations once qualified.

1.8.2 Bereavement Care Training

Bereavement care training was not something that was given priority in clinical practice as the demands of updating annually on mandatory training had to take priority (Baxter and Baron, 2011). The SANDS audit (2016) found that only 46% of Trusts had this as part of their mandatory training. As will be discussed in section 1.8.3 there is no stipulation as to what this training includes. It can vary from 30 minutes only to a full day (SANDS, 2016) and in many Trusts there is no mandatory

provision at all. Any healthcare professional who is providing care for bereaved parents experiencing perinatal loss cannot be expected to be able to provide adequate evidence-based care if they have not been given the knowledge and skills through appropriate training to do so. Having the experience in all aspects of midwifery from training, through practice including as a bereavement midwife, to education, it became apparent to the researcher that there was an opportunity to investigate what is required to train midwives to the level of proficiency in bereavement care by the point of registration; this was also recognised as essential by Homer, Malata and Hoope-Bender (2016) and Warland and Glover (2019).

1.8.3 Bereavement care in the curriculum

Currently the student midwife is expected to be competent in perinatal bereavement care on qualification which is unreasonable if the training has not been sufficient as to facilitate this. There is much to cover within the midwifery curriculum (NMC, 2019) in order to provide the student midwife with the knowledge, skills and abilities required to make then a safe practitioner. This means that there are competing demands for time within the course structure and content in order to cover all mandatory elements. As with national initiatives the focus on prevention is a very important and essential component; better to not need bereavement care through reduction in perinatal mortality. However there are still families who do need it and students do need to be equipped with a basic level of proficiency in the knowledge and skills required in order to care for these families. This is not necessarily only covered in the university setting but also within the clinical practice area whilst being supervised by midwives the student is working with. Therefore the need for inclusion of bereavement care within the curriculum and in post registration training must not be overlooked.

The next logical step would be to incorporate that into the midwifery programme so student midwives would receive the training required whilst they have protected classroom and learning time rather than qualifying without the necessary skills and then potentially not receiving any further training. Therefore, the training of midwives is also relevant to the current situation. Though student midwives are taught about loss and bereavement, many finish their training feeling very under prepared to care for parents in this situation (Mitchell, 2005; Alghamdi and Jarrett 2016). Student midwives have often reported being told to stay out of the room in cases where there is perinatal loss, or they actively avoid it. Though this is anecdotal, it does raise the issue that talking about death is something that can, and often is avoided. In this

case how can we expect a midwife to become competent in something that she/he is not necessarily supported to experience within his/her training.

At inception of this research the standards for pre-registration education for midwives (2009) contained one sentence regarding the need for inclusion of bereavement care training in midwifery education:
'providing care for women who have suffered pregnancy loss, stillbirth or neonatal death.' (NMC, 2009 p28).

This is very ambiguous and is open to an immense variety in interpretation and how this is included and incorporated into the curriculum. This sentence also does not recognise need for specialised care or needs of families experiencing perinatal loss in a variety of differing circumstances.

The revised and updated standards do include some more detail regarding bereavement care (see figure 2 below), but the Nursing and Midwifery Council (NMC) have only recently approved these in early October 2019 and officially launched in early 2020. Although it is a positive step to have this increased inclusion of bereavement care in the standards that must be followed by all HEIs delivering midwifery education, there is a still a potential for a large degree of variance when it is decided how this is implemented and taught.

Future Midwife Standards for Pre-registration Midwifery education

6.79 work in partnership with the woman, her partner and family as appropriate, and in collaboration with the interdisciplinary and/or multiagency team, to plan and implement compassionate, respectful, empathetic, dignified midwifery care for women and/or partners and families experiencing perinatal loss or maternal death, and demonstrate the ability to:

6.79.1 provide care and follow up after discharge to women and/or families experiencing miscarriage, stillbirth, or newborn infant death, and understand the care needed by partners and families who experience maternal death.

6.79.2 provide end of life care for a woman or for a newborn infant.

6.79.3 arrange provision of pastoral and spiritual care according to the woman's, father's/partner's, and family's wishes and religious/spiritual beliefs and faith.

6.79.4 support and assist with palliative care for the woman or newborn infant.

6.79.5 offer opportunities for parents and/or family to spend as much private time as they wish with the dying or dead infant or woman.

6.79.6 support the parents of more than one newborn infant when a newborn infant survives while another dies, recognising the psychological challenges of dealing with loss and bereavement and adapting to parenthood at the same time.

6.79.7 provide care for the deceased woman or newborn infant and the bereaved, respecting cultural requirements and protocols.

6.79.8 support the bereaved woman with lactation suppression and/or donating her breastmilk if wished.

6.79.9 provide clear information and support regarding any possible postmortem examinations, registration of death

(NMC, 2019, pp 48-49)

Figure 1.2: Nursing and Midwifery Council proficiencies for perinatal loss

1.9 Existing training provision

There is also variance currently between who is the person teaching the bereavement sessions. The theory practice gap has been reported to be influenced

by the clinical expertise of the lecturer providing the sessions; it can be made worse if the perceived clinical credibility of that person is not seen as valid (Saifan, AbuRuz, Masa'deh, 2015). The researcher is a lecturer who teaches the bereavement sessions for student midwives on the 3yr programme within the HEI she is employed by. It became apparent that not all HEIs have someone with experience specifically in perinatal bereavement care providing the teaching sessions for this topic. The experience the researcher gained whilst undertaking the bereavement midwife role in practice prior to her role in academia gave a greater insight into the holistic care families require before, during and after the hospital stay in addition to the midwifery care required by all women. Having insight into clinical practice, specialist practice and now education it became quite clear that there was a discrepancy between the training that midwives need and the provision of this.

There is presently some provision of education packages in relation to perinatal loss. The Stillbirth and Neonatal Death Society (SANDS) are a charity who formed in the early 1970's when bereaved parents came together. This organisation has evolved and developed into a very influential power for change and good practice in support of families experiencing perinatal loss and the midwives caring for them. They have developed some learning outcomes that they incorporated into a teaching package, which was piloted in 2016 (Bewley, Maher and Titherley, 2016). These were formulated after a teaching session to one cohort of student midwives in their second year and their feedback informed the development of the teaching resource package. The researcher has also used these resources and obtained student feedback, which was mixed. There is a good basis on which to build, but there would be improved validity with a larger number of students involved from different universities and varying stages of their training.

The Royal College of Midwives (RCM) (2018) have an e-learning package called 'One chance to get it right: bereavement care'. This is designed to be a supplementary educational tool but not replace face to face teaching. It covers the importance of parent led care and the impact perinatal loss can also have on professionals using text and videos. The whole package is estimated to take 3.5 hours. This could be used by HEIs to supplement the face to face teaching given throughout the course.

Stephen and MacDuff (2012) conducted a scoping study into the need for education and training for bereavement care for NHS Education for Scotland. Whilst the review is interesting to read and has many relevant points in the need for education and

training to adequately prepare staff, there was only one article relating to perinatal death within the literature review. There was noted to be a lack of clarity or consistency in what education and training was provided which can support the need for the formulation of a proficiency framework that could be used nationally to ensure a standard level of education and training is advocated. This should have a positive impact on the care of bereaved families.

1.10 Current challenges in delivery of perinatal bereavement care

1.10.1 Underprepared staff

Ellis, Chebsey and Storey et al (2016) conducted a systematic review of the research available around parents and healthcare professionals' experiences of care after stillbirth with the view to inform research and training and so improve care. They found that the current provision of care in the context of stillbirth is inconsistent which is problematic. Key issues for parents were that they felt their care was not prioritised by staff and that the actions of staff had a memorable impact on them. This impact can be either positive or negative depending on the actions and care from staff. The staff wanted improved training and a supportive environment and student midwives expressed the view that they felt completely underprepared for dealing with this situation and so avoided it as much as possible.

1.10.2 External factors

This illustrates that it is not necessarily that staff have not the skills or the recognition of the need to provide the necessary care but that the demands on the practice area and time available meant that they were unable to either attend training or give the families the priority they needed. It may also be indicative of a lack of provision of any training either due to provision by the employer or funds to support this. This can be related to staff wanting to work in a supportive environment. Parents can recall both acts of kindness and sensitive care as well as insensitive comments or actions for a lifetime.

1.10.3 Insensitive care

Small insensitivities can have a very profound effect on bereaved parents and stay with them (Gold, 2007). When staff are caring for and interacting with bereaved families any insensitive care, including ignoring partners, can have a lasting negative impact (Siasskos, Jackson, Gleeson et al 2017). Being involved in bereavement care during training and even as a qualified midwife can be infrequent so it is also key to

consider how the proficiency of staff can be maintained using other methods (Baxter and Baron, 2011). This will be considered further when discussing educational theories and application to practice when discussing theoretical considerations in Chapter 2 section 2.1.

1.10.4 Self-care for staff

Moulder (1999) found that students were worried about being able to cope with their own feelings whilst providing care; the word 'revulsion' was used. The word revulsion may seem overly strong, but it may reflect that this is the first time the midwife has dealt with the loss of a baby, or simply that it is unbearable no matter how much experience the midwife has. This has not changed over time as Doherty, Cullen, Casey et al (2018) also found students felt underprepared to provide care. The physical appearance of the baby will vary according to gestation and also dependant on the time interval from death to delivery. Post-mortem changes do occur in utero causing amongst others, maceration of the skin. This can be very distressing to encounter if the midwife has not been prepared or trained for it, and in turn her reaction can cause distress to the family (SANDS, 2016). Therefore it follows that the more prepared the midwife is to provide care in these circumstances the less likely they are to react in a way that may cause or compound the distress to the parents.

1.10.5 Effects on future care

In a study by Lafarge, Mitchell, Breeze et al (2017) the perceptions of the health professionals caring for women undergoing pregnancy termination for fetal abnormality (ToPFA) were compared with women's accounts of the experience. It was found that the women's accounts and health professional perceptions were closely matched which is a positive finding though this does not mean that it was from positive experience and good care. This means that the health professionals were providing appropriate care at the time of the termination though equally it may mean that the care was not adequate and that both health professionals and women felt that the care could or should have been better. However the health professionals lacked insight into the long term effects of the loss and coping processes which indicates there is a gap in knowledge which can affect the after care provided. The care for bereaved parents following any loss is crucial. This will not only affect how they cope at the present time, but also can have positive or negative effects which can last for many years. This will not only affect the family emotionally but also in future pregnancies and mental health in the long term (Hughes and Goodall, 2013; Jackson, Flenady and Siassakos, 2016). This is an aspect of bereavement care for

families experiencing perinatal loss that this research will address through the investigation into the areas of proficiency required for those healthcare professionals caring for them.

1.10.6 Societal factors

It is noted that there are a great many societal factors that can affect the way women experience and cope with ToPFA, and this complexity must be acknowledged in order to ensure women are supported appropriately (Lafarge, Rosman and Ville, 2019). These factors include varying views on ToPFA and the surrounding ethical and moral debates. The acceptance that the baby may/will not survive if abnormalities have been diagnosed may almost have to be revisited, or maybe it is a different acceptance once the baby is actually delivered and is not alive. To care for parents in this situation there needs to be an awareness of this as the parents may have many questions or doubts in the time from diagnosis to delivery. This can include questioning the diagnosis, questioning their decisions which can include feelings of guilt that they are causing the death of their baby themselves. At the point of delivery, the then the reality of seeing their baby there is then direct evidence for them that the baby is not alive. Even when prepared for this, parents may react very differently than they thought they would. Kobler and Limbo (2011) examined the need for palliative neonatal care and acknowledge the presence of both hope and grief at the time of diagnosis. This reflects that doubt in the diagnosis and hope that there may still be a chance the doctors were wrong or that their baby may still survive. This is an extremely difficult situation for all and one which the healthcare professionals caring for these families need to be well prepared for in order to provide appropriate care and also deal with it themselves.

1.10.7 Clinical environment

If the environment is supportive for staff providing care this can have an effect on how care is prioritised: if the leadership on the unit is such that care for parents experiencing perinatal loss is prioritised (staff supported to provide this care one to one for example) then this could have a positive effect on the way the parents felt, they were cared for. O'Connell, Meaney and O'Donoghue (2016) found that the labour and birth experience was central to all stories told through their research into parents' experience of care. This is true for all parents, but more so for the bereaved families as this was one aspect of parenting that they also experienced. The interactions with the care giver were centrally important to their experience: indeed the midwife who delivered the baby is in the unique and privileged position of having

seen, held, known the baby also. It was noted within this review that continuity of carer was an important aspect of care to parents (Ellis, Chebsey and Storey et al 2016).

The experiences of staff and parents are intertwined, and they can have a symbiotic relationship; if not supported it follows this can be a destructive one. The staff have negative effects (guilt) of not being able to provide the care they want, and the parents do not feel they have had the care they need. Parents' distress was reported to be caused by midwives just following guidelines and not appearing to care (Siasskos, Jackson and Gleeson, 2017). As previously discussed, it may not be that the midwives do not care. The ability to provide the care required could be affected by the clinical environment through factors such as inadequate staffing levels, inadequate resources, and a culture within the unit where bereavement care is not prioritised.

1.10.8 Inequality in care provision

Equally the training the midwives have and support from peers can also affect the quality of care provided; midwives may want to give the appropriate care but do not have the knowledge, skills, and abilities to do so, and this can be for a variety of reasons as has been mentioned. A key message that came from the Lancet series on stillbirth was that there is still a plethora of inequality (Lancet Series, 2016) in care provision. This includes health professionals not always knowing not only how to support families, but even how to approach the subject of the loss (Murphy, 2016). This discrepancy and inequality between the care required and the care received by parents has been evidenced over the years (Davis, Stewart and Harmon, 1988; Mitchell, 2005; Gold, 2007; Ravaldi, Levi and Angeli et al, 2018) and is still an issue in clinical practice today. Siassakos, Jackson and Gleeson et al (2017) conducted a multicentre study in the United Kingdom (UK) and found there was still an unacceptable inequality and variation in the care parents received after stillbirth. The importance of the care parents received, and the support midwives and other healthcare professionals have to provide this care cannot be underestimated. This research is aimed at addressing the care inequalities that are evident through addressing the training required by the staff and ways in which this can be equitable nationally.

1.11 Summary: The Problem

It is apparent from the evidence discussed that there is a lack of consistency around the provision of bereavement training in perinatal loss and particularly what this training should include. The provision of training is also inconsistent with regards to the time allocated if it is provided and who delivers the training. These are all factors that can affect the quality of the training and influence the perceived theory practice gap. Indeed there is no discussion on the evaluation of the training in respect of the learning of the participants through an assessment strategy, but the focus is on the perception of the participants as to whether they have learnt anything or not. There is evaluation through participants experience or whether they found it useful or not, but no way to evaluate the effectiveness of the training or the content through the change/improvement of the knowledge of the participants. The researcher aims to address these issues through the research undertaken the results of which are discussed within this thesis.

The time devoted to perinatal bereavement and the focus of the teaching and learning within the curriculum is open to interpretation as previously discussed. The discussion around what constitutes proficiency can be brought into this aspect of the discussion. The theoretical underpinnings of the relevant areas related to perinatal loss, training and proficiency will now be discussed and explored further.

Chapter 2: Literature Review

2.1 Introduction

It has been established that midwives are required for the provision of midwifery and maternity care and so specialist training providers are necessary to ensure training of midwives continues to support the profession. The scope of practice for midwives covers many aspects of care from conception through to the postnatal period (NMC, 2019) and as such student midwives need to achieve proficiency in many areas as stipulated by the NMC so as to complete their training successfully and enter into the workforce as qualified midwives. As has been discussed they will care for families experiencing perinatal loss which is an incredibly challenging aspect of clinical practice even for experienced midwives. The problem identified in chapter one is that there is inconsistency as to the quality of the training provided and how the level of proficiency is achieved. As Siassakos, Jackson and Gleeson et al (2017) found there is still an unacceptable inequality and variation in the care parents received after stillbirth which links directly to the problem as identified; the training and preparation midwives have for this role.

There are many theoretical aspects of education, grief, and proficiency to be considered when addressing this problem. These will now be explored in more detail. These will then be considered when examining the evidence available to date regarding the provision of education relating to perinatal loss in both the theoretical and practice settings. An extensive literature review has been conducted and will form the basis of the discussions and evaluation around what is available at present and where the gap in knowledge lies.

2.2 Theoretical considerations

2.2.1 Overview

It is important to consider the theoretical underpinnings around the concepts involved in this research. This will help to provide context and basis for the approach taken and methods employed (Crotty, 1998). The subject of this research is based around competence, education and perinatal loss which also involves grief. The theories identified by the researcher as most closely related attached to this are educational theories, competence theories and grief theories. These will be discussed in turn.

2.2.2 Educational Theories

Educational theory will inform the majority of this discussion as the aim of the proposed research is the formulation of a proficiency framework and teaching and learning strategies to implement this within pre-registration midwifery training. Variation theory of learning was generated through the development of phenomenography by Marton (1986) and detailed by Samuelsson and Pramling (2016). Lo (2012) discussed this theory and gives a particularly good example to illustrate the central theme: you can only know what you need to know if you also know what you don't need. This comes with experiential learning, trial, and error, learning from others. The example given to illustrate this is that you cannot know what English language is if you do not know another language that is not English. If you know nothing else, it is just language.

This is an excellent illustration of the need always to be dynamic in our teaching and learning as we are constantly faced with new ways to understand the world. In the subject of perinatal loss with regards to teaching and learning the student may not realise there are significant differences in how the baby will look at different gestations or how the time elapsed after death may affect appearance. If they believe a baby will always look like the typical newborn baby image at term, then they will not be aware that they need to learn that there are differences. The lack of awareness of what to expect when they see a baby at an earlier gestation or with maceration can be what triggers the feeling of revulsion as discussed earlier (see section 1.11.5) (Moulder, 1999). The difference in appearance can be a shock if unexpected and the midwife is unprepared for this. This then would illustrate the need to include input from the experts who care for families experiencing perinatal loss and who have an insight into what can be encountered and what families value in the care they receive. They are the practitioners with the expertise that enables them to understand and advise on the key elements that must be included in order for midwives to be prepared to care for families experiencing perinatal loss at any gestation and in any circumstances.

Kolb developed his learning cycle in the 1980's and it centres round the premise that understanding is not fixed but is shaped by experience and is a continuous process. His cycle focuses on learning through integrating ideas and understanding with existing knowledge, testing this and reflecting on the outcome. This continuous reflection on practise leads to increased expertise (Mathieson, 2015). This theory sits comfortably within the beliefs of the researcher that we construct our world through

experience and social interaction and that learning is a continuous process. Equally this also fits with variation theory of learning (Lo, 2012) as not everyone has the same experiences even when in the same circumstances. Previous knowledge will affect how each person perceives and understands each situation. Therefore, to enable the formulation of competencies and then teaching methods a number of participants from varying backgrounds of expertise and experience are required to get a greater breadth of understanding. Dewey also believed that education should not be separate from life and that behaviour modification will occur when someone is able to relate that behaviour to his or her experiences (Bates, 2016). This relates to and emphasises the importance of the learning and experience that occurs in practice placement.

Kolb also developed a learning style inventory in which he proposes there are four types of learners; divergers; assimilators; convergers; accommodators (Bates, 2016). A study conducted by D'Amore, James and Mitchell (2012) examined the learning styles of first year undergraduate nursing and midwifery students. They found that these students were divergers (29.5%), assimilators (28.8%), accommodators (23.9%) and convergers (17.9%). Divergers are seen as being imaginative and sensitive which fits with the idea of the caring profession. This study reported finding most nursing and midwifery students were in the diverger and assimilator groups although there was very little difference between the groups, apart from the convergers who were around 10% lower. This latter group are seen as being emotionally detached which is a quality less associated with nursing and midwifery. The results demonstrate that there were a variety of all types of learners which again supports variation theory of learning in that different groups of people learn in different ways. This in turn indicates the need for a set of competencies and teaching package that delivers content in a variety of ways and facilitates and assesses a variety of knowledge, skills and abilities including practical and theoretical.

Blooms taxonomy relating to cognitive domains is often used as a basis for preparing learning objectives (Bates, 2016). Learning objectives are linked to competencies as the competencies identified need to be fit for purpose to ensure the learning objectives can be met. Blooms taxonomy contains six categories of skills, leading from lower order to more sophisticated cognitive processing; knowledge; comprehension; application; analysis; synthesis; evaluation (Butcher, 2015; Adams, 2015). These are all cognitive domains and are very relevant to teaching and learning but may not be considered as comprehensive when considering health care

training. Psychomotor and affective skills, so the way a student can care and empathise, as well as carry out physical tasks, are also important, especially when being assessed in practice (Adams, 2015). This must be considered when preparing students for any healthcare related profession, including student midwives learning and preparing for caring for bereaved parents.

Vygotsky (1978) developed the concept of the zone of proximal development. He theorised that the student is able to perform to a certain level independently, however the teacher can stretch (scaffold) this learning and so enable the student to reach a higher level of learning. This scaffolding will assist the learner and need not be a one off event but is continuous so supporting the assertion by Kolb that learning is a continuous process. Lave and Wenger continued developing Vygotsky's theory and developed the idea of communities of practice. This refers to communities that emerge when people come together where learning is central (Mathieson, 2015) and it can be seen that these communities are formed when cohorts of student midwives come together to do their midwifery training. There may be shared meanings and stories that develop within these communities such as stories from practice placement experiences. It would follow that it would be essential that student midwives from varying cohorts and allocated practice placements were included in any research into midwifery training. This would give a wider variety of experiences and knowledge from which it is anticipated common themes will emerge. These common themes will have greater validity if they come from more than one source.

Providing care for families experiencing perinatal loss is a situation that causes anxiety within student midwives (Mitchell, 2005; Alghamdi and Jarrett 2016) and one which they feel underprepared for as has been discussed. This has illustrated the gap in training that is present and needs to be addressed. A key aspect of this is understanding that people learn in different ways which must be considered when developing any training programme. Add to this the necessity for the identification of what they need to learn in particular will assist in developing a training programme that is not only appropriate in terms of content but also in terms of delivery of that content. This is the focus of the research in order to develop just such a programme that will facilitate the learning, knowledge and understanding required to provide appropriate and effective bereavement care for families experiencing perinatal loss.

2.2.3 Competence Theories

Competence is key to providing safe care. Kings College London National Nursing Research Unit (2009) published an article questioning what competence is in nursing and how we assess it. It concluded that there is no nationally accepted definition of competence at that time and how it is assessed is subjective in nature. As yet there is no definition for proficiency to be found in any NMC standards for the training and education of pre-registration nurses and midwives, yet it is a term that has been used throughout these documents. This is a problem that exists historically and continues to this day. The NMC (2019) document now titled 'Standards of proficiency for midwives' has changed to use the term proficiency rather than competence, something that is echoed in the updated nursing standards documents. Proficiency is defined as having a high degree of knowledge and expertise that implies competence (Cambridge Dictionary, 2021). Therefore though there is a very recent change in terminology the outcome of competence in the skills detailed remains salient. Not all HEIs have yet had updated curricula approved on these standards so still use the term competence within their curricula but this will change. By the end of 2022 all curricula will be updated, and the term proficiency will replace that of proficiency, so the decision has been taken to use proficiency in this thesis to be in line with terminology used nationally. Please note that any time the term competency is used this is also referring to proficiency.

A systematic review of the varying conceptions of competence/proficiency was conducted by Fernandez, Dory and Ste-Marie et al (2012) as they also note that a straightforward definition is not present in the literature. They reviewed a sample of fourteen definitions of competence; there is agreement that competence consists of knowledge, skills and other components but there is not consistency in what the 'other components' are. The consensus is that competence is seen as a combination of components which can be related to midwifery training. This can translate to the clinical practice area where each setting (i.e. antenatal) has a cluster of competencies within it, and all have to be achieved to achieve the overall pass for the cluster. These may be achieved in a variety of settings where antenatal care is delivered such as antenatal clinic, community, and the antenatal ward. The perinatal loss proficiencies that are the focus of this research also fit with this concept of competence, as there will be many singular competencies that will form competence in perinatal loss bereavement care as a whole.

The methods for assessing proficiency also need to be addressed. Norman, Watson, Murrells et al (2002) discuss the findings from a study in Scotland designed to test the methods used for assessing proficiency in nursing and midwifery students. The overarching finding was that there is no single method that is reliable for assessing competence, as different methods address different abilities. This can be linked to the differing learning styles previously discussed. The proficiency framework required to enable midwives to be competent in the provision of perinatal bereavement care will be discussed in relation to the best way to facilitate learning around these. It is anticipated that the options around being covered in theory or practice will be part of the discussion as well as methods of teaching interactive and experiential or more text based. These can be related to the methods of assessing competence in that a practical skill is observed, or written assessments are marked using a re-determined marking grid. As the midwifery training is 50% theory and 50% clinical practice placement (NMC, 2019), it follows that a variety of methods to assess competence would be employed to fit the nature of the proficiency being assessed (Bergsmann, Schultes and Winter et al, 2015).

2.2.4 Grief Theories

Grief is a key aspect of perinatal loss; this thesis will consider the evidence base in this area to inform perinatal loss teaching and competencies. Freud (1961) viewed grief as a solitary process whereby the mourner detaches themselves from the world to work through the grief, the psychological purpose of this being for the mourner to release themselves from the bond with the dead person. Where this may differ in stillbirth, for example, is that there are only one or two mourners who physically 'knew' the deceased. The future grandparents, whilst being affected by the loss may see their own child (the bereaved parent) as their prime concern, as they have never actually met the unborn child or have a shared history. Buglass (2010) sees the bereaved person as mourning the life shared with the person who died; the parents, particularly the mother has physically felt the kicks and physical symptoms of having the baby grow inside her. This will nurture the sense that she has shared the months of pregnancy with the baby, including all the thoughts and feelings that she has had and so a shared life. This can also include her partner who will have experienced hands on feeling the baby kick and may also have had dialogue through hearing the mother's reports of how she feels and what is happening internally, as well as the partners voice being heard. However, they cannot share stories of the baby's life with others and their stories as you would if it were a grandparent who has died. Many family members and friends will have met and known this person and have shared

stories and memories with which to remember them and share the happiness from these and the grief from the loss.

This can make the grief and bereavement even more isolating and disenfranchised so require a differing understanding and in turn training for the care giver. Doka (2008) defines disenfranchised grief as experiencing a significant loss such as the loss of a baby and the resultant grief is not openly acknowledged or publicly mourned. This may be particularly relevant in perinatal bereavement due to TopFA as this is at a gestation before 24 weeks in the majority of cases, and the parents may not have discussed the pregnancy so much with friends or relatives when it is earlier gestation and known there are potential problems which may mean that they will have to make very difficult decisions about whether to continue with the pregnancy or not (Antenatal Results and Choices (ARC), 2021). Attig (2004) discusses that perinatal loss can be included within the scope of disenfranchised grief when there has been a failure (by society or close contacts) to appreciate and that this is a significant loss.

Robinson, Baker and Nackerud (1999) explored the nature of prenatal attachment on perinatal loss. This wholeheartedly supports the concept that attachment begins at the point of conception and continues throughout pregnancy and all milestones to giving birth, seeing and touching the baby and providing care. The mother who delivers a stillborn baby, for example, will still go through these stages of attachment if she chooses to see and hold the baby and may give care such as a bath or dressing the baby. However, for this mother providing care does not continue in this way, and they must then say goodbye to their baby. As previously discussed, this is a loss of the future that may have been.

Theories of grief can be useful to assist the understanding of the health professional caring for the bereaved, but each has a unique experience and care must be individual and personalised as much as possible (Buglass, 2010). Kubler-Ross completely changed how physicians treated dying patients when she authored her book ‘On Death and Dying’ in 1969 (Kubler-Ross, 1969). This cycle consists of the mourner working their way through five stages that are: denial, anger, bargaining depression and acceptance. This supports the use of grief cycles but equally recognizes that they are not linear, and some stages may precede others, or be returned to.

In 1999 Stroebe and Schut proposed a then new model of coping with bereavement called the dual process model (Stroebe and Schut, 1999). This model proposed that there are two aspects involved in the grief process which involve loss-oriented coping and also restoration-orientated where the bereaved person is bouncing between the two; at times confronting the loss and other times attending to the way life has changed for them. This is a very dynamic model and illustrates well the individual and non-linear route that grief can take (Buglass, 2010).

2.2.5 Theoretical Considerations Summary

It is the experience of the researcher that when parents have found out through a scan that their baby has abnormalities, then they have more scans and discussions, these parents are more likely to want to discuss postmortem and funeral before the baby is delivered. If the parents have just been told their baby has no heartbeat, they are less likely to want to see the bereavement midwife, or discuss these issues, until after the baby has been born. This illustrates that it will be different not just for different parents but equally differing circumstances as to what the parents need and are ready for (Fahey-McCarthy, 2003).

The main message from these theories appears to be that people 'work' their way through grief in a very individual way that does not follow any set path but is very dynamic in nature. They require a midwife they feel safe with and trust to care for them. The midwife is required to be competent in caring for these parents which in turn links to the midwife having the appropriate training and education to fulfil this proficiency. This is the focus of this research.

2.3 Literature Review Method

The method of literature review for this research is that traditionally used in a graduate thesis and the results will inform the research question. A literature search is undertaken to enable the researcher to synthesise the extant literature and usually identifies the gaps in knowledge that the study addresses (Pare and Kitsiou, 2017).

2.3.1 Literature Review Question

The question to be asked of the literature needs to include consideration of the research question and the scope of the literature review. The terms used need to correlate to the information being sought and so result in the relevant literature being identified so as to assess clearly and comprehensively what is knowledge is present

and evidence where, if any, gap in knowledge exists. This informs the search strategy which will be discussed in section 2.2.2.

2.3.2 Search Strategy

The inclusion of greater detail in the Future Midwife standards is an indication that the need for appropriate bereavement care for families experiencing perinatal loss is being recognised (NMC, 2019). A literature search was undertaken to establish what is currently known regarding the training required and teaching methods used to facilitate learning. The search strategy including databases and search term are included in Appendix 6. Over one thousand studies were identified for review, of which twelve were identified for inclusion. The inclusion and exclusion criteria for this review are detailed below.

2.3.3 Search Terms and PICO framework

Please see table 2.1 below and appendix 6 for the search strategy used to perform the literature search.

PICO Elements	**Keywords**	**Search Terms**	**Search Strategies**
P (**P**opulation)	Midwives or nurses providing perinatal bereavement care	Midwife/Nurse	Midwife OR midwives OR midwifery OR student midwife OR Nurse OR nurses OR nursing OR student nurse
I (**I**ntervention)	Training and/or education in bereavement care	Training, education, bereavement	Knowledge OR knowledgeable OR Training OR trained OR Education

			Bereavement OR bereaved Stillbirth OR stillbirths OR stillborn OR still birth OR Neonatal death OR Perinatal
C (**C**omparison)	Provision of training, education		As above
O (**O**utcome)	Lack of training, education, competency in bereavement care for perinatal loss		Competency OR competencies OR competent (* for all terms) OR Knowledge OR knowledgeable OR Training OR trained OR Education

Table 2.1: PICO table

2.3.4 Inclusion criteria:

- Educational approaches to the teaching and learning strategies for student nurses or midwives in relation to perinatal loss. This covers the period from confirmation of pregnancy to 28 days of age of the neonate and includes termination of pregnancy for fetal abnormality.
- The scope of knowledge required by student midwives/nurses or qualified midwives/nurses to provide appropriate care for families experiencing perinatal loss.

- Any investigation, qualitative or quantitative, of the competencies required and teaching and learning methods employed in relation to perinatal death.
- All articles written in English.
- Timescale included are the years from 1970 to 2021. It was decided to include any articles available from 1970 to gain an historical perspective if that was to be found. This was when the concept of perinatal loss began to emerge in the scientific literature (Fenstermacher and Hupcey, 2013).

Also included was literature where the outcome reported was regarding either:

- The efficacy of the teaching method employed.
- The knowledge and skills required by nurses/midwives to be competent in care after perinatal loss.
- Any proficiency framework developed for this area.

2.3.5 Exclusion Criteria

- Studies that focus on how delivering care to bereaved parents affects midwives and nurses.
- Studies that focus on specifically establishing the need for further training to support the midwives and nurses providing bereavement care through care provision. These often had a focus on care provision not education provision: whilst not the focus of the research it was concluded that care was not adequate as clinicians were not adequately prepared or trained.

A number of databases were searched using EBSCO. Maternity and Infant Care database, CINAHL and also NHS Evidence was also searched using the same search strategy. The databases and search strategy are detailed in Appendix 6. The outline of the search strategy using PICO framework in table 1 was repeated on the 4th June 2020 and the 10th of December 2021 to ensure all current literature was included in the results.

This process produced a total of 1040 articles for review. A review of the reference list for the Stillbirth and Neonatal Death Society (SANDS) Guidelines for Professionals (2016) was undertaken, relevant references were obtained, reviewed, and included when appropriate. A review of the reference list of appropriate journal articles was also undertaken and additional appropriate studies sourced. These

searches were considered comprehensive and provided the relevant material for the literature review. All papers were reviewed using the inclusion and exclusion criteria: please see the results below in figure 2.2: PRISMA diagram.

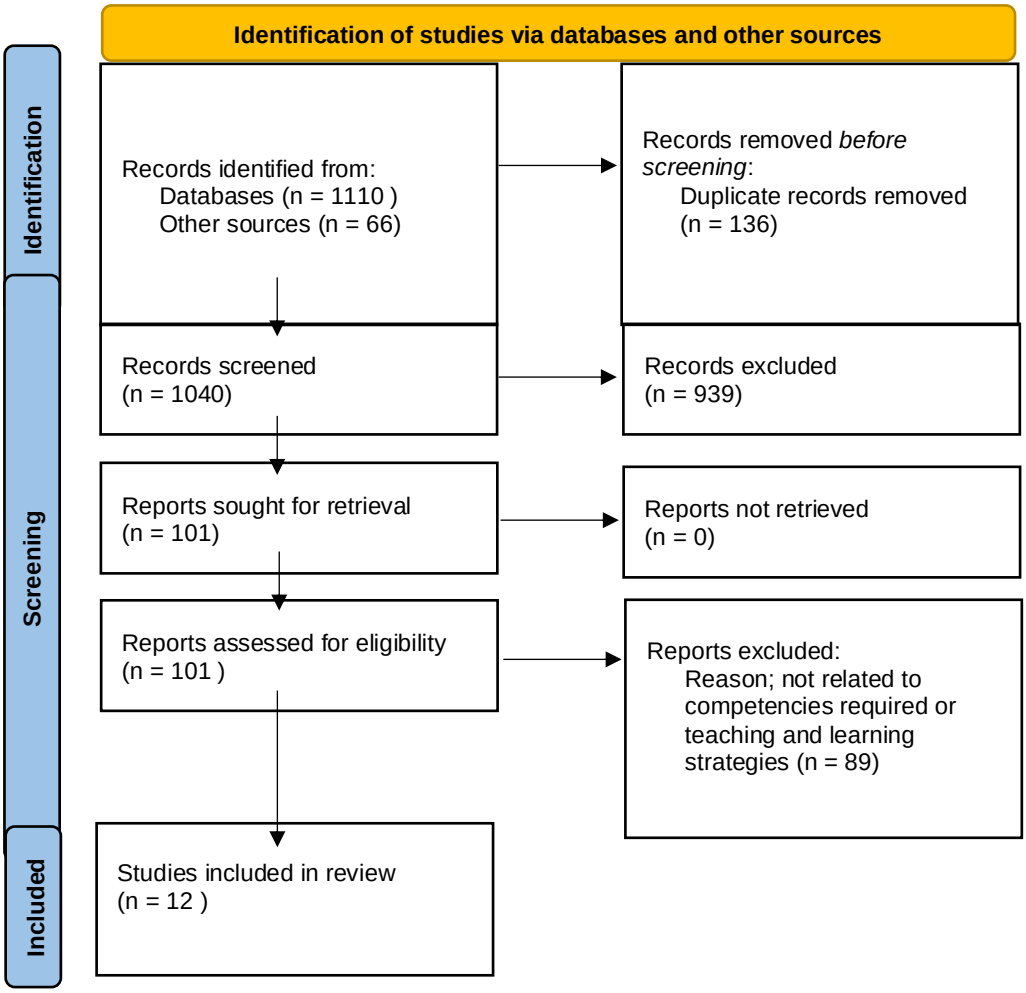

Figure 2.1: PRISMA Diagram

2.4 Challenges in the literature

At present there is a limited body of evidence available with regards to competencies required for training in perinatal loss care. There were only twelve studies identified using the inclusion/exclusion criteria as detailed in section 2.2 and then screened by the researcher. The twelve studies identified for inclusion are detailed in the Critical Appraisal Skills Programme (CASP) table as detailed below in table 2. The CASP table is recommended by the World Health Organisation and Cochrane which is a global independent network of researchers, professionals, patients, carers, and people interested in health and health research. It is useful in aiding understanding of qualitative research (Long, French and Brooks, 2020) by providing an accessible summary of the literature and research available in a concise manner which allows for summary information to be available instantly and appraised.

Reference	Country	Title	Sample	Methods	Focus of research	Findings
Forster, E.M and Donovan, H. (2016)	Australia	Enhancing Bereavement Support Skills Using Simulated Neonatal Resuscitation	10 student midwives (convenience sampling)	Observation of video of simulation and audio tape of debrief	Can simulation aid student learning in supporting bereaved parents.	4 themes: 1) feeling unprepared; 2) communication changes; 3) the value of simulation; 4) student reactions.
Doherty, J., Cullen,S., Casey,B., Lloyd, B., Sheehy, L., Barry,T., McMahon, A and Coughlan,B (2018)	UK	Bereavement care education and training in clinical practice: Supporting the development of confidence in student midwives	41 final year student midwives (convenience sampling)	Longitudinal sequential mixed methods: Questionnaire pre/post and 3 months after workshop.	The effect of a 1 day workshop on confidence in student midwives providing bereavement care to parents following perinatal loss.	Participation in the workshop increased confidence in providing bereavement care and self-awareness.
Ratislavova, K., Buzgova, R and Vejvodova, J (2019)	Czech Republic	Perinatal palliative care education: an integrative review.	14 studies included.	Integrative review (systemic literature review)	Analyse the effectiveness of teaching healthcare professionals' perinatal palliative care.	Perinatal palliative education is essential in pregradual (pre-reg) education for midwives and neonatal nurses.
Cartwright, P. and Read, S (2005)	UK	Working with practitioners to develop training in peri-natal loss and bereavement: Evaluating three workshops.	16 Health Visitors and 5 midwives.	Pre and post workshop questionnaires and focus groups.	Evaluation project: evaluating three half day workshops.	Identified need for education and the importance of multi-disciplinary training.
Colwell, P. (2017)	UK	Building confidence in neonatal bereavement: The use of simulation as an innovative		4 discussion sections and 2 simulated scenarios: evaluated through questionnaire	The use of simulation as a harm free, educational approach to bereavement training.	The simulation session enhanced practice.

		educational approach.		(Likert scale) and open questions.		
Gardiner, P.A., Kent, A.L., Rodriguez, V., Wojcieszek, A.M., Ellwood, D. et al (2016)	Australia	Evaluation of an international educational programme for health care professionals on best practice in the management of a perinatal death: Improving Perinatal mortality Review and Outcomes Via Education (IMPROVE).	758 participants in Australia: 55% were midwives, the remaining were doctors nurses and other health professionals..	16 item questionnaire pre and post each workshop: used Likert scale and open ended questions.	Determine the effectiveness of the IMPROVE programme for health professionals which is delivered as six interactive skills based stations.	The IMPROVE programme is effective at increasing confidence and knowledge of participants in managing perinatal death.
Hollins Martin, C.J., Forrest, E., Wylie, L. and Martin, C.R. (2014)	UK	An evaluative survey to assess the effectiveness of using an interactive workbook to deliver bereavement education to undergraduate student midwives.	179 student midwives in 2nd and 3rd year of training.	Understanding Bereavement Evaluation Tool (UBET): a scored questionnaire completed pre and post completion of workbook.	Develop an interactive workbook for teaching student midwives bereavement care in clinical practice.	The workbook is an effective method of teaching bereavement care to student midwives.
Hollins Martin, C.J., Robb, Y. and Forrest, E. (2016)	UK	An exploratory qualitative analysis of student midwives views of teaching methods that could build their confidence to deliver perinatal bereavement care.	179 student midwives in 2nd and 3rd year of training.	Survey: free text comments. From the UBET questionnaire: thematic analysis.	To explore the views of student midwives on the teaching strategies that could build confidence to deliver bereavement care.	Three themes: 1) increased classroom interaction 2) Importance of reflection 3) Need for experience

Warland, J. and Glover, P (2019)	Australia	Tertiary education regarding still birth for student midwives: The tears 4 SMS project.	10 out of 19 program leaders from Australian Universities the deliver UG midwifery education	Online survey with free text	Investigate the current content of stillbirth education in undergraduate midwifery curricula in Australia.	There is room to improve and standardise appropriate stillbirth curriculum nationally.
Doherty, J., Coughlan, B., Casey, B., Lloyd, B., Sheehy, L. et al (2018)	UK	Student midwives education needs and their experience of attending a bereavement education workshop.	12 student midwives	Focus groups after delivery of the workshop.	Aim to improve student midwives confidence in delivering bereavement care to parents after pregnancy loss and perinatal death.	All students could benefit from a workshop to increase confidence in bereavement care.
Power, A. and Rea, T. (2016)	UK	Clinicians in the classroom.	n/a	Student feedback.	Discussion around bringing the realities of clinical practice into the classroom.	Gives students an invaluable insight into the role of the bereavement midwife and parents experiences.
Barry, M., Quinn, C., Bradshaw, C. Noonan, M. and Atkinson, S. (2017)	UK	Exploring perinatal death with midwifery students using a collaborative art project.	Purposive sample of 6 post registration midwifery students.	Face to face semi-structured interviews.	Explore the influence of Amulet artwork on midwifery students perceptions of caring for parents experiencing perinatal death.	Four core themes: 1) entering the mother's world and hearing her pain 2) the journey of grief and bereaved parents unique experience. 3) Facing challenge of providing effective bereavement care. 4) Maintaining compassionate practice.

Table 2.2: CASP table

Eleven of the twelve articles selected included either teaching strategies and/or tools for bereavement training for healthcare professionals. One article was around the effect of having the Bereavement Midwife as the person delivering the session (Power and Rea, 2016). Seven articles used questionnaires which elicited both quantitative and qualitative data in the form of free text supplementary answers. The other methods used include focus groups, interviews, and thematic analysis as you can see in the CASP table (Appendix 8). It is clear from research that a variety of teaching and learning strategies have been employed when delivering bereavement training to health professionals caring for families experiencing perinatal loss but less emphasis on the person who leads these sessions. The usefulness and applicability of these approaches and the methods used were examined and linked to the methods employed for this research.

Two distinct themes emerged from the literature, which are approaches to the delivery of bereavement education, and the effectiveness of bereavement education. These are both applicable to the research proposed as the delivery and content of the bereavement education and how effective this may be including the method of delivery. The delivery of education must have a framework to follow which informs the content. This is lacking within the literature at present and is one aspect this research will address. Another aspect is what is the best way to facilitate learning for this content which relates to the effectiveness of any approach and is addressed by this research.

2.5 Emerging concepts

2.5.1 Delivery of education

2.5.1.1 Workbooks

Workbooks have commonly been used in healthcare education and have both advantages and disadvantages. However, there is extremely limited evidence around their efficacy so assessing this is limited and does rely potentially on experiential assessment and anecdotal evidence (Christensen and Lynch, 2020). They can be in various formats, commonly paper and now progressing to an electronic format. The efficacy of the workbook is potentially determined by the format and interactive nature of the content. Equally the student may complete this workbook, but if it is not checked in some way, either by the lecturer marking it, or by fact checking this in class, then the student may have completed this with incorrect information and then keep this as a resource. This is not effective in either assessing learning or

promoting further development. Harper, Worthington, and Griffin et al (2014) used the workbook as a tool in a mental health context with undergraduates. This was self-directed use and was found to be as effective as group therapy though these findings are limited by the small sample size.

Hollins Martin et al (2014) conducted a study to evaluate the effectiveness of an interactive online workbook. A questionnaire was conducted before and after the workbook was used and results supported that a workbook was an effective tool in improving the students understanding of bereavement care. There was a statistically significant improvement in the self-reported perceived level of learning from the participants.

Hollins Martin, Robb, and Forrest (2016) then carried out an exploratory qualitative analysis of student midwives and their views on which teaching methods could build their confidence in delivering bereavement care. Thematic analysis was used on responses to previous research on the use of a workbook (Hollins Martin et al, 2014) as previously discussed. The qualitative responses were analysed using thematic analysis. The themes that emerged were increased classroom interaction including reflection and experience. The use of case studies which progress and unfold alongside delivery of the midwifery course are becoming more common place and can be delivered within a workbook format. This is aimed at developing critical thinking and analysis as the clinical picture unfolds (Carr, 2015). This would be a more interactive way to use a workbook and apply the content to practice situations.

An effective workbook would need to consider all learning styles or the practical and physical aspects of giving care which would be included in a more comprehensive teaching package as is proposed in this research. A workbook may be part of that, but it is the experience of the researcher that there would need to be a variety of teaching tools required.

2.5.1.2 Simulation

Forster and Donovan (2016) used clinical simulation around neonatal resuscitation with final year student nurses to explore the impact of this in relation to perinatal bereavement. This is one situation in which the death of a baby can occur but can be a highly charged and acute one which can be unexpected. Amod and Brysiewicz (2019) explored the use of simulators in midwifery emergencies as this is an approach where students can practise skills required in rare emergencies or experiences that they may not experience in practice. Perinatal bereavement care is required from

antenatal to intrapartum to the postnatal period and so it is unlikely the student can gain experience of all aspects and scenarios whilst in practice. Therefore the use of simulation is potentially invaluable. This is an aspect of perinatal loss that this research addresses. Within a proficiency framework, the skills required are one aspect, but the most effective way to facilitate learning is an equally important aspect to consider.

Colwell (2016) also used simulation as an approach to neonatal bereavement teaching for paediatric nurses and midwives. She had found that evidence shows a scarcity of experience, knowledge and education in this area leads to a lack of confidence in delivering care for midwives and nurses. This study took the form of having four discussion groups and then two simulated scenarios. The overall finding was that the simulation did enhance practice and that it is an approach that should be developed in this area. The simulated scenarios can be linked to the use of case studies as discussed as used within workshops. Harley, Darley, and Carroll et al (2020) evaluated the use of virtual reality technology for story telling which the students found very powerful and engaging. This may be another technological advancement that can be incorporated to the simulation approach to teaching and learning that would enhance the active learning experience for students. This supports this research into teaching and learning for students experiencing perinatal loss as this may provide opportunity for a safe environment to learn skills without direct patient contact which brings with it the potential to cause harm. It is a new approach which can be examined within the scope of this research.

Much of the literature around the use of simulation in nursing and midwifery supports its use as facilitating learning in a safe environment (Catling, Hogan and Fox et al, 2016; Harley, Darley and Carroll et al, 2020; Amod and Brysiewicz, 2019) and can also include peer support within the discussions around the simulation. Shepherd and Burton (2019) highlighted that there is a lack of a conceptual framework for simulation in healthcare education and that this is something that needs to be addressed. Briese, Evanson and Hanson (2020) propose the application of Mezirow's transformative learning theory to the use if simulation. This would involve the pre-briefing before any simulated scenario and the de-briefing that can take place afterwards. This is invaluable in accentuating the learning that can take place through reflection and also promotes the importance of the discourse with peers that can occur during this debrief. The use of simulation in many aspects of perinatal loss could be invaluable, from simulation of delivery at differing gestations to the breaking of bad news all within a

safe environment for the student where they can learn without fear of doing harm. This aspect is examined by this research and explored further.

2.5.1.3 Workshops

Workshops are useful and can be implemented in many different ways. Much of the simulation discussed, or the use of scenarios can be conducted in a workshop setting so there is much cross over between these elements of approach to education. Interprofessional learning is an essential part of any midwifery course (NMC, 2019) and often takes place as a workshop involving other healthcare professionals. There is evidence that this can be used effectively and again promotes the usefulness of role play and scenarios in a very interactive learning environment (Villadsen, Allain, Bell et al, 2012; De La Torre, 2016). Communication is a vital skill for midwives and links to a core element in the NMC Code (2018) which is the standards by which nurses and midwives must practice. Cooper, Nayia, Thoirs et al (2020) developed a clinical communication workshop which enhanced and developed an increased awareness regarding aspects of communication. In perinatal loss communication forms a central aspect of care, particularly around difficult conversations from breaking bad news to discussing options for burial. A workshop that incorporates these aspects would give opportunity for students to learn how to communicate effectively in these circumstances. Again, there is elements of role play, simulation, and interaction within this, that this research will address when examining the competencies required in perinatal loss care. Price, Mendizabal-Espinosa and Podsiadly et al (2019) found that using interprofessional education involving student midwives and children's nursing students improved knowledge and confidence around perinatal and neonatal palliative care and proposes that there is potential value in extending this to include students outside of healthcare also.

Cartwright and Read (2005) evaluated the impact of the delivery of three bereavement workshops to assess gaps in knowledge and further develop the workshops to be delivered. The participants were Health Visitors which serves to emphasise the multi-disciplinary reach of perinatal loss. The evaluation of the workshops was positive in that it helped to increase confidence by talking openly in a constructive and supportive environment. This further emphasises the positive effect of an interactive learning environment which can inform the creation of tools to support learning. This is a narrow focus on one aspect of care in this study which is valuable but part of a larger spectrum. The research proposed for this thesis would

be aiming to establish a more comprehensive proficiency framework to address all aspects of care.

Gardiner, Kent, and Rodriguez et al (2016) evaluated an international programme of education that was delivered to health professionals across Australia and modified for use in Vietnam, Fiji and the Netherlands. The target audience was those involved in the multidisciplinary team involved in perinatal loss. The mode of delivery was workshops using skills based stations with a focus on stillbirth. This was a significantly larger study than others within this review in that 891 participants attended the programme, and the workshop was very interactive in the form of the skills based stations, but the focus was on the effectiveness of the workshop as a whole. This is the common method used within these studies evaluating workshops. The learning stations were 1) communicating about postmortem, 2) postmortem and placental examination, 3) investigation of perinatal deaths, 4) examination of babies who die in perinatal period, 5) classification of perinatal deaths and 6) psychological and social aspects of perinatal bereavement. As is evidenced by these there was an emphasis on postmortem and investigating the cause rather than the hands on care required by the parents or the emotional support. This is a differing perspective to those discussed previously and serves to demonstrate the scope of bereavement care; it is not just the emotional side but also the clinical aspects of care that require proficiency as an integral part of a holistic approach. The holistic approach is examined in more detail through this research by including aspects of care from the pregnancy continuum; antenatal to intrapartum to postnatal.

2.5.1.4 Blended approach

The learning theories discussed in chapter two section 2.1.2 illustrate that there are different types of learners so a blended variety of approaches of delivery would be most appropriate. Nunohara, Imafuku and Saiki et al (2020) used video case based learning to assist learning of clinical based decision making by midwifery students which was found to encourage students to have a more holistic approach to care. This fits with the updated pre-registration standards (NMC, 2019) which support a more holistic approach to the curriculum and to care. Video based case studies can be embedded within electronic workbooks and promote the interactive nature of the workbook and the learning process.

This is an area that requires further exploration which this research will address. A workbook with focus on perinatal loss with differing mediums of delivery (video, text,

group work) would provide the interactive aspect but still allow for the student to demonstrate their own work. It also gives opportunity to have families tell their story through video so as to be able to reach a large number of students but not have to retell and relive the loss multiple times. It is acknowledged this would be with consent from the parents with time bound review of the use of this content. Students can watch this in their own time and a safe place as it can be upsetting for them to watch, and they may feel more comfortable doing this in private. This research also examines how this workbook would be best implemented to have the greatest efficacy within the three year course.

This is useful and could inform teaching practices but still does not address what it is that the students need to know, the competencies. This is a key aspect that this research will address in order to support and inform any teaching and learning package. It is key to note that the experience of caring for families experiencing perinatal loss is not always available in practice for students, or they shy away from this if they feel under confident (Ellis, Chebsey and Storey et al, 2016). Therefore, it may be that enabling the experience to be gained in a safe setting such as the classroom may be one way to enable the students to gain some experience.

2.5.2 Inclusion of the student in care (practice)

Doherty, Coughlan, and Casey et al (2018) conducted an exploration of the effectiveness of the delivery of a bereavement workshop using focus groups. The participants were twelve student midwives in their final year of training. The findings were supportive of the interactive role-play element were the most beneficial part of the day. This links with the findings from the studies discussed where simulation was used. This is also a very interactive method of teaching and further supports interactive methods as being most useful in perinatal bereavement education. Interactive methods can be useful to support learning where experience in clinical practice may be limited.

The use of simulation within healthcare education has risen dramatically and become commonplace over the last twenty to thirty years not just in the UK but internationally (Motola, Devine and Chung et al, 2013). This has partly been as a consequence of potential for clinical placements to fall short of providing the experience required to equip students with the fundamental clinical skills required (Hilton and Barrett, 2009). There is increasing evidence within the literature regarding simulation in midwifery but

there is very little evidence regarding simulation in teaching around perinatal bereavement. For example, neonatal resuscitation is taught as part of the course requirements (NMC, 2019) this is in the context of successful resuscitation.

It is noted by Siassakos, Jackson, Gleeson et al (2017) that stillbirth is an emergency to the parents but not always to staff. This is an example of an aspect of care that is not necessarily salient to the student yet is key to the parents. This is something that can be included in learning in either simulation or practice placement in order for the student to have an awareness of issues such as this. It is necessary for the student to be included in care and not excluded. Baxter and Baron (2016) noted that students who wanted to have experience in clinical practice but were actively dissuaded from this by the midwives they were working with. This hampers the learning and development of knowledge and skills to equip the student to be able to care effectively for families experiencing perinatal loss up to and after qualification. The student needs to be included in care provision.

2.5.3 Focus on the emotional/psychological aspects of care

2.5.3.1 Creative approaches

Creative approaches to education in midwifery and healthcare are emerging and more evidence is now available to support this which will now be discussed and evaluated. These creative approaches have a focus on the emotional and psychological aspects of care. Midwifery has long been recognised as both an art and a science, not one or the other (Jackson and Sullivan, 1999). Therefore, creative approaches to teaching and learning within the scope of midwifery can have a valuable contribution to make to student midwives' curriculum. Uppal, Davies, Knowles et al (2014) used creative images to enhance the holistic approach to midwifery care and propose these should be included within the curriculum. Spirituality and the meaning of birth lends itself well to be explored through the creative arts (Mitchell and Hall, 2007). There are often so many competing demands for the time the student has within the course that these approaches have traditionally been given less credibility or importance (Noble and Pearce, 2014). Incorporation of creative approaches in relation to learning opportunities around dignity and respect were used by Hall and Mitchell (2017) with positive outcomes. There are certain aspects of midwifery care that lend themselves well to a more creative approach. Dignity and respect are core aspects of care that all parents should have, and particularly sensitive in the care of parents and their baby within the realm of perinatal loss. All possible approaches to the development of

midwives who are competent in bereavement care in perinatal loss will be explored within this research.

Barry, Quinn, and Bradshaw et al (2017) used an art project to explore perinatal death and bereavement with a group of six post registration student midwives (had qualified as a nurse before going onto midwifery training). The purpose was to explore the influence of the Amulet artwork on the students' perceptions of caring for parents who experience perinatal death. The Amulet artwork is a collaborative exhibition by an artist who worked with women to explore the hidden world of perinatal loss. It was evaluated positively and emphasises the need to think laterally around the teaching methods employed and not be restrained by the traditional classroom methods that are usually employed.

2.5.4 Absence of reference to practical/clinical care: bias of focus on emotional not physical care (safe care)

As has been discussed in 2.5.3 there is a focus on emotional care following perinatal loss. There is an absence of any evidence regarding the recommended teaching and learning with regards to the physical aspects of care which are as important. For example, someone who has a baby who has died in utero is still at risk of bleeding excessively post- birth (postpartum haemorrhage) and this clinical aspect of care should not be overlooked. In the SANDS teaching package (Bewley, Maher and Titherley, 2016) the clinical aspects covered as risk factors which may increase the risk of a woman experiencing perinatal loss. These risk factors are also elements of care that need to be addressed within the programme for student midwives. An example would be a woman with pre-eclampsia; this is a risk factor for IUD, but equally is also a risk to maternal health. This risk does not disappear at births and there is still risk of eclamptic fit up to three days post- birth (Bothamley and Boyle, 2020). The woman may be on medication that needs to be reviewed, or if severely ill may have close monitoring of blood pressure and fluid balance. This is not to be forgotten and superseded by the emotional and psychological care required. A holistic approach is ideal, and this must include the physical clinical aspects of care. The clinical aspects and overall holistic physical care required by all women is not covered. This is a gap in knowledge and one that does need to be addressed.

A contributing factor in the bias towards the emotional and psychological care may be that this is supported by the relevant support organisations and the limited time

given to teaching regarding perinatal loss. Warland and Glover (2019) conducted a survey across all Australian Universities that deliver undergraduate midwifery education. The midwifery program leaders were invited to take part in the online survey. The results were that whilst a diverse material was included in the teaching and different approaches to teaching employed, the time allocated to this was relatively small. This is an aspect that will be examined within the scope of this research to ascertain if this is the case in the UK. The time allocated to bereavement training is not stipulated so has the potential to vary immensely between the HEIs delivering the curriculum. This method is similar to that chosen for phase one of this current research.

Many papers and research focus on the aftercare following a loss which is the time after birth and communication between the midwife/healthcare professional and the parents (O'Connell, Meaney, O'Donoghue, 2016; Ellis, Chebsey, Storey et al, 2016; Ravaldi, Levi, Angeli et al, 2018; Lafarge, Mitchell, Breeze et al, 2017). Whilst this is key this does expose the lack of any focus on the physical, clinical care the woman requires and the relevance of this.

2.5.5 Theory/practice gap

Power and Rea (2016) looked at the effect of the person who delivers the bereavement session, in particular the bereavement specialist midwife. The effect of having someone who is specialist in the subject coming into the classroom and facilitating the teaching session was the focus. This was not a structured research paper but more an informal exploration. The students were asked for feedback after the session, which was overwhelmingly positive. This relates to objective one of the proposed research, looking at who it is who delivers the bereavement sessions in each HEI. When teachers just stand and teach from a PowerPoint presentation (PPT) or talk and do not promote student engagement this is not an effective way of supporting student learning, whereas being passionate about your subject and delivering the session with enthusiasm and knowledge can motivate the students to learn (Ketteridge et al, 2015). There were no other articles identified on this subject which may be an area which requires further investigation and will be examined within this research. It has been previously discussed that the validity and clinical currency of the person providing the theory does have an effect on how applicable this is to practice and using real life examples (case studies) can support the theoretical elements being covered (Saifan, AbuRuz and Masa'deh, 2015). In turn this does address the theory practice gap.

The relevance of experience to learning was discussed in relation to educational theories in section 2.1.2. In order to narrow the perceived theory practice gap, the inclusion of students in the care of families experiencing perinatal loss is key. This is supported by the perspective that it is also key to establish alternative methods of delivery of training when this is limited for students which is where simulation is a method that can be employed. The care parents require and receive is key to their wellbeing and recovery and the theory aspect of practice should not be separate to the real life experience for the student and the families. It must not be forgotten that these students go onto become the qualified midwives caring for these families. If they are not given the opportunity to develop the knowledge, skills and abilities required whilst in training then how can they be expected to provide the quality and standard of care required.

2.6 Integrative literature review

Within the evidence reviewed Ratislavova, Buzgova and Vejvodova (2019) undertook an integrative review of the literature around the methods and effectiveness of teaching healthcare professionals in perinatal palliative care. A systematic search was carried out which then identified fourteen studies that met the inclusion criteria. The findings correlate to those discussed so far in this chapter. All studies considered bereavement education to be effective. Questionnaires or interviews were used for evaluation and innovative teaching strategies that encouraged interaction such as simulation were found to be particularly positively evaluated. This would also support the inclusion of these methods within the curricula to support the student where opportunities in clinical practice may be limited.

2.7 Summary: Implications for the research

A consistent finding throughout this discussion is that there is a lack of bereavement education around perinatal loss, and that students felt very under prepared for providing care to parents when they lose a baby at any gestation. There is also a unanimous consensus that the care provided has an impact on the parents and how they cope afterwards, hence the need for more training. All methods of teaching and delivery had a positive effect on the outcome of improving confidence and knowledge and a great emphasis was put on the value of interactive learning environments and approaches. Equally recommendations were also that more research and improvements are needed in the area of perinatal bereavement education (Homer, Malata and Hoope-Bender, 2016; Warland and Glover, 2019). This does support the

need for some more standardised and national approach to bereavement training in perinatal loss as this is not the case at present.

Whether using simulation, workshops, or workbooks to deliver the content, the emphasis on these being interactive and engaging to be effective was salient throughout the literature. In many cases these approaches overlapped as simulation was delivered in a workshop. There is an argument here for methods to be used that complement the content and each other so as to maximise the learning opportunity. This will also be inclusive so as to incorporate delivery that is accessible to different types of learners. This has been discussed alongside educational theories in section 2.2.2.

The absence of any inclusion of physical, clinical care is an area that must be addressed as has been discussed in section 2.5.4. A holistic approach to care is supported by NMC (2019) standards and guidelines and promotes safe care. Therefore, this demonstrates a gap in knowledge which this research will address.

The main aim of this research is to enable and facilitate teaching and learning in bereavement issues by identifying the key concepts and areas which much be included. This includes practical issues surrounding delivery as well as a holistic approach when parents experience perinatal loss to work towards a good standard of care for all. This is such an important and emotive subject it is essential that it be handled with care and given the importance it deserves. There are core principles for bereavement care as advocated by SANDS (2016), but no structure of competencies designed to support the teaching and learning required to enable student midwives and midwives to obtain proficiency in these. Also, many of the practical issues, which have been reported to and experienced by the researcher, are not currently addressed within these core principles.

It is important that there is there a clear proficiency framework to identify the knowledge and skills required to provide appropriate and sensitive care for families experiencing perinatal loss. This is central to being able to create a teaching and learning package as these competencies will form the heart of this. Around that a package of teaching and learning approaches must be used which suit the subject matter involved and facilitate the learning required. The experience and perspectives of both teachers and learners to ensure that a teaching package is as valid and comprehensive as possible. There is no such structured proficiency framework established or created specifically

for training healthcare professionals to care for bereaved parents and their families experiencing perinatal loss as has been evidenced by this literature review.

This research will create a Perinatal Loss Proficiency Framework (PLPF). Using this framework there will be an exploration of the most appropriate approaches to incorporate these within the curriculum or and module delivery. This will pull together not only the valuable resources that are already available but also enable the creation of new and innovative materials, for example, using virtual reality, to support delivery.

2.8 Ontological considerations

The ontology, epistemology, and theoretical perspective (philosophical stance) of the researcher will undoubtedly also influence these (Crotty, 1998). Silverman (2013) also notes that for qualitative research theoretical models shape the methods used, and there are no right or wrong methods, just methods that are appropriate to your research topic. This translates as ensuring that the methods employed are those that will result in the data required to answer the question being asked. If the research question asks details of experience the qualitative methods would suit this question rather than quantitative methods that would produce hard data or numbers. The interest and focus is on the way people construct their world. It follows from this that the researcher has a pragmatic approach to research which will be discussed further in chapter 3.

2.9 Research Question

The research question for this study is:

'What knowledge, skills and abilities constitute competence in caring for bereaved parents experiencing perinatal loss and how can these competencies be developed in student midwives undertaking the 3yr BSc (Hons) Midwifery programme.'

As stated, the question is further supported by the following aims and objectives below, and together they will inform the direction of further decisions regarding the details of the design and methodologies used.

2.8.1 Aims.

- To develop a proficiency framework that incorporates the identified knowledge, skills, and abilities to be included in the 3yr BSc (Hons) Midwifery programme.

- Develop teaching and learning strategies for implementing these proficiencies so that all student midwives are trained to a level of proficiency in caring for bereaved parents by the point of registration.

2.8.2 Objectives.

- Assess what is already provided for perinatal bereavement training in the UK in HEIs to inform phase two.

- Engage experts in perinatal loss in order to collate the content required to inform training for student midwives in the 3 year BSc (Hons) Midwifery programme.

- Identify teaching strategies required to facilitate learning required for 3yr BSc (Hons) midwifery students to achieve these proficiencies by the point of registration.

Chapter 3: Methods

3.1 Introduction

The literature identified in chapter two illustrates the variety of methods used in research into training and education issues around perinatal loss; these have been a mixture of both qualitative and quantitative methods. Ontological consideration and the beliefs of the researcher have also been introduced in section 2.6. The need to understand what proficiency is required as stated in the research question is interlinked with the 'why' each proficiency is valid and necessary. For example, rationale for the inclusion of simulation in teaching and learning around perinatal loss links to the evidence that students find experiential learning essential and that it helps to bridge the theory practice gap (see section 2.4.5). A mixed methods approach was employed in this research using survey, Delphi technique and nominal group technique; the rationale for this will be discussed in order to provide the 'why'; the rationale for the methods used. Each phase will be discussed in turn and the ethical considerations will be discussed in detail.

3.2 Methodological approach

3.2.1 Background

The methodologies employed for any research are intertwined and influenced by the ontology of the researcher and their view of how we construct knowledge and understand the world (Creswell, 2015). It is essential for the reader to be informed of the ontology and epistemology to understand the research proposed and methodologies and methods employed. These issues and the methodologies used to facilitate this understanding and put the research in context will now be discussed in more detail.

Perinatal loss has always been a challenging topic to address. It is something that many families will experience but is not necessarily easy to talk about or that comes up in everyday conversation. Equally, as has been shown by the issue around students being prevented from participating in care, it is an issue that can also be avoided in practice. Talking about bereavement in any instance is something that can be difficult; in perinatal loss it can be even more so. The methods used need to enable these conversations to occur and develop. The Delphi technique in particular allows for these conversations to occur between professionals whilst breaking down the barriers caused by familiarity, power imbalance (due to level of seniority or links in professional capacity) and encourages equal participation. There are

approximately 177 maternity units in the UK (Kings Fund, 2010). According to the SANDS audit (2016) 62% of units has at least one bereavement specialist midwife which is approximately 151 spread over the UK. As mentioned in chapter one, section 1.2 there are approximately 39,070 midwives on the NMC register in the UK. This equates to just 0.27% of the midwives in the UK. They are the experts in caring for families experiencing perinatal loss and as such are key participants in this research. As it is their area of expertise, they will be experienced in discussing this challenging topic in its entirety and so will be sharing their experience and values; a key aspect of understanding their ontology.

The voice of service users is of key importance in any healthcare research and is vital in perinatal loss. This is a sensitive subject and can be very challenging to discuss in any circumstance. As the aim of the research is to establish an educational tool the experts from practice who have knowledge of the structure of midwifery education and also the guidelines and pressures that guide midwifery practice are essential as participants in this research. They have an overview of many aspects of perinatal loss and differing priorities within this. The service user will have their own experience but not the global insight into midwifery education and practice so whilst their voice must be included it should also be done in a sensitive and appropriate way. The support and inclusion of the Stillbirth and Neonatal Death Society (SANDS) facilitated this in that they were the voice of the service user as the research developed and then facilitated review of the findings by a parent panel whose feedback could then be considered and influence the final outcomes of the research.

3.2.2 Research Paradigm

It has always been the underlying belief of the researcher that we live in a socially constructed world where our own history, experiences and beliefs shape the way we interpret the world and what happens. This goes some way to explain the relevance and importance placed on the world view and experience of the participants. The participants include not only the bereavement specialist midwives but also the students who are actively engaged in the midwifery course and so have their own experiential learning in university and practice and understand the concepts involved.

The research paradigm that guides the researcher in this instance and informs the philosophical position they take has undergone quite substantial revision during the progression of ideas as this research project evolves. It has consistently been the

underlying belief of the researcher that we live in a socially constructed world, where our own history, experiences and beliefs shape the way we interpret the world and what happens. This has not changed as an overarching belief and theoretical perspective. However, the methods available to purely qualitative research are not able to cover the enquiry required.

The researcher has a pragmatic approach to research; Creswell (2014) associates a pragmatic worldview (paradigm) with mixed methods approach which as a methodology is around 25 years old (Creswell, 2015). Hence it would naturally lean towards a mixed methods approach to intertwine these differing layers of knowledge. This would correspond to the researcher's beliefs that neither quantitative nor qualitative approaches can give a full understanding and explanation of the research question being asked.

Guba and Lincoln (1994) do note that paradigms can be seen themselves as human constructions; the limits we place on quantitative and qualitative research are constructions in themselves. The choice of research questions and methods can reflect the researcher's epistemological understanding of the world and so is linked (Feilzer, 2010). The conclusion was reached that a pragmatic approach to this research was most appropriate, and this will now be discussed in more detail

Pragmatism would deceptively appear to be relatively new and is not mentioned in Crotty (1998), nor Guba and Lincoln (1994) in their discussion of research paradigms. Pragmatism has actually been around for a great deal longer being first heard of and conceptualised by James in the 1870's (Bacon, 2012). Creswell (2014) associates a pragmatic worldview (paradigm) with mixed methods approach, which, as a methodology, is around 25 years old (Creswell, 2015). Dewey, another founding father of pragmatism proposes that pragmatists view the world as having differing parts, some objective, subjective, or a mixture so breaking free from the constraints of only following one or the other approach (Feilzer, 2010). Morgan (2007) discusses the concept of experience as advocated by Dewey, in that our beliefs are interpreted to generate our actions, and these actions are then interpreted to generate our beliefs.

Safazadeh, Irajpour, Alimohammed et al (2018) explored reasons behind the theory practice gap within emergency nursing education. One of the barriers was not only the clinical validity of the lecturer but also the clinical expertise and environment in

the practice placement. Wang, Zhao, Hu et al (2017) support the concept that one of the most important factors in effective teaching is the efficacy of the lecturers as they are in essence the bridge between theory and practice. This supports the need to include practitioners who are experts in the care of families experiencing perinatal loss, but they also require expertise in teaching and learning in order to facilitate this for the students. The crossover of the specialist into the classroom (see section 2.4.5) is also relevant to this conversation and needs to be considered when advocating who is best to provide the theory aspects of the course.

The experiential learning that the participants have had will also then have an impact on the way that they experience grief, understand concepts and theory and then translate this through the teaching and learning they provide for the students, whether this be in the classroom or in practice. It is key that any method used not only draws out what competencies are important to include but also why. Understanding the why will help understand the participants rationale and also give them an opportunity to articulate where their understanding and rationale has come from. Quantitative methods may draw out the data required as to what each proficiency would be, and qualitative methods would then give opportunity to incorporate the participants worldview and experience in the rationale for their answers. This would give the opportunity to identify any shared experience around any of the competencies and further support inclusion of these within the resultant framework.

3.2.3 Exploration of alternative paradigms

As there are no existing proficiency frameworks identified the researcher considered grounded theory to possibly be an appropriate methodology for this study. Grounded theory develops ideas and theory as it emerges from the data (Crotty, 1998; Noble and Mitchell, 2016). However, whilst a proficiency framework has not been developed as yet, there is evidence around what proficiencies midwives need to know including some learning outcomes for some teaching materials which have been created. Therefore, the Perinatal Loss Proficiency Framework resulting from this research would be an original contribution to the knowledge base available, but it would not be generating this from the absence of previous knowledge or evidence as a result grounded theory would not be an appropriate methodology to adopt.

On further investigation grounded theory was linked with pragmatism tenuously as, with pragmatism, understanding gained is based on the results of the inquiry. The

researcher is seeking answers or explanations rather than testing them (Star, 2007). In her book on grounded theory Charmaz (2014) links pragmatism, grounded theory, and symbolic interactionism. Symbolic interactionism is seen to be more concerned with subjective meaning rather than objective structure (Carter and Fuller, 2016) and the methods employed would not necessarily generate the information required to answer the research question.

3.2.4 Mixed Methods

The knowledge required to care for bereaved parents needs to incorporate a variety of variables as not every baby is stillborn or dies in the same circumstances. It is imperative that the knowledge and experience of experts is accessed to inform the construction of competencies. It would be difficult to ask participants, who are geographically separated, to convene face to face or even online and take part in this kind of research as is required to create a valid proficiency framework. These experts will have their own views on what should be included in a proficiency framework and the knowledge that is being sought is to be evidenced through the identified common themes that emerge. The method for this aspect of the research and more discussion regarding its validity can be found in section 3.3.3.

In the context of this research, we can ask what competencies are required, but also why these are important and where they fit within the scope of bereavement care delivery. The question being asked would naturally lean towards a mixed methods approach to intertwine these differing layers of knowledge. This would correspond to the researcher's beliefs and as discussed in section 3.2.2 that neither quantitative nor qualitative approaches can give a full understanding and explanation of the research question being asked and so a pragmatic approach is that which best fits the purpose of the inquiry. Cohen, Manion and Morrison (2011) discuss pragmatism as using the methods that work to best approach the investigation, what is needed to answer the questions. They do warn that it should not be an 'anything goes' approach but have standards that ensure they must produce useful answers to the research questions. Creswell (2014) describes the pragmatic worldview as adopting the mixed methods approach, which gives a more complete understanding of a research problem. This fits with the researcher's view of the world and assists with the understanding of the participants worldview in that there is no one true reality and though statistics may give some understanding of the findings, it may take deeper investigation generating richer data to provide a fuller explanation and understanding of what these statistics represent. This can enrich the knowledge and understanding

generated by the findings and further improves the validity (Morgan, 2007). The caution of not using an 'anything goes' approach has also been taken into consideration when deciding on the methods to employ for each phase.

3.3 Mixed Methods; Multi-phase design

The design for this research is mixed methods multi-phase where each phase then informs the next (Creswell, 2014). The methods that will be used in each phase will now be discussed in detail in order to explain the rationale for each method and explicitly demonstrate the validity in relation to the information required by each phase.

3.3.1 Overview

Phase one is concerned with setting the scene in that it is an overview of the provisions and resources for perinatal bereavement teaching that are in place at present. Phase two of the research is to create a comprehensive Perinatal Loss Proficiency Framework, essentially what needs to be covered in any perinatal loss training. Phase three is focussing on the methods that would be most appropriate and effective to facilitate the teaching and learning of these proficiencies, so relates to the effectiveness of any approach.

The three phases are illustrated by Figure 3.1 below to show how the research approach is structured and explicitly links to the research objectives.

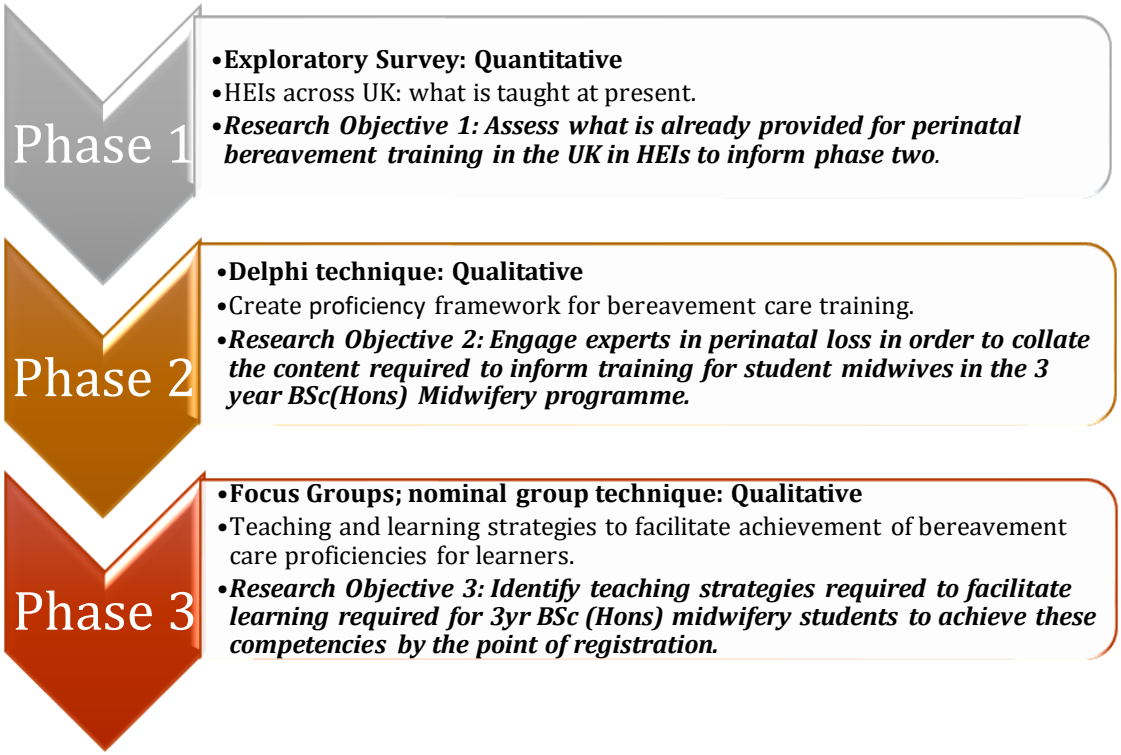

Figure 3.1: Research phases 1-3.

3.3.2 Phase One: Survey

In phase one the objective was to find out what is already provided in relation to perinatal loss teaching but at a high level. This included the number of hours dedicated to the subject and who provided the training. The term HEI will be used as is the recognised term for universities, though the Nursing and midwifery Council (NMC) use Approved Education Institution (AEI) to refer to those who have been approved by the NMC to deliver nursing and midwifery courses. As the HEIs are spread across the UK it had to be a method that allowed for remote participation and did not require extensive instruction or was time consuming. Therefore, the use of online survey platform to distribute and retrieve the data was a method that was easy to use for participants and allowed the remote access at a convenient time.

3.3.3 Phase Two: Delphi Technique

In phase two the objective was to produce a Perinatal Loss Proficiency Framework. The Delphi technique was determined to be the most appropriate method to use; the rationale for this will be explored further below. The use of the Delphi technique is not new in the realm of healthcare research (Cornick, 2006; Keeney, Hasson and McKenna, 2001) so is a method that has evidence of validity for use within this subject area.

Cornick (2006) used a Delphi technique to produce guidelines for neonatal nurses, so has been used in healthcare also. Keeney, Hasson, and McKenna (2001) undertook a critical review of using the Delphi technique in nursing research. They concluded that the Delphi technique is a good and valid way of gaining consensus from a number of experts through a series of round of questionnaires. The benefits are that many experts who would not normally be able to be in the same place at the same time can be brought together and consulted until consensus is obtained. Also the participation is anonymous so there should be no effect from knowing who the other participants are such as hierarchical or knowledge of expertise. This may be an issue if all participants are experts in their field as others may know some participants by reputation or possibly another connection. This may have an effect on the responses given so this effect is mitigated.

The experts for the purposes of this research are bereavement specialist midwives and lecturers from HEIs who teach bereavement care in university. As discussed in section 3.2.1 there are approximately 151 bereavement specialist midwives which equates to 0.27% of the midwifery workforce. It must be acknowledged that these figures are approximate and calculated with the available information. These experts are spread over the UK in varying NHS Trusts and HEIs so using the Delphi technique method allows a unique opportunity for these experts to be jointly consulted and work together to contribute to the creation of the proficiency framework. It also lends validity to the resulting competencies as they will have been generated by those in the direct contact with bereaved parents over the continuum of perinatal bereavement. These experts are also those who are aware of the academic requirements and experience of issues that come up within teaching sessions with both qualified staff and students across healthcare professions Rea and Power (2016).

One further advantage of the Delphi is that it allows for anonymity of the participants. As they are anonymous and not contributing in a face to face forum it allows for all voices to be equal regardless of status within the bereavement midwife community or vocal assertiveness. Perinatal loss is a challenging topic to discuss and everyone including experts have their own views on what is important and why; we have to be mindful that this could also come from personal experience of perinatal loss which can make any discussions even more challenging.

The loss of a baby through perinatal death at any point is a prospective loss and as has been established the bereavement care required by a family who have lost a baby in this way must have its own set of competencies. There is the physical act of giving birth and the challenges this may pose that may not be present when the baby is alive. These are not issues in any other circumstance but are something that the student midwife must be competent to provide care for (Siasskos, Jackson, Gleeson et al, 2017).

For the purposes of this research, by using the Delphi technique then a large number of experts in the field of perinatal bereavement will be contributing to the formulation of competencies required which should ensure that all relevant knowledge, skills and abilities are identified and included. The actual wording of these proficiencies will also be discussed at this time until consensus is reached. A pilot study was undertaken prior to implementation of the Delphi round one to test the validity of the questions being asked.

3.3.4 Phase Three: Nominal Group Technique

Phase three of the study requires consideration of the teaching and learning strategies required to facilitate learning in the student midwives to enable then to achieve proficiency in bereavement care by the point of completion of their course and registration with the NMC. As has been mentioned many times perinatal loss is a challenging subject and therefore the method employed for phase three needs to be one which facilitates an open discussion without participants feeling under pressure to stand up and contribute in a way that may mean they are challenged in a public way for their contributions. Students are novices rather than experts when it comes to perinatal loss. However, when it comes to their learning throughout the 3 year midwifery course they may be seen as the experts in that area.

The teaching and learning strategies required to enable the student midwives to achieve competence in the bereavement care competencies identified in phase two need to acknowledge the differing ways in which students learn, and what the optimum strategies for teaching would be for these particular competencies. Therefore, alternative methods were explored that would still elicit the information required but in a more time efficient way. Nominal group technique (NGT) is a consensus method similar to the Delphi technique. However, NGT requires face to face discussion in small groups whereas Delphi is more remote as has been discussed. The small groups are noted to be ideally 2-8 participants per group (McMillan, King and Tully, 2016). This is

similar to the ideal size for focus groups. There would potentially be a wealth of information and guidance that can be generated by engaging with students and guide the researcher in the generation of teaching and learning strategies and materials. Therefore, the data generated by the NGT focus groups will have a dual purpose of inclusion within this research and also form the basis for future research.

NGT was first detailed in the 1960's (Delbecq and Van de Ven, 19710. It was used in social psychological research as a way to enable group decision making. The issues around the question are discussed then prioritised through group discussion and deliberation. As the participants not only involved in the generation and collection of the data, but the group discussion also then facilitates the analysis. This should mean that any researcher bias is minimised. Potter, Gordon, and Hamer (2004) used NGT in physiotherapy research. They noted that the questions that form the focus of the session should be clear and stimulate discussion, and that the session should be facilitated by an expert on the topic for discussion. This will be discussed further in but can be noted now that the researcher is an expert on the topic in question which fits with this.

3.3.5 Quality Measures

Tobin and Begley (2004) propose that for research to be assessed as dependable there needs to be a clearly identifiable process that is clearly documented. Therefore it is essential that the process for each phase is clearly documented within this thesis. The method and process will be discussed in detail within the data collection detailed in section 3.4.1, 3.4.2 and 3.4.3 in order to address this. This will include discussion around the participants and the representativeness of the sample in each phase. Guba and Lincoln (1985) do discuss the credibility of a study and can be determined by the researcher checking the findings and interpretations with the participants. As consensus methods have been employed for both phase two and phase three this then addresses this issue. The findings are validated within the process using consensus from the participants.

Researcher reflexivity is also seen as central to assessing the quality and trustworthiness of the research and assists with the audit trail (Nowel, Norris, White et al, 2017). Researcher reflexivity has been included throughout this thesis and chapter seven focusses on this aspect.

3.4 Data collection

The participants, recruitment, methods of data collection and analysis will now be discussed in detail for each phase in turn. This will be followed by a discussion around the ethical considerations that were considered and addressed by the researcher after which ethical approval was applied for and obtained prior to commencement of data collection. The design for this research is mixed methods multi-phase where each phase then informs the next (Creswell, 2014). The phases are illustrated below; each phase will be discussed in more detail.

3.4.1 Phase One: Assessing current provision

The initial exploratory survey has the purpose of collating data of existing bereavement training being provided at present. This survey will aid the researcher in determining the questions required for phase two (Creswell and Plano, 2011).

3.4.1.1 Phase One Sample

In phase one an explorative survey was sent to all Higher education Institutions (HEI) in the UK to assess what number of teaching hours are assigned to bereavement care in the 3yr BSc (Hons) Midwifery programme and what form this takes. This will provide quantitative data without any actual content of the sessions. The purpose is to provide a baseline picture of the number of hours dedicated to this subject and who delivers these sessions. This will give an overview of how much time is dedicated to teaching bereavement care and to obtain an indication of the expertise of the person delivering the sessions. If someone has a special interest or experience in this area this may impact on the content and quality of the teaching and learning, as is the experience of the researcher and feedback received from students.

3.4.1.2 Phase One Participants

The survey questionnaire is in the form of a survey monkey link sent by email to all HEIs in the UK (England, Wales, Scotland and Northern Ireland). This was sent to the Lead Midwife for Education (LME) within each HEI and ask for participation or information from the lecturer who leads on bereavement teaching within the team. It is a statutory requirement by the NMC that there is an LME within each HEI delivering midwifery education (NMC, 2016). The details of each LME (name and email contact) are available on the NMC website and so the researcher is able to contact each identified LME. This enables all HEIs within the UK that deliver midwifery education to be contacted to take part in the survey so giving a

comprehensive picture of the provision of bereavement care training within all midwifery programmes. An introductory email detailing the study and asking for completion of the survey was sent to each LME. One week after the introductory email, a further email with the link to the online survey was sent. This was done in quick succession in order to keep the information salient to the LME. It may have been better to have a longer window between sending the first information email and then the survey to allow for workload, time to check email and forward on. Not everyone works full time so may not have been working the days the emails were delivered. It is hoped that the introductory email will set the scene so as to encourage participation and allow time for the relevant lecturer to be made aware if necessary. (E-mail detailed in Appendix 1). The survey consists of 6 questions (Chapter 4 section 4.2.2) and the estimated time for completion is less than 3 minutes.

It is well recognised that email surveys are popular for academic research but can elicit poor response rates to even as low as 2.5% in some marketing (Ding, Poquet and Williams, 2018). It is hoped that the simplicity and minimal demand on time will be factors that mitigate for this and enable as many participants as possible to complete the survey. Equally, the nature of the subject matter, perinatal loss, and its relevance professionally to the participants from both a midwifery and educational standpoint it is hoped will mean there is a motivation to complete the survey.

3.4.2 Phase Two: Consulting the experts to create Perinatal Loss Care Proficiency Framework (PLPF)

Phase two consists of a Delphi technique to enable the participation of the relevant professionals. This is essential in the creation of competencies in bereavement care as these experts are aware of the overall requirements for proficiency but also the day to day practical ramifications and effects of good or not so good care. Cornick (2006) used a Delphi technique to produce guidelines for neonatal nurses, so has been used in healthcare also as well as in education (Gordon, Baker, Catchpole et al, 2015). Soriano-Vidal, Vila-Candel, Navarro-Illana et al (2016) used the Delphi technique method to identify research priorities in midwifery. Therefore, the Delphi technique has been used in research in similar fields to the one covered in this study. Keeney, Hasson and McKenna (2001) undertook a critical review of using the Delphi technique in nursing research. They concluded that the Delphi technique survey is a way of gaining consensus from a number of experts through a series of round of questionnaires.

3.4.2.1 Phase Two Delphi technique

After each round of the Delphi the information is then collated, and these experts can reconsider their answer in light of the information provided by the other experts. This can continue but the more rounds, the higher the dropout rate of the experts so it is best to keep it to two to three rounds at the most (Landeta, 2006). The benefits are that many experts who would not normally be able to be in the same place at the same time can be brought together and consulted until consensus is obtained. Also, the participation is anonymous so there should be no effect from knowing who the other participants are. This may be an issue if all are experts in their field as others may know some participants by reputation or possibly another connection. This may have an effect on the responses given so this effect is mitigated (Hasson and Keeney, 2011). Please see detail of Delphi technique below in figure 3.2.

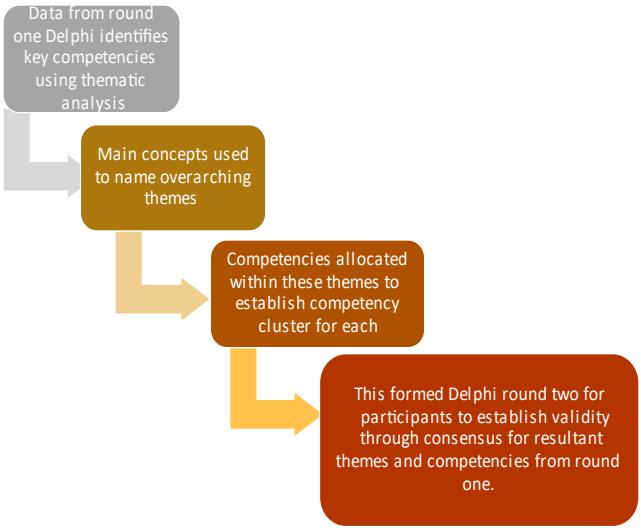

Figure 3.2: Delphi process

3.4.2.2 Phase Two Sample

The sample population approached are bereavement specialist midwives across the UK and the bereavement lecturers from all HEIs as identified from the exploratory survey with at least one year experience in a bereavement specific role. Using purposive sampling is necessary in this instance as the participants are required to have expertise in the subject matter. It was noted by Keeny, Hasson and Mckenna (2001) that the 'experts' that are more likely to remain engaged are those who are more likely to be affected by the outcome. In the experience of the researcher, bereavement specialist midwives are dedicated to the improvement of bereavement care for all parents which is related to the preparedness of midwives to provide this

care. These experts are spread over the UK in varying NHS Trusts and HEIs so using the Delphi technique method allows a unique opportunity for these experts to be jointly consulted and work together to contribute to the creation of the proficiency framework.

3.4.2.3 Phase Two Participants

If a Trust has a bereavement midwife there will generally only be one (SANDS, 2016), and they may be the person who teaches the bereavement sessions within the HEI if there is no lecturer with specialist knowledge. Therefore, these experts who are spread out across the UK and it would be extremely difficult, if not impossible, to get this group together. This is in relation to time demands and also where the geographical location of the meeting would be. As these experts are spread across England, Scotland, Wales, and Northern Ireland there is no one location that would suit all, and most would then incur travel costs also. Using the Delphi technique method mitigates for these factors and allows collaboration of expertise and knowledge that may not be possible otherwise. With the use of mediums such as MS Teams increasing throughout the covid pandemic this may be one way for all to meet face to face. However, this is not ideal for open discussions due to potential delay when speaking or connection problems and also may hinder equal contributions from all. By using email to send the Delphi technique each participant has time to consider their reply. Possibly more importantly it allows for each participant to have an equal voice; when in open face to face discussions there are often some who are more vocal or will speak up more readily as compared to others.

3.4.2.4 Phase Two Recruitment

The researcher has links within the professional world of bereavement care and issued a request for interested parties through the SANDS website, Royal College of Midwives (RCM) website and when presenting at the RCM/SANDS joint conference in September 2017. An email (Appendix 3) with information regarding the study was then sent to identified potential participants including an invitation to participate and more information regarding the study and what participation would include as detailed in a participant information sheet and consent form (see Appendix 4). A reply was then requested at this point to agree participation and complete the consent form.

An email with the link to the Delphi technique was then sent with a specified return date. A period of four weeks was given to allow for time to completion of the first round taking work pressures into consideration. Also, the first round consisted of open ended questions which it was considered, require time for thought and contemplation with longer answers.

The literature suggests that a classic Delphi technique requires four rounds (Hasson and Keeny, 2011) and each round will require an analysis of the responses. Round one will generally allow for freedom in responses of which the researcher then must collate. It will be essential that the researcher word the questions in the first round carefully so as to ensure the correct question is asked and understood. Piloting these questions before implementation would highlight any need for change of wording. The second round would then consist of the analysis of round one, themes emerging and identified, then round three could involve some statistical analysis so as to indicate where consensus has been reached (Thangaratinam and Redman, 2005). The cut off for identifying consensus will need to be identified by the researcher prior to commencing and has been reported to be anything between 51%-80% (Keeny, Hasson and McKenna, 2001). The first round Delphi technique questions are detailed in Appendix 4. The end result of this survey should be consensus on the core competencies required for a student to be assessed as competent in bereavement care of parents' experience stillbirth or neonatal death.

A pilot round one questionnaire was sent to two bereavement specialist midwives who had agreed to take part in the study; it was explained that this was a pilot round, and the questions may change slightly depending on the results from this. There was a total of 28 participants recruited for phase two; Connelly (2008) suggests that the pilot study sample should be 10% of the larger participant group. This equates to three participants which is a small number but reflective of the group. Only two participants were able to return the pilot in the time available. They were midwives with extensive experience in bereavement care and the responses were similar, so a judgement was made that given the timeline this was sufficient to validate the questions and continue with phase two. The pilot responses elicited the information required by the researcher, so no change was then necessary prior to the implementation of round one.

3.4.2.5 Phase Two Data Analysis

The data from the Delphi technique comes from open ended questions and requires thematic analysis. As data from round two is qualitative in nature it requires analysis which complements this. Braun and Clarke (2014) discuss the use of thematic analysis including a discussion around its suitability particularly for applied research such as that involved in health research. In this way the analysis is carried out in a robust way but then presented in a way that is accessible to those who are not in the world of academia.

Braun and Clarke (2006) propose a six phase model for thematic analysis of data which is essentially identifying, analysing, and reporting patterns. This should not be viewed as a linear model, where one cannot proceed to the next phase without completing the prior phase, the researcher can move between the phases as is applicable when analysing the data.

with the data: the researcher must become intimately conversant with the data reading and re-reading as is required..
Coding: The researcher must code each data item.
Searching for themes: A theme is a coherent and meaningful pattern in the data relevant to the research question.
Reviewing themes: This involves looking at the themes and assessing whther they work within the data generated as a test of validity.
Defining and naming themes: This is necessary for the researcher to then structure the write up of the data and also tell the story of how the themes fit together.
Report writing: continuous and iterative.

3.4.3 Phase Three: The student perspective

Phase three will involve the use of nominal group technique (NGT). Nominal group technique (NGT) is a consensus method similar to the Delphi technique. However, NGT requires face to face discussion in small groups whereas Delphi is more remote as has been discussed. The small groups are noted to be ideally 2-8 participants per group (McMillan, King and Tully, 2016). The process by which the NGT is facilitated will be discussed within data analysis.

3.4.3.1 Phase Three Sample

The student midwives will participate in focus groups as detailed. The invited participant numbers were six participants per group. There were two focus groups,

one in Berkshire and one in London. This is reflective of the HEI at which they are studying which has two bases, one in each area. These bases have a number of practice placements as partner where the students attend for their practice hours and experience. This allows the researcher to involve students from up to five Trusts in London and three Trusts in Berkshire. As practice can vary from Trust to Trust, even in whether there is a bereavement midwife or bereavement suite (SANDS, 2016) this allows for a range of experiential learning the students have been exposed to as well as the theory sessions they have had in university. The students are essentially the experts required for as participants in this instance as they are the ones who are directly involved in receiving the teaching and how this facilitates their learning (McMillan, King and Tully, 2016).

3.4.3.2 Phase Three Participants

The students invited to participate are from the second and third year of their training. This was a decision taken by the researcher as these students have had experience of both practice and theory delivery in university on which to base their judgements and assessments. Students in their first year of training may not have experienced a wide range of teaching and learning techniques and settings until their first year is a complete so will not be able to consider the full range available.

3.4.3.3 Phase Three Recruitment

The researcher spoke to students in two cohorts in year two and two cohorts in year three inviting them to participate in the focus groups for phase three. They were informed that participation was voluntary, and they could withdraw their participation at any time. Any students who were interested in participation were invited to contact the researcher and the first six students to contact from each year (three from year two and three from year three) and each site (London and Berkshire) were selected.

3.4.3.4 Phase Three Data Analysis

The ideas to be discussed in these groups have been generated by phase two. The proficiency themes form the four groups of ideas to be considered. The individual competencies within these groups are then reviewed by the participants. They are asked to identify the method best suited to teach/learn these. Colour coded post it notes were used to write the resultant ideas on and stuck on four relevant posters, one for each theme and set of competencies. The students were then asked to review the ideas written on the post it notes and re-rank them. This follows the

process detailed by McMillan, King and Tully (2016) who discuss how to use the NGT. Nominal group technique (NGT) is a consensus method similar to the Delphi technique. One difference is NGT requires face to face discussion in small groups whereas Delphi is more remote participation. The small groups are noted to be ideally 2-8 participants per group (McMillan, King and Tully, 2016).

3.4.3.5 Covid pandemic impact

The covid pandemic did impact upon phase three of the research, due to a national lockdown in March 2020 which prevented further focus group data collection. The NGT technique is designed for face to face interaction and not appropriate for quick translation into video call. The London focus group that did take place with two participants and generated a significant amount of data. This was discussed at depth in consultation between the researcher and supervisor resulting in a decision to use the data that had been collected from the face to face groups only.

3.6 Ethical Considerations

3.6.1 Ethical approval

As this research does not involve patient care or patients themselves directly then the NHS ethical approval via the Health Research Authority was not required. Ethical approval must be sought from the HEI within the researcher is a student and also the HEI which will provide the students for the focus groups. In this instance the HEI is the same for both so ethical approval was sought from the HEI in question.

The HEI in which the researcher is employed and also a student stipulates that an online University Research Ethics Risk Assessment form be completed as well as the CNMH ethical approval form. To complete this application, it is necessary to have completed the participant information sheet and consent form and provide copies of any tools used to collect data. The participant information and consent forms were submitted with the relevant documentation and application form. Ethical approval was granted before commencing phase one of the research.

3.6.2 Ethical considerations for students

There is a research ethics code of practice (2014) document that is there to guide the researcher when considering the steps necessary to obtain ethical approval for their study. An essential part of any research is that the participants are protected. This includes ensuring they have time to consider the research before agreeing to participate and then signing a consent form. Participants were assured of the right to

withdraw to mitigate any social desirability or pressure. There is the dual aspect of the role of the researcher in phase three as they are both researcher and also lecturer within the team teaching the students who are the participants for the focus groups. Bereavement is taught in year one and two of the BSc (Hons) Midwifery course. The students selected for participation were in year two or three of the course and had already had the bereavement sessions in question. There was no assessment pending covering bereavement and no further sessions that the researcher was involved in for these students. Therefore, any contributions did not affect any future progression on the course. Equally as the competencies were already identified there was no question over their validity but rather what teaching and learning approach may be best suited.

3.6.3 Ethical considerations for healthcare staff as experts

It is pertinent to note that due to the nature of the research this can take an emotional toll on the participants but also the researcher. As part of the role of specialist midwife within each Trust there is the opportunity to have a conversation with a manager, Professional Midwifery Advocate (NHS England, 2017) or peers. Charities such as Child Bereavement UK also provide supervision for healthcare professionals involved in bereavement care (Child Bereavement UK, 2020). There is also the network of Bereavement Specialist Midwives which was one route to identify participants for this study who provide peer support. Therefore, there are a variety of support opportunities for the researcher and participants should they feel it is required. If any concerns were flagged regarding any participant data regarding concerns with practice, then the researcher can consult the NMC for guidance of how to proceed.

3.7 Summary

The methods to be employed in each phase have been discussed. This includes the process regarding participant recruitment and data analysis. This discussion will now continue in chapter 4 with the findings presented from phase one, phase two and phase three.

Chapter 4: Findings

4.1 Introduction

The multi-phase mixed methods approach where each phase then informs the next (Creswell, 2014) has enabled the researcher to approach the research with the methods best suited to the research question.

The research question for this study was:

'What knowledge, skills and abilities constitute proficiency in caring for bereaved parents experiencing perinatal loss and how can these proficiencies be developed in student midwives undertaking the 3yr BSc (Hons) Midwifery programme.'

Each phase is linked to the objectives as illustrated in figure 4.1 below.

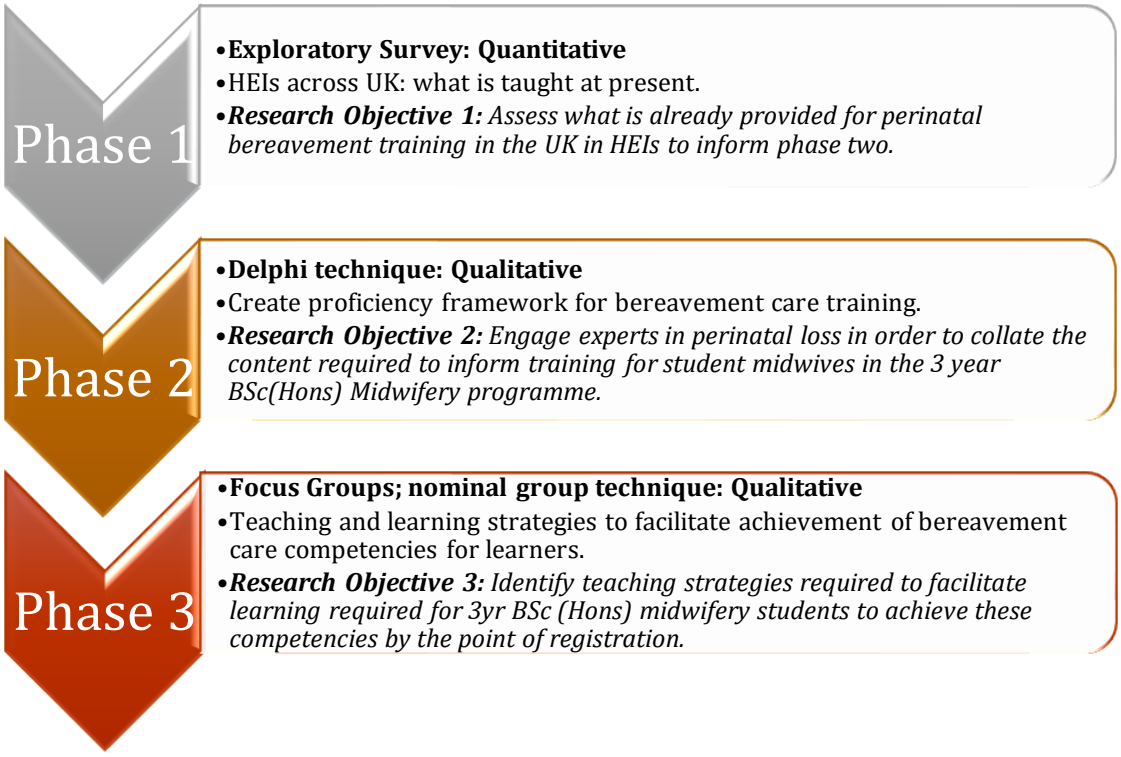

Figure 4.1: Research methods

The methods employed in each phase have been discussed in turn in Chapter three. The findings from each phase will now be presented in reflecting the progression of the research as it was undertaken with iterative building of phases. This is particularly relevant for phase two to phase three. Phase two is an important stage as this is where the perinatal loss proficiency framework is created through the

analysis of the data and phase three requires this framework to inform the structure of the nominal group technique (NGT).

4.2 Phase One.

4.2.1 Summary

Phase one is linked to research objective one; *Assess teaching provision on perinatal loss in the UK in (Higher Education Institutions) HEIs.; time dedicated to perinatal bereavement teaching and who delivers this*. The aim of phase one was to assess the national picture. As has been established in Chapter 1 section 1.2 it is clear to see that 20-30,000 midwives or more could be involved in the care of parents experiencing perinatal loss which is 51-76% of the midwives who are registered with the NMC and practice in the UK. This is midwives in practice, not specifically bereavement specialist midwives of whom there may only be one or possibly none in a Trust (SANDS, 2016).

There are six questions in total with quantitative and qualitative data. The numerical answers can be quantified and there is an option to add comments so adding qualitative data to give context. The questions were formulated through discussion between the researcher employing their expertise in bereavement care and education and another bereavement specialist midwife who also contributes to student midwife education.

As previously discussed, an exploratory survey via an online platform was the method for this phase. The main aims of phase one was to establish how many hours are dedicated to teaching bereavement care, over how many sessions and who delivers the sessions. This is relevant as a bereavement specialist midwife may have differing insights and case scenarios for discussion, so deliver a different session to someone who does not have the specialist knowledge. The survey was designed to be short and have questions that were quick to answer to try to encourage completion of this. This survey was sent to all Lead Midwives for Education (LME) in UK identified through NMC LME database which records the name and contact detail for every HEI which provides midwifery education as it is mandatory to have an LME in post.

As the response rate was on 28% this will have an impact on the validity of the findings. The responses of the 72% who did not participate may have significantly changed the findings.

There was an introductory email sent out introducing the researcher, the research and the purpose of the survey, followed the next day by the email with a link to the survey. The deadline for completion was 10 calendar days later. This may have had an impact on the completion rate due to lack of time to complete or deadline missed due to workload, annual leave or sick leave. Saleh and Bista (2017) note in their research into survey responses that whilst online surveys are the fastest way to deliver surveys, the number of unsolicited surveys makes the response rate lower than that of postal or phone delivery. They also found that one reminder to complete significantly increased the response rate of online surveys. A reminder email was not sent therefore this would be one aspect that could have been implemented to improve response rates.

Below are the number of LMEs contacted, one within each HEI in the UK that provides midwifery education leading to registration with the NMC.

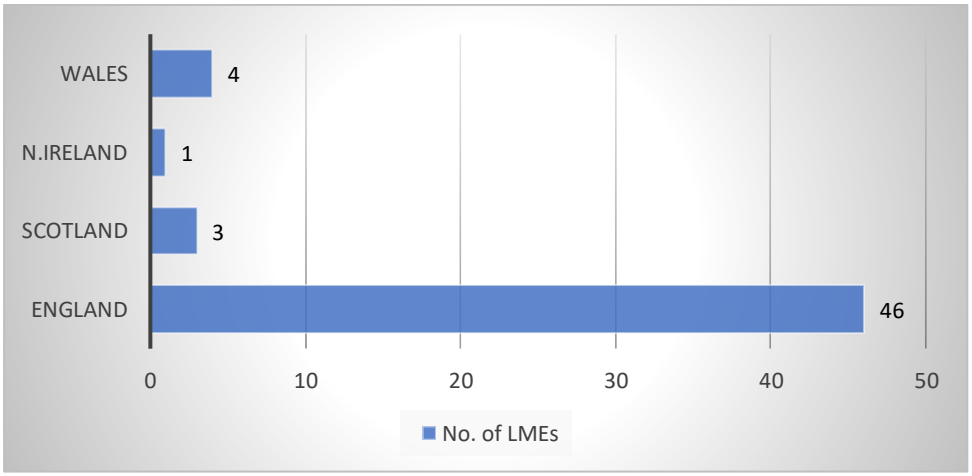

Figure 4.2 No. of LMEs

Total = 54 Total Responses = 15 = 28%

The response rate was disappointing as the survey was only six questions and should only take up to two minutes to complete. A breakdown of the individual questions and the responses are detailed below. The results will be further explored in the discussion chapter.

Phase 1 results

4.2.2.1 Who delivers the bereavement sessions in your HEI to student midwives?

The person delivering content to the students is one aspect that can vary; the extent of expertise and experience of the person leading the session can have a positive or negative effect (see section 1.8.2; 4.2.3).

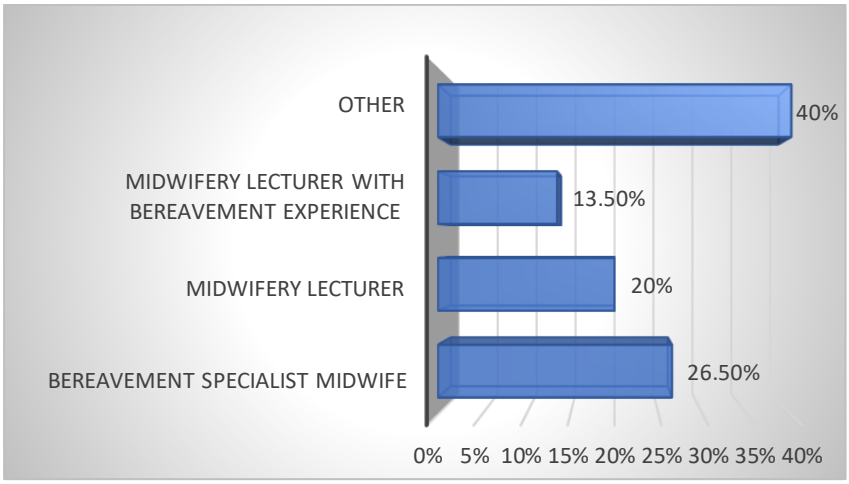

Figure 4.3 Who delivers session

Other was included as an option as many external organisation and charities such as SANDS do offer education support. As they are experts if there is no expertise within the midwifery lecturer team it is common practice to utilise external speakers in order to have that expertise available to the students. These results illustrate that in 40% of sessions these were delivered by someone other than a Midwifery Lecturer.

4.2.2.2 How many sessions are included in the 3 year BSc (Hons) Midwifery training in your HEI?

This information will aid illustration of the time dedicated to bereavement training in the HEIs at this time.

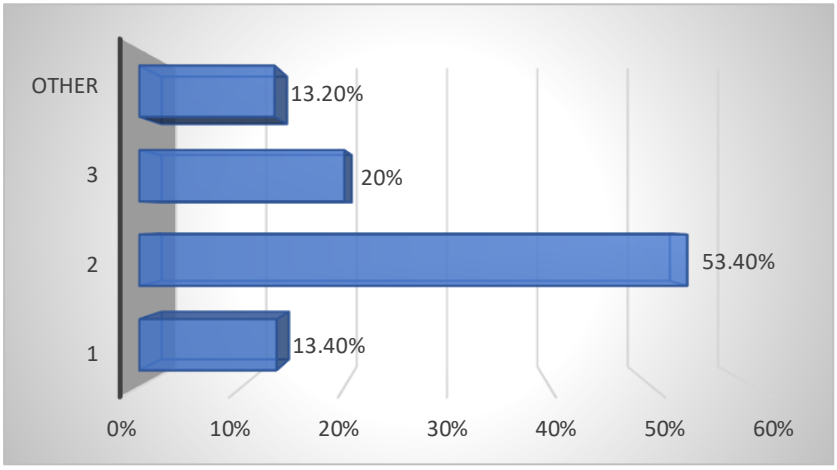

Figure 4.4 Time dedicated to training

Other: Bereavement is incorporated into other modules so no identified number of sessions or hours. This can make it difficult to assess exactly what is covered and it is not seen by the students as a subject within its own right. The needs of bereaved parents do differ to that of parents who have a live baby and as such require focus and specific content to the sessions.

4.2.2.3 In which year of training are these taught?

The year of training is relevant as the students will have had very little exposure to bereavement in practice in their first year, whereas the third year students will have had more. The discussions around theory and practice and bridging the gap are relevant here.

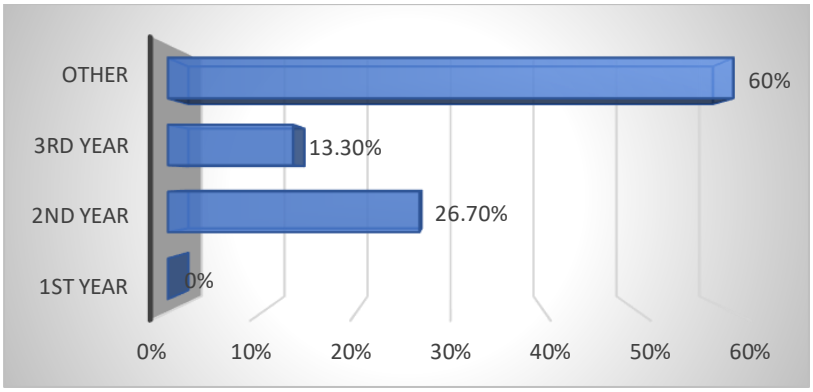

Figure 4.5 When is training taught

*__Other__: 60%; 1st and 2nd, 2nd and 3rd yr or all years.

The majority of responses are in 'other' demonstrating the large degree of variance in the approach to inclusion of bereavement session within training. This is relevant as the students in their first year may be less likely to care for bereaved parents as the focus is on normality whereas by third year, they are more likely to have encountered these situations in practice. However, the nature of practice is that first year students may encounter these parents and so need some preparation; these results demonstrate that training is spread across all three years with the majority in second and third year (see section 4.2.4).

4.2.2.4 How many hours are dedicated to bereavement training in total over these sessions?

The number of sessions is relevant as above but the number of hours within each session may vary.

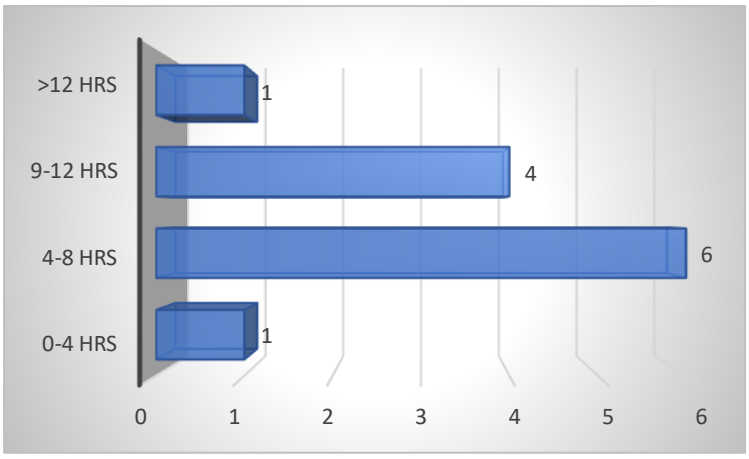

Figure 4.6 How many hours

There is a very wide variance in the time dedicated to bereavement training which demonstrates inconsistency nationally (see section 4.2.5).

4.2.2.5 How many cohorts do you have in the BSc (Hons) Midwifery 3 year program per year?

Many HEIs only have one cohort per year and larger class sizes than those who have two cohorts.
cohort = 83.5%

cohorts = 13.5%

This demonstrates the majority of HEIs have only one cohort; when there are two cohorts there is opportunity for a student who has missed a session in a particular year to catch up with the next session delivered to the next cohort within the same year.

4.2.2.6 How many students do you have per cohort?

This is for information to ascertain class sizes and compare to 4.2.2.5.

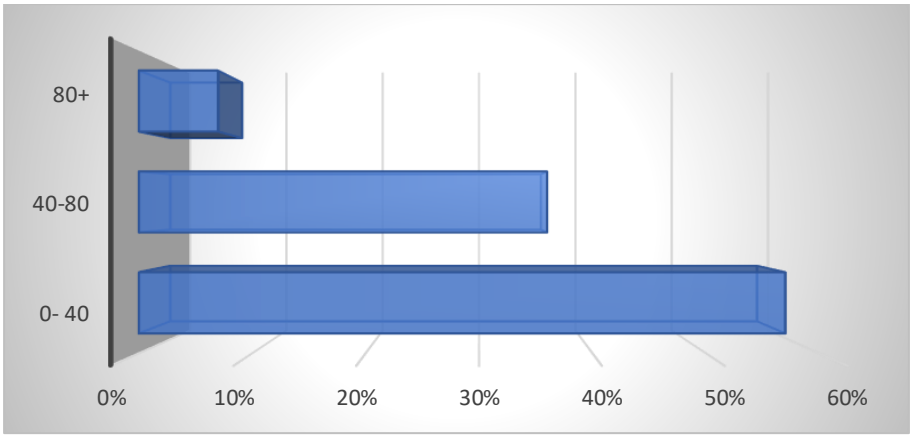

Figure 4.7 How many students per cohort

Ranged from 17 to 100 students, though the smaller numbers can be attributed to the HEIs with two cohorts per year, so the student numbers are less per cohort than if it is just one cohort per year. However, the result that almost 60% had a class size of 40 or less demonstrates that some single cohort HEIs have smaller cohorts.

It is interesting to note the variance between HEIs not only in the time allocated to the subject of caring for families experiencing perinatal loss, but also the professional delivering the session, when it is taught and how often it is revisited. This inconsistency further supports the continuation to phase two where the question of what exactly it is that students need to know is addressed.

4.2.3 Facilitating the session

The first question was aimed at identifying who delivered the theory sessions. There has been a series of articles exploring the role of clinicians in the classroom (Power, 2016) which included an exploration of a Bereavement Specialist Midwife teaching student midwives in theory in the university setting (Power and Rea, 2016) and in practice (Power, Rea and Fenton, 2017). It was surmised that there was value in someone linked with practice and the link to reality and the practice placement where care occurs. It was powerful to have the realities of current practice including real life case scenarios into the classroom and lends validity to the learning that takes place. The results from the survey carried out for this research show that 80% of sessions are led by someone from within an external organisation (such as SANDS), a bereavement specialist midwife or a midwife with bereavement experience. This evidences the role of the specialist in the classroom is valued and being utilised in the majority of teaching provision. These are not all necessarily clinicians but are linked with bereavement expertise either through practice or perinatal bereavement support organisations.

4.2.4 When are sessions delivered

Just over half of the HEIs have two sessions on perinatal bereavement within the three year training course. The sessions are taught across all years with 60% being taught in either 1st and 2nd, 2nd and 3rd year or all years (see section 4.2.2.3 for visual representation of this). The other 40% are taught on one single year which is either 2nd or 3rd year. This does align with most midwifery courses focussing on normality in the first year as the students require a base knowledge of what is normal before moving on to understand complications and the abnormal (NMC, 2019). However, there is an argument for an introduction earlier as some students may care for

families who have experienced perinatal loss in their first year, whether it is the current pregnancy or subsequent pregnancies, even in their first placement. The researcher has had feedback from students she has taught that they request an introduction in the first theory block before their first practice placement as it is supporting parents experiencing perinatal loss that causes them a great deal of anxiety. This will be discussed later in relation to phase three results.

4.2.5 Time allocated to bereavement sessions

The number of hours dedicated to perinatal bereavement training was found to be between three and fifteen hours over the three year programme. To put this into context the requirement by the NMC in relation to theory hours is that there is a minimum of 2300 over the three year programme. This is 0.65% (maximum) of the minimum number of hours required. There is a huge amount of information that needs to be covered in midwifery training and the curriculum as a whole as is stipulated by the NMC (2019) Standards of Proficiency for Midwives. This is what guides the curriculum planning, and all modules have to be mapped against these proficiencies in order to be approved for delivery which is why it is so key that the proficiencies include key elements of perinatal loss bereavement care as this is what will guide the attention given to this area. When this survey was carried out the standards for pre-registration education for midwives (2009) was the document on which the midwifery programmes were based. This contained one sentence regarding the need for inclusion of bereavement care training in midwifery education. The updated NMC (2019) Standards of Proficiency for Midwives has a more extensive section on this which has been detailed in section 1.5 of this thesis and is included here for clarity.

4.3 Phase Two

4.3.1 Summary

The Delphi technique is the method utilised in phase two as discussed in Chapter 3 section 3.4.2. Keeney, Hasson, and McKenna (2001) concluded that the Delphi technique is a good and valid way of gaining consensus from a number of experts who would not normally be able to collaborate and also allows anonymity to mitigate for power imbalance and allow an equal voice for each participant. Phase two is linked to research objective two.

As the audit carried out by SANDS (2016) only 62% of Trusts had a bereavement specialist midwife in post at that time. There are 223 NHS Trusts in the UK in 2019 (Emmett, n.d). As each Trust will generally only have one bereavement specialist midwife, if any (SANDS, 2016) then this was the most viable method to allow the participation of as many as possible. Using these statistics this equates to 151 bereavement specialist midwives in post. This is a specialism where practitioners are linked through a National Bereavement Midwife Forum and the annual Transforming Loss Conference. There are very strong links through the National Bereavement Midwife Forum within the bereavement midwife community, therefore it is valid to assume that many of these practitioners will know or know of each other. There may be a power imbalance within this that would make face to face groups less productive as some participants may feel inhibited by the others present. This could be prominence within the bereavement midwife community, length of time in post and experience and so on. The Delphi method mitigates for this through remote contact and anonymity; given the high potential for familiarity in this group this is seen as even more valuable. This could be key in allowing freedom to answer allowing equal opportunity for all to contribute (Landeta, 2005). To have a valid outcome form the Delphi technique it is essential that each participant has an equal voice. If one or more are inhibited and do not participate in full this could lead to vital insights or content being lost which would make the resultant proficiency framework incomplete.

As detailed in Chapter 3 section 3.4.2.3 an introductory email was sent put via contacts form the Transforming Loss Conference, the National Bereavement Care Pathway mailing list and also the National Bereavement Midwife Network as has previously been detailed. There were a number of responses from participants who wanted to take part but did not think they had the time or capacity to do so. In the end there were twenty eight participants who completed the consent form and were sent the round one Delphi technique with open ended questions (see Appendix 4). The response rate of 61% who completed this was lower than expected after the initial engagement by email and gaining consent. All were emailed individually so as to maintain anonymity, and this allowed for open communication between participant and researcher as it was a private correspondence. The deadline was extended when response rate was low, and this did aid improvement in response rate.

4.3.2 Delphi technique structure

The Delphi technique process is detailed in figure 4 section 3.4.2.1. As the first round was open ended questions this did require time to consider the replies and then write these up; this needed to be open ended. If the questions had been more leading questions so as to make answering easier or directed, then this would have introduced researcher bias into the results as the researcher was creating the questions. The questions were created through using the perspective of the pregnancy journey through antenatal, intrapartum, and postnatal to capture all aspects of care and all gestations of loss including the differences encountered at differing gestations. These questions were repeated once with a clinical focus and secondly with an emotional, spiritual and cultural focus. The structure of the first round reflects the knowledge and proficiencies required to be competent at the point of registration by the NMC and the physical, emotional, spiritual, and cultural aspects as highlighted in the Standards for Proficiency for Midwives (NMC, 2019).

The response rate is detailed below in figure 4.8. The reasons and implications linked to this will be addressed in the discussion chapter section 5.8. Following thematic analysis on the first-round responses the second round was sent out. Round two of the Delphi technique is detailed in Appendix 5. There was a consensus rate of 100% from the second round, therefore there was no rationale to carry out a third round as no changes would be made.

There was then opportunity for a validation round which will be detailed and discussed in 4.3.4. There were an increased number of participants as this was determined by the number of participants who were taking part in the workshop (see section 4.3.4. This was not a round three but a separate validation round to further test the validity of the findings from the Delphi with a large number of healthcare professionals involved in bereavement care which is why the number of participants is much larger than round one and two.

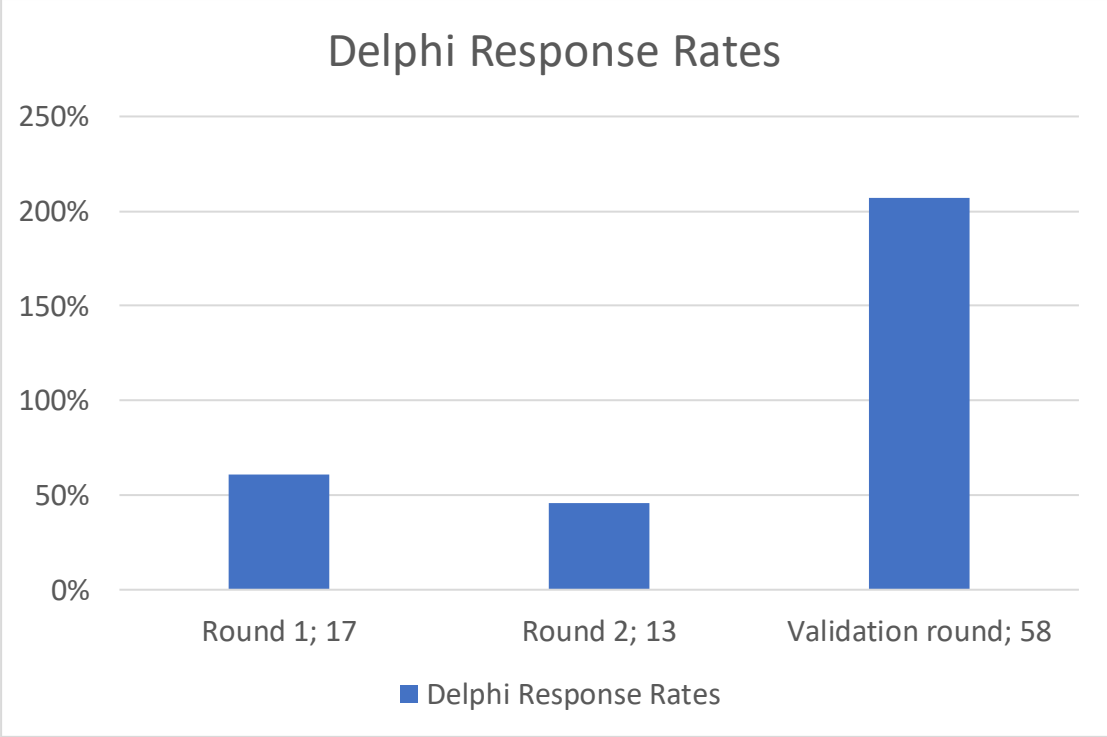

Figure 4.8: Delphi response rates

4.3.3 Thematic Analysis

Qualitative text from the Delphi was analysed using thematic analysis following the five steps as detailed in Braun and Clarke (2006). The emergence of themes is not necessarily dependent on their prevalence and is reliant on researcher judgement. For this research the thematic analysis was deductive in that it was driven by the researchers theoretical and analytic interest in this area (perinatal loss) (Braun and Clarke, 2006). This also links to the fact that the researcher has expertise in this area, which can be positive but can also be a limitation. The researcher must have insight to the degree in which this influences their interpretation of the data. This will be addressed in section 4.3.5. Analysis of the data is in line with a tradition which comes from a constructionist paradigm where the thematic analysis interacts with discourse analysis, resulting in thematic discourse analysis (Singer and Hunter. 1999). This is when broader meanings are assumed to be underpinning what is actually said/written in the data, not taking what is explicitly stated. The thematic analysis was undertaken using these principles for this research. The sixth step is the now in progress in the writing up of the findings. The codes emerged from the data through immersion within the responses to the Delphi round one and identifying of correlated segments of data resulting in a list of codes. These were then sorted

into themes. Table 4.1 below details excerpts of initial notes, the resulting codes and then themes into which these fit.

Initial notes	Codes	Themes
'monitoring for signs of infection'; 'clinical care'; 'good knowledge of analgesia'; 'postnatal check'; 'management of third stage'; 'appropriate pain management'; 'understanding of investigations'; 'knowledge of lactation suppression'; discussing delivery process'; 'how delivery of a stillborn infant may differ to a liveborn infant'.	Basic clinical care Pain management Clinical care at delivery Clinical care specific to stillborn baby	**Practical clinical skills**
'grieving process'; 'impact that pregnancy loss has'; 'be calm, patient'; 'respect when parents meet baby'; 'offer condolences'; 'family led care'; 'non-judgemental'; 'signpost to bereavement counselling'; 'empathetic'; 'understand cultural and spiritual needs';	Spiritual needs. Grief processes Counselling Empathy Religious beliefs Emotional support	**Emotional and spiritual support**
'being able to listen'; 'be direct and honest'; 'saying I'm sorry'; 'time to ask questions'; 'breaking bad news'; 'skilled supportive listening'; 'record family wishes';	Listening Verbal communication Non-verbal communication Breaking bad news	**Communication**
'awareness of stillbirth certificate'; 'certification'; 'midwife responsibilities'; 'pregnancy loss checklist'; 'National Bereavement Care Pathway'; 'terminology and legal definitions'; 'local arrangements for Coroner'; 'MBRRACE surveillance forms'; 'knowledge of written support'.	Certification for each circumstance Terminology, legal aspects Funeral Reporting Record keeping	**Paperwork**

Table 4.1: Thematic analysis

These initial notes were made capturing the relevant items and coding them (using the process detailed in Chapter 3 section 3.4.2.5). These were then sorted into themes, reviewing these as the process progressed and defining and naming these

once validity had been tested by the review process. Please see figure 4.9 below for the resultant themes.

Theme 1
Practical clinical skills
Theme 2
Emotional and spiritual support
Theme 3
Communication
Theme 4
Paperwork

Figure 4.9: Themes

4.3.3.1 Themes

The data which informed the resultant themes had to then be collated into competencies in order to create the proficiency framework and be applicable to practice. This incorporated all the key knowledge, skills and abilities identified by the participants in the Delphi and formed the basis for round two of the Delphi in order to facilitate review by the participants as per the Delphi process (see figure 5). Further exploration and detail of this process will follow.

4.3.3.1.1 Collation of round one responses into competencies

An example of how individual responses were collated in order to create a resultant proficiency is:
Individual responses;
'Clinical care – maternal observations, urinalysis, venepuncture, good documentation.'
'Identical to those needed when caring for any woman's wellbeing, careful monitoring for signs of infection, MEWS, emotional support.'

These were both applicable to the proficiency:
Importance of still providing routine AN/intrapartum/PN care.

The competencies within each theme were then re-examined in relation to the knowledge, skills and abilities included to ensure no aspect had been missed. There was some overlap within this in that some competencies could have been allocated

to more than one theme, but the allocation was then dependent on the perspective identified. An example of this is:
Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care. (Theme: Emotional and spiritual support)

Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents. (Theme; Communication)

In these cases, the researcher has made a professional judgement as to where the proficiency best fit using their experience and expertise. This is supported by the training the researcher has had with SANDS and through their clinical experience with midwives and bereaved families, and involvement with the National Bereavement Midwife Forum where best practice is shared. This judgement was based on what the proficiency was and using experience of delivering both theory in university and working in practice and also the aspect of care and proficiency to which it was applicable. The second round of the Delphi would then test the validity of this through responses and consensus from the participants. As can be seen in the example above there are differing perspectives on the same aspect (cultural and religious beliefs) therefore the allocation to different themes. The proficiencies included within each theme also formed part of the review process in round two where participants could agree or disagree with any aspect. Please see figure 5 for illustration of the process.

For the practical implementation of the Perinatal Loss Proficiency Framework (PLPF) the allocation to themes is less critical as all will be included; it is the inclusion of the proficiency itself that is of greatest importance at this stage so that no aspect of care is excluded or missed. The aim is to have a comprehensive framework as a basis for identifying what students and midwives need to know when caring for families experiencing perinatal loss. This will be explored further in Chapter 5.

In round two of the Delphi technique the collated responses were sent to the participants for their opinion. Round two is detailed in Appendix 5. The collated responses took the form of the suggested competencies for inclusion. The format for any teaching and learning to be achieved in the NMC documents and guidance takes the form of competencies or now the term proficiencies is used. Therefore, it was essential that the same language and format was followed in order for the resultant proficiency framework to be valid. This then allowed the participants the opportunity to review the responses which included the responses of others and decide whether

they agree with each proficiency or if they wish any amendment or removal. There was 100% consensus agreement for every proficiency.

The consensus of 100% for round two of the Delphi technique supports the thematic analysis and resulting Perinatal Loss Bereavement Care Proficiency Framework and provides evidence that this was valid and appropriate. The survey was sent to all twenty eight original participants as the reasons for not responding to round one were lack of time rather than lack of interest and expertise it was proposed that they would still have valid feedback on the competencies that had been created. There were thirteen responses; it was not cross referenced whether these were the same participants that had responded to round one as the input was anonymised though this may have been a factor that should have been included. In retrospect it may have added depth to the discussion to have an awareness of this data.

Spending time with the Bereavement Specialist Midwife is a proficiency within practical clinical skills. There was 100% consensus that this should remain as a proficiency, the time scale was where there was disagreement. Unanimous opinion was that one week was unrealistic and what would be valuable and possible is to spend one day with the Bereavement Specialist Midwife. This was then changed to one day per week as per the responses. Due to the consensus rate of 100% there was then no requirement to continue with a third round. The resultant competencies clustered into themes as detailed in Appendix 9.

4.3.4 Validation Round

The opportunity arose to further test the validity of the Perinatal Loss Care Proficiency Framework through the invitation for the researcher to speak at a Transforming Loss Conference shortly after completing the Delphi technique survey. This is held annually, supported by SANDS, BLISS, and the RCM for all who are involved in caring for families who are experiencing perinatal loss. Therefore, this was an invaluable opportunity to have a large number of professionals involved in bereavement care for perinatal loss in one place with their undivided attention and capture their experience and input. The sessions the researcher was involved in was a workshop related to bereavement care training. The second round version of the Delphi technique (with the one proficiency amended to one day with a bereavement midwife as discussed in section 4.3.3.1) was given to all participants to complete during the workshop. There was an initial discussion to establish the basis for the research, the process to that point and what was being asked of the potential

participants. Consent was inferred from the completion of the Delphi, but it was made very clear by the researcher verbally that this was voluntary.

The opportunity to have a validation round was a planned and valuable addition to determining the validity of the findings and add depth of understanding to the findings. The Delphi technique round two (amended for one day with the bereavement specialist midwife) was used for this with the addition of the question around how many years bereavement experience the respondent had.

Fifty eight questionnaires for the Delphi validation round were completed; there was 100% consensus agreement with the competencies detailed in the survey. In addition to the competencies each respondent was asked to state how many years' experience they had in perinatal bereavement care. Forty three (74%) of respondents included this detail: they had between 1 to15 years' experience with an average of 8.5 years in caring for families experiencing perinatal bereavement.

4.3.5 Researcher reflexivity

The researcher is an expert within a set of experts, and this has to be acknowledged in respect to the influence this may have. The participants in the Delphi are the experts and generate the data; in the Delphi it is recognised that the identification of the competencies through analysis of the data is a process that could be influenced by the pre-existing knowledge and expertise of the researcher. The researcher must be aware of this and question the analysis judgement at each step to ensure the analysis is not being manipulated to agree with the preconceptions and beliefs of the researcher. The external safety mechanism to avoid this is the Delphi round two. The participants will review the resultant analysis of their round one response and can agree or disagree at this point. There will be disagreement if the researcher has interpreted the data in a way that fits with their beliefs but was not the intention of the participant. The resultant PLPF has also been presented to SANDS representatives in order to get service user input.

There is value brought to this research by the researcher being an expert in that they are a combination of practitioner, educator and researcher and so looking at the subject matter from varying perspectives. This also brings with it an awareness of the variance in priorities depending on which perspective has focus and so combining these gives a unique view and collates these priorities bringing all together. This will also then have an impact on how this is translated into practice in

both the education setting and the practice setting; the impact can be enhanced through a deeper understanding of how theoretical knowledge and practice interact.

4.3.6 Themes with related competencies

The individual competencies are allocated within each theme; this will now be illustrated and supported with the data in the form of direct quotes from the Delphi technique round one responses.

Researcher; Critical reflection

Each theme will be discussed with some direct quotes and the related competencies. Reflecting on how these were created it was an ongoing iterative process that utilised the joint perspective of both educator and expert knowledge from practice that the researcher has. The comments and responses from the Delphi round one were collated in order for the researcher to group together responses that all related to each other and together resulted in an individual proficiency. This is an element of the Delphi technique and validation obtained by the resulting analysis and competencies being sent back to the participants as the Delphi round two. On reflection this process was even more important as it was essential that the researcher was not fitting the data into what she believed should be the outcome (competencies) but was interpreting these with a professional eye that was agreed by those participants who provided the raw data. Their agreement with the themes and competencies reflects the agreement with the researcher's interpretation of the raw data and translation of this to a proficiency framework. Though the researcher brings their own knowledge and expertise and biases, this was in line with the expertise and data generated by the expert participants.

4.3.6.1 Theme 1; Practical Clinical Skills.

The theme of practical clinical skills came through clearly within the data. When care for parents who have lost a baby is discussed this is often with a focus on the emotional and psychological aspect of care which is of course of huge importance. However, the data from round one supports the element of the importance of the physical clinical care, and this should not be forgotten but be part of a holistic approach.

The quotes from participants all come from round one of the Delphi as this was where the rich data was provided and used for the thematic analysis and creation of

competencies. This applies to all themes and quotes. Round two was agree/disagree (see Appendix 5). As all quotes are from round one and anonymised the identifier for each is the same. There was the opportunity for free text but there was very little provided as all participants agreed with the competencies created. Each participant was a midwife involved with at least one year or more of experience in delivering bereavement care.

The educational material available at present has an absence of practical clinical skills included (see section 2.4.4). The results from the Delphi are very clear that this is a key aspect of care and must be included in any proficiency framework. As has been discussed the confidence parents have in a midwife providing care is the affected by the confidence they have in giving the care (see section 1.11.1). The ability to incorporate these practical skills is essential to not only safe care but also to the perceived proficiency of the midwife in the eyes of the parents. There were numerous quotes form participants relating to this; identifiers are P (participant) and their number. A few examples are:

'students need to understand the basics to build on' (P 2)
'need to be monitoring for signs of infection' (P 4)
'don't forget clinical care'(P 10)

These are the practical aspects of care that will apply to care for a woman in any situation included in the proficiency 'understanding the importance of routine antenatal, intrapartum and postnatal care'. There is then care that is specific to someone who has lost a baby such as:

'there needs to be knowledge of lactation suppression' (P 5)
'discussing delivery process' (P 7)
'How delivery of a stillborn infant may differ to a liveborn infant'. (P 3)
'use skills as they would with alive baby, skin to skin, cuddling, dressing baby' (P 11)

Lactation suppression relates to the fact that the mother will still lactate but there will be no baby to feed which can be distressing. The student needs to understand lactation and then also the mechanisms available to the bereaved parent to supress this. Equally the student needs to know the mechanisms of labour and how to deliver a baby, but also then that delivering a baby with no muscle tone (as they are not alive) can be different and they will need to be prepared for this.

The quotes above illustrate the need to include these basic clinical skills and not have the full focus of care and any training only on the emotional and psychological aspects of care. Indeed one quote which summarises this from all aspects is:
'A birth resulting in bereavement is still a birth' (P 10)

See Figure 4.10 for the competencies identified.

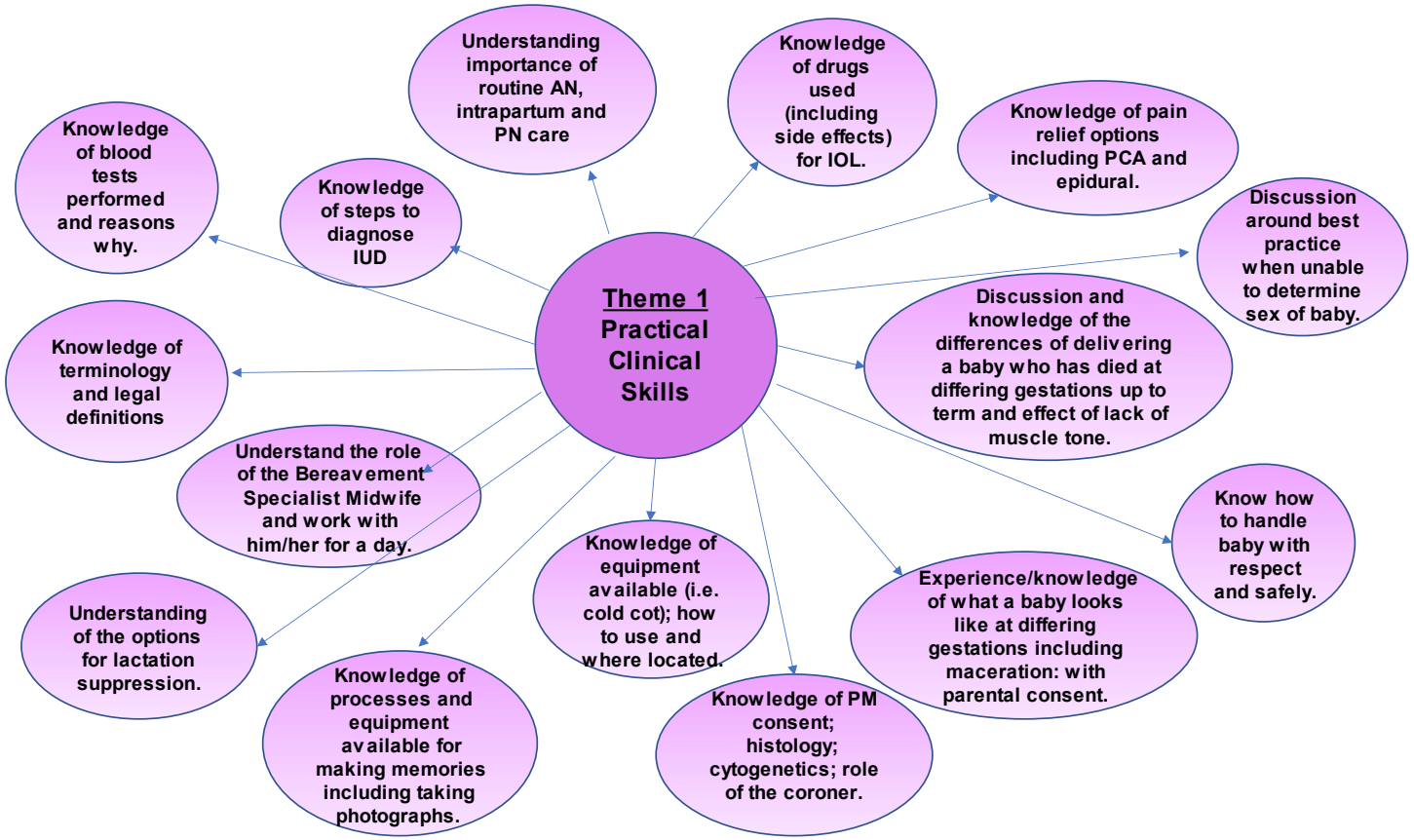

Figure 4.10: Theme 1; practical Clinical Skills.

4.3.4.2 Theme 2: Emotional and Spiritual Support

The emotional and spiritual aspect of care is an essential element of a holistic approach to caring for parents experiencing perinatal loss. This is one which is well recognised and acknowledged. The first quote here is repeated from theme one as it bridges both; *'A birth resulting in bereavement is still a birth'.* This relates to appreciating that the clinical physical care is required, but also that the way the baby is addressed and spoken about with the parents should not differ from that of a live birth. This can include using the baby's name and handling baby respectfully and with care.

One element of providing care that students have reported being anxious about is showing their own emotions. This is also reflected in one of the comments from round one:

'Empower students to support parents, not the other way round' (P 4)
'empathetic'. (P 14)
'be calm, patient'. (P 6)

It is clear that the training needs to encompass educating the student to be able to function and provide care within this very emotional time for parents. There is also a need for the incorporation of this into understanding of the longevity of loss and the individual nature of the care required.

'appreciate the impact that pregnancy loss has'. (P 15)
'understand cultural and spiritual needs'. (P 14)
'must be family led care'. (P 1)

These elements have informed the creation of the competencies:

Gain an understanding of the long lasting positive effect of good care and the negative long lasting effect of poor care (includes understanding the longevity and uniqueness of the loss of a baby).

Understand that grief is individual and not governed by gestation.

See figure 4.11 for the competencies identified.

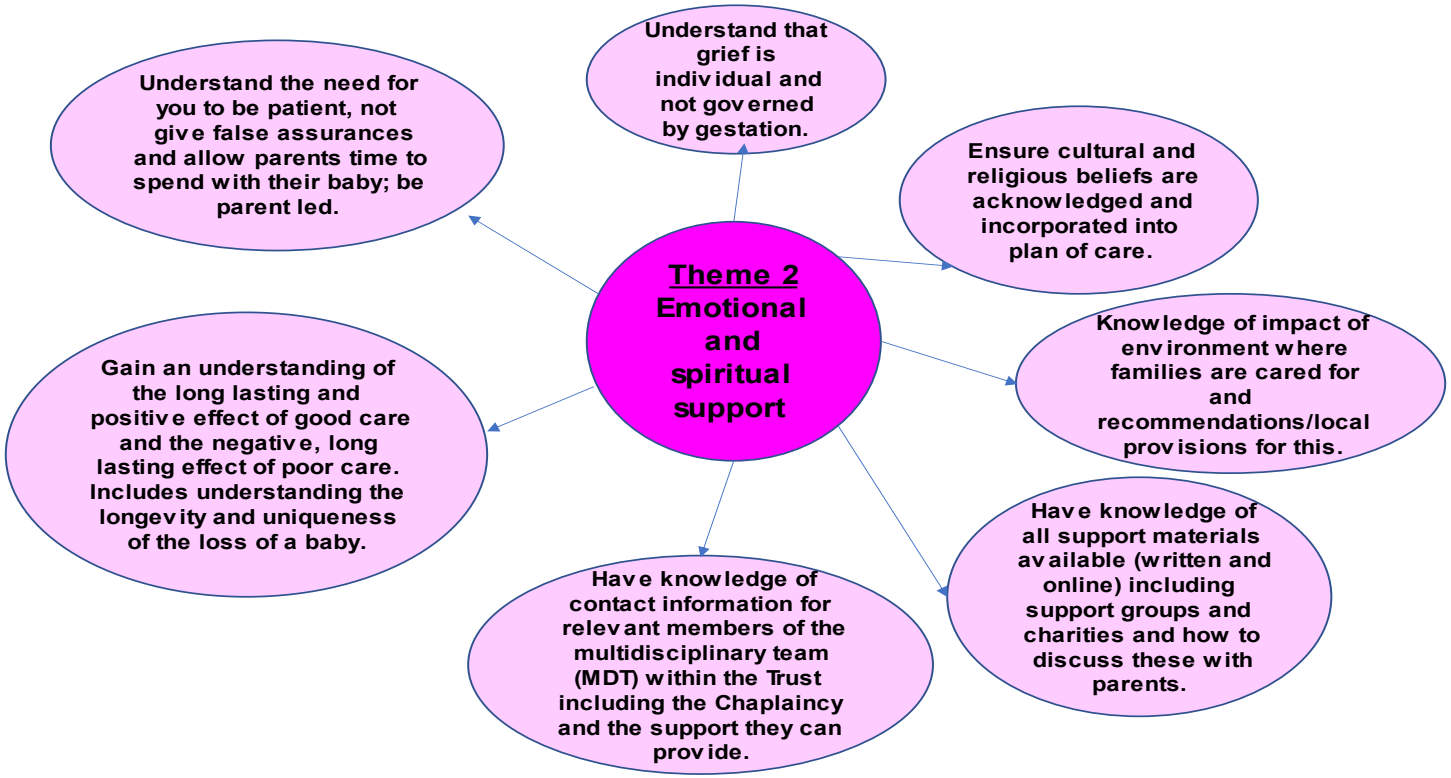

Figure 4.11; Theme 2 Emotional and Spiritual Support

4.3.4.3 Theme 3: Communication

Communication is an important element of any care and is detailed in The Code (2018) which is the professional code of conduct that applies to all healthcare professionals registered with the Nursing and Midwifery Council. The effect of poor communication is widely evidenced as has been discussed in Chapter 1 section 1.11. Therefore, it is not surprising that communication was identified as a theme.

Communication takes many forms, verbal, non-verbal, written so this theme encompasses these.
'Know what not to say' (P 17)
'being able to listen' (P 5)

These responses illustrate it is important to learn not only what to say but also when to say nothing.

The proficiency that encompasses these elements is:
Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents.

One key element that came up again and again is breaking bad news and what is best practice. This is then a proficiency from these elements which also includes elements form other quotes:
'Breaking bad news and all communication fundamental to good bereavement care' (P 12)
'be direct and honest' (P 4)
'saying I'm sorry' (P 11)

As communication does involve written elements there is then some overlap with the next theme; paperwork, as this has all elements of written information and documentation contained within it.

See figure 4.12 for the competencies identified in communication theme.

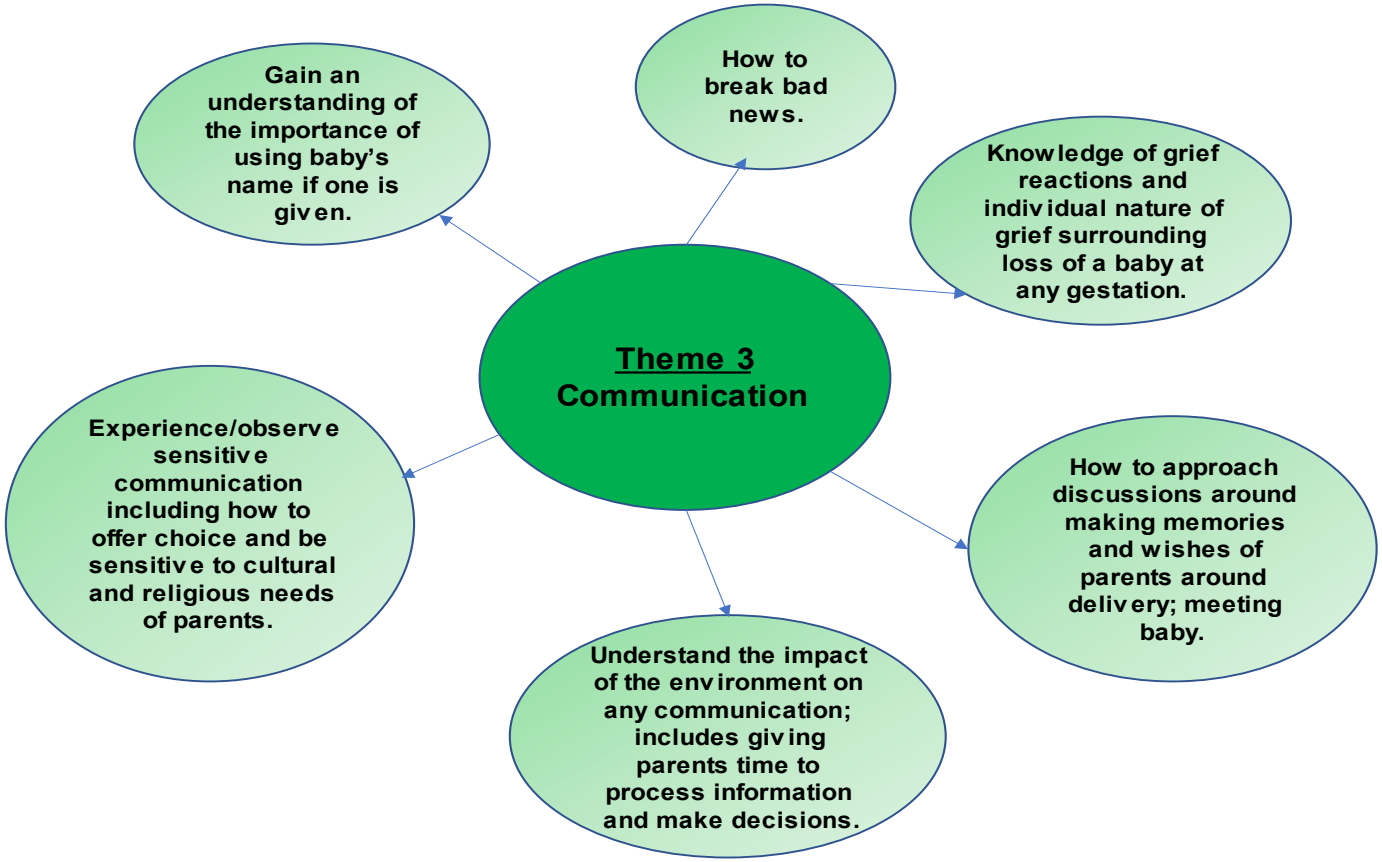

Figure 4.12: Theme 3; Communication

4.3.4.4 Theme 4: Paperwork

Documentation is again another aspect of clinical care which is essential (NMC, 2018) and contributes to communication between healthcare professionals caring for the woman and her family. The added significance of this when a baby dies is that if not completed correctly it can have consequences of delaying any investigations and subsequent follow up or the funeral. This in turn can have a positive or negative effect on the parents depending on if it is done correctly and in a timely manner or not.

These quotes emphasise the ongoing nature of professional practice and continuing professional development, especially in the care of families experiencing perinatal loss.

'Basics for students so have an awareness but is not overwhelming' (P 12)

'Takes time to understand even post qualifying' (P 9)

If the midwife is caring for the family, they may not be the one responsible for completing all documentation and so this is when the Bereavement Specialist Midwife is even more valuable. She/he will have an in-depth working knowledge of the essential paperwork including the consequences of it not being correctly completed. This is supported by the following comments:

'Huge implications if paperwork not completed correctly' (P 2)

'All paperwork should be discussed as can be a legal requirement' (P 7)

'National Bereavement Care Pathway' (P 8)

'NBCP is the way forward' (P 16)

The National Bereavement Care Pathway is a nationally available and recommended tool which can guide midwives when they are negotiating care for families experiencing perinatal loss. This is evidence for the following proficiency:
Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS.

See figure 4.13 for the proficiencies identified in this theme.

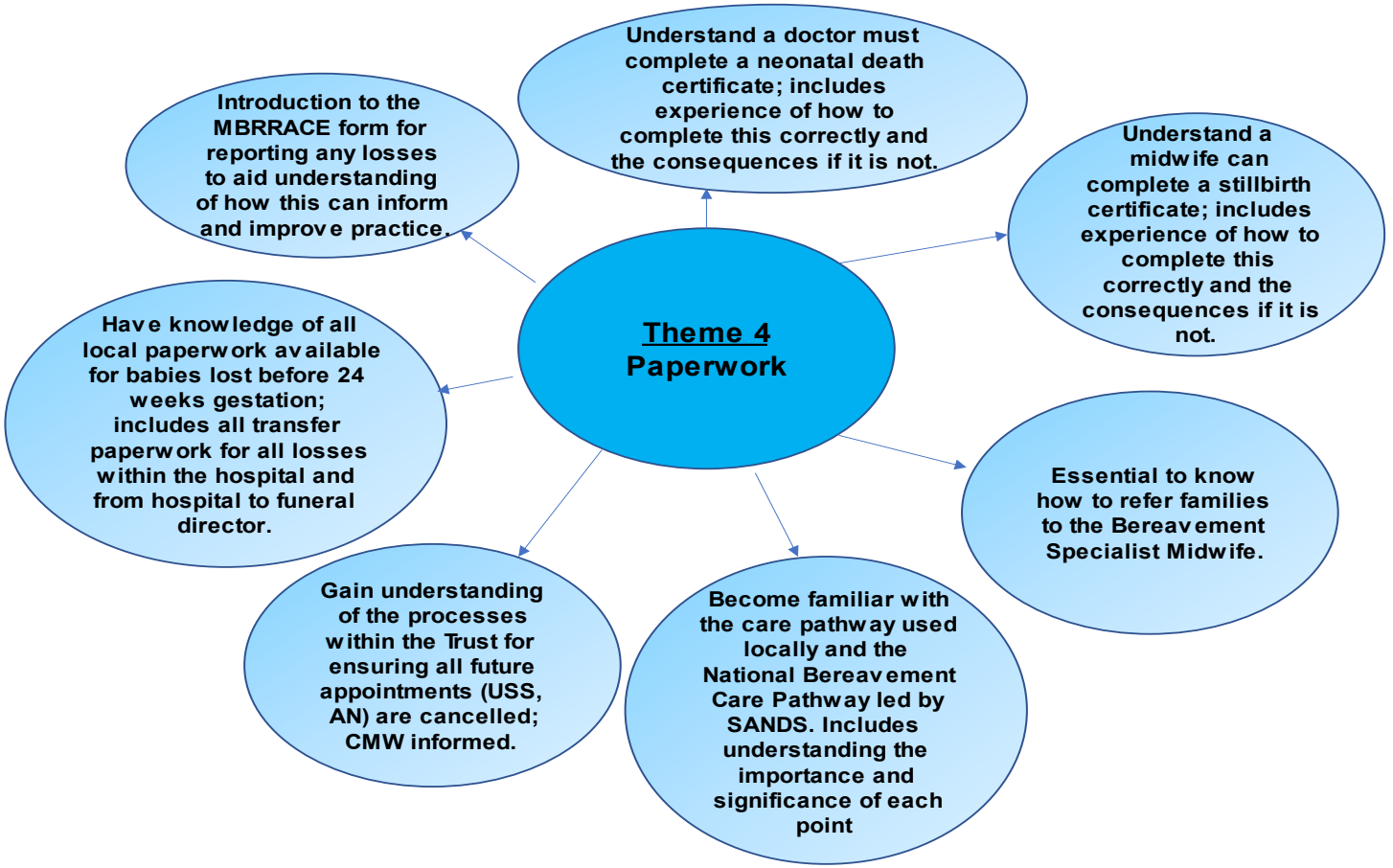

Figure 4.13: Theme 4; Paperwork

The final question on the Delphi technique was related to the scope of inclusion regarding application of the PCLF. The question is stated below and relates to parents undergoing losses at any gestation and babies lost through termination for abnormalities. The word 'termination' implies a decision to discontinue but that is not necessarily a useful or correct way to frame what decisions parents need to make when they are informed their baby has abnormalities which may or may not be compatible with life. If anything, there may be added guilt for the parents as they are choosing to end their baby's life and so are in even more need of the psychological care detailed within this framework.

'Finally, if you can consider this last question

Should all competencies apply to losses at any gestation (so can be applied to nurses working in gynaecology) and all families of babies lost through termination for abnormalities?'

There was 100% consensus these competencies should be tailored to apply to all healthcare professionals caring for families suffering the loss of a baby at any gestation.

4.3.5 Perinatal Loss Proficiency Framework (PLPF)

This is the PLPF converted into a format ready for implementation (table 4.2) which will be discussed further and mapped to midwifery training in chapter 5 section 5.1.3.

Theme 1: Practical Clinical Skills	Theme 2: Emotional and Spiritual Support
• Importance of still providing routine AN/intrapartum/PN care. • Knowledge of terminology and legal definitions. • Knowledge of steps to diagnose IUD. • Knowledge of blood tests performed and reasons why. • Knowledge of drugs used (including side effects) for IOL. • Knowledge of pain relief options including PCA and epidural. • Knowledge of impact of environment where families are cared for and recommendations/local provisions for this. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Know how to handle baby with respect and safely. • Knowledge of equipment available (i.e. cold cot); how to use and where located. • Knowledge of processes and equipment available for making memories including taking photographs. • Knowledge of PM consent; histology; cytogenetics; role of the coroner. • Understanding of the options for lactation suppression. • Discussion around best practice when unable to determine sex of baby. • Understand role of the Bereavement Specialist Midwife and work with them for a day.	• Understand the need for you to be patient, not give false assurances and allow parents time to spend with their baby; be parent led. • Understand that grief is individual and not governed by gestation. • Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care. • Have knowledge of all support materials available (written and online) including support groups and charities and how to discuss these with parents. • Have knowledge of contact information for relevant members of the MDT within the Trust including the Chaplaincy and the support they can provide. • Gain an understanding of the long lasting and positive effect of good care and the negative, long lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby.
Theme 3: Communication	**Theme 4: Paperwork**
• How to break bad news • Knowledge of grief reactions and individual nature of grief surrounding loss of a baby at any gestation. • How to approach discussions around making memories and wishes of parents around delivery; meeting baby. • Understand the impact of the environment on any communication; includes giving parents time to process information and make decisions. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents. • Gain an understanding of the importance of using baby's name if one is given.	• Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS. Includes understanding the importance and significance of each point (some following competencies will be covered within this but are detailed specifically at present). • Essential to know how to refer families to the Bereavement Specialist Midwife. • Understand a midwife can complete a stillbirth certificate; includes experience of how to complete this correctly and the consequences if it is not. • Understand a doctor must complete a neonatal death certificate; includes experience of how to complete this correctly and the consequences if it is not. • Have knowledge of all local paperwork available for babies lost before 24 weeks gestation; includes all transfer paperwork for all losses within the hospital and from hospital to funeral director. • Introduction to the MBRRACE form for reporting any losses to aid understanding of how this can inform and improve practice. • Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.

Table 4.2: Perinatal Loss Proficiency Framework

4.4 Phase three

Phase one and two have considered what it is that needs to be included in any proficiency framework, the time dedicated to this and who delivers the content. The missing element within this is the exploration of the student experience in relation to teaching and learning within a practical healthcare course, and the valuable perspective they have on how it is best to approach the subject of perinatal loss for them. Phase three is linked to research objective three: *identify teaching strategies to facilitate learning required to achieve these competencies.* There were two groups for the nominal group technique (NGT) (see Chapter 3 section 3.3.4) process for phase three, one in Berkshire and one in London to reflect the two sites of the HEI. Eight participants were invited to each focus group. In Berkshire five of the eight participants were able to attend on the day. In London two of the eight participants were able to attend. There was a plan to repeat this due to their only being two participants. Due to the covid 19 pandemic this was not possible. The implications of this will be explored further in the discussion chapter. There was representation from year 2 and year 3 of the BSc (Hons) Midwifery course.

Each participant was given four sets of coloured post it notes. Each colour corresponded to a theme created by phase two. Once the participants had completed their own notes with no interaction with each other they were invited to place these post-it notes in the corresponding flip chart. They were then encouraged to review all notes in each theme and if required seek clarification on any points written. They were then asked to rank the ideas of environment and any rationale from one to maximum five. In this instance this was done through discussion, mediated by the researcher, and the post it notes moved on the flip chart to reflect the ranking. In the Berkshire group there was then a general discussion around the teaching and learning required for these competencies which resulted in a comprehensive plan for the 3 year training programme; this was an extra and unexpected outcome from the group.

The participants were encouraged to use more than one post-it note per theme to ensure comprehensive inclusion of and not limit the scope of the ideas. Following the conclusion of the NGT sessions and consensus being met, the number of post-it notes for either theory delivered in university or practice for each theme were then counted. This was calculated as a total for each theme from each group. The result was not always a clear decision for either theory or practice. In some instances,

theory had been stated as being simulation in particular which can have differing value placed on it as will be explored further in the discussion chapter.

4.4.1 Environment

The results for the students in each site focus group on environment for learning competencies in each theme are illustrated in table 4.2 below. This illustrates clearly that all themes contained competencies which would be suitable for university and practice; no theme was situated solely within a single learning environment. This also is in line with the nature of midwifery training which is 50% theory and 50% in practice.

Themes	Group	Environment	Consensus
Practical clinical skills	London	University: 38.5% Practice: 61.5%	Practice with simulation sessions.
	Berkshire	University: 22% Practice: 78%	Practice with simulation sessions.
Emotional and spiritual support	London	University: 50% Practice: 50%	Both theory and practice as aspects to learn in both.
	Berkshire	University: 71% Practice: 29%	Theory including simulation sessions.
Communication	London	University: 36% Practice: 64%	Practice with simulation sessions.
	Berkshire	University: 55% Practice: 45%	Practice with simulation sessions.
Paperwork	London	University: 30% Practice: 70%	Practice; guidelines and care pathways.
	Berkshire	University: 44% Practice: 56%	Practice; guidelines and care pathways.

Table 4.3: focus group outcomes

The findings will be discussed further now within each theme. The area seen as most appropriate for teaching and learning the skills within each theme in turn will be discussed so as to expand on the information in the tables above. The participants were using post it notes and themselves and as such had not written identifiers on

these. This allowed for freedom of expression using anonymity as much as was possible within the group setting. All students were in the second or third year of the course and had some experience in practice of caring for women and families experiencing perinatal loss.

4.4.2 THEME: Practical clinical skills.

The groups both found that practice was predominantly the environment where the competencies would be learned, and experience gained for this theme. This is not surprising as the theme title 'Practical Clinical Skills' would lend itself to this creation form the practical aspect of care. The specific areas where practice was seen as the most appropriate learning environment were:

'blood tests, drugs, pain relief and making memories'. (Berks)
'Understand the equipment and what it looks like' (London)
'Time with the bereavement midwife' (London)
'Practice especially when you work with an experienced midwife' (Berks)

These aspects can only take place in the practice setting and so would not be possible to cover in the theory setting/classroom. However, there were areas where university was seen as the most appropriate learning environment:

'Postmortem consent and histology, also role of the coroner' (Berks)
'How to handle babies respectfully' (Berks)
'Information on the drugs used' (London)
'Terminology' (Berks)

These aspects can be covered in the classroom; for example, information on drugs and postmortem consent is something that can be discussed. Teaching and learning occur within a theoretical setting, though they do then transfer to the practice setting as long as this link is made explicit by the teacher. It is essential that this is an integral part of the teaching and learning package in order to minimise the theory-practice gap (see section 2.4.5).

Any aspects of care within competencies which can be taught in the University setting so the baseline knowledge can then be translated to the practice setting to experience their application in reality.

4.4.3 THEME: Emotional and spiritual support

This theme was allocated to equal emphasis on university and practice in the London group and 71% to university in the Berkshire group (see table 4). There was cross over of some areas that were seen as being important in both theory and practice such as being aware of what support groups there are. This may be due to the fact that some Trusts or geographical areas may have support groups and mechanisms specific to them so not available nationally. The local provision would be learned from being in the practice area.

The areas where university was seen as the most appropriate learning environment:
'To learn the theory around cultural and religious beliefs' (London)
'Maybe a charity could come into theory to talk to us' (Berks)
'Online learning re charity support' (London)
'Look at research on what good care looks like, and what bad care is' (London)

The areas where practice was seen as the most appropriate learning environment:
'Practice good to get to know the support information and names of support groups'
'Familiarise yourself with the bereavement pack and what it has (emotional support)' (Berks)
''In many ways you need to learn on the job' (London)
'You yourself can receive emotional support from your mentor' (London)
'Witness how your midwife gives emotional and spiritual support' (Berks)

The midwife supervising the student and the student themselves can often support each other as they are both experiencing giving care to a specific family. This is an area that can only occur in the practice setting, though discussion and feedback regarding this can be encouraged in the classroom. This way best or poor practice can be discussed and made sense of in a safe space and professional discussion occur at a distance from the clinical event.

4.4.4 THEME: Communication

This is a theme that was worrying to the participating students in that they are worried they will not know what to say or say the wrong thing. Again, there was crossover of certain areas between university and practice such as learning from those with experience.
The areas where practice was seen as the most appropriate learning environment:
'Make notes on how the midwife communicates to women in practice.' (London)

'Learn from those who communicate well' (London)
'Use guidelines in practice and see how choices are communicated' (Berks)
'Learn how to use/be aware of facial expressions and all communication' (Berks)
'How to cope with silence' (Berks)

Observation of others is large part of experiential learning in clinical practice and the value the students place on that is evidenced in these quotes.
The areas where university was seen as the most appropriate learning environment:
'Simulation to practice breaking bad news' (Berks)
'Knowledge from others who have been through it themselves' (London)
'Discuss making memories, what is appropriate' (Berks)
'Simulation and role play' (Berks)
'What is effective communication, body language, tone of voice' (London)

The rationale for these aspects to be learned in university is that it is a safe space. If using group work or simulation, then mistakes can be made without causing any psychological harm to parents.

4.4.5 THEME: Paperwork

The importance of paperwork and it being filled correctly was another area that caused anxiety in the students within the focus groups. Again, there was crossover between the areas to cover in theory and practice such as the care pathway. University was a good place to become familiar with it and practice was a good place to learn how to use it in reality.

The areas where practice was seen as the most appropriate learning environment:
Time with bereavement midwife to view real life paperwork' (Berks)
'See them (certificates and forms) being filled in' (Berks)
'Use care pathway' (London)
'Flowcharts and things for the parents' (London)
Many of these aspects are specific to the practice area (vary Trust to Trust) and so the practice setting is the most appropriate area to encounter these.

The areas where university was seen as the most appropriate learning environment:
Workbook, use examples of paperwork and MBRRACE to understand what is expected'
'Proper training on stillbirth paperwork' (London)

'Read previous cases' (Berks)
'Looking through things beforehand so we know what to expect' (London)
'E-learning module' (Berks)
These aspects of paperwork are national and so would be applicable to all students regardless of where their practice placement is. This will have influenced the allocation to university for these competencies.

4.4.6 Plan for three year training programme

The participants in the Berkshire group then went on unprompted to further discuss what should be included in what year of the course so as to be suitable and complement the other content delivered within each year. The researcher allowed the discussion to continue and develop as the students were very passionate in their discussions and ideas. The students were very keen to look not only at where to learn these competencies, but how the teaching and learning would fit into the course as a whole in order to maximise learning. The outcome of this discussion was documented and summarised. Please see table 4.3 below:

Year 1	Year 2	Year 3
Classroom theory and introduction of workbook.	Simulation and continue with workbook.	Classroom theory to consolidate learning through collaborative completion of workbook.

Table 4.4: 3 year plan

The first year session should include background into why perinatal bereavement care is important including risk factors for perinatal loss and basic, key points for good practice. The introduction of the workbook was key as it was proposed it would be with the student throughout their three years and be worked through alongside the theory elements.

The second year was seen as a key point to include simulation around areas such as delivering a baby with no muscle tone and breaking bad news. This would be complemented by the workbook.

The third year was a theory session designed for the cohort to work collaboratively with each other and guided by the lecturer. As students will have had varying opportunities for experience in practice this was a way to share knowledge,

experience and learn from each other and ensure all had the opportunity to complete the workbook and have a valuable resource to take with them at the end of it.

Researcher; Critical reflection

The use of a workbook has been discussed as a useful format to support learning in healthcare education (see section 2.4.1.1). It is interesting that the students themselves not only saw the workbook format as one that they would find useful but were quite clear on the way in which it should be implemented. The integration of this to the sessions throughout their training, use in practice and then consolidation at the end of year three would supply them with a useful resource that has been completed in both practice and theory settings so addressing the theory practice gap also. The implementation of this can be supported by these findings generated from the student perspective and the content moderated to ensure the competencies form the PLPF are at its core. This offers a vital opportunity to guide the implementation of the PLPF as it needs to be fit for purpose to be useful. As a researcher this is a vital insight to gain and one to be utilised in practice.

4.4.7 Considerations: Covid effect

The covid pandemic and national lockdown in March 2020 has had a significant impact on wider society and in particular the healthcare sector as a whole. The demands on qualified staff in practice has been immense and there has been disruption to some cohorts of students having been removed from practice at the beginning and the many changes that occurred before the return to the established training progression and placements. The progress of this research has been affected by the demands on both healthcare in practice and education including the ability for participants to engage at times. This has to be considered within the context in which the research was undertaken.

4.4 Summary

Phase one has demonstrated the inconsistency present in the approach and resources given to teaching and learning in relation to perinatal loss in midwifery programmes. The time allocated to this subject as well as who delivers the session varies between HEIs and in turn can affect the quality of the session and the learning that occurs as has been discussed. This inconsistency can be directly related to the

care parents receive as this is partially dependent upon the knowledge, skills and abilities that the midwife caring for them has.

In phase two a comprehensive framework of the competencies required was developed using the Delphi technique allowing collaboration and consensus among experts in the field of bereavement care. The findings from the first round were collated into four themes. Within these themes the data was then sorted and collated into competencies related to each theme. These competencies are the format used in practice for assessment and were collated by similar topic/focus of care which also was assisted by the researcher expertise. These were then sent out as round two and there was 100% consensus agreement that these themes and competencies within each were valid. The comments within one proficiency resulted in an amendment to spend one day with a bereavement specialist midwife rather than one week which was seen as unachievable due to numbers of students and often only one specialist midwife in post.

The resultant PLPF covers all aspects of care from the clinical physical to psychological and can be adapted for other fields of nursing as it is inclusive of care of women at any gestation or postnatally. This allows for applicability across professional boundaries to include anyone involved in the care of families experiencing perinatal loss.

Phase three then captured the student voice as they are currently experiencing life in practice and theory as a learner and have valuable contributions to make when it comes to the application and implementation of the PLPF within the structure of the curriculum. Students from second and third year of the course participated. They have had some experience in practice and of teaching and learning environments and strategies so could have an informed discussion regarding best practice and environment for learning and achieving the competencies within each cluster. As this phase includes the most relevant environment to learn these competencies, whether it be in theory or in clinical practice this can further inform the application of this research and provides the basis for post-doctoral research.

The implications for the research and for future research plans in relation to these findings will now be discussed in depth in chapter 5, discussion chapter.

Chapter 5: Discussion

5.1 Introduction

It is a tragic and sad truth that not every pregnancy will result in the birth of a healthy baby. There are many policies and campaigns to reduce the perinatal death rate as discussed in Chapter 1 section 1.4, but there is still and will always be a need for high quality care for families who experience loss. As has been established in Chapter 1 section 1.2, 51-76% of all midwives on the NMC register will care for families experiencing perinatal loss. This is a significant portion of the midwives in practice. As this number includes midwives who are not necessarily in clinical roles (such as Head of Midwifery or in education) the proportion of those who have hands on clinical roles will be even higher. It was noted in the introduction by Hughes and Goodall (2013) the care received by families at the time of bereavement can have a significant and lasting impact on them and so it is crucial, that as healthcare professionals, we get it right. The healthcare professionals caring for these families require training and education to prepare them to provide holistic and appropriate care (Ellis, Chebsey and Storey et al, 2016; Robertson, Aldridge and Curely, 2011; Ravaldi, Levi and Angeli et al, 2018).

This research aimed to identify the competencies that are required to ensure that all midwives are prepared and proficient to deliver safe, holistic care to families experiencing perinatal loss. Midwives and nurses cannot be expected to be competent in perinatal bereavement care on qualification if the training has not been sufficient as to facilitate this. It has been evidenced in Chapter 1 sections 1.7.2 and 1.7.3 the inclusion of training in this area is inconsistent as such the level of proficiency of staff caring for families will reflect this. It is this inconsistency that has established the research aim and objectives for this research in order to provide an evidence-based framework to use nationally on which to base all training provision.

The findings from this research have enabled the creation of this comprehensive Perinatal Loss Proficiency Framework (PLPF) detailed in section 5.1.2 table 5.1. This also includes mapping of all proficiencies to each year of midwifery training with suggestions for implementation in section 5.1.3 table 5.2. The framework is comprehensive as it covers all aspects of care for all losses. As this is comprehensive in this way it can be adapted for inclusion in learning and teaching for healthcare workers who may not work within a maternity setting but still may come

into contact with families experiencing loss, such as Accident and Emergency, Paramedics, nurses on a gynaecology ward. Therefore, the potential application of this framework is far reaching.

5.1.2 Perinatal Loss Proficiency Framework

Theme 1: Practical Clinical Skills	Theme 2: Emotional and Spiritual Support
• Importance of still providing routine AN/intrapartum/PN care. • Knowledge of terminology and legal definitions. • Knowledge of steps to diagnose IUD. • Knowledge of blood tests performed and reasons why. • Knowledge of drugs used (including side effects) for IOL. • Knowledge of pain relief options including PCA and epidural. • Knowledge of impact of environment where families are cared for and recommendations/local provisions for this. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Know how to handle baby with respect and safely. • Knowledge of equipment available (i.e. cold cot); how to use and where located. • Knowledge of processes and equipment available for making memories including taking photographs. • Knowledge of PM consent; histology; cytogenetics; role of the coroner. • Understanding of the options for lactation suppression. • Discussion around best practice when unable to determine sex of baby. • Understand role of the Bereavement Specialist Midwife and work with them for a day.	• Understand the need for you to be patient, not give false assurances and allow parents time to spend with their baby; be parent led. • Understand that grief is individual and not governed by gestation. • Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care. • Have knowledge of all support materials available (written and online) including support groups and charities and how to discuss these with parents. • Have knowledge of contact information for relevant members of the MDT within the Trust including the Chaplaincy and the support they can provide. • Gain an understanding of the long lasting and positive effect of good care and the negative, long lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby.
Theme 3: Communication	**Theme 4: Paperwork**
• How to break bad news • Knowledge of grief reactions and individual nature of grief surrounding loss of a baby at any gestation. • How to approach discussions around making memories and wishes of parents around delivery; meeting baby. • Understand the impact of the environment on any communication; includes giving parents time to process information and make decisions. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents. • Gain an understanding of the importance of using baby's name if one is given.	• Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS. Includes understanding the importance and significance of each point (some following competencies will be covered within this but are detailed specifically at present). • Essential to know how to refer families to the Bereavement Specialist Midwife. • Understand a midwife can complete a stillbirth certificate; includes experience of how to complete this correctly and the consequences if it is not. • Understand a doctor must complete a neonatal death certificate; includes experience of how to complete this correctly and the consequences if it is not. • Have knowledge of all local paperwork available for babies lost before 24 weeks gestation; includes all transfer paperwork for all losses within the hospital and from hospital to funeral director. • Introduction to the MBRRACE form for reporting any losses to aid understanding of how this can inform and improve practice. • Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.

Table 5.1 Perinatal Loss Proficiency Framework

5.1.3 Perinatal Loss Proficiency Framework: Content mapped to 3 yr course

Year 1

Theme content	Guidance for implementation
• Importance of still providing routine AN/intrapartum/PN care. • Knowledge of terminology and legal definitions. • Knowledge of impact of environment where families are cared for and recommendations/local provisions for this. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Know how to handle baby with respect and safely. • Knowledge of processes and equipment available for making memories including taking photographs. • Understand the need for you to be patient, not give false assurances and allow parents time to spend with their baby; be parent led. • Understand that grief is individual and not governed by gestation. • Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care. • Understand the impact of the environment on any communication; includes giving parents time to process information and make decisions. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents. • Gain an understanding of the importance of using baby's name if one is given. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents.	• Map to what is already included in modules. For example when discussing AN/IP/PN care add content for caring for families experiencing stillbirth/ToPFA/NND. • Establish a teaching session(s) to deliver the content and link to future sessions to demonstrate scaffolding of learning and relevance to ongoing training. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. knowledge of how to handle a baby with respect and safely.

Year 2

Theme content	Guidance for implementation
• Understand the role of the Bereavement Specialist Midwife and work with him/her for a day. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Knowledge of blood tests performed and reasons why. • Knowledge of drugs used (including side effects) for IOL. • Knowledge of pain relief options including PCA and epidural • Have knowledge of all support materials available (written and online) including support groups and charities and how to discuss these with parents. • Have knowledge of contact information for relevant members of the MDT within the Trust including the Chaplaincy and the support they can provide. • Gain an understanding of the long lasting and positive effect of good care and the negative, long lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby. • How to break bad news • Knowledge of grief reactions and individual nature of grief surrounding loss of a baby at any gestation. • Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.	• Have links with the bereavement midwives in the Trusts so student placement with them can be facilitated. • Sim day for breaking bad news; delivery of baby with no signs of life at 20, 28 and 37 weeks gestation (demonstrate link to yr 1 content). • Summary of all tests conducted including blood and HVS for unexplained loss with rationale for these. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.

Year 3

Theme content	Guidance for implementation
• Knowledge of PM consent; histology; cytogenetics; role of the coroner. • Understanding of the options for lactation suppression. • Discussion around best practice when unable to determine sex of baby. • Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS. Includes understanding the importance and significance of each point (some following competencies will be covered within this but are detailed specifically at present). • Essential to know how to refer families to the Bereavement Specialist Midwife. • Understand a midwife can complete a stillbirth certificate; includes experience of how to complete this correctly and the consequences if it is not. • Understand a doctor must complete a neonatal death certificate; includes experience of how to complete this correctly and the consequences if it is not. • Have knowledge of all local paperwork available for babies lost before 24 weeks gestation; includes all transfer paperwork for all losses within the hospital and from hospital to funeral director. • Introduction to the MBRRACE form for reporting any losses to aid understanding of how this can inform and improve practice.	• Final teaching session (s) that consolidates prior learning and includes post mortem. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. Essential to know how to refer families to the Bereavement Specialist Midwife.

Table 5.2 PLPF mapped over three year midwifery training

The findings from each phase will be discussed from an integrated holistic viewpoint in the relation to the research aim and will include consideration as to how they can contribute to perinatal bereavement care and the education of the healthcare professionals who provide this from a national perspective. The definition of proficiency is something that is addressed in the framework as to what level of knowledge students need to attain to achieve these, but it can still be refined. Different health professionals may require a varied level of proficiency i.e. paramedic as opposed to a midwife who is the lead carer. This would be considered when implementing the PLPF within any course.

5.2 Themes

The key themes identified in relation to related competencies for inclusion, as detailed in Chapter 4 section 4.3.3 were:

Practical clinical skills: these are the areas of care that are applicable to all women including birth emergencies, and the practicalities of delivering care when a baby has died. For example, delivering a baby that has died in utero so has no muscle tone.

Emotional and spiritual support: this is the psychological care that is required when a baby dies at any gestation or after birth, including taking spiritual beliefs and needs into consideration.

Communication: the verbal, non-verbal and written communication that is important for families experiencing perinatal loss. This ranges from breaking bad news to completing necessary certification correctly and the consequences if this is not done.

Paperwork: paperwork is also linked with communication and is key to understanding the importance of the correct documentation being completed correctly in relation to completion of care pathways in order to facilitate safe care, to completing the necessary notifications and understanding the significance of this.

The analysis offers an opportunity to enable the bereavement midwives in practice to establish and confirm these are the main areas that are appropriate to be incorporated into a proficiency framework related to caring for families experiencing perinatal loss. The questions used for the Delphi technique followed the care of a pregnant woman as it is in practice; segmented in to antenatal, intrapartum and postnatal care. As perinatal loss can occur in differing ways at differing points during pregnancy or after birth this was seen to be a way to capture this. The nature of the care given is also differentiated into physical, clinical care and psychosocial, spiritual, and cultural care. An example of clinical care may be taking a blood pressure or

carrying out a vaginal examination. Psychosocial care is caring for the woman's psychological and social needs which are equally important. However, these two perspectives of care differ in the way they are fulfilled and the knowledge, skills and abilities that are required to be competent within them (Davison, Geraghty and Morris, 2017) hence the separation of these two aspects of care for the purposes of the Delphi technique and the way they integrate and complement each other will be discussed further. Whilst they are identified separately holistic care is an amalgamation of all care required and is the approach which should be employed when caring for women and families at all times (NMC, 2019). This is key to understand the PLPF in its entirety and facilitate the incorporation of the student voice from phase three (chapter four section 4.4) in a plan for implementation of a teaching and learning package. The comprehensive nature of the framework addresses the gap in knowledge and in the literature of the lack of focus on the physical, clinical care which is integrally linked to the emotional and psychological care and wellbeing of the family. The research findings not only support this but address it with practical guidance on what needs to be included and also how to facilitate the teaching and learning for the framework.

5.3 Application of findings

5.3.1 Inclusion of the student in care (practice)

These findings build on the progress already made with the recent expansion on the inclusion of bereavement care within the Standards for proficiency for midwives (NMC, 2019). This is an opportune time to review how the Perinatal Loss Proficiency Framework can be implemented within midwifery training curricula. There is no doubt that there needs to be a far greater inclusion of training linked with perinatal loss within the midwifery training programme. There is evidence that student midwives are often not given the opportunity for experience (Mitchell, 2005; Baxter and Baron, 2011; Alghamdi and Jarrett, 2016) and feel very under prepared for caring for parents experiencing perinatal loss. The proficiency framework in its current form can be incorporated into theoretical modules and practice assessment documents. Embedding the framework within both areas will also contribute towards addressing the theory practice gap (see section 2.4.5) as there is opportunity to link the content across both.

There is currently a national practice document in England called the Midwifery Ongoing Record of Achievement (MORA). The MORA is being incorporated into the

curriculum development all HEIs in England are going through as part of incorporating the new Standards for proficiency for midwives (NMC, 2019). This document has recently been updated and is to be implemented nationally. Any change will need to be presented and agreed across all HEIs and also then approved by the NMC so is a complex process. It is reviewed and updated periodically, and this is when any changes could be incorporated; it would not be possible to change this at this time until the next update, but this does not mean that the proficiency framework could not be implemented. There are proficiencies included within this that can be mapped to the proficiency framework such as

'P10.15 supporting the bereaved woman with lactation suppression and/or donating her breastmilk if wished '

(MORA, p118)

This would allow then further mapping of the remaining competencies to the module content as appropriate and relevant throughout the three year programme. The findings will contribute a clearer understanding of the competencies required to achieve the knowledge, skills that will contribute to safe care in perinatal loss. As this safe care includes both physical and psychological it is key that the PLPF is seen as a whole and implemented as such. This includes giving the student the opportunity to experience and learn in clinical practice and not be shielded from these cases as has been the case (see Chapter 2 section 2.4.2). In Chapter 4 section 4.3.5 the students in the focus groups identified which competencies within the PLPF are appropriate to learn in practice and which in university though there may be some overlap. There were a significant number assigned to learn in practice which further supported the relevance not only of inclusion of these within a practice assessment document, but equally the opportunity for students to experience caring for families at the time of perinatal loss. The desire for the students to be involved in the care and learn from the midwives they work with as found within phase three supports the literature which has also identified that students feel they do not get the experience that they need.

This research supports the inclusion of students in the care of families experiencing perinatal loss in the practice setting as is evidenced in the PLPF and the findings from phase 3 and discussed. Doherty, Coughlan, Casey et al (2018) looked at student midwives education needs and how a bereavement education workshop improved their preparedness for practice. It was noted within this study that many students found they were excluded from caring for women experiencing perinatal loss. They were actively encouraged not to, or only there to assist with doing

observations or getting refreshments. There were other instances where they may have viewed the body of a stillborn baby but had not participated in the care of the mother. This gives a disjointed and not necessarily constructive experience, and it is hard to see how this could provide a sound understanding of the care required by the parents. This study did find that though the workshop was useful the lack of exposure to perinatal loss in practice was the greatest barrier to becoming more confident in providing care.

Hollins Martin, Robb, and Forrest (2016) shared this finding. They carried out an exploratory qualitative analysis of student midwives' views on what teaching methods would improve their confidence in delivering perinatal bereavement care. Whilst the focus was on the use of a workbook the main findings of what else would aid confidence the results were increased interaction in class, reflection, and increased exposure to experience in the clinical setting. This supports again the assertion that students are not being given the opportunity to care for parents and learn the competencies required to provide perinatal bereavement care now or when they are qualified. If the competencies were part of the training programme, then this would support the need for students to have this experience in practice. This could then be guided by whether practice or university be the best area to cover the competencies in question.

5.3.2 Absence of reference to practical/clinical care: bias of focus on emotional not physical care (safe care)

While previous studies have focussed on the emotional and psychological aspects of care there has been an absence of inclusion of the physical clinical care. As discussed in Chapter 2 section 2.4.4 this may have been influenced by the aspect of care that had the greatest relevance was seen as the care after the loss. There is a variety of resources available for bereavement care education which cover some aspects of the Perinatal Loss Care Proficiency Framework but not all. The teaching package SANDS had developed (Bewley, Maher and Titherley, 2016) was formulated after a teaching session to one cohort of student midwives in their second year and their feedback informed the development of the teaching resource package. Whilst the six learning outcomes within this which do cover some similar topics such as communication, the nature of grief and grieving and midwifery skills need to provide support, the link to physical clinical care was absent.

As has been evidenced by the findings in phase two there are many more aspects to the knowledge, skills, and abilities to enable healthcare professionals to provide effective bereavement care that have been identified through the Delphi technique and resultant proficiency framework. The fact that this Perinatal Loss Proficiency Framework has been created by a set of experts with extensive specialist knowledge on the frontline and in education and supports the comprehensive nature of the findings and has built on the learning outcomes identified in the SANDS resources.

Families value having someone care for them who makes them feel safe and this is linked to the midwife themselves feeling confident in their skills and practice. The practical element of care, such as an awareness of what the baby might look like in differing circumstances or delivering a baby with no muscle tone (see Chapter 2 section 2.4.4) is an integral component of this aspect of care; the findings support the inclusion of this within any teaching and learning package. The comments from the experts who were the participants also support the importance of the inclusion of the practical aspects of care (see Chapter 4 section 4.3.6.1).

The literature around the inclusion of simulation around perinatal bereavement care which can be linked with practice (Forster, and Donovan, 2016: Colwell, 2017) and bereavement workshops (Doherty, Cullen and Casey et al 2018; Cartwright and Read, 2005; Gardiner, Kent and Rodriguez, et al 2016; Hollins Martin, Forrest and Wylie et al 2014) have shown that the result in participation was an increase in the confidence of the participants in delivering bereavement care. However, these were focussed on the care following bereavement and not the aspects involved from diagnosis through to birth. The focus is on the emotional aspects of care and communication but does not include many of the practical competencies which have been identified in this proficiency framework. To feel confident in the care of those looking after you need to feel confident in their abilities. If the midwife caring for a woman who is delivering a baby who has died in utero is confident and feel competent this will translate through the care she gives and how she interacts with the woman and her family. The development of a workbook that incorporates these elements would build on the excellent resources already available.

What has been evidenced through phase two and the proficiency framework to enable this confidence and proficiency is that both physical and psychological perspectives are essential, which is holistic care. This gap in recognition of this has been addressed by this research and is evidenced in the findings. The midwife needs

to have knowledge of the differences between delivering a live baby or a baby who has died with no muscle tone. This will enable him/her to deliver the baby competently and adjust practice as required. When the midwife can anticipate there may be differences in appearance of the baby depending on gestation and the time interval between death and birth this allows him/her to conduct the birth without having to cope themselves with any unexpected issues and so inspire confidence in the family in their care. This also enables the midwife to have adequate preparation and coping mechanisms when caring for families experiencing perinatal loss (Sheen, Spiby and Slade, 2015).

The findings from phase three which involve the voice of the learner also support the inclusion of the practical aspects of care. Section 4.3.1 emphasised the students wish to feel more confident in handling the baby and knowing what the baby would look like as much as the need to understand what good emotional and psychological care looks like. The link to using a workbook as a basis for learning throughout the entire midwifery course also links to the discussion on educational theory in section 2.1.2. An example would be the scaffolding of learning discussed (Vygotsky, 1978), building a sound base and then building on this throughout the course and as more experience is gained.

5.3.3 Focus on the emotional/psychological aspects of care

In section 2.4.3.1 we discussed the creative approaches from the literature in relation to learning the emotional and psychological care required by families. There is also a focus on this in the existing training provision as discussed in section 1.7.3 and 1.7.4. The findings of this research wholly support the need for inclusion of this aspect of care as one part of the care required. The gap identified is the effect of confidence in the physical aspects of care. This reinforces the need for a holistic approach and these aspects, whilst can be discussed separately cannot exist apart. Women and families will feel well cared for by a midwife who is confident and well prepared by his/her training to provide holistic care. If one part of this is missing (i.e. what it is like to deliver a baby with no muscle tone) this can affect the confidence of the midwife if training has not prepared them, and in turn have a negative effect on the perception of the care received by the family (Chapter 1 section 1.11.4) as has been discussed. The findings of this research not only support the existing training available but complement this by incorporating this element with the practical skills, including paperwork, to provide the resultant PLPF.

5.3.4 Importance of Paperwork

The significance of the awareness of paperwork involved from record keeping to legal documentation was a significant finding in this research which has not been identified prior to this. The element of paperwork was a separate question as this did not fit within the aspects discussed explicitly but can have a significant impact on the wellbeing of the family following perinatal loss and does link to both physical, psychological care and communication. Documentation and record keeping is a key element in the requirements of the NMC (2019) for students to qualify as a midwife and are a key element of communication between health professionals caring for a woman in pregnancy. This question was aimed at the additional paperwork required when there is perinatal loss. The documentation required varies depending on the situation and can have significant consequences, such as delaying the funeral if not completed correctly. Unless the midwife has even a minimal understanding of these consequences the importance of completion of these documents and forms, the significance of non-completion cannot be understood. If for example the funeral has to be delayed this can have an impact on the psychological wellbeing whether it is the delay or the element of having to follow up the reasons why and also contact the hospital again. This may also possibly involve having to attend to pick up the documents required if they were not ready prior to discharge. This in itself can be traumatic for either parents or a member of the family which can be avoidable. Paperwork is included as key element of care required, part of communication but is also involved in all aspects of care. That is why paperwork was included as a separate question, but this may also have influenced the emergence of it as a separate theme. It was clear that there was a common understanding of the relevant areas that participants saw as key to being included in training as there was a consistency across responses as to what these were.

5.4 Theory/practice gap

The relevance of experience to learning was discussed in relation to educational theories in section 2.1.2. In order to narrow the perceived theory practice gap, the inclusion of students in the care of families experiencing perinatal loss is key as has been discussed in section 5.3.1. The findings of this research fully support the need for integrated theory and practice so bridging this gap as much as possible is essential.

In phase three the participants have identified what aspects fit best in either university or practice and indeed some fit both. It is key that any learning strategies

bridge both areas so as to link these. This is supported by the learning theories discussed in section 2.1.2 such as Kolb (Mathieson, 2015). His theory is that understanding is not fixed but is shaped by experience and is a continuous process. Any theory delivered in the classroom must then be supported by the appropriate experience in practice. This also supports the finding that students need to be involved in the care of families experiencing perinatal loss in practice and not shielded from it. This also links to Vygotsky (1978) who proposes that the teacher can stretch (scaffold) this learning and so enable the student to reach a higher level of learning. This scaffolding is continuous so supporting the assertion by Kolb that learning is a continuous process. This continuous process must be supported by theory and into practice, so these are not seen as two separate entities but complement each other. Safazadeh, Irajpour, Alimohammadi et al (2018) found also that having the academic and practical environment very separate was a contributor to worsening the and so any link between the two will bring theory and practice realities closer together. The PLPF includes working with the bereavement midwife for a day so getting specialist input, and the lecturers actively engaging specialists in the teaching of theory sessions will assist this.

The effect of having someone who is specialist in the subject coming into the classroom and facilitating the teaching session was an element that helps to bridge this gap (Saifan, AbuRuz and Masa'deh, 2015: Power and Rea, 2016). The validity they have as a teacher and clinically current has the effect of the teacher in the class relating the theory to what is actually happening in practice at that time. This research supports the use of clinicians such as the bereavement midwife in the classroom and being involved in the training programme for student midwives and evidence from the findings of this survey is that is what is happening at present. The bereavement expertise is then linked to the follow up care required by families and may not include the clinical aspects of care as detailed in phase two of this research. These are key aspects which should not be omitted so may be an area for improvement. One solution is that the sessions are delivered by a team approach so as to complement each other and ensure the content is comprehensive. If someone has a special interest or experience in this area this may impact on the content and quality of the teaching and learning in a positive way; this may include parents sharing their stories and experiences also (SANDS, 2016). This will have some bearing on the discussion of findings and recommendations for a teaching package;

the person/persons delivering the teaching is an important component which can affect the outcome/learning opportunity.

The PLPF also supports the involvement of practice as a learning environment; how the theory practice gap is minimised could be influenced by the involvement of another aspect of practice, namely the service user. Parents who have experienced loss frequently speak at conferences and events to share their experiences in the hope that it helps healthcare workers learn and those parents who come after them get a better experience. It is the experience of the researcher to have service user involvement in the curriculum in general and also has had bereaved parents come into class to speak to the students.

5.5 Existing education provision and gaps

The findings from the survey in phase one (section 4.2.1) also support the literature where it is noted that provision of perinatal bereavement training and then bereavement care is not consistent (Siassakos, Jackson, Gleeson et al, 2017; Hollins Martin, Forrest, Wylie et al, 2013; Baxter and Baron, 2011). The findings from phase one serve to confirm these findings and further support the need for change to address this. It serves to support the literature and information regarding this at present and supports the continuation to phase two of the research.

The variance in when sessions are delivered has significance; 60% had either years 1 and 2, 2 and 3 or all 3 years of training; therefore year one is included within this. As was discussed students in year one may find an introduction useful, but they are less likely to experience caring for families who have lost a baby in practice in year one as the focus is on normality. This relates to the debate in section 2.1.1 where it is theorised that education should not be separate from life and that practical experience does complement theoretical elements of training.

This research supports not only the integration of both theory and practice elements for all aspects of teaching and learning, but also that the first year of training should involve an introduction to the subject and guided learning through a workbook. Year two was seen as a more crucial point in the three year training course which would relate to the teaching of complications and emergencies within the second year. Section 2.4.1.1 evidences the existing use of workbooks and value that they have.

The students in phase three have built on this by making the workbook and integrated element of the teaching package and classroom activity. In section 2.1.2 educational theories are discussed including Kolbs learning cycle; the workbook being integrated throughout the three years links to this in that learning and understanding is a continuous process and shaped by experience and continuous reflection on practice (Mathieson, 2015). The workbook is used in theory and practice also the providing a bridge between theory and practice so addressing the theory practice gap (see section 2.4.5).

The content of the bereavement training in care of families experiencing perinatal loss is paramount and there is no comprehensive framework to inform this and give consistency and equity across training institutions. This in turn leads to inequalities in care as not all student midwives and midwives are trained to an equitable standard, so this is the basis from which to start.

5.6 Teaching Strategies

Phase three links to research objective three: *identify teaching strategies to facilitate learning required to achieve these competencies.* Nominal group technique was the method employed for this phase which allows for the participants to take an active part in the consensus and outcomes of the research. The Perinatal Loss Proficiency Framework which forms the basis for discussion is more comprehensive than has been generated previously. This means that any research carried out on methods of teaching and learning in relation to perinatal loss bereavement is focussed on the emotional aspects of loss and care. The participants were very enthusiastic and keen to take part as they generally felt that this was an area in which they were under prepared for practice. The students were from year two and year three of their training. Year one students were not included in the invitation to take part. The rationale for this was that they had not yet experienced a full year of theory and practice and the first year has a focus on the normal physiology and practice. Therefore, it would be less likely that they had had any exposure to families experiencing perinatal loss and equally experience with women who have complications or complex pregnancies.

It was key that students from the latter part of their training were involved. These are the situations which can be more challenging and once a student has had experience with more complex cases, they can then identify what gaps there are in their knowledge. Year two and year three students who have had more experience in

practice and more input in theory may have a more extensive awareness of the gaps in training. This will also include experience of differing teaching and learning strategies throughout their training to date. As was supported by variation theory of learning (Lo, 2012) you can only know what you need to know if you also know what you don't need which comes through experiential learning and learning from others. This is reflected in the literature in which any intervention has resulted in the increased confidence or preparedness for practice which is evidenced within every piece of research included in the literature review. However, one aspect of not feeling prepared may mean that you are not fully aware of what you need to be prepared for. The focus in the literature and, for example the NBCP, on the emotional care and follow up following perinatal loss may lead to the student seeing this as the focus and not be aware of the practical aspects of care, such as birth of baby at differing gestations and how this varies, and so then not be aware that this is something they need to know.

Colwell (2017) explored the use of simulation in the training of paediatric nurses and midwives for neonatal death. The learning outcomes were related to communication, caring for the self and caring for bereaved families. Again, although these are included in the proficiency framework developed in phase two, they are only part of it and there are many more aspects of care and skills to consider. As discussed in section 2.4.1.2 there is a need to be exposed to these situations and in practice which is possibly being hindered for a variety of reasons. Warland and Glover (2019) had a focus on stillbirth in particular when examining undergraduate education for midwives. They found the time devoted to the subject was relatively small and that there was scope to improve the inclusion of stillbirth in curricula nationally. The implementation now of the Standards for Proficiency for Midwives (NMC, 2019) offer the opportunity to implement the Perinatal Loss proficiency Framework within the curriculum as new modules and content are written.

Having the competencies included is one aspect, but how these competencies translate to teaching and learning is another. As was discussed in the literature review and above there are many methods employed to facilitate this learning from art (Barry, Quinn and Bradshaw et al 2017) to workbooks (Hollins Martin, Forrest and Wylie et al 2014), workshops (Cartwright and Read, 2005) and poetry (Patterson, Begley and Nolan, 2016). What is evident from this, and the literature review is that there was not a comprehensive proficiency framework, but equally there was not a consensus to the teaching and learning approaches to use, nor how differing

approaches may complement each other. Therefore, there is also a gap in knowledge of not only the comprehensive proficiency framework, but also which teaching and learning approaches and methods would best facilitate learning. As midwifery and nursing are practical professions with the course consisting of 50% theory and 50% practice (NMC, 2018; NMC 2019) it follows that learning takes place in both these environments. It is also clear from the different approaches explored in the literature that a variety of methods would be required to fit with the variety of competencies identified as discussed in section 2.4.1. As the competencies identified within the themes range from the practical clinical care to emotional care and communication it is evidenced within the findings from phase three (see section 4.4) that a variety of approaches and learning environments would be necessary to facilitate teaching and learning for these.

Phase three covered the exploration of teaching methods but also where it would be most suitable to learn these competencies; in the practice placement or in theory blocks which are taught lectures and simulation sessions. As the practical clinical skills theme would imply from the title it follows that the findings show practice placement was where the majority found to be the most appropriate learning environment. This was not 100%, and the theory element was based around learning in simulation settings. This can count towards practice learning in nursing but is not allowed in midwifery in the UK at present (NMC, 2018; NMC, 2019). This may change as this rule is under review after the UKs exit from the European Union. However, as has been discussed, the use of simulation can give a safe place to develop clinical skills in a controlled environment.

5.5 Applicability across professions and settings

The aim had been to ensure that the Perinatal Loss Proficiency Framework was comprehensive in order to inform both pre and post registration education with regards to perinatal bereavement care. The rationale was that if the framework covers all aspects of perinatal loss this can then be amended for specific scenarios or groups of healthcare professionals. This has been done already with the National Bereavement Care Pathway (NBCP) in that there are five care pathways for differing situations from miscarriage through to sudden unexpected death in infancy. Adopting this approach would mean that the Perinatal Loss Proficiency Framework can inform modules or resources around all aspects of loss and the content relevant to that loss is then utilised for specific resources. An example would be the participant comment

'*Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone'* in the practical clinical skills theme would not be relevant for a neonatal nurse who would be caring for parents when they experience neonatal palliative care and death. This would not need to be included in the training resources specifically for them.

The themes are not clearly defined and separate from each other but do have a small degree of overlap. As an example, in the emotional and spiritual support theme participant comment: *Gain an understanding of the long lasting and positive effect of good care and the negative, long-lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby*. This can be considered in the perspective of practical clinical skills or also communication as both good care and poor care would be aspects of these themes also. The understanding of the *effect* of these aspects of care is what has placed this within emotional and spiritual care. The effect is on the psychological wellbeing of the parents and how this is affected and affects their psychological and emotional recovery after the loss. Therefore, it should be that the competencies that make up this framework should be considered as part of a whole and alongside each other but not necessarily as separate entities.

There will be some, as has been mentioned, that are applicable in some cases and not others (stillbirth and not neonatal death) and there will be others, such as the example just given which are applicable across all perinatal losses. This reflects the individual nature of loss and the vast scope of scenarios that perinatal loss encompasses. This will be discussed further in relation to implementation in the recommendations chapter. The literature is very clear in that many studies have identified that further training is necessary for those professionals caring for families experiencing perinatal loss as has previously been identified and discussed. The nature of the training required is also identified. For example, Forster and Donovan (2016) evaluated the use of simulation in the training of students in relation to bereavement care in neonatal resuscitation. This supported the role of simulation in the training, but the actual competencies required were not identified. Colwell (2017) also utilised simulation in the training for dealing with perinatal bereavement. Again, it was found that the simulation sessions enhanced practice but there was no detail of the specific competencies this would relate to. If training is to be implemented nationally in order to train all healthcare professionals to a level where all families get the bereavement care they deserve, then these have to be of a national standard. This has been identified and evidenced by the roll out of the National Bereavement

Care Pathway (NBCP). This is an initiative backed by Government and as many as twelve baby loss charities but there are still gaps in the service where this is not being implemented fully and in every NHS Trust. Recently the implementation of the NBCP has been identified as an essential action to improve bereavement care by the Ockenden Review (2022) which will hopefully have the impetus to improve the implementation of the NBCP and in turn have a positive effect on practice and the care of bereaved families.

The opportunity for the PLPF to be implemented across healthcare professions opens up further possibilities for interdisciplinary learning and training. Cartwright and Read (2005) workshops for midwives and health visitors which were designed to explore issues around clinical practice in perinatal loss. The focus was more around local and national perspectives, theory and inter-professional cooperation and professional responsibilities. This demonstrated the importance of inter-professional learning and communication between different healthcare professionals involved in care during perinatal loss. The aspect of inter disciplinary working was raised and is part of the proficiency framework participant comment: *Have knowledge of contact information for relevant members of the multidisciplinary team (MDT) within the Trust including the Chaplaincy and the support they can provide.* The role of the obstetrician in bereavement care should not be overlooked as they are an integral part of the team caring for the family and work very closely with the midwife to provide care. The proficiency framework can also be amended for use with obstetricians so as to ensure there is equity of expertise across professions. The emphasis on multidisciplinary team working has always been important and is gaining momentum. The improvement in care outcomes when a team works well together is illustrated through PROMPT multidisciplinary training which is now a standard approach to training for birth emergencies (Liberati, Tarrant and Willars et al, 2019).

5.6 Implications for practice

The use of simulation for the theory aspect was something that was seen as key for preparation for practice across all themes. The birth of a baby at differing gestations and no muscle tone is something that could be facilitated in the simulation setting. This was seen as a safe place to learn skills and facilitate discussion between the students. This concept of the safe place applied to many aspects of care from

communicating to practical skills to role playing scenarios and testing out their beliefs on their peers through classroom discussions.

In communication this came across as particularly relevant. Communication within emergency situations has long been known as a key element in safe care and as such is included in all emergency training sessions. However, in relation to perinatal bereavement communication can relate to breaking bad news. This is not necessarily and acute situation, but one that requires a skilled communicator who also is aware of the effect of the environment. Students and midwives may feel that they are very afraid of saying the wrong thing when it comes to communicating with parents who are experiencing perinatal loss. If this is done using real life scenarios in a simulated session, then this is a safe place where they can try to develop the skills without fear of causing harm to parents if they say the wrong thing.

It was also clear that the students would value the introduction to many concepts and examples of real-life scenarios, care pathway and so on before they have their first practice placement as they would feel better prepared. As was discussed previously it is not expected that a student would be participating in the care of a woman experiencing perinatal loss especially in their first practice placement. However, this cannot be guaranteed and is something that had raised anxieties within the students in the focus groups. The experience of both staff and the families was seen as a valuable resource, and this is supported by the value placed on the clinician in the classroom (Power and Rea 2016). This would support the involvement of the bereavement specialist midwife not only in the practice setting, but also coming into the classroom and delivering theory sessions. The students did not comment on the possibility of service user involvement in the theory sessions. This was surprising as service user involvement in the training of student midwives from recruitment through to graduation is very much advocated for and valued by the NMC (2019) and is an essential element of any curriculum including the approval process. It is very common for families, whether it is mum, dad or grandparents, to be involved in events such as the Transforming Loss conference as their voices and stories so powerful and a reminder of why with perinatal bereavement care it is so crucial to get it right.

Another resource which was not identified in either focus group is the NBCP in particular. Pathways were mentioned however which is positive that they are being used in practice as the students had an awareness of them. There are two e-learning

modules to complement the NBCP pathways and aid an understanding their application. These could be used to complement any teaching package which is developed in relation to the Perinatal Loss Proficiency Framework detailed in phase two. In July 2020 more than 50% of NHS Trusts had signed up to use the NBCP pathways, and the Ockenden report (2020) has included the implementation of the NBCP as an action. This underlines the importance of the adoption of this tool to support practice.

5.7 Three year course plan

One unexpected but informative finding was the discussions in the focus group that led to the students themselves devising a way in which the teaching and learning for the perinatal bereavement proficiency framework would look if implemented through the three year course. This was an interesting outcome of the discussions at the end of the focus group. The students had become very enthused throughout and were very keen to see how all the elements would fit together to include all the identified competencies comprehensively and realistically from phase two into teaching package (Section 4.3.2, table 4.3).

The workbook was seen as a constant throughout and something to complete as experience was gained and theory taught through the three years. It was a strong recommendation that the workbook had to have a sense of purpose and result in being a valuable resource that the students could then use as they started their career in midwifery after qualification. This reflects the workbook proposed in Hollins Martin, Forrest, and Wylie et al (2014). This was an interactive workbook to teach student midwives about bereavement care in clinical practice. It was found in that study that the workbook was an effective teaching method. The proposal developed in the focus group takes this resource a step further and see it as complementing classroom theory, simulation, and practice. This also reflects scaffolding where the students learn in small manageable steps and that programs using student led sessions would be highly beneficial (Nordlof, 2014). The enthusiasm shown by the students for this task demonstrated a desire to have training in perinatal bereavement care that prepared them for the reality of the situation in practice. The creation of this plan is indicative of this, and the student led nature of the endeavour should be nurtured and progressed as this may benefit the students and then, in turn, the parents that they care for. It is not in the table but experience in practice

placement would continue alongside this as the students have 50% of their course in the clinical area.

5.8 Challenges and Limitations

There are a number of limitations and challenges that were apparent throughout this research. These will be examined phase by phase initially then collectively.

The survey used in phase one survey is very high level and did not drill down into what the bereavement sessions actually cover. In retrospect this may have been more useful than the questions regarding numbers of students in each cohort though the purpose of these was to determine the size of classes as this can have a bearing on the quality of teaching and learning experience (Wright, Bergom and Bartholemew, 2019). However, more relevant would have been key concepts covered in the sessions themselves as this would enable a deeper level of comparison between HEIs and the content delivered within each course. The low response rate was also an issue which was identified by the researcher. To mitigate for this the researcher did use follow up emails as planned, though in retrospect it is possible the LME was not the best person to send the request to. They may not know the answers required without further enquiry which takes time and effort which can affect the ease with which the survey can be completed. It would have been better to identify who was responsible for delivering the sessions and send the survey to them, but there was no direct way to access this information. The LME is the only person identified within a directory (the NMC register) that it is possible to find contact details for. Therefore, they would have been the contact for finding out the information regarding the lecturer responsible for bereavement sessions. Whether requesting this information would have been more successful or not is debatable but a change that may have improved the response rate.

Phase two employed the Delphi technique which requires experts as participants. As the number of bereavement specialist midwives is still limited (SANDS, 2016) this made the pool for participants small and exclusive. It also became apparent that the during phase two many participants were frustrated as they wanted to complete the Delphi but never had enough time to give the response the attention required. It was always the demands from practice which were cited as the issue which is indicative of the workload and demanding practice environment the participants worked within. The deadline for completion was extended to mitigate for this but there was still not enough time for all to complete. Whether the findings would have been different had

there been 100% response rate is debatable. As there was 100% consensus after round one this may indicate that there was a common understanding of the competencies required without disagreement and less likely to change with further contributions. The validation round confirmed and validated the findings from round two of the Delphi. Forty three (74%) of respondents in the validation round had between 1 to15 years' experience with an average of 8.5 years in caring for families experiencing perinatal bereavement care this is an indication that the findings are valid.

The competencies identified within the PLPF are numerous and this may make application in practice challenging. They will need to be condensed and mapped to the MORA and curriculum whose modules and course delivery will differ between HEIs. The modules each HEI has, and their content will vary so it would be up to each HEI to map against their modules. The practice document within England and Ireland is now a national document so the mapping against the proficiencies in that could be more consistent. The theory practice gap is well documented (see section 2.4.5 and 5.4) and can affect the success of application of theoretical knowledge in practice. As HEIs will have variation in delivery this can affect the consistency of the application of the PLPF and the impact it has on the care parents experiencing perinatal loss receive.

Phase three was limited by the numbers of participants particularly in the London focus group. This was further compounded by the emergence of the covid pandemic which then made it impossible to repeat this focus group face to face, in the same way as had been carried out in Berkshire. This would mean that findings were not necessarily comparable between the groups, so the data obtained by the existing London focus group was examined. This can then have implications for the validity and generalisability of the findings.

The environments to facilitate learning for various competencies within the themes were identified but this has limitations. The students were placed in a total of four different Trusts for placement so did have experience of different placement areas, but only within the framework of the HEI they were undertaking the course with. Other HEIs may structure the course in different ways allowing for differing learning experiences and so this may generate different ideas or identification of teaching strategies and environments. Also, the complexity of the realities of midwifery practice may make it impractical for some of the suggested learning to occur in that

environment. Equally the application of theoretical knowledge to practice is then affected by interpretation and experience of practices within the Trust the student is placed at. These factors can all have an effect on the learning outcomes for the students and vary from one HEI to the next.

5.9 Validity of the findings

Rigor is best achieved and demonstrated through comprehensive planning, application of researcher reflexivity, and clear and honest communication between the researcher and the reader with regards to the study, methodology and its results (Johnson, Adkins and Chauvin, 2020). The researcher reflexivity has been woven through the thesis in order to be explicit in the application of this. The data tools employed in each phase have been discussed in chapter four and in section 5.8 around the challenges and limitations.

The aims and objectives of the research have guided the decision making around the data collection tools to be employed. The Delphi technique allowed experts from across the United Kingdon to participate in the research and also ensured there was equal opportunity for each participant voice and data to be included. The validation round then further validated the findings and resultant PLPF so demonstrating the robust nature of the findings and appropriateness of the methodology. The further consensus technique of nominal group technique for phase three did result in an overview of the teaching and learning strategies to be employed in that the facilitation of this in either the practice setting, or the university setting was identified. This is an area that requires further study to delve deeper into the detail of this and develop a specific strategy. This level of detail was not possible within the scope of this Professional Doctorate thesis and the findings do provide the basis for the further study.

5.10 Summary

This research has developed a comprehensive and original Perinatal Loss Proficiency Framework (PLPF). This framework is original as there was no existing teaching and learning package that encompassed all elements included in the PLPF. Implemented in practice the impact of the PLPF will be improved training for student midwives and midwives, and as a consequence an improved standard of care for parents experiencing perinatal loss.

This research has been supported by the All-Party Parliamentary Group (APPG) for baby loss and SANDs, the letters of support can be found in Appendix 10. These groups also wish to have the findings presented to them once completed. This is a significant indicator of the importance of the need for a more consistent approach to perinatal bereavement care training. It is also an indication that there is a lack of this and so that gap in knowledge. The support from influential external organisations should aid in the dissemination of findings. Also, if the findings are supported by these groups this also lends validity and acceptance of them and so will aid implementation. As SANDS deals with all aspects of perinatal loss there is scope to liaise with them to develop learning resources or modules specifically for differing professional groups such as neonatal nurses or nurses working in gynaecology as this is often where care for families experiencing perinatal loss of up to 20 weeks gestation will occur.

The findings from phase one indicate that there is a national variation on the time and resources given to teaching perinatal bereavement care within the midwifery 3yr degree programme. It has also long been recognised that what is being taught is not enough to prepare student midwives to care for families in these circumstances. The resulting Perinatal Loss Proficiency Framework developed in phase two gives a comprehensive summary of the key areas that need to be covered within the training programme. This can be utilised to form the basis of a plan which details how this will be implemented in practice.

Some of the competencies do not need to be separate as they are within the findings. These were split into themes for the purposes of demonstrating the thematic analysis through which the data had undergone, and findings been arrived at. For the practical application some may be linked to form specific teaching sessions using scenarios or case studies as has been used within healthcare education with positive outcomes. For example, the differences in delivering a baby with no muscle tone to a baby who is alive can be addressed in a simulation session. This teaching session could start with exploration of communication and breaking bad news and then lead onto the practicalities of delivery afterwards.

The scope for the Perinatal Loss Proficiency Framework to be implemented and incorporated into education delivery for nursing, midwifery and obstetricians is immense. The comprehensive nature of the framework is such that it can be amended, competencies included or excluded as appropriate, to inform education

and practice across the board. The recommendations for practice and implementation will now be further discussed in chapter 6.

Chapter 6: Conclusions and Recommendations

6.1 Introduction

Perinatal loss and bereavement care is an area that significantly impacts families and the health professionals caring for them. This is a challenging subject to discuss and even more challenging to provide the care in practice and as such it is even more important that we have these discussions and get the care right. The care provided can make an enormous difference to the families and on those providing the care. There is inconsistency and lack of equity in the education provision for this and in turn the care that families receive. This research aimed to assess the existing provision of bereavement training for student midwives, create a proficiency framework which comprehensively includes all aspects of knowledge required and to inform the training that is required and discuss how this can be incorporated into the 3 year BSc (Hons) Midwifery course. There is support for this research from the government through the APPG and families through the Stillbirth and Neonatal Death Society (SANDS) as there is national recognition that a comprehensive approach to bereavement care training in perinatal loss is not yet available and is a gap in knowledge.

6.2 Key Findings

The key findings for this research will be discussed by each phase in turn linking to the aims of the research as stated in chapter 2 section 2.8.1. The key findings from each phase are collated to inform the recommendations for implementing and impact in practice and for future research.

6.2.1 Phase one key findings

Phase one key finding was that there is variance between HEIs as to what resources, including time, are given to the inclusion of perinatal loss within the curriculum. The impact this has on care for bereaved families is evidenced in chapter one section 1.11.9 and section 1.12 as the preparedness and proficiency of staff caring for families is intertwined with the experience of care these families have. The finding that this is inconsistent then in turn means the care the families receive is not of a consistent standard which in turn affects not only how they experience care, but also how they then cope with the bereavement afterwards (see section 2.1.4).

6.2.2 Phase two key findings

Phase two key finding was the creation of the comprehensive Perinatal Loss Proficiency Framework (PLPF). There was no existing proficiency framework or training provision that incorporates practical clinical care as well as the emotional, psychological and spiritual care that parents and families need when experiencing perinatal loss. The findings also include the importance of paperwork and acknowledgement of the consequences for the family i.e. funeral arrangements impacted if these aspects were not fully understood and completed correctly. This is directly addressing the first aim of this research:

To develop a proficiency framework that incorporates the identified knowledge, skills, and abilities to be included in the 3yr BSc (Hons) Midwifery programme.

Please see table 6.1 below for the PLPF in an format ready for implementation as included in chapter 5 section 5.1.3 table 5.2.

Year 1

Theme content	Guidance for implementation
• Importance of still providing routine AN/intrapartum/PN care. • Knowledge of terminology and legal definitions. • Knowledge of impact of environment where families are cared for and recommendations/local provisions for this. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Know how to handle baby with respect and safely. • Knowledge of processes and equipment available for making memories including taking photographs. • Understand the need for you to be patient, not give false assurances and allow parents time to spend with their baby; be parent led. • Understand that grief is individual and not governed by gestation. • Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care. • Understand the impact of the environment on any communication; includes giving parents time to process information and make decisions. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents. • Gain an understanding of the importance of using baby's name if one is given. • Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents.	• Map to what is already included in modules. For example when discussing AN/IP/PN care add content for caring for families experiencing stillbirth/ToPFA/NND. • Establish a teaching session(s) to deliver the content and link to future sessions to demonstrate scaffolding of learning and relevance to ongoing training. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. knowledge of how to handle a baby with respect and safely.

Year 2

Theme content	Guidance for implementation
• Understand the role of the Bereavement Specialist Midwife and work with him/her for a day. • Discussion and knowledge of the differences of delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone. • Experience/knowledge of what a baby looks like at differing gestations including maceration: with parental consent. • Knowledge of blood tests performed and reasons why. • Knowledge of drugs used (including side effects) for IOL. • Knowledge of pain relief options including PCA and epidural • Have knowledge of all support materials available (written and online) including support groups and charities and how to discuss these with parents. • Have knowledge of contact information for relevant members of the MDT within the Trust including the Chaplaincy and the support they can provide. • Gain an understanding of the long lasting and positive effect of good care and the negative, long lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby. • How to break bad news • Knowledge of grief reactions and individual nature of grief surrounding loss of a baby at any gestation. • Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.	• Have links with the bereavement midwives in the Trusts so student placement with them can be facilitated. • Sim day for breaking bad news; delivery of baby with no signs of life at 20, 28 and 37 weeks gestation (demonstrate link to yr 1 content). • Summary of all tests conducted including blood and HVS for unexplained loss with rationale for these. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.

Year 3

Theme content	Guidance for implementation
• Knowledge of PM consent; histology; cytogenetics; role of the coroner. • Understanding of the options for lactation suppression. • Discussion around best practice when unable to determine sex of baby. • Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS. Includes understanding the importance and significance of each point (some following competencies will be covered within this but are detailed specifically at present). • Essential to know how to refer families to the Bereavement Specialist Midwife. • Understand a midwife can complete a stillbirth certificate; includes experience of how to complete this correctly and the consequences if it is not. • Understand a doctor must complete a neonatal death certificate; includes experience of how to complete this correctly and the consequences if it is not. • Have knowledge of all local paperwork available for babies lost before 24 weeks gestation; includes all transfer paperwork for all losses within the hospital and from hospital to funeral director. • Introduction to the MBRRACE form for reporting any losses to aid understanding of how this can inform and improve practice.	• Final teaching session (s) that consolidates prior learning and includes post mortem. • Link to National Bereavement Care Pathway as a teaching resource. • Map to relevant proficiencies in the MORA; establishes link with theory and practice. This also demonstrates what areas can be either experienced or consolidated in practice i.e. Essential to know how to refer families to the Bereavement Specialist Midwife.

Table 6.1 PLPF mapped over three year midwifery training

It was the aim to develop the PLPF and the validation round of the Delphi was an immensely powerful validation of the findings as the total experience in bereavement care of those participating exceeds 368yrs. There have been many valuable educational resources available, but this is the first which is created with a holistic approach and is a comprehensive framework of the knowledge, skills, and abilities that all healthcare professionals should have achieved to provide appropriate and adequate care to families experiencing perinatal loss. This is the first time the expertise of so many working with bereaved families has been collated to provide such a wide ranging and all-encompassing collection of competencies that would equip the health professional with the knowledge that they need to care for any family experiencing perinatal loss. This framework can be tailored to suit differing specialities as discussed, but for midwifery the full framework is applicable. Midwives will meet women and families at all gestations suffering all losses so need to have the skills to care for them.

The key findings for phase three address the teaching and learning strategies and environment and relate to the second aim of this research:
Develop teaching and learning strategies for implementing these competencies so that all student midwives are trained to a level of proficiency in caring for bereaved parents by the point of registration.

The way in which to tailor the education package has been explored in phase three and recommendations have emerged from this. The question of what aspects are best addressed in practice and which in theory including some discussion of how some aspects cross both. This both highlights and to some extent addresses the theory practice gap that can exist particularly in healthcare course. One way to address this is to have the experts from practice come into the classroom and deliver the theoretical component using case histories from practice. Service users can be particularly powerful when they come in to tell their stories and their experiences also to support the theoretical element.

One outcome which was unexpected was a plan for where and when the content and competencies should be placed in the 3 year course, and how an interactive workbook can be used within this to support the progression of knowledge through the years. The use of workbook, simulation and combination of theory and practice blocks demonstrates the way in which bereavement care can thread through all aspects of the course.

There is scope for a far wider and more in-depth exploration and study of this area and the findings from phase three can provide a starting point for this. This will form the basis for further research and development of a comprehensive teaching package which includes guidance on how best to implement the theory and structure course content.

6.3 Summary

The PLPF can be amended for delivery across professions; one limitation of the framework is that it is comprehensive and as such would need to be modified which may lead to key elements being excluded if not modified appropriately. Also as there are so many competencies included within this it may be challenging to implement these in practice in what is an already very full curriculum. These are challenges which can and should be overcome in order to implement the PLPF in a way that can have the maximum impact on the care for families experiencing perinatal loss. This should include nurses, medical staff and all healthcare workers who come into contact with these families. The PLPF is created with each theme containing competencies which makes it easy to take those relevant to the specific professional role in order to have the widest impact.

It is essential that there is widespread dissemination of these findings and support for implementation. Through this there can be a more standardised approach to perinatal loss in education and in practice nationally and internationally. This is essential in order to support the nurses, midwives and other health professionals providing the care and improve care for the families receiving it.

6.4 Recommendations

There are several recommendations to emerge from the findings of this research.

- There needs to be greater consistency of training provision for healthcare professionals providing care for families experiencing perinatal loss which can be facilitated by implementation of the findings from this research.
- The Perinatal Loss Proficiency Framework (PLPF) should be incorporated into all pre-registration midwifery courses.
- The PLPF should be amended for use in specialities i.e. gynaecology and incorporated into pre-registration nursing courses using applicable content. This can also support inter-professional learning.

- The PLPF should be used to create a post graduate module on perinatal loss; this should be created in conjunction with charities within the field of perinatal loss in order to gain accreditation. This can provide a basis and requirement for Bereavement Specialist Midwife qualification.
- Dissemination of findings is essential through relevant journals and presentation to APPG, SANDS and through conference or presentations.
- Funding has been approved by UWL for the creation of a Perinatal Loss Masterclass to be developed and delivered in 2022 using the PLPF.
- Propose future research using the PLPF as a basis for further exploration of a teaching and learning framework to best support the achievement of these competencies.

Chapter 7: Portfolio; Author Reflexivity

7.1 Introduction

Research is a critical element in the pursuit of knowledge and a greater understanding of the world we live in (VITAE, 2011). When undertaking any research, the researcher themselves will continuously utilise the process of critical reflection when examining the literature around their subject and their interaction with this. Critical reflection is interlinked with critical thinking and awareness that are essential skills of any researcher (White et al, 2006). To truly reflect on something is an opportunity to learn and make amendments from it, if necessary, but also to acknowledge what went well (Ghaye and Lillyman, 2010). Boud et al (1985) propose that reflection is a very active process, which consists of exploration and personal discovery, which can lead to unexpected outcomes. It is this process of learning through reflection that has shaped my progress and sometimes taken me down routes I did not expect to go. Moon (1999) discusses the process of journal writing as a way to facilitate an exploration of the self and your own personal constructs. The writing of reflective accounts of your experiences in practice has been a part of my professional career for as long as I can remember.

The purpose of this portfolio is to evidence the reflective process that I have gone through as a researcher throughout the progression of my Professional Doctorate and critically discuss and analyse this development using the Vitae Researcher Development Framework as a tool. The model I will use for reflecting is Gibbs reflective cycle (1988) detailed below.

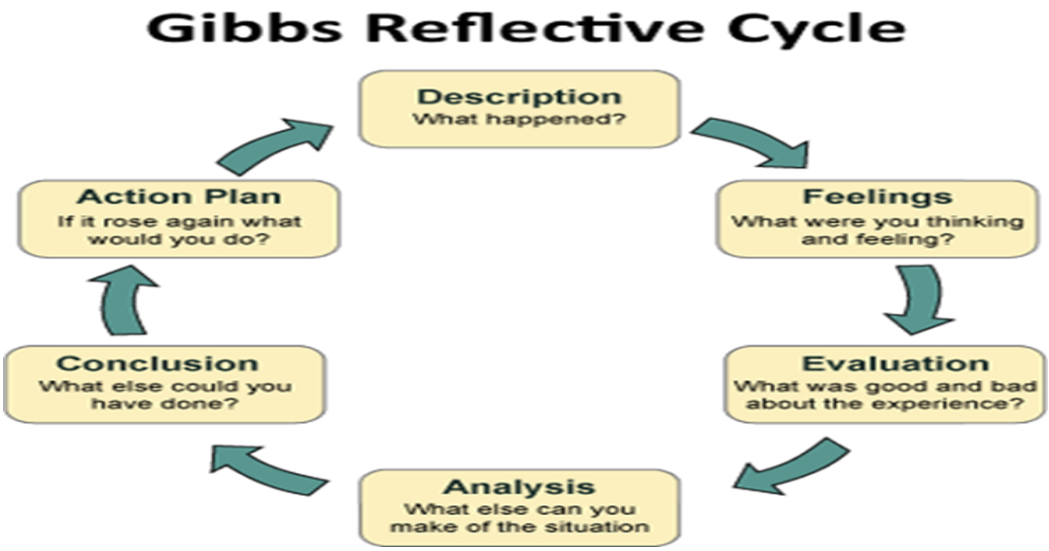

Figure 7.1: Gibbs Reflective Cycle

7.2 Impact of undertaking the study on the researcher

It is important to understand the background to the route I have taken to arrive at the focus I have for my research. Since beginning studies my research has undergone substantial revision and change. I had started with peer assessment as a subject. After initially scoping for this and trying to come up with a suitably focused research question I soon realised that this was not the subject choice that I was most passionate about which is essential in any research undertaken for a Professional Doctorate or PhD. The first subject I had focused on was student attrition. This focus came from me through my role as a midwifery lecturer. My interest in this had increased as I gained experience and encountered more students who left the programme for varying reasons. I did continue with this and complete significant reading, literature and initial research proposal. I have previously submitted a reflective piece for a previous module when researching this subject. Much within this reflection is still valid. There are references to how having leadership skills, good communication and also self-awareness can influence stakeholders, research progression and even engagement from participants. This is all transferrable and certainly not wasted time or insights. However, again the spark of interest was not enduring. My background is in high-risk midwifery, psychology and I was bereavement specialist midwife for three years. I had completed my MMedSci dissertation on bereavement care and knew when I started the doctorate that I did not want to study this further at that time. I did need a break.

Whilst having a break meant not using this subject for my research focus, I had taken over developing and delivering all bereavement teaching for student midwives at the HEI in which I work. This gave a more rounded insight and developed a keen interest within me in regard to this aspect of bereavement care; training the staff who would look after these families. I have since become further involved with the Stillbirth and Neonatal Death Society (SANDS) and realised the gaps that exist in the training and teaching available. It was when I was asked to speak at the Sands annual conference on the subject of student midwife education in bereavement care that I realised this is where my passion lay, and I no longer wanted to have a break from this. It is where my knowledge is, and I can see a way that my research would be useful and may actually make a change to improve the care that bereaved families receive through being cared for by midwives who have the knowledge they need to provide good care.

7.3 Vitae

The Vitae Researcher Development Framework (2011) is a tool for all researchers. It provides a framework to identify the knowledge, skills and attributes for a researcher to be successful. The RDF has four domains and within these it is evident that not only do the themes of engagement and communication emerge, but also that critical reflection is an essential component. The four domains are knowledge and intellectual abilities (Domain A), personal effectiveness (Domain B), research governance and organisation (Domain C) and engagement, influence, and impact (Domain D) (Vitae, 2011).

Using each domain in turn, two descriptors chosen as a framework for this reflection. The subheadings within these will inform the discussion and this will also be linked to the progression of my research.

7.3.1 Domain A

7.3.1.1 Knowledge and Intellectual abilities

As previously discussed, I have explored other subjects before concluding that researching the competencies and teaching strategies needed to equip student midwives with the knowledge, skills and attitudes required to care for bereaved parents. When exploring these subjects, it has become apparent that my expertise in caring for bereaved parents gives me a unique insight into the skills required and so to assess the knowledge base that already exists with a critical eye. I did not feel I had this with the previous subjects. I am acutely aware that there are many advances currently being made within bereavement care, which primarily are being led by SANDS. This group formed in the early 1970's but has become more structured, organised and effective within the last 5-8 years.

Having received an invitation to speak at the annual conference held by Sands, Bliss and the RCM in 2017 this raised awareness of my place in the specialty of teaching student midwives on bereavement care. This has been identified as an ideal opportunity to ask for cooperation and participation and expressions of interest in taking part. I have found that the community of health professionals involved in bereavement care are very motivated and often go above and beyond what is required of them to ensure families receive good care. It is hoped this will spill over into a desire to assist with any research, which has this as the ultimate goal. There is now a clear contribution to original knowledge in the creation of a set of competencies agreed by experts in the field and application of these. There will be a

greater opportunity to disseminate and have these adopted nationally as SANDS will support this. In this I am considering more than one perspective as the findings from my research could inform the creation of a module for post registration midwives to study also. This may also contribute to future research within the discipline of bereavement care. These are in phase 5 of the subject knowledge descriptor. It is my belief that I would never have come to the conclusions I have and made the progress with the final focus on bereavement care without first realising that some subjects I was interested in, I did not have enough knowledge or enthusiasm for to enable this progression to happen.

The last two years has been a journey of discovery regarding the research methodologies and techniques. It has taken a great deal of reading texts on the methodologies (Crotty, 1998; Creswell, 2015) and then reading reports of studies that have used these to determine what would be the most appropriate methodology for my research. This has also been altered as my ideas have progressed. I did read that you need to know what you don't need before you can fully understand what you do need (Lo, 2012). This applies to research methodologies in that you need to know what each approach will give you in terms of the information you can find from the way you can ask the questions to what form the data will take. This also relates to relates to phase 3 of this vitae descriptor in that the researcher must understand a variety of methods and appreciate the value of each. However, the usefulness of the methods chosen must be justified which I have attempted to ensure has been done in the methodology chapter I have just written. It took a great many hours of reading and then questioning my own understanding, as well as discussions with my peers, to come to conclusions.

The research question will inform all of this and that is influenced by the researcher's worldview. I have never wavered from the view that we socially construct our world and our experiences and interactions with others affect our perceptions and beliefs. Pragmatism has been identified as the theoretical perspective that best fits with the views and beliefs I hold as the researcher. It also fits with the need to use mixed methods within this study to obtain the findings in a way that will best answer the research question. There is no point using methods one is familiar with, or that may prove easier to implement, if they don't answer the question being asked. There is a need to pilot the tools created to ensure that they also are asking the question in the correct way to get the information required. This can involve carefully reading emails before sending or preparing for conversations before picking up the phone as well as

the creation of research tools. However, it is also useful to have the insight to realise when I am coming at any interaction from inside my own story and take a step back, a deep breath, and think before communicating.

I have found over the last two years it has been extremely useful to trial different techniques to understand the practical reality of them. In taught sessions this consisted of carrying out a short semi-structured interview; analysing a short recording of an interview; using NVivo to name but a few. This ties in with my belief that our knowledge is shaped by interaction and experience. The knowledge I had from reading guidance regarding semi-structured interviews did not fully prepare me for the stuttering start I had to starting to ask questions. This made me realise how well prepared you must be before starting. Equally, the time it took to transcribe a couple of minutes of interview recording, then trying to identify themes was much more difficult and time consuming than I had anticipated. I did also run a small focus group in practice as a pilot when I was focusing on student attrition. Keeping a group on task and discussing the relevant subject was challenging.

This experience has helped develop my confidence in knowing which methods are suitable including the number of participants to ensure I can realistically complete the research in the time I have. The knowledge of the reality of how long it is going to take to analyse the data from semi-structured interviews and focus groups has led to me amending my plans and reduce number of participants.

I have found that having progressed through the Professional Doctorate changing my research question and focus has meant that I have had to search for literature on each subject. Initially I made an appointment with the university academic support librarian to ensure I was searching in the correct way in order to access the information and literature I needed. The biggest fear is that you search but are inefficient with the terms you use and miss a key piece of literature. This enabled me to use terms effectively, save my searches and set alerts should new literature come onto the databases. This gave me confidence that I had the literature I needed, but also doing searches for the different subjects gave me more practice and experience using the search strategies.

Searching for literature does involve ensuring you are using the correct language (words) as does using research terms. This has been a most challenging aspect of my research progress to date. To use the research terms, you must first understand

what they mean. Texts vary in their definition, and you almost need to come to your own conclusion of how to define a term. I believe now that his is acceptable as long as the core beliefs are there, and you can justify your decision. I found when reading about pragmatism that what this term means had changed from its inception to present day and had been used loosely to allow researchers to use mixed methods. For example, Cohen, Manion and Morrison (2011) discuss pragmatism as using the methods that work to best approach the investigation, what is needed to answer the questions, but they do warn that it should not be an, 'anything goes' approach. There must be standards employed that ensure they must produce useful answers to the research questions. One of my favourite references is Guba and Lincoln (1994) who note that paradigms can be seen themselves as human constructions; the limits we place on quantitative and qualitative research are constructions in themselves. This helps me understand the variations within definitions. This all relates to LO 5.

When reading the researcher development framework and choosing which descriptors to use for my reflection I really felt that creativity was central to the role and development of myself as a researcher. Again, the progression through ideas has assisted development in this area, as I have had to constantly question myself as to why I have chosen a subject and also justify any change to my peers, lecturers and supervisor. This cannot happen without having an inquiring and questioning mind. Equally I have had to defend my ideas which includes testing the boundaries, as we were constantly encouraged to open our ideas up for discussion in class. This can leave you feeling quite vulnerable as what makes sense in your own head does not always seem so logical when you say it out loud!

However, I feel confident enough in myself as a person that I am willing to be open to criticism and at times continue the discussion and question the criticism. Looking reflectively over my working life and academic experience I believe this has developed through my practice as a midwife and then as a lecturer. I have always had to be able to defend my decisions in practice and plan of care. Equally, when I began as a lecturer the students are often ready to challenge information you present, and you need to have confidence in your knowledge. The one aspect that has really made me open up further is the realisation is that a large part of this is being able to admit you don't know something or accept when you are wrong without allowing negative feelings to stunt your progress and development.

Throughout the Professional Doctorate we have been encouraged to develop new and inquisitive ways of thinking by being challenged. I have now found that colleagues who are also studying whether at the same stage as me or a year behind do come to ask my advice or discuss their ideas with me. This is evidence to me of my own progression as I relish the opportunity to discuss and debate regarding all aspects of research. My growing confidence is what led me to supervise a dissertation student as this offers further opportunities for this debate, which involves a great deal of reading and improving understanding. The key part for me with any growing confidence is always to check myself that growing confidence does not mean I start to think I know it all. I always question myself as I am conscious of missing something, this was developed by the constant reflecting and questioning practice as a midwife. These are all skills that involve critical analysis that relates to LO 1.

7.3.2 Domain B

7.3.2.1 Personal Effectiveness

As previously discussed, I had recognised that my passion did lie within the remit of bereavement and perinatal loss and so this guided my progress through the initial subject change. I'm finding now, as is in phase 3 and 4 that this is inspiring others. There are now ideas generated by students I have worked with around supporting students who return to training after perinatal loss, and midwives returning to practice after perinatal loss.

With regards to perseverance the setback of changing subject was something that did at first affect my progress. However, I realised that I had to focus on the transferrable skills and knowledge from the work I had completed already and not on the negatives. I realise now this is what helped me make that change and see that it was still possible to continue and complete the Doctorate in the timeframe I had given myself. The self-reflection aspect of this sub domain is essential in my professional life as a midwife. It was a natural development to continue this in my life as a researcher and has supported the development of my research from ideas to planning the execution of each phase and how to analyse the data. It is part of clinical practice where a plan of care is made there should also include a plan for evaluation of this. It was key to transfer this planning to my research so that I amended my plans for execution of each stage as progress was made. A Plan Do Study Act (PDSA) cycle (NHS Improvement, n.d) was invaluable in this process and gave structure to my actions.

Self-confidence falls within this domain and part of this is developing the skills required to defend my thesis when it comes to my viva, or indeed any professional discussion around my research and findings. This has been encouraged from the start of my studies and I can really see the value in this now. Engaging in a discussion regarding the teaching and learning resources already available and why my research with add to this, not replicate has been one of my favourite things. This has required the development of confidence in my own ideas and research and the value that it has. It can be difficult to accept that you do have the right to be in the conversation, and that your ideas and the information you generate are valid and valuable. The confidence to accept this comes from confidence within your knowledge base and understanding of the subject which is another reason why changing to bereavement relating to perinatal loss was a positive change. This is a subject that I am passionate about, but also have a great depth of knowledge. The caveat to this is not to be too blinkered by your own knowledge and expectations that you are not open to new ideas or unexpected outcomes. The insight and awareness that this is a drawback should be enough to mitigate for it.

Time management skills are essential, and this becomes more apparent as the research progressed and moved on from taught modules. The meetings with my supervisors provided the essential deadlines that I require. As my work is extremely busy it was a balance between managing day to day work and ensuring time was allocated for the research. When carrying out the research this was not such a problem for me as I was scheduling in and doing tasks which involved others. Reflecting on this, because it involved others and therefore meant that they had to schedule in time to their day I would make every effort to ensure arrangements were not changed. When it comes to the writing up stage it was easier to be distracted by other tasks or make excuses around why I did not have time. We have had a curriculum reapproval with UWL and the NMC which was a huge piece of work, and also there has been the covid pandemic. This is still ongoing and has caused an enormous amount of work for us around our midwifery students in practice and moving to online teaching. At that time the only flexible area was my research and the focus had to change away from this to the immediate situation for some months.

Whilst the pandemic continues, I have become more responsive to the situation, another aspect to this domain. Responsiveness is discussed in relation to opportunities; to me this means not just seeking opportunities but also amending

plans to maximise the opportunity you have in extreme situations such as the pandemic we are in. The way technology has now been incorporated into working and everyday life has had some benefits. It is possible to arrange a supervisory meeting as required via MS Teams. This has enabled all parties to meet and discuss 'face to face' when this has been previously more difficult to arrange. It has also meant that I have been able to meet in this way with i.e., SANDS representatives to discuss ongoing progress so as to maintain those external relationships also.

My career development is intrinsically linked with my research as I am on an academic career path. I have realised that I did need to move career family so as to enhance the role research plays in my career (the emphasis on it) and also to open the possible progression to Associate Professor and Professor. I have identified post-doctoral research that I wish to continue with when the Professional Doctorate is complete and had discussions around this already. This will contribute to establishing my reputation within the discipline and professional community.

7.3.3 Domain C

7.3.3.1 Research Governance and Organisation

This domain is focused on not only how you conduct and organise your research activities but also on professional conduct. As a midwife I am very familiar with being guided on professional conduct by the Nursing and Midwifery Council (NMC) Code of Professional Conduct (2018). Therefore, I am very conscious of my actions and whether they are professional or not. This is something I am particularly aware of around all forms of communication. This awareness is transferrable, and I do apply it in my research. Given the nature of my focus on perinatal bereavement, it is even more critical that all language used is sensitive and appropriate.

In regard to research management, it has taken a great deal of reflection and modification of my project to finally get to the point of undertaking the research as I have previously discussed. The use of PDSA cycles were invaluable and having that structure to follow meant that the process was very clear and so assisted with my communication of this. If I could change anything so far it would be that I had come to the realisation that I was going to change my focus sooner. I have already discussed that I did have to go through the process and experience that I did to come to understand that a change was necessary so possibly this happening earlier would not have been an option anyway.

7.3.4 Domain D

7.2.4.1 Engagement, Influence, and Impact

This domain has a focus on the attributes and knowledge that a researcher needs to be able to engage and work with others including an understanding and aim for the research to have impact on society. I have taken my research to the All Party Parliamentary Group (APPG) on baby loss and SANDS, both of whom have given written evidence of their full support. This was beneficial in that relevant groups agreed that the research was necessary (so a gap in knowledge was agreed) but also that there was an awareness and an agreed support for dissemination of findings once complete. This relationship building aids the influence and impact of my research beyond the world of academia and into clinical practice where change is needed.

On reflection of the progress my research has made it has become more salient that there are varying perspectives which require further investigation. By this I mean further study into the teaching and learning approaches that best suit the proficiency framework generated by this research to enable the impact from this to be maximized. Equally through discussion with peers and stakeholders the needs of health professionals returning to practice after perinatal loss has evolved into something that requires further investigation as there is a gap in knowledge and policy. It is exciting to realise that the research I am completing for my Professional Doctorate can have an impact on practice around perinatal loss and the families this affects, as well as stimulation of further research and impact on practice from this.

7.4 Academic output and impact

Presented research proposal at SANDS/BLISS/RCM joint annual conference: Transforming Loss in Sept 17 (see Appendix 11).

Presented findings to date and validation round undertaken at SANDS/BLISS/RCM joint annual conference: Transforming Loss in Sept 18 (see Appendix 12).

Presented findings to date at the UWL Research Seminar in October 2018 (see Appendix 13).

Presented findings and plan for implementation at the National Bereavement Midwife Forum in London in October 2018 (see Appendix 13).

Presented research to UWL Research Conference July 2019 (see Appendix 14).

Journal output:

Jones, J. (2018) Care after Pregnancy Loss. *International Journal of Birth and parent Education.* 6:2. (see Appendix 15).

The development of a new curriculum through the updated Standards for Proficiency for Midwives (NMC, 2019), a change in role to Course Leader, approval for and development of the Midwife Degree Apprenticeship and then the covid pandemic have all had an impact on my being able to have time to complete my thesis and create further outputs. However this has not stopped the efforts to ensure there is impact from the findings.

7.4.1 Impact on practice

I am a senior midwife on the Ockenden Review since January 2019 and have contributed to case reviews and report writing which has had a significant effect on maternity services and practice including bereavement care. This is shortly coming to conclusion this year with the publication of report two.

I have met with SANDS on 30th April 2021 to discuss using the PLPF to inform the creation of a postgraduate, post registration module for delivery at level 6 or 7. The aim after discussions is that this module would be supported by SANDS and have the seal of approval from them. This could be modified for delivery as a supporting qualification for a bereavement midwife role or for professional development for nurses and midwives and also obstetricians. This module will be created in line with UWL quality processes and standards, as well as complying with SANDS standards and approval. The All Party Parliamentary Group on baby loss that has supported this research has been informed of findings and I am awaiting a date to present these to them. I am meeting with SANDS again as preparation for this module has begun and it is planned for launch in September 2022.

Funding has been approved by UWL for the creation of a Perinatal Loss Masterclass to be developed and delivered in 2022 using the PLPF. This will be aimed at inter-professional learning so attendance will be encouraged form all healthcare

professions who will participate in caring for families experiencing perinatal loss. The invitation to attend can also be extended to service users through Maternity Voices Partnership, SANDS and other appropriate organisations.

The impact on practice through training and dissemination has the potential for promoting best practice nationally for parents experiencing perinatal loss. The promotion of the module including support for this from SANDS and using the National Bereavement Care Pathway as a learning resource within this has the potential for standardising the level of proficiency for all health professionals and practice environments in order for parents to receive the care they need. I am incredibly passionate regarding this after having cared for so many families over the years and experiencing first-hand what effect good and poor care can have on them.

7.4.2 Impact on researcher

As the researcher the impact of carrying out this research has been two fold. Firstly there is the impact of being immersed in the world of perinatal loss. This is something I am familiar with after working clinically as a bereavement specialist midwife, so I have coping mechanisms and opportunities to debrief that I have previously established. The real difficulty was being able to lift myself from the clinician focus to a researcher focus and have a more strategic view of why this research is needed and establishing the link to theoretical knowledge underpinning this. It has been a struggle at times particularly for my supervisors who have encouraged me unwaveringly, though I am sure were frustrated many times!

The impact of having to find the time and energy to complete this research have at times proved harder than anything. There have been personal and very traumatic events as well as the pandemic and all that brought. It has taken so much longer than anticipated though that may be my unrealistic expectations. With hindsight it is good to set deadlines but not set these which are destined to fail. This does nothing but discourage and at times cause despair. My close colleagues, family and supervisors have been very instrumental in supporting me through to the finish.

7.5 Implications for the research

Reflection is an essential part of any research and an important tool for the development of the researcher. It is through this reflection that new ideas and ways of thinking development and so innovative ideas. Without these ideas for new

research would be few and far between. Throughout my studies on the Professional Doctorate, I believe my knowledge, confidence and inquiring nature has developed. It has been a long progression of reflection, change and evolving ideas to arrive at my focus now on bereavement care in perinatal loss. However, through reflection I understand and believe that I would not have arrived at this point without having first gone through the stages and ideas that I have. It has all enriched my understanding of research, what it means and what is needed to be a researcher. I have planned my next steps, and I must ensure that reflection is part of that process through to the conclusion of my study and beyond. I have a meeting with SANDS in March 2022 to commence the creation of the Perinatal Loss PG module to be developed with their involvement and support. This begins the use of the PLPF to influence training and practice for midwives and further training and integration to nursing programmes will continue from this.

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Appendix 1: Participant emails, phase one.

Good afternoon,

My name is Julie Jones and I am a Senior Lecturer in Midwifery at the University of West London. I am currently undertaking research into the training required by student midwives to achieve competency in providing bereavement care at the point of registration. The research is supported by the Stillbirth and Neonatal Death Society (SANDS), and the All Party Parliamentary Group (APPG) on Baby Loss.

I am now embarking on **Phase 1** of the research which involves undertaking an exploratory survey into the training included in the BSc(Hons) midwifery (3yr) course throughout the UK at present. **I will shortly be emailing a link to a survey conducted through Survey Monkey, which has only 6 questions. I would be extremely grateful if you could take a few minutes to answer these questions.**

Phase 2 involves using a Delphi technique to collate answers from experts in the field of bereavement care. The aim is to develop a proficiency framework that incorporates the identified knowledge, skills and abilities to be included in the 3yr BSc(Hons) Midwifery programme. If this is something you would like to be involved in, or know someone with expertise who would like to be a participant, then please let me know and I will send further information about the Delphi technique and what is involved.

I have already been invited to discuss the proficiency framework with the NMC once the first draft of the new pre-registration standards have been written and also present findings and invite discussion at the next Transforming Loss Conference in September 2018.

Your participation in Phase 1 is an essential part of this research and as such is highly valued. I appreciate your time and consideration and will email the link to the survey tomorrow with further instruction.

Kind regards,

Julie

Julie Jones

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Appendix 2: Participant email, phase two.

I (Julie Jones) am a midwifery lecturer and former bereavement specialist midwife undertaking research as part of a Professional Doctorate in Health Sciences. The research aims to answer the following question; 'What knowledge, skills and abilities constitute competence in caring for bereaved parents experiencing stillbirth or neonatal death and how can these proficiencies be developed in student midwives undertaking the 3yr BSc(Hons) Midwifery programme.' These could be transferrable to a post gradate module in bereavement care. At present there are no nationally recognised, structured proficiencies required to be completed by BSc(Hons) Midwifery students specific to bereavement care. The purpose of this research is to formulate a competency framework for bereavement care for parents who suffer a stillbirth or neonatal death. This is phase 2 of the research that is designed to produce a competency framework as agreed by a large number of experts from across the UK. The ultimate aim is that more parents will receive the bereavement care they need.

To make this valid and comprehensive it is essential there is participation from experts in the field of bereavement care for parents who have lost a baby through stillbirth or neonatal death. I am contacting you as I would consider you to be such an expert and would really value your input.

The participant information sheet provides further detail of what is required and how to contact he researcher to become a participant and the consent form that you will need to sign and return. If you have a colleague whom you consider would be a suitable participant then please forward this information to them and copy me in. The more expert voices that are heard the better.

I look forward to hearing from you ideally within the next week. I appreciate this is a short time but the aim is to bring the findings to the NMC before the final draft of the new pre-registration standards for midwifery education are completed. Thank you so much for your time and consideration.

If you have any queries regarding this please do not hesitate to contact me.

Kind regards,

Julie

Julie Jones

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Appendix 3: Participant information and consent forms.

Participant Information Statement; Phase 2.

What knowledge, skills and abilities constitute competence in caring for bereaved parents experiencing stillbirth or neonatal death and how can these competencies be developed in student midwives undertaking the 3yr BSc(Hons) Midwifery programme.

An invitation to take part in this research study: Phase 2.

You are invited to take part in a research study. Before you decide if you would like to participate you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You can ask any questions to clarify any points and if you would like any more information, please ask. Take time to decide whether or not you would like to take part.

What is the research study about?

At present there are no nationally recognised, structured competencies required to be completed by BSc(Hons) Midwifery students specific to bereavement care. The purpose of this research is to formulate a competency framework for bereavement care for parents who suffer a stillbirth or neonatal death. This is phase 2 of the research which is designed to produce a competency framework as agreed by a large number of experts from across the UK.

The research study is being carried out as part fulfilment of the Professional Doctorate of Health Education programme. This will result in a thesis that aims to answer the research question.

Why have I been invited?

The Delphi technique method requires experts in the field to take part in 3-4 rounds of completing a questionnaire using their knowledge, skills and experience to come to a consensus agreement as to what a comprehensive competency framework should consist of. You have been invited as you are an expert in the field of bereavement care following stillbirth or neonatal death.

Do I have to take part?

No. It is up to you to decide if you want to take part. Participation is entirely voluntary and you are under no obligation to take part in the study. If you decide to take part, you will be given a consent form to sign to show that you agreed to take part. You are free to withdraw at any time, without giving a reason. Taking part in the study will not affect your practice or

employment in any way as anonymity between participants and in dissemination of results is maintained.

What will happen to me if I take part?

You will be asked to complete round 1 of the Delphi technique by answering set questions regarding what competencies should be required to be completed by student midwives to achieve competency in bereavement care by the end of training and at the point of registration with the NMC. The results of this are collated by the researcher and sent out for further discussion/clarification by participants. This is then repeated until consensus is reached on what the core competencies should be. This can take up to 4 rounds and does require a certain degree of commitment from the participant. Up to 4 weeks is given for the completion of each round.

What will happen if I want to withdraw from the study?

If you withdraw from the study all the information and data collected from you, to date, will be destroyed and your name will be removed from the study files.

Ethical approval

The study has been given ethical approval by The Research Ethics Committee of the University of the West of London and in line with the University of West London Research Governance Policy 2015. SANDS (Stillbirth and Neonatal Death Society) have also given their support to this study.

How will the data be collected?

The data will be collected electronically by emailing the completed Delphi technique to the researcher. Your identity will be known to the researcher but anonymous to all other participants. Your identity will not be used in any way for the purposes of the research.

How will the data be stored?

The data will be stored on a locked and passcode protected memory stick; password protected file on a laptop.

Can I be identified from the data?

No. All information which is collected from you during the course of the research will be kept strictly confidential, any information which leaves the university will have your name removed so that you cannot be recognised. Your identity will remain anonymous to everyone except the researcher throughout the research process. Hard paper and recorded data will be stored in a locked cabinet, within locked office, accessed only by researcher. The electronic data will be stored on a password protected computer known only by researcher.

The survey responses will be assigned a unique reference code. This code will be used during the research study. A master list identifying participants to the research codes data will be held on a password protected computer accessed only by the researcher. Your name will not be used on any research data or on any subsequent journal publications or any articles. All quotations used in any publications or articles will be anonymised.

The latest data protection guidance will be followed and all data will be stored and used in accordance with the Data Protection Act 1998. Any electronic data stored on computer will be password protected. After the study, the transcripts will be stored in a locked cupboard or filing cabinet for up to five years and then the data will be destroyed in line with the data protection act.

What do I do next?

If you wish to take part in this study, please read all the information carefully before making a decision. If you have any questions or if you require any further clarification, please contact Julie.jones@uwl.ac.uk or the research student's supervisor Rowan Myron (rowan.myron@uwl.ac.uk). If you decide to take part in the study, please contact Julie Jones by e-mail to inform her. Please read and sign the enclosed consent form; print and sign. Can you then please e mail a scanned copy of the signed document.

Contact details:

Professional Doctorate Research student: Julie Jones; Julie.jones@uwl.ac.uk

Supervisor to research student: Rowan Myron; rowan.myron@uwl.ac.uk

Thank you for taking the time to read this information sheet.

Consent Form

Primary research study to examine: What knowledge, skills and abilities constitute competence in caring for bereaved parents experiencing stillbirth or neonatal death and how

can these competencies be developed in student midwives undertaking the 3yr BSc(Hons) Midwifery programme.

	Tick box if applicable
1. I agree to participate as a volunteer in this study	☐
2. I have read and understood the information sheet for the study	☐
3. I have had time and opportunity to consider and understand the information provided	☐
4. I have had the opportunity to ask questions related to all aspects of the study, and have had my questions answered satisfactorily.	☐
5. I agree to participating in a Delphi technique that will be completed by electronic files.	☐
6. I agree to the use of anonymous quotations related to this research, and I understand that these may be used in other publications related to this study.	☐
7. I agree that my participation is voluntary and that I can withdraw at any time, without giving any reason for my withdrawal or notification.	☐
8. I understand that withdrawing from the research study will not result in any adverse consequences to my practice or employment.	☐
9. I understand that withdrawing from the study will not affect my future within the field of bereavement care.	☐

Name of participant Signature of Participant ☐

_____ _____ Date

Name of researcher Signature of Researcher Date

☐

Appendix 4: Delphi technique round one.

Delphi technique

Round 1 Questions.

Please answer all questions with as much information and detail as you can so as to ensure the findings are as valid and comprehensive as possible.

1. What clinical skills/aspects of clinical care do student midwives need to achieve competency in when caring for a woman and her partner with IUD antenatally?

2. What clinical skills/ aspects of clinical care do student midwives need to achieve competency in when caring for a woman and her partner with IUD during labour?

3. What clinical skills/ aspects of clinical care do student midwives need to achieve competency in when caring for a woman and her partner with IUD/stillbirth at the time of birth?

4. What clinical skills/ aspects of clinical care do student midwives need to achieve competency in when caring for a woman and her partner with IUD/stillbirth/NND postnatally?

5. What do student midwives need to know and achieve competency in when caring for the emotional and psychological needs of a woman and her partner with IUD antenatally.

6. What do student midwives need to know and achieve competency in when caring for the emotional and psychological needs of a woman and her partner with IUD during labour?

7. What do student midwives need to know and achieve competency in when caring for the emotional and psychological needs of a woman and her partner with IUD/stillbirth at the time of birth?

8. What do student midwives need to know and achieve competency in when caring for the emotional and psychological needs of a woman and her partner with IUD/stillbirth/NND postnatally?

9. Are the above competencies applicable when caring for women undergoing termination of pregnancy for fetal abnormalities?

10. Are the above competencies applicable when caring for women experiencing fetal loss before 24 weeks gestation? If yes from what gestation?

11. What are the key aspects of the paperwork required after IUD/stillbirth/NND that you consider student midwives should be aware of and therefore should be included in any competency framework.

Appendix 5: Delphi technique round 2.

Delphi Round 2

The themes below have emerged from a consensus of expert opinion in Round 1. Within each identified theme there are sub themes that have been identified by you and your peers to be included in the competency framework; please indicate whether you agree or disagree about each statement and please do give your reasons (at this stage, the reasons why you may agree or disagree are just as important in the process).

Practical Clinical Skills

The first set of sub themes deal with practical clinical skills, please give your opinions on the importance of including -

- Importance of still providing routine AN/intrapartum/PN care.

Agree/Disagree Reasons:

- Knowledge of terminology and legal definitions

Agree/Disagree Reasons:

- Knowledge of steps to diagnose IUD

Agree/Disagree Reasons:

- Knowledge of blood tests performed and reasons why.

Agree/Disagree Reasons:

- Knowledge of drugs used (including side effects) for IOL.

Agree/Disagree Reasons:

- Knowledge of pain relief options including PCA and epidural.

Agree/Disagree Reasons:

- Knowledge of impact of environment where families are cared for and recommendations/local provisions for this.

Agree/Disagree Reasons:

- Discussion and knowledge of the differences delivering a baby who has died at differing gestations up to term and effect of lack of muscle tone.

Agree/Disagree Reasons:

- Experience/ knowledge of what a baby looks like at differing gestations including maceration; with parental consent.

Agree/Disagree Reasons:

- Know how to handle baby with respect and safely.

Agree/Disagree Reasons:

- Knowledge of equipment available (i.e. cold cot); how to use and where located.

Agree/Disagree Reasons:

- Knowledge of processes and equipment available for making memories including taking photographs.

Agree/Disagree Reasons:

- Knowledge of PM consent; histology; cytogenetics; role of the coroner.

Agree/Disagree Reasons:

- Understanding of the options for lactation suppression.

Agree/Disagree Reasons:

- Discussion around best practice when unable to determine sex of baby.

Agree/Disagree Reasons:

- Understand the role of the Bereavement Specialist Midwife and work with him/her for a week.

Agree/Disagree Reasons:

Emotional support including sources of support for parents and staff.

The second set of sub themes deal with the emotional support for parents that is often needed, please give your opinions on the importance of -

- Understand the need for you to be patient, not give false assurances and allow parents time to spend with their baby; be parent led.

Agree/Disagree Reasons:

- Understand that grief is individual and not governed by gestation.

Agree/Disagree Reasons:

- Ensure cultural and religious beliefs are acknowledged and incorporated into plan of care.

Agree/Disagree Reasons:

- Have knowledge of all support materials available (written and online) including support groups and charities and how to discuss these with parents.

Agree/Disagree Reasons:

- Have knowledge of contact information for relevant members of the MDT within the Trust including the Chaplaincy and the support they can provide.

Agree/Disagree Reasons:

- Gain an understanding of the long lasting and positive effect of good care and the negative, long lasting effect of poor care. Includes understanding the longevity and uniqueness of the loss of a baby.

Agree/Disagree Reasons:

<u>Communication</u>

The third set of themes deal with communication skills, please give your opinions on the importance of -

- How to break bad news

Agree/Disagree Reasons:

- Knowledge of grief reactions and individual nature of grief surrounding loss of a baby at any gestation.

Agree/Disagree Reasons:

- How to approach discussions around making memories and wishes of parents around birth; meeting baby.

Agree/Disagree Reasons:

- Understand the impact of the environment on any communication; includes giving parents time to process information and make decisions.

Agree/Disagree Reasons:

- Experience/observe sensitive communication including how to offer choice and be sensitive to cultural and religious needs of parents.

Agree/Disagree Reasons:

- Gain an understanding of the importance of using baby's name if one is given.

Agree/Disagree Reasons:

<u>Paperwork</u>

The last set of themes deal with the importance and relevance of paperwork required, please give your opinions on the importance of -

- Become familiar with the care pathway used locally and the National Bereavement Care Pathway led by SANDS. Includes understanding the importance and significance of each point (some following competencies will be covered within this but are detailed specifically at present).

Agree/Disagree Reasons:

- Essential to know how to refer families to the Bereavement Specialist Midwife.

Agree/Disagree Reasons:

- Understand a midwife can complete a stillbirth certificate; includes experience of how to complete this correctly and the consequences if it is not.

Agree/Disagree Reasons:

- Understand a doctor must complete a neonatal death certificate; includes experience of how to complete this correctly and the consequences if it is not.

Agree/Disagree Reasons:

- Have knowledge of all local paperwork available for babies lost before 24 weeks gestation; includes all transfer paperwork for all losses within the hospital and from hospital to funeral director.

Agree/Disagree Reasons:

- Introduction to the MBRRACE form for reporting any losses to aid understanding of how this can inform and improve practice.

Agree/Disagree Reasons:

- Gain understanding of the processes within the Trust for ensuring all future appointments (USS, AN) are cancelled; CMW informed.

Agree/Disagree Reasons:

Finally, if you can consider this last question

All competencies apply to losses at any gestation (so can be applied to nurses working in gynaecology) and all families of babies lost through termination for abnormalities.

Agree/Disagree Reasons:

Thank you very much for your time and thought, they are very valuable to us in developing these competencies.
If you have any questions please don't hesitate to contact me at Julie.jones@uwl.ac.uk

Appendix 6: Literature Search Strategy

Databases searched

CINHAL

Medline

Academic Search Elite

Psych Articles

Psychinfo

ERIC

Maternity and Infant Care

NICE Evidence

Domain 1:

Midwife OR midwives OR midwifery OR student midwife

OR

Nurse OR nurses OR nursing OR student nurse

Domain 2:

Competency OR competencies OR competent (* for all terms)

OR

Knowledge OR knowledgeable

OR

Training OR trained

OR

education

Domain 3:

Bereavement OR bereaved

Domain 4

Stillbirth OR stillbirths OR stillborn OR still birth

OR

Neonatal death

OR

Perinatal

OR

Dead baby in utero

OR

Childbirth

Appendix 7: Ethical Approval

Ms Julie Jones

Student no: 21133268

College of Nursing, Midwifery &

Healthcare
Research Ethics Panel
Paragon House
Boston Manor Road
Brentford TW8 9GA
Tel: +44 (0)20 8209 4110/4145
Email: cnmh.ethics@uwl.ac.uk

8 March 2018

Dear Julie

Re: Application for Ethical Approval UWL/REC/CNMH - 00306 - *Competency in Bereavement Care: Stillbirth and Neonatal death: What do Students need to know?*

Thank you for sending in your application for approval. The Panel has considered this and approved the research. However, please make the following amendments to your consent forms before they are distributed:

Recruitment and Information to Participants

- Consent forms: Phase 2 and 3 – please amend to include a statement suggesting the content will be confidential
- Please amend to include a date by which the candidate can withdraw their consent/data
- Consent form Phase 3: Please add statement that the candidate is consenting to the interview being audio recorded.
- Please add to the consent form that the audio recording will be deleted once transcribed, and then stored in a protected space.

Please also send us copies of the amended forms by 22 March 2018 via the CNMH.ethics@uwl.ac.uk address.

If the research does not progress, or if you make any changes to your research proposal or methodology can you please inform the Committee in writing as this may entail the need for additional review. It is your responsibility, as the principal investigator, to submit a report on the progress/completion of the research twelve months from the date of this letter. The Committee wish you well with your research and look forward to your report.

Yours sincerely

Heather Loveday

Professor Heather Loveday
Director of Research
Richard Wells Research Centre
Joanna Briggs Institute Collaborating Centre
Email: heather.loveday@uwl.ac.uk

College of Nursing, Midwifery and Healthcare

Minor Amendments to Ethical Approval

- Please use this form if any changes are made to the project (you do not need to amend the original application form: if major changes are required a new application may be necessary).
- Research Students: please ensure that your Director of Studies checks and approves this amendment.
- Please also attach any documents that need to be changed as a result of this amendment (consent form, risk assessment etc).

PLEASE CHECK THE RELEVANT BOX

(NB. double click on the check box and select 'checked')

MEMBER OF STAFF x☐ RESEARCH STUDENT ☐ (MPhil, PhD, EdD, PsychD etc)

EXTERNAL INVESTIGATOR ☐ STUDENT (Other) ☐

PERSONAL DETAILS	
Name of applicant for this amendment :	Julie Jones
Name of applicant for original application (if different from the above):	
Other investigators:	
Email:*(all correspondence will be sent by email unless otherwise requested)*	Julie.jones@uwl.ac.uk
FOR STUDENTS ONLY:	
Programme of study:	DHSc

Mode of study (full-time/part-time)	Part time
Director of Studies:	Rowan Myron (Principal Supervisor)
FOR EXTERNAL INVESTIGATORS ONLY (please see Section 4.5 of the Ethical Guidelines):	
Name of Academic Assessor:	

PROJECT DETAILS

Title of project & ethics reference number:	***Competency in Bereavement Care: Stillbirth and Neonatal death: What do Students need to know?* 00306**		
Start date of original project:	June 2018	Final Approval Date of Ethics Application:	08.03.2018

Please briefly outline the changes made to this project and reasons for these. If the original application was not in your name, please give details of the original applicant and the reason for your involvement.

In phase 3 I was going to interview participants and audio record. This, due to time constraints and the sizeable content of phase 2 meant that this changed to carrying out two focus groups with student midwives and using nominal group technique. Therefore no audio recording was used and no identifying information was collected or retained from the participants at all as was planned originally for Phase 3. This was included in the original ethics application.

Ethical Implications of amendment:

There is no ethical implication.

Risk Implications of amendment (including whether the original risk assessment needs to be amended – if so, please attach):

No amendment required.

Data Protection Implications of amendment:

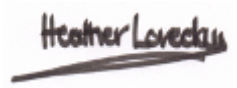
No data protection implications.

Signatures: *Please use an electronic signature or type your name*

Applicant: Julie Jones

Date 19.11.2019

Director of Studies: Not applicable

Date: 

Applicant for original application (if other than yourself):

Date: 20.11.2019

OFFICE USE ONLY

☐ Approved (considered to be a minor amendment)

☐ - no further action required ☐ - minor conditions (see below)
☐ - major conditions (see below) ☐ - comments (see below)

☐ Departmental approval needed (Ethics Approval Form attached)
☐ New Ethics Application Required
☐ Other – see comments below

Conditions/ Comments

Name & Position:

Date:

Appendix 8: Letters of support: SANDS and APPG

12 October 2017

To whom it may concern

Support for J. Jones's work on scoping and producing a competency framework and associated teaching tools for bereavement care in midwife training

I write on behalf of Sands, the stillbirth and neonatal death charity, in support of the work being undertaken by Julie Jones, RM Lecturer (Midwifery) University of West London, to produce a competency framework, and associated teaching tools, for midwives in training.

Every year in the UK, over 5,000 families are bereaved when their baby dies before, during or shortly after birth. The National Perinatal Epidemiology Unit's 2013 survey of bereaved parents *Listening to Parents* highlighted the importance of communication.

Parent bereavement support groups report that the way parents are told news about their baby's death is critical and can have a profound impact on the way parents view the quality of care they receive. For all the women in the survey and their partners the possible death of their baby was a shock; the way this news was given and how their baby's death was confirmed were extremely important aspects of their experience of care.

NPEU 2013 *Listening to parents after stillbirth or the death of their baby after birth*. Available from: www.npeu.ox.ac.uk/listeningtoparents

Sands
Stillbirth & neonatal death charity

Victoria Charity Centre
11 Belgrave Road
London SW1V 1RB
t: 020 7436 7940
e: info@uk-sands.org
www.uk-sands.org

Currently, there is wide variation in the care that bereaved parents receive, not just between units, but also within. We consider that all parents should have the highest quality of bereavement care. The most effective way of meeting this ambition is to ensure that all midwives entering the profession have the skills required to deliver this. Julie's work is therefore crucial, and we wholeheartedly support and endorse her approach.

Yours faithfully

Laura Price PhD Senior Research Officer

1st March 2018

To whom it may concern

As Co-Chairs of the All Party Parliamentary Group (APPG) on Baby Loss, we would like to state our interest in the research being conducted by Julie Jones. The aim of this research is to create a bereavement care competency framework that will inform the training of student midwives and midwives at post graduate level and be implemented nationally. The ultimate goal is to ensure that all midwives have adequate training and so are equipped to provide the care that bereaved parents need. The APPG has an onoing interest in improving the quality of bereavement support for parents who have lost their babies, so improvements in the training and support of midwives could help contribute to this goal.

The APPG for baby loss would like Julie to present her interim findings to the Group (once completed) after which we will consider what action, if any, might be needed at government level which we may be able to support/advocate.

Your sincerely,

Will Quince MP
Co-Chair of APPG on Baby Loss

Antoinette Sandbach MP
Co-Chair of APPG on Baby Loss