Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period

by

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Abstract

It is a tragic reality that some infants are anticipated to be stillborn or only live minutes to hours after birth. Nurses providing care during labor, delivery, and recovery (LDR) are in a key position to support families who experience such perinatal losses, and the quality of the care they provide can have an enduring impact on families' healing and bereavement. Limited empirical work has been conducted examining the behaviors nurses engage in to provide perinatal palliative care (PPC) during the LDR period. Thus, nurses have little by way of evidence to support them in providing care. To address this gap in the scientific literature, this study examined and described: the critical behaviors required for expert nursing care of families receiving PPC during LDR; the factors promoting or hindering their ability to do so; and the consequences of achieving or not achieving these behaviours. Interpretive description, a qualitative methodology placing emphasis on yielding knowledge for clinical practice, was utilized and Benner's From Novice to Expert model served as the foundation for the theoretical forestructure of this study.

A purposive sample of seven registered nurses deemed as experts by their colleagues were identified through a peer nomination process at two urban tertiary care centres on their respective LDR units. A total of 12 semi-structured face-to-face audio recorded interviews were conducted and transcribed verbatim for thematic analysis. A conceptual model illuminating how nurses cultivate expertise in PPC in the LDR setting emerged from the data and is inclusive of a description of the actions and considerations expert nurses engage in while providing care for families experiencing perinatal loss during the distinct stages of LDR. The outcomes of providing expert nursing care during perinatal loss have also been identified.

Laboring patients and their families can be best served during this delicate time of life by equipping nurses with evidence to inform their practice. By understanding how nurses cultivate expertise in PPC during LDR, educators, administrators, and managers can better support nurses to hone their ability to care for families experiencing perinatal loss.

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Dedication

To Stephen Michael and Annika Paige. This thesis is dedicated to you. Stephen, it has been your grounding presence, generous spirit, and unconditional love that has helped me to reach the finish line.

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Chapter One: Introduction

This first chapter will describe the background and context for the present study by providing: (1) a statement of the problem; (2) a reflection; (3) the research questions; (4) underlying assumptions, and; (5) definitions of key terms that relate to expert nursing practice and perinatal palliative care.

Statement of the Problem

It is a sad and tragic reality that some infants are anticipated to be stillborn or are only expected to live minutes to hours after birth. A stillbirth occurs when an infant is not born alive after 20 weeks gestation, or weighs more than 500 grams (Statistics Canada, 2019). An early neonatal death is the loss of an infant less than one week from birth (Statistics Canada, 2019). In Manitoba over a five-year period (2005 to 2010), more than 170 families received a prenatal diagnosis of a life limiting condition for their fetus during pregnancy. The majority of these infants were either born still or died during birth, and families most often faced this loss while being cared for on a labor and delivery unit (Lee, Stenekes, & Harlos, 2014). These circumstances require healthcare providers to skillfully weave the tenets of palliative care into the tapestry of labor and delivery care. The care of these families, from the time of learning of a life limiting diagnosis for their fetus into their bereavement period after the loss of an infant, is known as perinatal palliative care (PPC) (Balaguer, Martín-ancel, Ortigoza-escobar, Escribano, & Argemi, 2012). PPC aims to assist parents grieving the anticipated loss of their infant in making choices throughout pregnancy and birth while providing coordinated, comprehensive services throughout the processes of birth and death (Limbo & Wool, 2016; Sumner, Kavanaugh, & Moro, 2006).

Existing models and care pathways to guide PPC for families anticipating a perinatal loss

have limited application in the context of labor, delivery, and the recovery (LDR) period. These models and pathways tend to describe care broadly across the healthcare system from time of diagnosis of a life limiting condition into the bereavement period and after the death of an infant (Balaguer et al., 2012; Cole et al., 2017; Dickson, 2017; Murdoch, Carragher, & McNamara, 2013; Wool, Black, & Woods, 2016), and as a result, details exclusive to the LDR process are often lacking specificity. Further contributing to the paucity of context-specific guidance for those obstetric nurses aiming to cultivate expertise and use evidence to inform their labor and delivery care for families during these trying times is that, until recently, research evidence for the palliative care of fetuses and neonates was assimilated with that of the care of older children at the end-of-life (Dent, Condon, Blair, & Fleming, 1996; Neidig & Dalgas-Pelish, 1991; Widger & Wilkins 2004).

Despite the limitations of existing PPC models and pathways, and the limited knowledge base that exists regarding the palliative care of fetuses and neonates, nurses in the LDR setting who provide one-to-one care for families in labor rise to the challenge of organizing and coordinating PPC when a perinatal loss is anticipated (Leuthner & Lamberg Jones, 2007; Limbo & Wool, 2016; Ramer-chrastek & Thygeson, 2005). What is less clear are the behaviors that nurses engage in to achieve this goal – particularly of those nurses who are recognized by their nurse peers as being exceptionally skilled at providing PPC. In order to build a sound empirical base of knowledge pertaining to the nature of expert nursing practice in PPC, expert nursing care for patients and families experiencing perinatal loss in the context of LDR must be examined and described.

Purpose of the Study

Given the vital role of the nurse in circumstances of perinatal loss in the context of LDR

care and the gap in literature describing expert nursing care in these circumstances, the purpose of this study was to: (1) develop a description of the critical behaviors required for the provision of expert nursing care for those families expecting a stillborn infant or an early neonatal death during the LDR period; (2) describe what factors promote or impede the ability of nurses to develop and carry out these behaviors; and (3) describe the consequences of being able or not being able to enact these behaviors when providing care. Utilization of interpretive description (Thorne, 2008), a qualitative research methodology that, by design, places emphasis on yielding knowledge for application in clinical practice (Thorne, Reimer, & MacDonald-Emes, 1997), facilitated the development of this description, and is appropriate given the aims and scope of the study.

Reflection

A reflective process is encouraged by Thorne (2008) throughout the duration of an interpretive description research project. These reflective means support researchers in their ability to articulate a meaningful, purposeful, manageable and logical research question, and to become mindful of the breadth and limits of that research question. Additionally, researchers can illuminate the theoretical forestructure of a study by locating themselves within their discipline, and by describing their personal connection with the beliefs they embrace in relation to the inquiry (Thorne, 2008). I will take this opportunity to reflect on my journey as an individual, and as a nurse, in developing a clinical interest and inquiry in this realm of study and to outline what I hope to achieve from this research project. Additionally, by making transparent my observations and feelings from my clinical nursing background, I acknowledge that as a researcher I am not without bias. My lens as a nurse will unavoidably contour each step of the research project, from the formation of an inquiry to the conclusions drawn from the data.

As an undergraduate student nurse, I took a great interest in palliative care, completing my senior practicum on an adult palliative care unit, and working on this unit for a short time after my graduation. Here, holistic, integrative, family and relationship centered care was the norm. The ethos of care extended beyond the care provided to dying patients and their families, and whole heartedly included caring for one another not just as professional colleagues, but also as people. In this care context, things like crying with families or patients and allowing for moments of stillness and silence were valued healthcare tools and had a place alongside pharmaceutical interventions and pain assessments. There was a clear understanding that coming to work meant facing the notion of mortality head on, together as a team, every day. From my perspective, there was an overarching acknowledgement that, although inevitable for all of us, death can sometimes be traumatic, complicated and difficult to cope with, and that even as healthcare professionals, grief is to be sometimes expected. On the whole, the staff had a robust rhetoric with which to express such sentiments with the families they cared for, and with one another. Each day, staff came to work prepared to talk about death, to face death head on, and to support one another in doing so. Overall, this was an environment where clinicians fostered one another as they developed expertise in the area of palliative care.

When I began my position on a labor and delivery unit it was like stepping into a different world. The distinction between these worlds was most potent where death was concerned. When the final push of labor is followed by silence, the room stands still as those present wait with breath bated for the screams of a new life sliding into the world. The hush of an unwell infant or one who is not alive hangs in the air with a stark solemnity, unmatched by anything else I have ever experienced.

From my perspective, unlike nurses on the adult palliative care unit, most obstetric nurses were not coming to work each day expecting to face death. When they were required to do so, the usual tenets of labor and delivery care did not always fit. For instance, the customary discourse you might expect to hear echoing down the halls of a labor and delivery unit, "You can do it, keep pushing, you'll soon meet your baby!", were not always suitable for a family whose baby would be born still or would only live moments after birth. On the other hand, standing quietly and somberly at the side of a woman at the peak of physical and emotional exhaustion was not necessarily appropriate either as even in the face of a forbidding prognosis, some families eagerly awaited the opportunity to spend a few cherished moments with their baby.

Some nurses seemed to have an aptitude for skillfully and sensitively managing these scenarios, whatever the family's hopes or expectations. These nurses conducted themselves in a measured and respectful manner, their tone of care adaptive to whatever the moment begged for, and all the while their provision of high quality labor and delivery care was unwavering. By contrast, other nurses seemed utterly bewildered and overwhelmed.

I began to wonder about what factors might have contributed to this discrepancy in the comfort level and ability of nurses to engage with families receiving a palliative approach to the care of their infant. I had not noticed such a wide spectrum of comfort and ability in nurses caring for dying adult patients and their families. I also wondered how nurses developed and honed their capabilities to provide perinatal palliative care when labor and delivery care is typically provided on a 1:1 ratio, behind curtains and closed doors. The intimate and private nature of labor and delivery care did not seem to readily facilitate opportunities for obstetric nurses to learn how to integrate palliative care principles into labor and delivery care from their colleagues who may have developed expertise in this milieu of care over time.

Through this project, I examined *what* expert nurses consider and *how* they go about providing care for families experiencing the death of their infant, and to illuminate how they balanced and simultaneously met care demands from the realms of both obstetric care and palliative care. My hope is that the results from this project will provide tangible insight for all obstetric nurses aiming to develop expertise in the area of PPC.

Research Question

It is an underlying assumption of interpretive description methodology that questions for research are often born out of clinical problems for which existing knowledge is not yet adequate to address (Thorne, 2008). In this case, although concepts and practices related to PPC are being increasingly studied, an inquiry specific to expert nursing care in the context of LDR had not been investigated to date.

A research question is to be informed by and to build upon the current knowledge base of a particular discipline in order to yield findings that contribute meaningfully to the body of evidence of that discipline; Thorne (2008) refers to this as disciplinary orientation. This project, for instance, took a disciplinary orientation to the profession of nursing, and more specifically drew on the unique knowledge of nurses working in the context of LDR care. This is not to say that findings from research outside of one's own discipline could not be employed in the clinical or academic setting as healthcare providers and scholars are working together in an increasingly interdisciplinary fashion (Thorne, 2008). It is only to say that distinct disciplines can best advance their profession and its knowledge base forward while honouring the theoretical underpinnings and the clinical and academic objectives of that profession (Thorne, 2008). Additionally, the value of experience in a particular discipline can serve as a powerful agent in

giving rise to practical and clinically relevant research questions advancing that particular field of study (Thorne, 2008).

Interpretive description, as outlined by Thorne (2008) was selected to illuminate expert nursing care for families anticipating or experiencing the death of their infant during the LDR period. Factors that hinder or promote the ability of nurses to develop and achieve expert practice in this care context were also of interest and were elucidated in the resulting description. The following research questions have been addressed:

1. What is expert nursing care for families anticipating an infant to be stillborn or to die in the early neonatal period?
2. What promotes the ability to develop and carry out expert nursing care?
3. What hinders the ability to develop and carry out expert nursing care?
4. What is the impact of achieving expert nursing care during the provision of PPC on:
    a. Patients/families?
    b. Nurses themselves?
    c. The larger healthcare team?
5. What is the impact of not achieving expert nursing care during the provision of PPC on:
    a. Patients/families?
    b. Nurses themselves?
    c. The larger healthcare team?

Assumptions Underlying the Study

1. Some infants are expected to be stillborn, or to live for only minutes to hours after birth. In these situations, patients and their families require care during their labor, delivery, and recovery period that is different from those expecting an infant who is anticipated to live.
2. More specifically, the care for families anticipating a stillborn infant or an early neonatal loss requires skillful implementation of palliative care principles and interventions by healthcare professionals in addition to the activities of standard labor and delivery care.
3. The role of obstetric nurses requires them to have the most contact with families receiving care in labor than other healthcare providers. This puts nurses in a unique position to describe expert practice required for palliative care in the context of a labor and delivery unit (Leuthner & Lamberg Jones, 2007; Ramer-chrastek & Thygeson, 2005).
4. The availability or absence of specialized knowledge, skills, and resources will impact families anticipating a stillborn or early neonatal loss (Limbo & Wool, 2016; Wool et al., 2016).
5. An expert obstetric nurse is not necessarily an expert at providing PPC. A nurse able to provide expert PPC in this context will also possess the attributes of an expert obstetric nurse.
    - Although perinatal loss is not uncommon, the family anticipating or experiencing a perinatal loss is not the "usual" patient on a LDR unit. As a result, it may take more time for a nurse to gain repeated

occasions in caring for these families in order to develop expert behaviors when compared to caring for families expecting a well infant.

- Nurses who may have worked for a substantial duration of time in obstetrics do not necessarily have a great deal of experience in caring for families requiring PPC.

6. The distinctive and often fast paced context of obstetric care presents unique challenges regarding the provision of palliative care.
7. PPC is care provided for a family anticipating or experiencing a perinatal loss. Here, the concept of family stretches beyond the dyad of the mother and infant and includes those people the laboring mother considers to be her family.

Definition of Terms

The following terminology is used in the subsequent chapters. It is important to note that the definitions presented in this section reflect their use in literature and practice but do not necessarily reflect how these terms have come to be operationalized through the analysis of data as presented in the fifth chapter.

Perinatal loss. Perinatal loss is most broadly defined as the involuntary loss of pregnancy from the time of conception through 28 days of life (Association of Women's Health Obstetric and Neonatal Nurses, 2017). These losses can occur by means of ectopic pregnancy, miscarriage, stillbirth, and neonatal death (Association of Women's Health Obstetric and Neonatal Nurses, 2017). The World Health Organization (2018) defines the perinatal period as beginning at 22 completed weeks of gestation and ending after seven completed days post birth and perinatal mortality as the death of a fetus or infant within that time frame. Statistics Canada (2019) offers a

slightly broader definition of stillbirth and early neonatal deaths and encompasses infants over 20 completed weeks gestation (or weighing more than 500 grams). This thesis project, has focused on perinatal losses classified as stillbirths and early neonatal deaths as they often transpire in the context of the delivery room. Admission criteria for the participating sites in this study typically reflects the definition offered by Statistics Canada (2019).

Stillbirth. A stillbirth, or fetal death, occurs when an infant is not born alive after 20 weeks gestation, or weighs more than 500 grams (Statistics Canada, 2019). In practice, clinicians often use the term intrauterine fetal demise to describe an infant who will be stillborn prior to the delivery.

Early neonatal death. An early neonatal death is the loss of an infant less than one week from birth (Statistics Canada, 2019). Neonatal deaths are more broadly defined as a loss occurring from birth through 28 days of life (Association of Women's Health Obstetric and Neonatal Nurses, 2017).

End-of-life care, hospice care, and palliative care. It is important to note that the terms end-of-life care, hospice care, and palliative care are often used interchangeably. Upon inspection of these terms, Izumi, Nagae, Sakurai, and Imamura (2012) found them to be distinct from one another in the following ways: Hospice care differs from the other terminology because it is limited in its association with a program or place of care. Palliative care stretches beyond hospice care because it is not bound by definition to a specific program or location. Overall, palliative care is broader than end-of-life care as palliative care should ideally be offered from the time of diagnosis to the end-of-life and throughout the course of the illness (Izumi et al., 2012). Contributing members of the National Consensus Project (2013) further reinforce this as they include the care of a patient at the end-of-life as one of the eight domains comprising

palliative care. Within this domain, end-of-life care activities for the patient and family are divided by the National Consensus Project (2013) into three phases, "predeath, perideath, and postdeath" (p. 33).

This study has examined the care provided when death of an infant in the delivery room has occurred or is imminent. For the purposes of this thesis, the terms palliative care and end-of-life care have been utilized interchangeably to describe this circumstance as both terms provide an accurate depiction of the nature of care at the heart of this project.

Palliative Care. The World Health Organization (2017) defined palliative care as aiming to improve the "quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (para.1). The World Health Organization (2017) affirms that palliative care:

- "provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life" (para. 2).

Perinatal palliative care. PPC is palliative care for expecting families who receive a potentially life limiting diagnosis for their fetus, including intrauterine demise resulting in stillbirth (Engelder, Davies, Zeilinger, & Rutledge, 2012; Wool, 2013b), and the birth of extremely preterm infants (Lemyre, Moore, & Canadian Paediatric Society Fetus and Newborn Committee, 2017).

PPC is initiated when a family receives a diagnosis during the antenatal period that limits the life of their fetus and carries through into the bereavement period (Balaguer et al., 2012). PPC aims to assist parents grieving the anticipated loss of their infant in making choices throughout pregnancy and birth while providing coordinated, comprehensive services throughout the processes of birth and death (Limbo & Wool, 2016; Sumner et al., 2006).

This thesis project has been specifically concerned with the provision of PPC during the LDR period within this broader timeframe.

Expert nurse, nursing expertise and expert nursing practice. At a most basic level, the term expert can be defined as mastery of a particular field and the acquisition and enactment of tacit knowledge (Collins, Evans, Ribeiro, & Hall, 2006). Ergo, an expert nurse can be said to have tacit knowledge particular to, and mastery of the domain of nursing.

A recent concept analysis revealed that a myriad of definitions have been offered over time to demarcate nursing expertise resulting in a somewhat tenuous understanding of the concept (Hutchinson, Higson, Cleary, & Jackson, 2016). In contrast with this ambiguity, it is safe to say that nursing expertise is possessed by expert nurses, and that these expert nurses enact expert nursing practice. Benner, Tanner, and Chesla (2009) characterize expert nursing practice

by the presence of "increased intuitive links between seeing the salient issues in a situation and ways of responding to them" (p. 137).

In an integrative review on expert nursing practice, Morrison and Symes (2011) found, in most instances, expert nursing practice required: (1) knowing the patient; (2) possessing intuitive knowledge; (3) engaging in reflective practice; (4) taking calculated risks; and (4) demonstrating skilled know how.

Benner (2001) described how the expert nurse is delineated from novice, advanced beginner, competent, and proficient nurses when she stated "The expert nurse, with an enormous background of experience, now has an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions" (p. 32).

It may be of importance to note that the term 'clinical expert' is often used synonymously with 'expert nurse' throughout the literature (Hutchinson et al., 2016).

Labor and delivery units. These are hospital units that admit and care for pregnant women and their infants through the duration of their labor and delivery, and their recovery from this process. Terms such as "perinatal", "birth", "obstetric", and "intrapartum" are frequently used to describe this setting and point of pregnancy, labor, and delivery. The care delivered here can also be referred to as "woman and child care", "maternity care", or "maternal child care". The patients receiving care on these units are the maternal-fetal dyad and the people who make up their support system. Typically during labor and delivery, one or two people are permitted to be present to provide support to the laboring patient. Some labor and delivery units continue to provide care to mothers and infants into the immediate postpartum period. Within these units,

delivery rooms are rooms outfitted with specialized equipment necessary for the safe care of laboring women and the delivery of their infants.

Obstetric nurses. Obstetric nurses, sometimes referred to as labor and delivery nurses, maternity nurses, intrapartum nurses, or perinatal nurses, are registered nurses who specialize in the care of pregnant women and their infants through the duration of the LDR period.

Facilitator. A facilitator is any factor that contributes to outcomes resulting in expert nursing care.

Barrier. A barrier is any factor that hinders the provision of expert nursing care.

Terminology relating to people receiving care. For the purpose of this study, the term family includes the maternal-infant dyad. It also includes any people the person in labor considers to be family. The person in labor who receives care from an obstetric nurse may be referred to throughout this document as a patient, mother, or parent. It is important to note that not all child bearing people identify as mothers or parents, nor do they all identify as women.

As mentioned, the term family refers to people present for the labor inclusive of and beyond the maternal-fetal dyad. Those individuals present with the patient in labor for the LDR process are referred to as support people. A support person can be the other parent or father of the infant, but may have a different relationship to the person in labor (e.g., friend, parent, sibling etc.).

Summary

The first chapter has provided an introduction to this thesis by: (1) highlighting its purpose and relevance through stating the research problem; (2) sharing a self-reflection of personal thoughts around PPC; (3) outlining the research questions stemming from the problem; (4) identifying underlying assumptions associated with the research questions; and finally, (5)

offering definitions of the concepts and terms relevant to perinatal loss, palliative care, and expert nursing practice. The second chapter will describe the function of a literature review in interpretive description research and will review the literature pertinent to this project.

Chapter Two: Review of the Literature

This second chapter will: (1) describe the search strategies used to complete this literature review; (2) discuss the use of literature in interpretive description; (3) provide an overview of the stages of labor and standard nursing care provided in Canada to help contextualize this study; and (4) appraise the current literature pertaining to PPC and expert nursing care with special attention paid to how these concepts appear in the literature related to the context of LDR settings.

Search and Retrieval Strategies for Literature Review

This search for literature was conducted in MEDLINE (Ovid), CINHAL (EBSCO host), and Scopus (Elsevier) databases. The search first employed MEDLINE to map key terminology to MeSH headings. The resulting MeSH headings, such as “Palliative Care”, “Perinatal Care”, “Pregnancy”, “Infant, Newborn”, “Prenatal Diagnosis”, “Fetal Diseases”, “Health Personnel”, “Nursing Care”, were searched in conjunction with terms commonly used in both clinical practice and the literature on the topics of concern in this thesis in an effort to capture the greatest number of applicable synonyms. Key words and phrases such as: (“perinatal palliative care” or “perinatal hospice” or “hospice adj3 utero” or “hospice adj3 womb” or “stillborn” or “stillbirth” or “neonatal death” or “intrauterine adj2 demise” or “fetal demise” or “pregnancy loss” or “incompatible with life”), (“palliative” or “hospice” or “end-of-life” or “terminal” or “death” or “dying” or “life limiting” or “life threatening”), (“infant” or “child” or “baby” or “neonate” or “fetus” or “foetus”), (“labor delivery recovery postpartum” or “labor and delivery” or “labour delivery recovery postpartum” or “labour and delivery” or “perinatal” or “antenatal” or “intrapartum” or “postpartum” or “birth*” or “obstetric*” or “maternity”), and (“expert nurs*” or “expertise adj2 nurs*” or “expert*” or “nurs*” or “care” or “practice”) were included.

The search results pertaining to PPC and expert nursing practice were appraised for their relevance in accordance with the purpose of this literature review and were considered for inclusion if a definition, model, description, or outcomes of either PPC or expert nursing practice were provided. Next, Boolean operators of "OR" and "AND" were employed to narrow in on results more specific to the research question at hand. The searches on PPC and expert nursing practice were combined, and at the time the searches were conducted, there were no sources that included both a definition, model, description or outcomes related to both PPC and expert nursing practice. Next, each of these searches were narrowed down by the context of labor, delivery, recovery, and postpartum care, and by the context of palliative care more generally to examine these concepts from the relevant contextual standpoints. This second search about palliative care was further refined by searching for sources where infants or fetuses were the recipients of care along with their families. It may be important to note that although literature regarding palliative care for infants in the neonatal intensive care unit was briefly examined, it was not included for the purposes of this literature review because this literature typically deals with issues regarding decision making around the initiation and withdrawal of life support and the use of other interventions that are not characteristically initiated or managed in the context of LDR.

The reference lists of pertinent journal articles were hand searched for additional resources. A brief search was also completed via Google scholar using a modified search strategy inclusive of some of the terms listed above. The researcher also examined the grey literature based on previous knowledge of resources commonly used in clinical practice such as practice guidelines and models of care for PPC that have been developed by various healthcare organizations.

Interpretive Description and Use of Literature

Thorne (2008) emphasizes how a literature review ought to bring to light that there are actors in the healthcare field that have "experiential access to that which has not yet been sufficiently documented, described, or interpreted" (p. 63-64) to warrant the gathering, interpreting, and dissemination of that information that will useful in clinical practice for a particular discipline. To this end and in accordance with the use of literature in interpretive description, this review of the literature will situate the study substantively within the existing knowledge on the topics of focus and within the disciplinary orientation of nursing. Furthermore, this literature review will offer a critical reflection on notable gaps in knowledge and supply comment on the strengths and weaknesses of the overall body of knowledge (Thorne, 2008).

Standard Nursing Care during the Stages of Labor

In most instances, the process of labor and delivery and the birth of a child is a tremendously momentous milestone for a woman and her family and friends. No two labors, even for the same woman, will be the same. The nursing care required in each scenario must be tailored to the labor at hand as it unfolds, thoughtfully accounting for the differences in presentation of each labor and the dynamic health status of the mother-infant dyad. For instance, where a caesarean section, or surgical birth of an infant, is indicated (and depending on when during the labor process it is indicated), some or all of the stages of labor will be bypassed and an entirely different host of interventions are then indicated. Complications can arise during any stage of labor and delivery requiring regular prudent assessments and timely interventions in response to the findings of those assessments. A variety of technologies, such as continuous or intermittent fetal heart rate monitoring using ultrasound detection, may be employed during labor

care to monitor the health status and safety of the mother and her unborn child where indicated. A nurse, along with the greater interdisciplinary healthcare team, must customize the care provided to a woman in labor and her family to their particular needs and preferences while ensuring the safety of both the woman in labor, and her infant. A nurse must judiciously and accurately keep a record of the care provided by documenting labor progress and all interventions in accordance with their local hospital policy throughout each of the four stages of labor. This section is intended to provide the reader with a general sense of the standard nursing care required for a low risk spontaneous vaginal birth for a healthy mother and infant with no serious pre-existing conditions in an effort to contextualize the literature review to follow about PPC and expert nursing. Additionally, the stages of labor must be well understood as described below as these stages will serve as a framework to organize the interview guide for this research project. This research project is particularly concerned with *how* nurses expertly integrate palliative care principals into the already complex and demanding context of labor and delivery care which will be described below.

First stage of labor. The labor process, for a vaginal delivery, is divided into four overarching stages, the first beginning with the onset of regular uterine contractions and coming to an end when the cervix is fully effaced and dilated (Perry et al., 2016). This first stage is more specifically divided into three phases which are classified based on the dilation and effacement of the cervix and are known as: the latent phase (0-3cm dilation), the active phase (4-7 cm dilation, moderate effacement), and the transition phase (8-10cm/full dilation and effacement) (Perry et al., 2016).

During the latent phase of the first stage of labor, a nurse must determine whether a woman is in true labor and whether she should labor at home and wait for her contractions to

increase in intensity, frequency and duration, or whether admission to hospital is indicated for reasons such as suspecting membranes have ruptured, if bleeding occurs, or if a decrease in fetal movements has been noted (Perry et al., 2016). Based on the assessment, the nurse must provide a woman with pertinent direction and education tailored to her needs in any of these scenarios.

If a woman has not already been admitted to hospital during the latent phase of labor for any of the reasons listed above, a nurse will admit the woman to the labor unit during the active (or in some instances the transition) phase of labor. At this time, a thorough review of the woman's prenatal record must be undertaken along with an initial interview, a physical exam to assess physiological parameters (e.g., maternal vital signs and fetal wellness via fetal heart rate monitoring), and a clinical evaluation of labor status. This will include, but not be limited to assessments such as a pain assessment, a pelvic examination to determine cervical dilation and effacement and station and position of fetus, a manual examination of abdomen and fundus to determine intensity, frequency and duration of contractions, performance of Leopold's Manoeuvers to determine the suspected position and size of the fetus, and confirmation of status of membranes with a Fern Test (Perry et al., 2016).

A nurse, along with the rest of the interdisciplinary healthcare team, must consider the information from all of these sources, including the expressed wishes and preferences of the woman in labor, to move forward with the most appropriate plan of care. During the active and transition phases of labor a nurse generally provides one-to-one care for a woman and her fetus, performing regular assessments of the mother and infant and providing supportive care. Supportive care during labor and birth can include encouraging different maternal positions depending on the position of the fetus to facilitate birth and as a comfort measure, providing emotional support to the woman in labor and her support person, advocating for the woman's

preferences and choices, and protecting the privacy of the woman in labor (Perry et al., 2016). Supportive care may also include education about the risks and benefits of pharmacological analgesia, securing the route for administration if the woman opts for pharmacological analgesia, and administering the selected agent (e.g., inhalation of nitrous oxide, administration of intravenous fentanyl, or administration of epidural or spinal analgesic agents (Perry et al., 2016). In the case of epidural or spinal analgesia, an anesthetist will be consulted to insert the catheter and administer the initial dose of medication, and the nurse will maintain this route and deliver and monitor continued drug administration. Each of these methods of analgesia requires a nurse to engage in a specific cascade of monitoring and assessments protocols. A host of other comfort measures may be used during the first stage of labor such as hydrotherapy, heat and cold therapy, or sterile water injections (Perry et al., 2016). Sterile water injections are best suited to ease lower back pain that some women experience in labor (Mårtensson & Wallin, 2008; Perry et al., 2016). Four to six intracutaneous injections of sterile water are delivered in the woman's lower back, irritating the sites of injection, thereby interrupting the pain signals from labor. These injections have been found to lower a woman's self-reported pain score by 60% for up to two hours (Mårtensson & Wallin, 2008).

Second stage of labor. The second stage of labor commences with a fully dilated cervix and is complete when an infant is born (Perry et al., 2016). At this point, a woman in labor will either have a spontaneous urge to bear down, or in the case of epidural analgesia may need direction to do so. During this stage, the frequency of intermittent fetal heart rate monitoring, if not already continuous, increases to every five minutes to ensure the fetus is receiving adequate circulation and oxygenation during its descent (Perry et al., 2016). While a woman is pushing, a nurse must monitor the effectiveness and progress of her efforts, encouraging her both

emotionally and physically. Support and direction will also be provided by a nurse to a support person should there be one present. A sound knowledge of maternal positions to facilitate the descent of a fetus is paramount. If the birth room is not already set up for the arrival of an infant, a nurse must ensure all necessary equipment is at the ready and test it to ensure its functionality (e.g., resuscitation equipment, instruments for delivery of the infant and placenta, materials to collect blood gases, a dose of oxytocin) (Perry et al., 2016). Other members of the interdisciplinary team will need to be contacted to gather when their expertise is required (e.g., obstetrician for delivery, neonatal resuscitation team should there be any indication for their presence such as meconium stained amniotic fluid, utilization of opiate analgesia during the first stage of labor, or a concerning fetal heart rate pattern). A nurse must be prepared to deliver the infant independently or with the support of other nursing staff should the other members of the interdisciplinary team be unable to arrive in a timely fashion. Nurses, in conjunction with other members of their healthcare team, must be prepared with the skills to anticipate and manage any number of complications that can occur during and immediately following the delivery of an infant such as a nuchal cord, shoulder dystocia, or a hemorrhage (Perry et al., 2016).

Once the infant is born, in instances where a well infant is anticipated, immediate assessment of the infant is required and the APGAR (Activity, Pule, Grimace, Appearance, Respiration) scoring system is employed at minutes one, five, and fifteen post birth (Perry et al., 2016). Should the infant appear well, the infant will be placed skin to skin with the mother to conduct the assessment. If there are any major concerns, the umbilical cord will be immediately cut and the infant will be placed on the warmer for assessment and further intervention such as suctioning or positive pressure ventilation. In most instances, immediately after an infant is born, a dose of prophylactic oxytocin will be administered by the nurse to the mother by means

of an intravenous or intramuscular route to encourage the third stage of labor and to decrease the risk of postpartum hemorrhage (Perry et al., 2016).

Third stage of labor. The third stage of labor begins once the infant is born and continues until the placenta is delivered, and is divided into two phases; the first being placental separation and the second being placental expulsion (Perry et al., 2016). During this time the nurse will continue to monitor the status of the infant and provide any interventions the infant may require. At this point, skin to skin contact between the mother and infant is encouraged and family bonding is supported. If applicable, breastfeeding can be initiated. Progress of separation and delivery of the placenta is monitored. Once the placenta is delivered, the nurse will inspect the organ to ensure it is intact. If remnants of the placenta are retained in the uterus, there are increased risks for postpartum hemorrhage and infection (Perry et al., 2016). Additionally, a nurse will collect blood samples from the placenta and umbilical cord at this time to: (1) determine the infant's arterial blood gases; (2) determine the required dose of immunoglobulin (WinRho) the mother may require postpartum should she have an Rh negative blood type; and (3) bank umbilical cord blood at the request of the family.

Fourth stage of labor. The fourth stage of labor follows the delivery of the placenta and lasts for approximately 2 hours afterwards. During this period the uterus re-establishes its tone and family bonding begins. This stage of labor is often referred to as the recovery period (Perry et al., 2016). During this stage of labor, the nurse performs frequent assessments of the mother's vital signs, level of bleeding, and status of uterine involution (Perry et al., 2016). Through these assessments, the nurse astutely monitors for imminent signs of impending complications such as infection or hemorrhage (Perry et al., 2016). Care of the newborn infant is also attended to during this period, and is inclusive of a full newborn assessment, administration of standard

medications such as antibiotic eye care and an intramuscular injection of vitamin K. The infant's vital signs are monitored regularly as they transition from life in utero to extrauterine life, with special attention paid to early signs of complications such as infection. Breastfeeding is established during this time and the nurse encourages an infant's first latch. Any feeding that occurs must be assessed for effectiveness and documented (Perry et al., 2016). Once the mother and infant are stable, care will be transferred from their labor and delivery nurse to a nurse who specializes in postpartum care.

In this description of nursing care during a low risk spontaneous vaginal delivery for a mother and infant with no pre-existing conditions, it is evident that a nurse requires a great deal of knowledge about this process. In order to execute such care, it is safe to say that nurses must possess some measure of confidence in their knowledge and a certain level of comfort with the care they provide. In instances when a fetus is known to have a life limiting condition and is anticipated to live only minutes to hours after birth or be born still, even advanced practice nurses, who often have more education and training than general duty nurses, lack confidence and comfort in the provision of care for these families, especially when compared with physicians (Wool, 2013). That nursing staff lacked confidence in facilitating PPC when compared to physicians was also echoed in the findings of a survey developed by Stenekes et al., (2018) to assess healthcare provider competency, attitudes, and knowledge about PPC. By empirically describing and documenting the critical behaviors of nurses deemed experts in the provision of PPC by their colleagues, knowledge that already resides with experienced nurses can be described, interpreted and disseminated in an effort to support nurses to build confidence, competency, and comfort in the provision of PPC.

Perinatal Palliative Care

What is PPC and who is it for? The number of children who die in the perinatal and neonatal period far surpasses the number of children who die at any other point in childhood (Carter, 2004; Harris et al., 2014; Institute of Medicine, 2003; Kiman & Doumic, 2014). These tragic losses may be resultant of, but certainly not limited to, any number of factors such as congenital malformation, infection, chromosomal abnormalities, or maternal complications in pregnancy (Engelder et al., 2012; Wool, 2013a). While some families elect for compassionate discontinuation of their pregnancy upon receiving a fatal diagnosis for their fetus, others elect to continue with their pregnancy. It is estimated that between 40% to 85% of families receiving an antenatal diagnosis of a lethal fetal anomaly continue with their pregnancy (Breeze, Lees, Kumar, Missfelder-Lobos, & Murdoch, 2007; Calhoun, Napolianto, Terry, Bussy, & Hoeldke, 2003; D'Almeida, Hume, Lathrop, & Calhoun, 2006; Lee et al., 2014; Widger et al., 2016). PPC is indicated and initiated when expecting families who receive a potentially life limiting diagnosis during the antenatal period elect to continue with their pregnancy (Engelder et al., 2012; Wool, 2013b), or anytime an infant's life may be limited prenatally, at the time of birth, or shortly after birth (Catlin, Brandon, Wool, & Mendes, 2015). This approach to care carries through into the bereavement period after an infant has died (Balaguer et al., 2012). PPC can be delivered in any location including the LDR setting in hospital or birthing facility, the neonatal intensive care unit, or at home (Catlin et al., 2015). As the vast majority of births in Canada take place in hospital, such as on an LDR unit (Public Health Agency of Canada, 2009), it is no surprise that the hospital is also the most predominant setting where Manitoban families deliver infants who are born still or die minutes to hours after birth (Lee et al., 2014). Overall, PPC is a comprehensive and holistic palliative approach to care and is integrated with standard medical

care for expecting families (Limbo & Wool, 2016). More specifically, PPC aims to assist parents who are grieving the anticipated loss of their infant in making choices throughout pregnancy and birth while providing coordinated, comprehensive services throughout the processes of birth and death (Limbo & Wool, 2016; Sumner et al., 2006). Sensitive and holistic PPC provided for these families during and after their perinatal loss can have a lasting impact on their wellbeing in the aftermath of the death of their child (Lisy, Peters, Riitano, Jordan, & Aromataris, 2016). Yet, how healthcare providers might provide this sensitive and holistic PPC in the context of LDR has yet to be described in the literature.

Limitations of existing models of PPC. Since PPC first appeared in the literature in the 1990's (Calhoun, Reitman, & Hoeldtke, 1997), numerous care pathways, models, and frameworks have been developed to guide practitioners as they facilitate the journey of a family with a diagnosis of a life limiting condition for their fetus (Balaguer et al., 2012; Cole et al., 2017; Dickson, 2017; Murdoch et al., 2013). These documents most often describe care particular to the geographical and cultural context for which they were created, none of which are specific to a Canadian context of care, and describe the process of PPC broadly across health settings leaving a paucity of detail particular to the LDR setting. For instance, many of these models, frameworks, and care pathways were created in contexts where midwives are the predominant care providers for women during pregnancy and childbirth such as in the United Kingdom (Dickson, 2017; Murdoch et al., 2013). Although the midwifery model of maternal child care is beginning to take a stronger hold in Manitoba and across Canada at large, at present, maternal child care in Canada is predominantly provided by obstetricians and nurses (Public Health Agency of Canada, 2009; The Vanier Institute of the Family, 2017) and it should not be assumed that models or care pathways produced for one mode of care delivery can be directly

adopted by another. Additionally, none of these models or care pathways were generated for a Canadian context and therefore do not reflect the needs of the unique Canadian population. For instance, considerations made more generally for Canadian maternity care by the Vanier Institute of the Family (2017) for populations of distinct Indigenous cultures, women with disabilities, or families of newcomers or refugees are not addressed in the existing models and care pathways. When care *during* the birth is directly addressed, preparation of a birth plan prenatally is routinely suggested, and following that birth plan with a focus on care providers being mindful of their presence by "being rather than doing" (Cole et al., 2017, p. 4) is recommended. Overall, these models and care pathways do not supply details or description regarding: (1) *how* a birth plan for a family experiencing perinatal loss can be carried out by a nurse while performing the many necessary assessments and tasks required during standard labor and delivery care, or (2) *what* particular behaviors strengthen their presence during a birth.

The Canadian Paediatric Society (van Aerde, Canadian Paediatric Society, & Fetus and Newborn Committee, 2001) published a position statement and set of guidelines for healthcare providers caring for families experiencing a perinatal loss over a decade ago, and in 2017, reaffirmed the existing guidelines. These guidelines touch on care provision prior to the death of an infant across healthcare settings and makes suggestions for healthcare providers such as: promoting parental attachment, encouraging parents to interact with their infant, creating mementos, involving relatives and friends as supports should the parents wish to do so, and providing reassurance to the parents. The Canadian Paediatric Society (van Aerde et al., 2001) broadly recognizes the role culture can have on influencing the meaning of death and the customs surrounding it, and suggests that, even in the face of cultural variation, there are a few "do's and don'ts" (van Aerde et al., 2001 p. 475) healthcare providers can adhere to. For

example, these guidelines endorse healthcare providers in demonstrating honesty when imparting information and in showing their own emotions when appropriate (van Aerde et al., 2001). By contrast, these guidelines discourage healthcare providers to exhibit behaviours of avoidance and to refrain from the use medical jargon in communication with families (van Aerde et al., 2001). Although created for a Canadian context of care, it is important to note the limitations of these guidelines. Namely, the role and impact of the nurse is not expressly addressed during any point during of the trajectory of care for a family experiencing perinatal loss aside from their possible contribution to creating keepsakes. This continues to leave nurses with little context specific evidence to inform their LDR care when an infant is expected to be born still or to meet the end-of-life shortly after birth.

The evidence base for PPC. Broadly speaking, various aspects of PPC have been examined with numerous methods from case vignettes (Berg, Paulsen, & Carter, 2013), to chart reviews (Harlos, Stenekes, Lambert, Hohl, & Chochinov, 2013), descriptive qualitative studies (Kavanaugh, Moro, & Savage, 2010), mixed methods studies (Wool et al., 2016; Wool & Dudek, 2013), and quantitative studies (Ben-Ezra, Palgi, Walker, Many, & Hamam-Raz, 2014; Lindley, Fornehed, & Mixer, 2013; Wool, 2013a). PPC has been investigated and described from a variety of perspectives such as those of parents (Berg et al., 2013; Hasegawa & Fry, 2017; Kuchemba-Hunter, 2019; Lisy et al., 2016; Wool, Repke, & Woods, 2017), nurses (Willis, 2019; Wool, 2013a), midwives (Martínez-Serrano, Palmar-Santos, Solís-Muñoz, Álvarez-Plaza, & Pedraz-Marcos, 2018), and physicians such as obstetricians, neonatologists, and geneticists (Korzeniewska-Eksterowicz et al., 2013; Wool, 2013a; Wool & Dudek, 2013). Several aspects of PPC have been studied adequately enough to warrant the production of systematic reviews (Ellis et al., 2016; Gandino, Bernaudo, Di Fini, Vanni, & Veglia, 2019), scoping reviews

(Shorey, André, & Lopez, 2017; Thornton, Nicholson, & Harms, 2019) and meta syntheses of the literature (Kingdon, O'Donnell, Givens, & Turner, 2015; Lisy et al., 2016). The aspects of PPC that have been more frequently studied primarily reside outside the context of LDR or amalgamate findings across healthcare settings, and as a result, recommendations lack specificity to the LDR context of care. These areas of focus include care after stillbirth (Ellis et al., 2016), bereavement care for parents after the death of a newborn (Thornton et al., 2019), provision of meaningful care throughout the trajectory of care from diagnosis of a life limiting condition into the bereavement period for a family anticipating a stillborn baby (Lisy et al., 2016), and healthcare provider experiences of perinatal loss from miscarriage to neonatal death across varying healthcare settings (Gandino et al., 2019).

One well documented aspect of PPC pertaining to the LDR setting regards the responsibility of healthcare professionals in supporting parents to make decisions around seeing and holding their stillborn baby during this highly emotional time of life (Kingdon et al., 2015). Kingdon et al., (2015) included 12 qualitative studies in their meta synthesis of the literature exploring the perspectives of mothers and fathers from six high income westernized countries published between 1983 and 2013. These researchers concluded that behaviors and attitudes conveyed by healthcare providers can influence the decision making process of parents to see or hold their stillborn baby during these incredibly difficult and dynamic moments. Healthcare providers are encouraged to "actively manage" (Kingdon et al., 2015 p. 14) contact between parents and their baby who was born still by considering the physical condition of the infant and the preferences of parents while providing information and options to the parents in a timely and sensitive manner, recognizing that time with their infant is limited. Through their analysis, Kingdon et al., (2015) determined: (1) the "actions and reactions" (p. 8) of the staff during and after a labor had

a lasting impact on the parent's wellbeing; (2) it is important for healthcare providers to acknowledge the stillborn infant as a baby at any gestational age and in any physical condition; (3) the only chance parents have to see and hold their baby and perform acts of parenting occurs in the moments after birth, and parents can experience regret about missing those opportunities; and (4) creating mementos is an important way to mark the existence of the infant and of parenthood. Even if parents do not see the value of mementos in the moment, they often remark on their value during their bereavement. Although these findings may be helpful for practitioners during their care of a family once a baby is born, they provide little information to guide staff in helping a family with birth preparations or during the labor and delivery process itself.

Another aspect of PPC that has been well documented within the context of LDR was illuminated in a scoping review conducted by Shorey, Andre, and Lopez (2017) which reported on the needs and experiences of healthcare professionals working in maternity units facing a perinatal death. Here, little distinction was made between the needs and experiences of nurses, midwives, and various medical specialists including perinatal pathologists, obstetricians, and gynecologists spanning across five continents. Through their analysis of 30 papers which met inclusion criteria, the needs of healthcare providers were identified as being related to requiring space and time to grieve, counselling, and the option to share in, rotate, or opt out of providing care for families facing perinatal death (Shorey et al., 2017). The review made clear that healthcare providers require social support, and highlighted that nearly every included study reported the need for formal training and education as being essential for healthcare providers facing perinatal death on maternity units (Shorey et al., 2017). Although their findings were not limited specifically to the context of maternity units, Gandino et al., (2019) reported similar findings in their systematic review on healthcare professionals' experiences of perinatal loss.

Their findings revealed that the lack of information and support available to guide healthcare providers in their care of families experiencing perinatal loss contributed to a host of difficult emotions such as feelings of inadequacy, self-doubt, and frustration as well as a variety of psychopathological responses such as post-traumatic stress disorder, burnout syndrome, and psychosomatic disorders (Gandino et al., 2019). Furthermore, a need for targeted vocational training on the topic of perinatal loss was cited as being imperative (Gandino et al., 2019). Together, the findings from these reviews further demonstrates the gravity of the need to provide healthcare providers with information regarding *how* to best provide PPC.

Within the synthesis and review type literature that is not specific to the LDR setting aforementioned, and embedded within broad recommendations for the care of families anticipating a perinatal loss, a few points with relevance specific to care of families during the LDR process are suggested. For instance, Ellis et al. (2016) propose that parents should be provided with ample information about the birth process immediately leading up to the birth including discussion about what to expect during a vaginal delivery and information about pain relief options that will be available for the laboring woman. In terms of the recovery and immediate postpartum period, Ellis et al. (2016) echo the recommendation made by Kingdon et al., (2015) emphasizing the role of direct healthcare providers in offering repeated opportunities to make memories with their infant immediately post birth should they feel it appropriate. Lisy et al., (2016) remind healthcare providers not to make assumptions about what parents anticipating their baby to be born still might be expecting regarding the delivery of their infant. For example, some parents may not realize they will need to go through labor at all, thereby emphasizing the role of healthcare providers in preparing parents for the logistics of the processes of both the birth and death of their child (Lisy, et al, 2016). Once a woman is in labor

and is being admitted to a hospital unit for delivery, Lisy et al. (2016) encourage healthcare providers to be sensitive to practical details such as the environment where a family anticipating a stillborn will deliver their baby and warn healthcare providers that sounds of other laboring mothers and their newborn babies might be upsetting.

Despite the growing evidence base in the milieu of PPC, there continues to be a sense of urgency for the development of further evidence to help inform the high quality care these families need (Carter & Jones, 2013; Ellis et al., 2016; Limbo & Wool, 2016). To date, not a single study has been conducted pertaining to how PPC might be delivered by nurses during the LDR process, a time when families even at the best of times, are challenged as they face peak physical, emotional, and spiritual exhaustion. Even when a healthy child is anticipated, nurses face the enormous responsibility of understanding and responding to the care requirements of infants and their families during the complex process of LDR. Given how little is known about PPC in the context of LDR, a descriptive study is both warranted and necessary and may provide tangible insights for nurses who must provide palliative care for an infant and family while simultaneously safely and competently managing the LDR care requirements of the same family.

PPC in Canada. In Canada, generalist palliative care can be provided for families anticipating or experiencing the death of their child across all health settings, including that of LDR, and in some instances teams with specialist knowledge in pediatric palliative care may be consulted to facilitate care (Widger et al., 2016). Pediatric palliative care is palliative care for children 18 (depending on the jurisdiction) and under with a diagnosis of a life limiting condition and can include the care of neonates and fetuses (i.e., includes neonatal *and* perinatal palliative care).

In 2012, Canada was home to 3 free standing hospices, and 10 hospital based programs dedicated to palliative care for the pediatric population including care for families facing a life limiting diagnosis for their infant (Widger et al., 2016). Additionally, Canada is now home to one perinatal specific hospice program in Ontario. In Manitoba, the Winnipeg Regional Health Authority Pediatric Palliative Care Service is available on a consultative basis to contribute to the care of families anticipating a perinatal loss (Harlos, 2016). Details about the form and function of this service will be outlined in the fourth chapter of this thesis. According to a cross-sectional descriptive study looking at specialized pediatric palliative care in Canada in 2012, the frequency of antenatal referrals to these teams of specialists is increasing (Widger et al., 2016), yet many families and their healthcare providers still face the death of their infant without specialist guidance as it is not always feasible or necessary (Quill & Abernethy, 2013). Such instances impacting feasibility of specialist involvement may be reflective of the growing demand for palliative care surpassing the number of specialist providers available, or that general providers may be under the impression that basic symptom management and psychological support are not their responsibility due to the constant involvement of specialist teams thereby overburdening the specialist team (Quill & Abernethy, 2013). Specialist involvement may not be necessary when patient care cases indicating palliative care can be capably managed by generalist clinicians (Quill & Abernethy, 2013). In such instances, general practitioners must take a leadership role in the facilitation of care and the coordination of services for families anticipating a perinatal loss. Often it is nurses who take on this responsibility (Limbo & Wool, 2016; Wool, 2013b). By focusing on bolstering the evidence with which nurses can call upon to cultivate expertise in the milieu of PPC, the quality of care received by Manitoban families experiencing perinatal loss may be impacted.

Quality PPC. Generally speaking, the Institute of Medicine (1990) defines quality healthcare as the extent to which healthcare services are aligned with current knowledge to guide practice and result in favorable outcomes. The concept of quality palliative care has been investigated at length and is often defined by a series of indicators (De Roo et al., 2013). These indicators have described quality end-of-life care for a host of different populations, and have been derived from various perspectives including families, health care providers, and patients (Bowman, Martin, & Singer, 2000; Clarke et al., 2003; Downey, Curtis, Lafferty, Herting, & Engelberg, 2010; Emanuel & Emanuel, 1998; Higgins & Prigerson, 2013; Widger & Picot 2008). In the instance of PPC in the context of LDR, not only must a healthcare provider consider quality indicators for palliative care, but also must consider and integrate care reflective of those indicators for quality pertaining to LDR care such as those developed by Ueda et al. (2017). Although these quality indicators are specific to midwifery care in Japan, several of these indicators would be readily transferable to nursing care in the context of LDR in Canada such as "discussed plan of birth" (Ueda et al., 2017, p. 7), and the assessment of the mother at admission and throughout the stages of labor (Ueda et al., 2017).

Widger and Wilkins (2004) undertook a literature review to identify key components of quality perinatal and pediatric end-of-life care. Although the findings encompass broad populations, settings, and reflect a variety of points along the trajectory of the life and death of a child, this work highlights considerations relevant for nurses caring for families in the LDR setting such as the importance of preparing parents for the care that will be received at the end of their child's life and helping parents to gain a sense of control through the transmission of accurate information.

Only recently has a set of quality indicators been developed to describe PPC in the prenatal,

intrapartum, and postnatal settings after the diagnosis of a life limiting fetal condition (Wool, 2015; Wool et al., 2016). Wool (2015) developed the Parental Satisfaction and Quality Indicators of Perinatal Palliative Care Instrument based on the 8 domains of quality care as outlined by the National Consensus Project (2013) including: (1) structure and processes of care; (2) physical aspects of care; (3) psychological and psychiatric aspects of care; (4) social aspects of care; (5) spiritual, religious, and existential aspects of care; (6) cultural aspects of care; (7) care of the imminently dying patient; and (8) ethical and legal aspects of care (National Consensus Project, 2013). Individual quality indicators included statements such as "The healthcare team treated my baby as a person", "When the healthcare team could not meet my wishes, they explained why", and "The healthcare team asked about my cultural or family traditions" (Wool, 2015, p. 305). Fourteen expert interdisciplinary panelists from Australia, Ireland, Portugal, and the United States further refined the instrument to include 45 quality indicators, 1 item regarding parental satisfaction, and 15 demographic questions (Wool, 2015). This instrument was then piloted with nine bereaved parents for further feedback yielding interesting considerations for future research but no further changes to the instrument itself (Wool, 2015). What is unique about this series of quality indicators and markers for parental satisfaction of palliative care is that each applicable indicator is assessed based on the three overarching periods throughout the pregnancy trajectory including the care received during the prenatal, intrapartum, and postpartum periods (Wool, 2015). This is of particular importance since a woman interacts with different healthcare providers in different settings throughout these varying stages of pregnancy, birth, and early parenthood (Wool, 2015).

Following its development, Wool, Black and Woods (2016) implemented this instrument with a convenience sample of 405 bereaved parents via a web platform in order to determine

which of the 35 quality indicators applicable to the intrapartum setting had the greatest impact on parental satisfaction in the intrapartum period and concluded that quality indicators regarding sensitive care such as "Health Care team helped me to cope with my emotions" (Wool et al., 2016, p. 351) and processes of care such as "Health care team worked with me to make a treatment plan for my infant" (Wool et al., 2016, p. 351) most accurately explained parental satisfaction. It may be important to note that these 35 quality indicators applicable to the intrapartum period fit into four broader categories representing the following aspects of care: (1) the provision of sensitive care; (2) knowledge and implementation of processes of care; (3) spiritually and culturally sensitive care; and (4) knowledge of and provision of resources (Wool et al., 2016).

More recently, Wool, Kain, Mendes and Carter (2018) reported on which of the 41 quality predictor items from the Parental Satisfaction and Quality Indicators of Perinatal Palliative Care Instrument (Wool, 2015) pertaining to the postnatal period most accurately predicted parental satisfaction after the birth of an infant with a life-limiting condition (Wool et al., 2018). The six subscales related to postnatal care included items based on: (1) compassion; (2) process of care; (3) infant treatment; (4) bereavement; (5) spirituality and culture; and, (6) end-of-life (Wool et al., 2018). Many of the indicators for this period overlap with those set out for the intrapartum period and apply directly to the care nurses provide in the LDR setting. In their analysis, Wool et al., (2018) determined the individual sub-scales predicted parent satisfaction at least 85.1% and as often as 90.3% of the time. Their analysis further discerned that 17 of the 41 quality indicators for the postnatal period were statically significant in predicting parental satisfaction (Wool et al., 2018). These included indicators such as "Health care team was compassionate", "Health care team provided comfortable, caring environment". "Health care team helped me

cope with my emotions", "Health care team assessed cultural and family traditions", and "Healthcare team invited me to participate in giving care to my baby at end-of-life" (Wool et al., 2018, p. 280).

Such a series of valuable and novel indicators outline *what* a nurse providing care for a family during perinatal loss might hope to achieve to enhance the quality of care they provide, and the parental satisfaction with their care, but falls short in specifically describing *how* a nurse might accomplish those outcomes. According to Benner (1982), the first step in improving the quality of patient care requires "recognition of the experienced nurse in positions of direct clinical practice along with the documentation and adequate description of their practice" (p. 407). If not the first step, expert nursing is certainly one integral component of quality patient care (Aitken, 2003; Christensen & Hewitt-Taylor, 2006; King & Appleton, 1997). For instance, the involvement of healthcare providers with specialist knowledge in palliative care can result in less-aggressive interventions at birth (Lee et al., 2014), allowing for families to cherish those precious moments with their infant. Sensitive care respecting the wishes and preferences of families also yield higher quality care and parental satisfaction with care (Wool et al., 2016).

How a nurse might expertly carry out behaviors to achieve such indicators of quality care while providing PPC has yet to be portrayed in the literature. An investigation into and a description of such behaviors will provide a practical evidence base for those nurses aiming to learn from experts in their field about how to provide care for families anticipating or actively experiencing a perinatal loss on a labor and delivery unit. Moreover, the provision of expert PPC is essential for these families as the support and guidance offered by healthcare providers during this delicate time of life can determine their level of satisfaction with the care they receive (Wool et al., 2016), and have an enduring impact on their healing process (Limbo & Wool, 2016).

Expert Nursing

Overall, nurses comprise the largest group of healthcare professionals involved in maternity care in Canada compared to other healthcare disciplines (The Vanier Institute of the Family, 2017) and Limbo and Wool (2016) ascertain that nurses are often the experts coordinating services, such as creating and carrying out a plan for pregnancy and birth, and identifying a family's priorities for their infant post birth. However, little is understood about what constitutes expert nursing practice in instances where PPC is indicated in the context of LDR. In order to begin to understand this phenomenon, a more general sense of what is meant by the concept of expert nursing must be realized.

Nursing scholars and clinicians alike have pondered the concept and implications of expert nursing since as early as the 1940's (Conrad, 1947). Recently, a concept analysis revealed that a multitude of definitions and characteristics have been offered over time to demarcate nursing expertise, resulting in a somewhat tenuous understanding of the concept and how it may be enacted (Hutchinson et al., 2016). In contrast with this ambiguity, it is safe to say that nursing expertise is possessed by expert nurses, and that these expert nurses enact expert nursing practice. Benner, Tanner, and Chesla (2009) characterize expert nursing practice by the presence of "increased intuitive links between seeing the salient issues in a situation and ways of responding to them" (p. 137). More specifically, an integrative review on expert nursing practice revealed in most instances expert nursing practice requires: (1) knowing the patient; (2) possessing intuitive knowledge; (3) engaging in reflective practice; (4) taking calculated risks; and (5) demonstrating skilled know-how (Morrison & Symes, 2011). Understanding the importance of these elements in the context of LDR nursing and the care of families anticipating or experiencing perinatal loss is vital to quality PCC care.

Expert nursing in palliative care. As expert nursing practice in instances of PPC in LDR have not been studied to date, a nurse in this scenario and setting might look to literature on expert nursing practice in instances of palliative care, and literature on expert nursing practice in the intrapartum setting and critically appraise and integrate what evidence they deem generalizable to their own care setting and situation. For instance, Degner, Gow and Thompson (1991) described the critical behaviors of ten experienced palliative care nurses and ten palliative care nurse educators while caring for dying patients. Here, critical behaviors emerged particularly in response to a death scene, to anger, to colleagues, and to the family (Degner et al., 1991). Additional critical behaviors materialized concerning the provision of comfort and to enhance personal growth and the quality of life of patient while dying (Degner et al., 1991). Since the time of this study, further studies investigating critical behaviors exhibited by expert nurses while caring for those receiving palliative care across populations and settings have further reinforced the evidence base regarding *what* expert nurses do when providing palliative care for particular populations in specific context bound settings (Harbeck, 1995; Hawkins, 1995; Johnston & Smith, 2006; McClement & Degner, 1995; Wowchuck, 2004). Such a valuable and novel approach to the study of expert palliative nursing care in the context of LDR has yet to be undertaken.

Expert nursing in LDR. In terms of the LDR setting, Downe, Simpson, and Trafford (2007) conducted a meta synthesis of expert intrapartum maternity care amalgamating studies exploring the care provided by both midwives and nurses. Overall, this meta synthesis determined that three main facets of expertise in this setting were those related to wisdom, skilled practice, and enacted vocation (Downe et al., 2007). Here, wisdom was developed through an ongoing process whereby knowledge was drawn from a variety of sources such as

theory and experience and resulted in an intuitive grasp of care provision and a tolerance for uncertainty throughout the process of labor and delivery (Downe et al., 2007). Skilled practice of expert care providers in the intrapartum setting requires them to have reflexive competence, meaning they can look beyond protocols and routine care to respond to swift changes in health status while creating and maintaining a safe space for the laboring woman (Downe et al., 2007). All the while, these experts in intrapartum maternity care are consistently confident in their abilities, integrate information from many sources to make judgements, and possess technical capacity and emotional intelligence when engaging in the many clinical skills required for care during the intrapartum period (Downe et al., 2007). Expert nurses and midwives enact their vocation by integrating their: (1) values and beliefs, such as having a sense of trust in a woman's physiological ability in the birthing process; (2) intuition, knowing that this is only one part of what guides care; and (3) engaging in companionship through actions such as being actively present with a woman though her labor. Although these findings are valuable and give a broad sense of how expert care by midwives and nurses have been described in the literature, a tangible description of *how* a nurse might embody these facets of expertise during patient care is not transparent.

Of the seven studies Down et al. (2007) included in this meta synthesis, the most salient nursing specific study was conducted by James, Simpson and Knox (2003) who explored how expert nurses viewed their role and influence on patient care. To accomplish this, James et al., (2003) identified and interviewed fifty-four expert labor and delivery nurses based on having at least five years of experience in a nurse managed labor practice model. In their analysis, James et al., (2003) identified that these expert nurses practiced intuitively by calling upon their previous experience to use "the past in the present" (James et al., 2003, p. 818) when making clinical

judgments. Their aptitude to perform complex nursing skills such as fetal heart rate monitoring enabled them to make space for valuable and simple caring interventions such as touch (James et al., 2003). These expert nurses were able to know their patient and let her body guide labor, in part, because they were comfortable with the endless divergent patterns of labor (James et al., 2003). As a result, expert nurses were able to tailor the care to that patient and to their unique presentation of labor. Furthermore, James et al. (2003) determined that expert nurses recognized the vulnerable state the maternal fetal dyad are in during the process of labor and delivery, and stood up to advocate for a safe and meaningful experience. Finally, expert nurses exercised autonomy confidently in making clinical decisions and found satisfaction doing so (James et al., 2003). Though valuable, the perceptions of these nurses and the subsequent findings of the study neglect to demonstrate *how* expert nurses care for their patients, and make no mention of whether these expert nurses view their roles differently when poor birth outcomes are anticipated, leaving this pressing paucity in the literature untouched.

Expert nursing in this study. Although the concept of nursing expertise remains to be somewhat nebulous, Benner's (2001) description of how the expert nurse is delineated from novice, advanced beginner, competent, and proficient nurses provides insight into the identification of expert nurses. Although nursing expertise can be somewhat difficult to explain, Hutchison et al., (2016) state that nurses often know an expert colleague when they see them, and it is this notion that underpinned this study's use of a peer nomination process to identify eligible participants that is described in the fourth chapter of this thesis. Benner (1982) concluded, "The expert nurse, with an enormous background of experience, now has an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions" (p. 32). This

sentiment is the backbone informing the understanding of the concept of expertise in nursing for this study, inspiring an investigation into not only *what* expert nurses *do* in instances of PPC, but also *how* and *why* they behave a particular way and provide care in a particular manner.

Summary

This literature review has outlined (1) the search strategies used to complete this literature review; (2) the use of literature in interpretive description; (3) an overview of the stages of labor and standard nursing care provided in Canada to help contextualize this study; and (4) an appraisal of the current literature pertaining to PPC and expert nursing care with special attention paid to how these concepts appear in the literature related to the context of LDR settings. As demonstrated through the literature review provided in this second chapter, PPC is an emerging field in healthcare and many valuable scientific contributions have been made to create the foundation for an expanding evidence base that can inform the PPC healthcare providers deliver. However, a paucity of evidence concerning expert nursing practice when PPC is indicated in the context of LDR continues to exist. The third and following chapter of this thesis will focus on the theoretical forestructure of this study.

Chapter Three: Theoretical Forestructure

Interpretive description does not explicitly require the use of a conceptual framework as in other research methodologies, and instead focuses on making transparent the "theoretical forestructure" of the study (Thorne, 2008, p. 64). The process of outlining the theoretical forestructure of the study includes: (1) identifying theoretical allegiances; (2) situating the study in the corresponding discipline; and (3) placing one's self within the area of inquiry (Thorne, 2008). In the first chapter, I offered a reflection on how my individual clinical experience as a nurse yielded this particular inquiry, addressing the second two points. This third chapter will focus on the first point by providing a description of the theoretical allegiance that influenced and helped to interpret and define the phenomena of interest. Benner's Novice to Expert Model (Benner, 1982, 2001) framed the understanding of the concept of expert nursing practice for this study.

Benner's Novice to Expert Model

Thorne (2008) encourages researchers to consider their discipline itself a theoretical allegiance. In addition to the impact my own views as a nurse have on shaping each step of this study, I will further situate this project in the discipline of nursing by utilizing Benner's Novice to Expert Model (Benner, 1982, 2001).

A concept analysis of nursing expertise found that Benner's Novice to Expert Model (1982) has underpinned the majority of studies that examine expertise in nursing practice (Hutchison et al., 2016), and this study will be no exception. The overarching aim of this project was to empower nurses to provide the best quality care possible by producing evidence for clinical practice which examined and described expert nursing practice when PPC is indicated in LDR. Benner's model (1982, 2001) proposes the first reasonable step to take toward redressing

this current gap in knowledge toward quality PPC is to recognize and describe the behaviors of expert nurses.

Benner's Novice to Expert Model is a nursing specific adaptation of the Dreyfus Model of Skill Acquisition (Dreyfus & Dreyfus, 1980). Benner (2001) employed this model of skill acquisition in a qualitative study involving in-depth interviews and participant observation of nurses at varying points in their career trajectories to determine its applicability to nursing. The Dreyfus Model of skill acquisition (1980) was based on a population of airline pilots and chess players, where both education and experience were considered to be foundational in the development of proficiency, and in some cases, expertise. Benner's interpretation of the concept of experience is notable as it does not merely constitute the passage of time, rather, Benner postulates that experience is "the refinement of preconceived notions and theory by encountering many actual practical situations that add nuance or shades of differences to theory" (Benner, 1982, p. 407)

Dreyfus and Dreyfus (1980), and subsequently Benner herself (1982), described five levels of proficiency, those being: (1) novice; (2) advanced beginner; (3) competent; (4) proficient; and (5) expert (Benner, 1982, 2001; Dreyfus & Dreyfus, 1980). As a nurse progresses through each of these stages, three main shifts pertaining to skilled performance occur. First, is a shift away from the use of stepwise principles toward the integration of knowledge derived from concrete past experiences. Second, is a shift toward viewing clinical situations holistically and developing an ability to identify the most relevant findings from an assessment. This holistic view contrasts with the understanding of a more novice nurse whose assessment is based on disparate objective findings without identification of which of those findings are most significant. Third, is a shift toward viewing the nursing role as one of active

performance rather than of detached observance (Altmann, 2007; Benner, 2001; Dreyfus & Dreyfus, 1980).

Table 1
Benner's Novice to Expert Model: The Five Levels of Proficiency

Level of Proficiency	Definition
Novice	**"**Beginners have no experience with the situations in which they are expected to perform tasks. In order to give them entry to these situations, they are taught about them in terms of objective attributes… [such as] weight, intake and output, temperature, blood pressure, pulse, and other such objectifiable, measurable parameters of the patient's condition" (Benner,1982, p. 403).
Advanced Beginner	"The advanced beginner is one who can demonstrate marginally acceptable performance. This [nurse] is one who has coped with enough real situations to note the recurrent meaningful situational components" (Benner, 1982, p. 403).
Competent	"Competence is evidenced by the fact that the nurse begins to see his or her actions in terms of long range goals or plans. The competent nurse lacks the speed and flexibility of the nurse who has reached the proficient level, but the competent stage is characterized by a feeling of mastery and the ability to cope with and manage the many contingencies of clinical nursing" (Benner, 1982 p.405).
Proficient	"The proficient [nurse] perceives situations as wholes…and can now recognize when the expected normal picture does not present itself. The holistic understanding of the proficient nurse improves his or her decision making. Decision making is now less labored since the nurse has a perspective about which of the many attributes and aspects present are the important ones" (Benner, 1982, p.405).
Expert	"The expert nurse, with her/his enormous background of experience, has an intuitive grasp of the situation and zeros in on the accurate region of the problem without wasteful consideration of a large range of unfruitful possible problem solutions" (Benner, 1982, p.405).

Adapted from "From Novice to Expert," by P. Benner, 1982, *American Journal of Nursing, 82*(3), p. 402-407.

Through her adaptation of the Dreyfus Model of Skill Acquisition (1980), Benner (1982) was able to describe the development of expert nursing practice to illuminate the knowledge embedded in clinical expertise. Benner (1982) posits that the first step toward enhancing the quality of patient care in particular clinical care settings is to describe and document expert nursing practice.

Critiques of Benner's Novice to Expert Model

As with most models, theories, and philosophies utilized in the field of nursing, numerous critiques of Benner's Novice to Expert Model (Benner, 1982, 2001) have been articulated. No model, theory, or philosophy is perfect and each has its unique limitations, so, in the case of its application to this study, such critiques certainly warrant mention.

Several critiques regarding Benner's (1982, 2001) use of the term expert have been offered. Rolfe (1997) points out that expert nurses are demarcated from their less proficient counterparts based on how they think during a particular clinical encounter, yet, this way of thinking is never explicitly described by Benner. Additionally, English (1993) criticizes the dearth of explanation offered to delineate what sets nurses who do develop expertise apart from those who do not, even in similar settings and over similar time frames.

Challenges concerning the measurement of the stages of proficiency have been noted (English, 1993; Gobet & Chassy, 2008; Nicol, Fox-hiley, Bavin, & Sheng, 1996), and the description of what is required of an individual nurse to progress through the stages has been perceived as lacking specificity and as being more theoretical than practically applicable (Gobet & Chassy, 2008; Shapiro, 1998). While acknowledging both the value this model adds to understanding the concept of expert nursing as well as several of the critiques that have been proposed, this research project aimed to further the discussion about expert nursing practice by

providing clarity and specificity around how expert nursing practice is enacted during the provision of PPC in the context of LDR.

Summary

With an awareness and appreciation of both the strengths and limitations of this model, it has served as the theoretical allegiance that informs the understanding of the development of expert nursing practice for this study. This model has further rooted this study in the discipline of nursing as Benner's Novice to Expert Model (1982, 2001) was adapted and developed by a nurse, is concerned specifically with nursing practice, and is intended for nurses who are interested in understanding the knowledge embedded in expert clinical practice. The next chapter will outline the methods that were used to conduct this study.

Chapter Four: Methods and Procedures

This fourth chapter will outline the methods and procedures used for this study and will provide a description about each of the following: (1) design; (2) setting; (3) sampling approach, inclusion criteria and recruitment methods; (4) data collection, data analysis and methods to enhance the scientific merit of the study; (5) measures taken to ensure participant confidentiality; (6) ethical considerations addressed; (7) timeframe; and (8) plans for research dissemination.

Design

A qualitative approach to research known as interpretive description (Thorne, 2008) was selected to describe expert nursing practice in the context of LDR when PPC is indicated. The use of interpretive description facilitated the illumination of a conceptual description of this phenomenon intended to be useful for clinical practice.

Setting

This study was conducted in a larger urban centre where labor and delivery care is typically provided at one of two tertiary care sites. The first was Health Sciences Centre, the largest health centre in Winnipeg employing over 8,000 interdisciplinary healthcare providers and volunteers (Health Sciences Centre, 2017). At Health Sciences Centre, the participating unit included one 13 bed LDR unit with baseline staffing of 17 registered nurses per day shift and 16 registered nurses per night shift (C. Finnbogason, personal communication, November 22, 2017).

The second site was St. Boniface General Hospital. This hospital employs 4,000 interdisciplinary healthcare providers and volunteers (St. Boniface Hospital, 2017). At St. Boniface Hospital, the participating unit included an 11 bed LDR unit with a baseline staff of 15 registered nurses each shift (S. Siewert personal communication, July 3, 2019).

Each of these sites employ approximately 100 nurses full and part time in the area of labor and delivery care (C. Finnbogason, personal communication, November 22, 2017; G. Hazlitt, personal communication, April 23, 2015; S. Mussell, personal communication, 2015). In addition to the participating units at both sites, the Women's Health programs each have an obstetrical triage unit, a neonatal intensive care unit, a fetal assessment unit, an antepartum and gynecological care unit, and postpartum specific care units.

At both sites, the nurse to patient ratio is one-to-one during active labor. One nurse can be responsible for the care of up to three patients depending on the stage of labor and complexity of the care required. Approximately 5600 live births, 35 stillbirths and 25 early neonatal deaths occur at each site annually (C. Finnbogason, personal communication, November 22, 2017; G. Hazlitt, personal communication, April 23, 2015; S. Mussell, personal communication, April 24, 2015).

One feature that distinguishes the availability of services within Women's Health programs at each of these sites is the availability of elective pregnancy termination. Health Sciences Centre's Women's Hospital provides services for expecting families that are inclusive of elective pregnancy termination known as abortion. In some instances, families who receive a life limiting diagnosis for their fetus may choose to terminate their pregnancy. In other instances, families may decide to continue their pregnancy to term, or until labor naturally occurs. At St. Boniface Hospital, except under life threatening circumstances, abortion is not typically performed.

The healthcare staff at both participating sites has access to the Winnipeg Regional Health Authority's Pediatric Palliative Care Service on a consultative basis. This service, comprised of one clinical nurse specialist and a team of physicians who rotate to provide 24/7

coverage, is focused on providing support for children and infants with life limiting conditions and their families. The service is particularly concerned with planning for and providing symptom management and end-of-life care (Harlos, 2016). The Pediatric Palliative Care Service attends to children, infants and their families in any care setting, including the context of LDR care, and provides telehealth and telephone support for families outside of Winnipeg (Harlos, 2016). The Pediatric Palliative Care Service may be involved with families who receive a life limiting diagnosis for their fetus prenatally, or may be consulted during the LDR process in instances of unexpected perinatal loss. In recent years, prenatal consults comprised approximately one quarter of all consults received by the service (Harlos, 2016). The service is consulted at the discretion of the front line healthcare providers working with any particular family and, as a result, is not necessarily involved in every instance of perinatal loss in the context of LDR care.

The provision of birth services in Manitoba requires healthcare providers to be sensitive to the unique needs of its population and to be aware of the healthcare challenges particular to the region. The population density across Northern Manitoba, Northwestern Ontario, and Nunavut is sparse, contributing to the limited access to healthcare resources such as specialty obstetrical services. Although efforts are being made to ameliorate the disparity in access to healthcare in remote communities, at present, some women from these communities are required to temporarily relocate to Winnipeg for birth services (Struthers, Winters, & Metge, 2014). Depending on the complexity of the care they require and their previous obstetrical history, women may need to travel, in many instances alone, to Winnipeg up to two months before their due date and stay in the city until after the birth of their infant (Struthers et al, 2014). Both sites provide care for women who have temporarily relocated from their communities during the last

trimester of their pregnancy. Healthcare providers must be attuned to the particular barriers and challenges these women face, such as: having limited social support, facing challenges in managing daily life while in Winnipeg, and experiencing restrictions in their choices and power (Struthers et al., 2014). Healthcare providers will want to be particularly attuned to the fact that, at the study sites in Winnipeg, travelling for birth services has been normalized and may not always be in the best interest of the women who are removed from their communities, or of the communities they have temporarily left behind (Struthers et al., 2014).

Sample and Recruitment

Although the concept of expert nursing practice is nebulous, Hutchison et al. (2016) state that nurses "recognize it when they see it" (p. 290). This provided grounds upon which to utilize a peer nomination process initially developed by Degner, Gow and Thompson (1991), and further utilized and refined by McClement and Degner (1995) and Wowchuck (2004), which identified a purposive sample of eligible participants. Nurses were invited to study information sessions at each of the two participating sites (see Appendix H for the information session script). Several information sessions were held at different times on each of the participating units in order to communicate information about the study to nursing staff on various shifts (i.e., days, evenings, and nights). During these meetings, the study was described and each attendee was provided with a nomination form that included general information about the study (see Appendix A). This form was intended to help nursing staff distinguish which of their nursing colleagues they would consider experts in the care of families anticipating or experiencing the death of their infant by asking the following question: "If there was a family on your unit experiencing perinatal loss, which of your nursing colleagues would you want at their bedside?"

All nurses working full or part-time were able to anonymously participate in this step of the study by appointing up to three of their nursing colleagues who came to mind when the sensitizing question was presented on the nomination form. Completed nomination forms were submitted by placing them in a locked ballot box that was conveniently located on the participating units. Nurses were encouraged to nominate themselves if they felt they were a good fit given the sensitizing question presented. Information about the study and the nomination forms were displayed next to the locked box for nurses who were unable to attend the information sessions in order for them to have had an opportunity to participate in this part of the study. The completed nomination forms were gathered by the researcher each week to tally the nominations. The duration of the nomination process was determined by the length of time it took to get as close to five nurses who met the inclusion criteria of having at least three nominations at each site. The nomination period lasted five weeks at Health Sciences Centre, and three weeks at St. Boniface Hospital.

In accordance with the previous studies that have used this method of nomination, a minimum of three nominations by three separate colleagues was required to meet inclusion criteria for an invitation for participation (McClement & Degner, 1995; Wowchuck, 2004). To meet the study inclusion criteria, the nominees had to have been registered nurses who work full or part-time on one of the participating units and be comfortable to consent to partake in interviews conducted in English. As in similar descriptive qualitative studies, a total of 10 participants comprised the recruitment target (Cernigoy, 2014; McClement & Degner, 1995; Wowchuck, 2004). However, in qualitative studies, the sample size is not dictated in advance, but is informed by the richness of the data obtained from participants. The seven participants recruited between the two sites agreeing to participate in the study proved to be excellent

informants. Characteristics of the nomination process and study sample are outlined in the following chapter. Eligible nominated nurses then received letters of invitation inviting them to participate in up to three face-to-face semi-structured interviews approximately 60 minutes in duration (see Appendix B). Distribution of letters of invitation happened in one of two ways: (1) unit clerks distributed sealed letters of invitation to the invited participants; or (2) unit clerks distributed letters of invitation by email on the researcher's behalf. A follow-up letter or email was issued by one of these methods to eligible participants who do not respond within two weeks.

Once a nurse responded to letter of invitation, the opportunity to participate in was discussed in greater detail with the researcher and informed consent was obtained (see Appendix C). Study participants were then asked to provide some demographic information (see Appendix D). Next, semi-structured interviews were conducted by the researcher and were arranged at a place and time that was suitable for both parties (see Appendix E for the interview guide). These interviews were audio recorded and transcribed verbatim for the purpose of data analysis. During interviews, nurses were asked to recollect a time they provided care for a family experiencing a perinatal loss. They were asked what their experience providing that care was like, and how caring for a family experiencing the death of their infant was different than caring for a family anticipating a well infant. Other questions were posed to engage them in a conversation about what they believed constituted expert nursing care for families who received PPC, and what factors promoted their ability to develop expertise and carry out PPC. Questions were also be asked about what made it difficult for them develop expertise or carry out this care. Finally, participants were asked about what the impact of achieving or not achieving expert PPC care was on themselves, their healthcare team, and the families they cared for.

Data Analysis

Demographic data was analyzed utilizing descriptive statistics in order to portray the population of nurses who participated in the study. All interviews were transcribed verbatim by a hired transcriber who received training about the Personal Health Information Act. The digital audio files of the interviews were provided directly to the transcription service by the researcher through an encrypted platform to maintain confidentiality. Any identifying information was excluded from the transcripts to ensure anonymity. The researcher checked the completed transcripts against the recorded conversations to ensure correctness and completeness.

In interpretive description, Thorne (2008) describes how techniques for data analysis may be critically appraised for their fit with the research question at hand and the associated conceptualization of what constitutes knowledge. In the instance of this study, thematic analysis as outlined by Braun and Clarke (2006) was utilized to guide analysis. Thematic analysis is a process whereby data is organized and described in rich detail, allowing for interpretation of aspects of the research topic (Braun & Clarke, 2006). First, the researcher became immersed in the data by repeatedly reading the transcripts, and formed the initial codes to facilitate the process of searching for themes (Braun & Clark, 2006). As new themes emerge during the process of analysis, the researcher contacted several participants to conduct additional face-to-face interviews with a focus on exploring emerging ideas and interpretations of those ideas. For instance, when participants were asked initially about the impact of care for families when it was perceived to have gone well or not gone well, nearly all participants remarked about the emotional responses of families during their hospital stay and speculated about their emotional responses after discharge from the hospital. Clarification was sought from participants to understand to what degree they expected their care to influence the emotional experience of

patients during and after the death of their child. By following up with study participants around this topic, it was determined that the parental experience of perinatal loss was inherently emotionally challenging, and that expert care was seen as still being achieved in the presence of difficult emotions. Participants were then asked about how they responded to these difficult emotions and what their goals were when addressing those emotions through their actions. Nurses described their intentions not to exacerbate the emotional challenges of perinatal loss, and to not cause further harm through their actions toward or interactions with their patients. Ultimately, these follow up discussions lead the understanding that mitigating emotional harm was an outcome of enacting expert care. This built in measure addressed interpretive authority, a quality consideration toward enhancing credibility, by ensuring emerging interpretations were true beyond the researcher's own bias (Thorne, 2008). Themes were refined and given definitions, and finally, questions such as "what are the implications of this theme?" (Braun & Clark, 2006 p. 24), and "what conditions may have given rise to it?" (Braun & Clark, 2006 p. 24) were posed by the researcher of the data to facilitate an interpretation of the findings. Asking such questions throughout the process of analysis helped to bring contextual awareness to how findings fit within the broader social environment they arose from, addressing another of Thorne's (2008) evaluative criteria for credibility.

Credibility can be broadly understood as "the extent to which a research account is believable, trustworthy, and appropriate" (SAGE Publishing, 2019, para. 1). Thorne (2008) more specifically articulates that measures taken to enhance the credibility of a research study are aimed at assuring "integrity of the [research] process and product" (Thorne, 2008, p. 101), and at keeping "data collection and analysis on target with the ultimate research purpose" (Thorne, 2008, p. 102). In order to further address the issue of credibility throughout the process

of data analysis, the researcher kept brief notes documenting her pathway of reasoning (Thorne, 2008). This pathway of reasoning, known as an audit trail (Thorne, 2008), was discussed with and overseen by Dr. Genevieve Thompson, the academic co-advisor on this project. Her consultation was sought throughout the process of data analysis to ensure sound analytic logic, with special attention paid to the interpretation of findings and any knowledge claims made as a result of what was concluded from the project.

Along with Thorne (2008), Braun & Clark (2006) assert the importance of making transparent the theoretical underpinnings and epistemological approach that will inform the understanding of what data are and of what constitutes knowledge throughout the process of analysis. My experience as a bedside nurse on an LDR unit reinforced my decision to take a constructivist approach to data analysis. While caring for families facing perinatal loss, I began to perceive the foundation of providing PPC as tailoring all care actions to the individual family by understanding what meaning expecting mothers and their families ascribed to their pregnancy, their infant and the purpose of that infant's life and death, and how the death of their infant impacted their own roles and identities. In addition to this, memento making (such as taking family photos, documenting the infant's footprints and handprints) is, for many families, a central part of paying homage to their child at this stage of their pregnancy loss trajectory. Nurses can help families to assign meaning to their experience of perinatal loss by thoughtfully documenting the existence of their infant and, in doing so, commemorate the life and death of their child. Through such actions, healthcare providers can support parents in constructing meaning in their experience of perinatal loss. Analyzing data with instances of meaning making such as these in mind bolstered my ability to keep the experiences of families central to the

project and to remain grounded in my constructivist approach in order to develop findings with epistemological integrity, another marker for credibility identified by Thorne (2008).

Confidentiality

Confidentiality is "the principle that information gathered from or about research participants in the course of a study is private and should only be revealed to third parties with the explicit consent of the individuals from whom the information was obtained" (SAGE Publishing, 2019, para. 1). In order to maintain participant confidentiality throughout the study a list of names and contact information of participants were kept in a secure file so that a summary of findings could be mailed to those participants who wished to receive a copy. Participants were assigned a code number and their names did not appear on any documents such as transcripts or demographic forms. The code number was used in place of their name to protect their identity and the identity of any colleagues or patients and families they discussed. Names and contact information was also stored separately from consent forms, and from a list of code numbers assigned to each transcript linking the participant to their data. During the course of the study, all data collection forms were stored in a locked cabinet at the University of Manitoba and were only reviewed by the researcher or project advisors. The digital audio recordings were shared with the transcription service on a password protected platform on a secure network. Digital audio files and other electronic information were stored on a password protected computer at the University of Manitoba. At the completion of the study, the data collection forms, transcripts, and digital audio files will be retained for a period of ten years, following which they will be destroyed and treated as confidential waste as per policies.

Ethical Considerations

Prior to the initiation of recruitment, ethics approval for this study was sought from the University of Manitoba Education and Nursing Research Ethics Board, and access for research was obtained from each of the participating sites. Given the delicate and sensitive nature of the topic of perinatal loss, prior to an interview the researcher invited participants to take a break or stop the interview at any point should they give verbal or nonverbal cues that they may be finding the interview upsetting. The researcher was sure to check in with participants during the interviews to ensure they felt comfortable to continue discussing their experiences and thoughts about this topic. Additionally, nurses were provided with contact information for counselling and support services in the event they found themselves in need of further support. This contact information was embedded in the informed consent forms (see Appendix C) for this project and was reviewed as part of the consenting process.

During interviews, some participants did indeed exhibit emotional responses such as tearfulness when recalling their experiences. In these moments, the researcher checked in to ascertain whether they would like to continue with the interview, take a break from the interview, discontinue conversation on that particular topic, or discontinue the interview entirely. All participants who exhibited emotional responses expressed a desire to continue their interviews and the discussion around the particular topic which evoked their emotional response. In fact, many participants remarked that having the opportunity to talk about their experiences related to perinatal loss openly had an overall positive impact on them. None indicated that they required further support as provided in the consent form, but it is possible they may have elected to contact the provided resource without informing the researcher.

Timeframe

Submission to University of Manitoba Education and Nursing Research Ethics Board (ENREB) was approved May 4th, 2018. Approval for research access was granted from Health Sciences Centre Research Impact Committee on May 10th, 2018 and from the St. Boniface Research Review Committee on July 12th, 2018. Recruitment commenced June 12th, 2018 and was completed September 28th, 2018. Data collection occurred between July 9th, 2018 and January 28th, 2019 with data collection and analysis running concurrently until June 2019.

Dissemination

Upon completion of this project, mechanisms of dissemination and knowledge exchange will include the following: (1) publication in scholarly journals such as the Journal of Obstetrics, Gynecology and Neonatal Nursing or the Journal of Perinatal and Neonatal Nursing; (2) findings will be presented at Winnipeg Regional Health Authority Palliative Care Rounds, and conferences such as the Canadian Association of Perinatal and Women's Health Nurses Annual Conference (Accepted for oral presentation in Vancouver in November 2019); (3) media engagement and distribution of findings via online platforms such as forums for perinatal loss support (i.e., perinatalhospice.org) and the Canadian Virtual Hospice; (4) findings will be shared directly with the WRHA Pediatric Palliative Care Team as their Clinical Nurse Specialist was consulted during the early development of this project to gain insights about whether the gaps in empirical knowledge about PPC in the LDR context were, in her opinion, reflected in clinical practice, and which of those gaps in empirical and clinical knowledge might be valuable to investigate for a Masters in Nursing thesis project; and finally, (5) findings will be shared with the healthcare staff at each of the participating sites during a brief presentation. At that time, a simple anonymous evaluation form (see Appendix G) will be also be administered to solicit

feedback from the healthcare staff. The responses provided on this evaluation form may help inform future educational activities and research. It is anticipated the form will take approximately five minutes to complete. In order to take next steps in ameliorating the gaps in knowledge pertaining to PPC in the context of LDR, this evaluation form will help identify future directions for research that look beyond gaps in empirical literature and encourage the generation of inquiries deemed necessary and practical by frontline healthcare providers. This evaluation form will ask healthcare providers what, if anything, they found helpful for their own clinical practice, and to identify areas they would like to know more about. Attendees of the presentation will be provided the evaluation form to complete on a voluntary basis at the end of the presentation. Completed evaluation forms will be returned to a locked ballot box conveniently located in the presentation room once the presenter has left the room. The ballot box will be collected by the researcher 20 minutes after the presentation is complete to provide time for healthcare providers to complete and submit the form into the ballot box anonymously.

Summary

This fourth chapter has outlined the methods of this study by describing the: (1) design; (2) setting; (3) sampling approach, inclusion criteria and recruitment methods; (4) plan for data collection, data analysis and methods to enhance the scientific merit of the study; (5) measures taken to ensure participant confidentiality; (6) ethical considerations addressed; (7) timeframe; and (8) plans for research dissemination. The fifth chapter will detail the findings of the study.

Chapter Five: Findings

Introduction

This fifth chapter will begin by outlining the characteristics of the nomination process and study sample. Next the study findings will be presented. During analysis, the data was organized into three overarching topics which will be described in the following order: (a) how expert nurses cultivate expertise in PPC in the LDR setting; (b) the outcomes of expert nursing care when PPC is indicated in LDR; and (c) the actions and consideration nurses engage in to enact expert PPC in LDR.

Characteristics of the Nomination Process and Study Sample

Nomination process. Information describing the nomination process is presented in Table 2. At Site A the nomination process spanned a period of five weeks from June 12, 2018 – July 17th, 2018, and just over three weeks from September 11, 2018 -September 28, 2018 at Site B. The beginning of the nomination process was based on when access for research was granted from the specific sites. The duration of data collection was determined by the time it took to recruit as close to five participants per site who met the inclusion criteria of having received a minimum of three nominations.

Table 2
Nomination Process

Site		Number	Percentage
Site A & B	Completed nomination forms	24	n/a
	Total number of nominees	35	n/a
	Received 1 nomination	23	66%
	Received 2 nominations	3	1%
	Received 3 or more nominations	9	26%
	Invited to participate	9	26%
	Total responses	7	n/a
	Response rate	n/a	78%
	Agreed to participate	7	100%
	Withdrew from study	0	n/a
	Attrition rate	n/a	0%
Site A			
	Completed nomination forms	16	67%
	Total number of nominees	26	
	Received 1 nomination	18	69%
	Received 2 nominations	3	12%
	Received 3 or more nominations	5	19%
	Invited to participate	5	19%
	Total responses	4	
	Response rate	n/a	80%
	Agreed to participate	4	100%
	Withdrew from study	0	n/a
	Attrition rate	n/a	0%
Site B			
	Completed nominations forms	8	n/a
	Total number of nominees	9	n/a
	Received 1 nomination	5	56%
	Received 2 nomination	0	0%
	Received 3 or more nomination	4	44%
	Invited to participate	4	44%
	Total responses	3	n/a
	Response rate	n/a	75%
	Agreed to participate	3	100%
	Withdrew from study	0	
	Attrition rate	n/a	0%

Note: Response rates were calculated based on the number of total responses received out of the total invitations to participate; The agreement to participate was based on the number of participants who agreed to participate out of the total who had responded

Overall, a total of 24 nomination forms were completed, and a total of 35 nurses received at least a single nomination. Of those, nine or 26% of all nominated nurses, met inclusion criteria of having received three or more nominations, and were invited to participate. Seven responded to the invite, two did not respond, and of those who did respond, all agreed to participate. No participants withdrew from the study.

At Site A, a total of 16 nomination forms were completed, and a total of 26 nurses received at least one nomination. Of those five, or 19% of all nominated nurses, met inclusion criteria of having three or more nomination, and were invited to participate. Four responded to the invite, one did not respond, and of those who did respond, all agreed to participate. At Site B, a total of eight nomination forms were completed, and a total of nine nurses received at least one nomination. Of those four, or 44% of all nurses, met inclusion criteria of having three or more nomination, and were invited to participate. Three responded to the invite, one did not respond, and of those who did respond, all agreed to participate.

It was interesting to note the variation in the proportion of nominated nurses who met inclusion criteria between the two sites. It was quite clear, during the nomination, interview, and data analysis processes that the expert nurses at Site B were well known by the nursing staff who participated the nomination process and by those who were participants themselves. This differed from Site A where discussion around particular expert nurses was far less specific. The reason for this difference between sites was not made clear during the nomination process itself nor during data collection and analysis.

Characteristics of the sample. Demographic information describing the categorical variables of the study sample are presented in Table 3.

Table 3
Demographic Profile of Study Participants – Categorical Variables

Characteristics		Nurses	%
Site	Site A	4	57%
	Site B	3	43%
Place of Employment	Site A LDR	4	57%
	Site A Women's health float team	0	0%
	Site B LDR	3	43%
	Site B Women's health float team	0	0%
Employment Status	Full time	2	29%
	Part time	5	71%
	Casual	0	0%
Gender	Female	7	100%
	Male	0	0%
	Non-binary or other	0	0%
Level of Education	Registered nursing diploma	2	29%
	Registered psychiatric nursing degree or diploma	0	0%
	Post-diploma degree in nursing	1	14%
	Baccalaureate degree in nursing	4	57%
	Baccalaureate degree in midwifery	0	0%
	Master degree in nursing	0	0%
Post Basic Education in Palliative Care	Yes	2	29%
	No	5	71%
Post Basic Education in Perinatal Care	Yes	4	57%
	No	3	43%
Number of Experiences Providing PPC	1-10	0	0%
	10-30	1	14%
	30-50	4	57%
	Greater than 50	2	29%

Of the seven participants, four were from Site A and three were from Site B. All of them worked on an LDR unit and the majority worked part time. Four of the participants occupied clinical leadership roles, while the other three held positions as general duty nurses. Most nurses described having experience as being in charge of their unit.

The majority of participants held a baccalaureate degree in nursing (57%), while 29% had a diploma in registered nursing. The remaining 14% had a post diploma degree in nursing. Most nurses (71%) had not received post basic education in palliative care, while 57% had received post basic education in perinatal care. Post basic education in palliative care was described as attending a palliative care pain relief workshop for LDR staff held at a local site, and as a two-day perinatal loss course in-service. In term of post-basic education in perinatal care, two nurses had received Canadian Nurses Association Perinatal Certification, and the others described attending a variety of perinatal conferences such as those hosted by the Association of Women's Health and Obstetrical and Neonatal Nurses and Canadian Association of Perinatal and Women's Health Nurses.

The majority of nurses estimated having cared for 30-50 families receiving PPC. Twenty-nine percent had cared for greater than 50 families while the remaining 14% had experience in providing care for 10-30 families anticipating perinatal loss.

All participants identified as female and preferred feminine pronouns (e.g. she/ her), and as such, the nurses in the study are referred to in this way throughout this chapter. Descriptions and interpretations about expert nurses are discussed in this way also but it is important to emphasize that other expert nurses in this milieu of care may not identify in this way.

Further to this, throughout the excerpts of qualitative data used in this document to support findings, laboring patients and their support people are often described with gendered

pronouns and roles (i.e., the mother, the father, the grandmother etc..). In the clinical context it, it is important to address each patient and their support people in a way that aligns with their gender identity and preferences.

Demographic information describing the continuous variables of the study sample are presented in Table 4.

Table 4
Demographic Profile of Study Participants – Continuous Variables

Characteristics	Range (*years)*	Average *(years)*
Age	29-57	40.8
Years of Experience in Nursing	4.25-36	14.5
Years of Experience in LDR	4.24-36	13.6

It is important to note here nearly all of the expert nurses in this study spent the entirety of their career in the LDR setting. As such, the majority did not have particular training or clinical experience in palliative care:

> I've worked in Labour and Delivery my whole career and there isn't any formal training on it. (H01-1 line 47)

Nor did they begin their careers with an expectation that they would be caring for families facing death as a somewhat routine requirement of their career:

> Well, I think that - dealing with loss is one of those things that you never really think about when you choose this for your career, right? So it's kind of a shock to the system that some - not only nurses, but support staff don't handle as well. (H02-2 line 108)

Interview characteristics. A total of twelve interviews were conducted over a period of about seven months between July 9th, 2018 to January 28th, 2019. Interviews ranged from 35 to 93 minutes and were on average 70.3 minutes in length. Of the seven participants, five

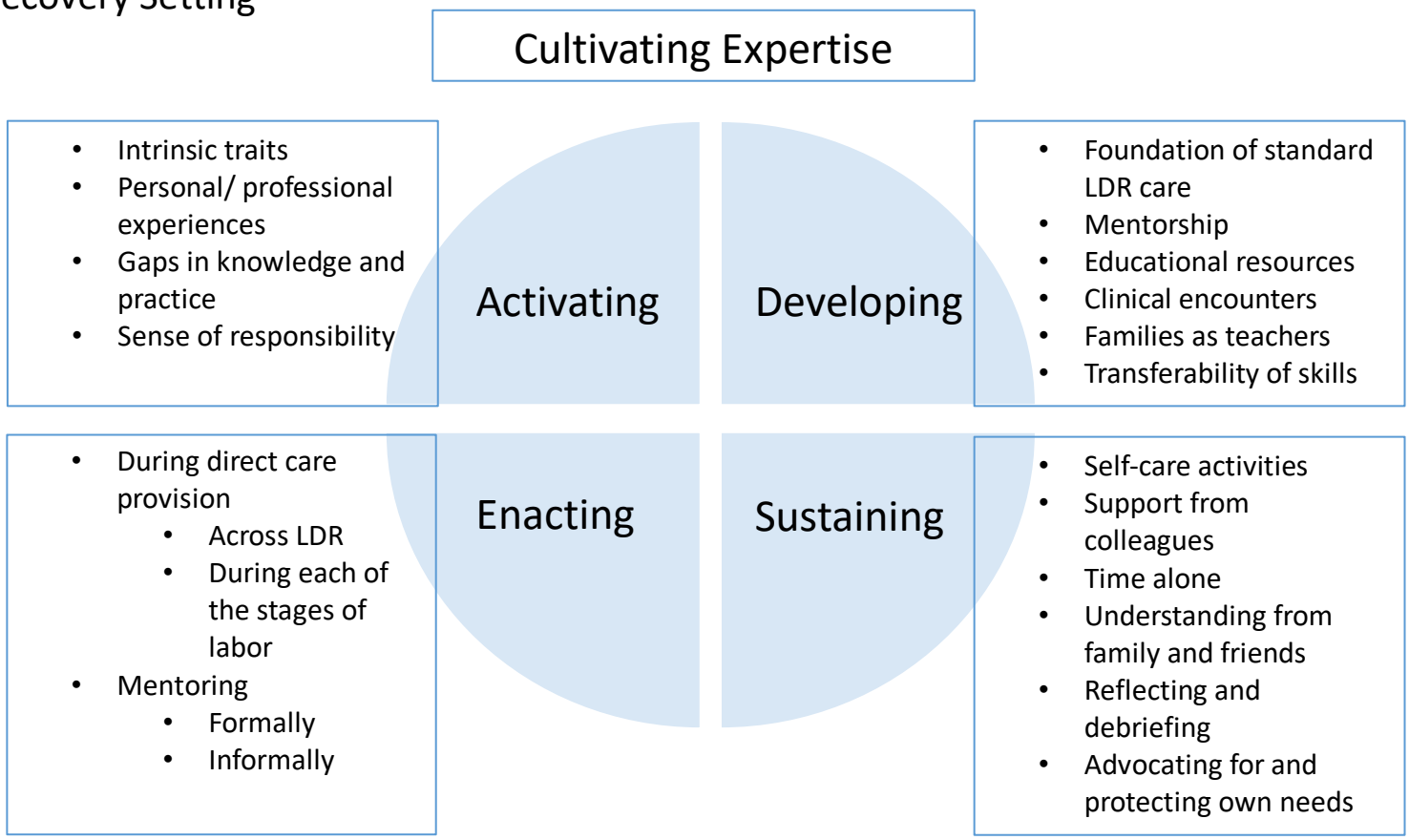
participated in two interviews each, and two participated in a single interview. Of the twelve interviews conducted, four interviews took place in a meeting room at a public library, six in a meeting room at one of the two participating hospital sites and, one study participant elected to meet for her two interviews at a café near her home.

Cultivating Expertise

Introduction. During interviews, participants were asked about what promotes their ability to develop expertise and what facilitates their ability to carry out expert PCC nursing care. They were also asked about what makes these things difficult. Overall, what expert nurses described has been interpreted as a series of actions and considerations that comprise a non-linear process of cultivating expertise. The theme of cultivating expertise will be presented along with an in-depth description of each of the related sub themes including: (a) activating expertise; (b) developing expertise; (c) enacting expertise; and (d) sustaining expertise.

Cultivating expertise in PPC in the LDR setting: A conceptual model.

Figure 1.1 Cultivating Expertise in Perinatal Palliative Care in the Labor, Delivery, and Recovery Setting



The definition of cultivation has several uses and definitions in the English language, and is a word that encompasses the four sub themes that were interpreted from the data.

Table 5
Cultivating Expertise Sub-theme Dictionary Definitions

Sub-theme	Definition	Source
Activate	To prepare	Miriam-Webster (2019)
Develop	To foster growth; to acquire	Miriam-Webster (2019); Oxford (2019)
Enact	To improve by labor, care, or study	Miriam-Webster (2019)
Sustain	To promote, support, encourage, and nurture	Collins (2019)

It was interesting to note that although nominated expert nurses recognized their own capacity for PPC, they sometimes grappled to find the words to articulate specific details about the cultivation of their own expertise, and to define what it precisely is that makes them experts.

> It's ... I don't know. It's just like it's in me. I can't really describe it. (S05-2 line 60)

Despite this, these nurses could more effortlessly engage in discourse about the expertise of their own mentors; other nurses they recognized as experts in this specialty. In some cases, it was seeing that they themselves now possessed similar traits to the mentors they described that they could begin to dialog about their own expertise.

> There are two in particular that stand out to me. One of them, I never had a conversation with her about her experiences but I got the impression that she went through maybe a similar experience; and so for her it was very almost therapeutic to help people through that. And, of course, she was empathetic and very sweet and ... the other one is similar to me, in that she just cares. (S05 -2 line 77)

Overall, factors influencing the cultivation of expertise in PPC can best be described by four overarching themes. Firstly, it was necessary for nurses to be sensitized to the need for

expert care in situations of perinatal loss during labor, delivery, and the recovery period. In becoming attuned to the need for expert care in this way, their expertise is activated. Secondly, once nurses were motivated toward expertise, they actively developed their aptitude for PPC, becoming masters of particular considerations to be made and actions to carry out during care. Some of these considerations and actions are specific to each of the stages of labor, while others pertain to an approach to care more broadly. Thirdly, as expertise was developed, it was enacted in situations of direct care provision for families, by mentoring other nursing staff, and by creating resources to bolster the ability of their colleagues to care for families anticipating perinatal loss in their context of care. Finally, it became evident that a number of supports and self-care behaviours were of paramount importance in order for expert practice in PPC to be sustained.

Table 6
Cultivating Expertise Sub-theme Definitions

Sub-theme	Definition
Activating Expertise	To acknowledge the need for expert PPC, their capacity to become an expert, and their commitment to learning to provide the best PPC possible.
Developing Expertise	To become acutely aware of essential considerations for PPC and to become highly proficient at anticipating and executing the actions required for provision of the best PPC possible.
Enacting Expertise	To implement the developed abilities and skills for PPC during direct care provision and mentorship of staff.
Sustaining Expertise	To attend to own needs in order to support ability to provide PPC on an ongoing basis.

The activation, development, enactment, and sustainment of expertise in PPC did not always occur in this particular order, nor were these aspects of expertise mutually exclusive from one

another. For instance, in the act of sustaining expertise by debriefing with a colleague, a nurse may further activate her commitment to expertise, having for instance, the impact of her expertise on her community of colleagues and on the family she cared for reinforced.

> Have good relationships with to be able to bounce ideas around [with colleagues], but also just to sort of reassure each other that you are doing the best that you can, and you did do the best you could do for that family, right? (H01-2 line 450)

Another anecdote that demonstrated the non-mutual exclusivity of these themes was illustrated when a nurse, who was mentoring her colleague, described learning something new from her mentee. Here, whilst enacting expertise through mentorship she simultaneously deepened her own development of expert practice through learning.

> …if I'm not assigned and someone else has a loss I will definitely go in ... you know, kind of stay behind the scenes but still help them, guide them through what they're supposed to do, teach them. And then through teaching, of course, I learn more. (S05-2 line 102)

Activating expertise. Activating expertise was an act of acknowledging the need for expert caregivers in instances of PPC and of identifying their own capacity to provide the best care possible in these situations. This involved: (a) recognizing that their own intrinsic traits as a person and as a nurse could be leveraged to serve this population; (b) having had a personal or professional experience that moved their interest in the subject of PPC; (c) recognizing that in their context of healthcare, there was a gap to be filled and an expert was needed; and (d) each of these, independently or in combination, giving rise to expert nurses naming a very strong sense of responsibility to develop and enact their skills in caring for families anticipating perinatal loss during labor, delivery, and the recovery period.

Intrinsic traits. Expert nurses discussed possessing particular characteristics that positioned them well for all that the provision of PPC asks of them as nurses, and as people who guide and support others during this delicate life experience. That is not to say that these traits were not resultant from a culmination of life experiences or were not influenced by the development of a professional practice in nursing, but rather these nurses had essentially arrived at a point in their career with these characteristics already in tow.

> For a lot of people it's just an, like an innate characteristic to want to help people and I don't know what draws them to that specific scenario, whether it's - I mean, in order to get better you have to immerse yourself in the situation. (S05-2 line 95)

These traits were inclusive of an empathetic approach to care.

> I mean, it all comes down to empathy, really. I would just hope that going into a room you just have to remember that these patients are going to remember this situation for the rest of their life, most likely, and what you do in there really can make a difference or ... you know, make a good difference or make a bad difference. So I would just hope that people would think that before going into the room. (S05-2 line 234)

A genuine desire to know and connect with the people they cared for was also important.

> I just really like people. I think nursing in general is caring, so you are hopefully bringing that to the table if you're in that profession, but just that connectedness with people and their experience. I like to know people's stories, it doesn't… good or bad. I think that that is an interest for me, but also that part of your job is being a facilitator and a guide through any kind of experience in the medical profession, whether you work in Labour and Delivery or something completely different, you are that face and the point of contact of that experience. (H04-2 line 59)

The importance of these traits was occasionally emphasized through description of the lack of their presence in clinicians who did not possess expertise in PPC.

> And they don't have that compassion. There's one that doesn't have a lot of compassion. I've never seen compassion come out of her mouth. And then there's one with fake compassion, which makes me just as angry. (S06-1 line 1259)

Being **s**elf-reflective was cited as a means to stimulate personal growth within and beyond the context of PPC provision. These traits were coupled with an inner strength and belief in oneself of being capable of performing the tasks required during the emotional terrain of PPC. One nurse described this when commenting on the practice of her mentors and on her own experiences:

> And I guess a lot of self-reflection to say this is how they did it, this is how I would do it. Sometimes I've just been terrified and I just jump right in, because if you're scared of things you're just going to avoid them, so okay, I'm going to do this and find the support there…I think just learning from each experience and every time or every situation that didn't go well or does go well, just to put that in your pocket and say, "Okay, this is good, this is what I'm going to do next time," kind of reflecting back on past experiences. (H01-2 line 866)

Another nurse drew on her own emotional resources to rise to the challenge of providing care as evidenced in the statement, "I feel like in most of the situations really able to channel a calmness and it's almost like I tell myself to be strong for the patient" (H02-1 line 304).

The position of wanting to relieve suffering in others was consistently expressed by participants, and in some way, it had drawn them to PPC. This desire to alleviate suffering was sometimes described as taking an awful situation and simply not making it worse.

> …but like what can I do to make this family's life not so terrible right now, you know? And when you start to think like that, people actually come back to the hospital and say thank you so much, like this wasn't a bad experience. And then you think, how could it not be a bad experience, like your baby died? (H01-1 line 429)
>
> ...you take that terrible situation and make that as okay as it can be, right. And it's not going to be okay, but it's not going to be worse because of it, when you're met with those qualities in your care provider, right. (H02-1 line 544)

Participants also embraced and internalized their role as a nurse in the relief of suffering as a deep and vested part of their own identity, and this fostered a sense of purposefulness through having an impact on the patients they cared for.

> I guess it's just to guide people through that, having seen it before, figuring out what they might need and trying to make those needs met. You really have a role in being able to do that. You can't take what happened away or change their whole experience or anything like that, but the time that you do have with them, you can make the most of it and try to cater that to whatever they need. (H04-2 line 91)

Another nurse emphasized this point when she stated:

> And like I said, for me, I learned to love looking after those patients as tragic as it was sometimes and as heartbreaking as it was sometimes. I don't know, I just felt that it was a part of my nursing career that I could do something really good in for parents who were going to go home without a baby and make it the best experience for them in that short period of time, right? (S06-1 line 713)

Personal or professional experiences. Driven by a personal familial experience or clinical encounter, nurses were moved to deliberately focus on their capability to provide

excellent PPC for others. Several nurses indicated having an experience in their own family life which motivated their sensitivity and responsibility toward other families experiencing perinatal loss. This seemed to deepen their sense of responsibility to families experiencing perinatal loss by heightening their empathy. In many instances, both personal and professional experiences were cited as having influence as one participant described "And some of it's based on my sister's experience and other reactions that I've seen to people. And our very first IUFD [intrauterine fetal demise] that I had, I mean I'll never forget them" (S06-1 line 286). Another participant described a personal experience with a loss in her own family further iterating the impact of personal experiences on activating expertise.

> I mean, my mother suffered a loss when I was a little girl, and so that made me start discussing the loss more with my mother, when I started getting into this. And she said back then – well, back then, it would have been in the early seventies – her doctor told her, don't even think about it as a baby. And she said there was no perinatal loss, there was no time to grieve, there was no - Nope, it was just…She was just told not to even think about it as a baby. And so she said she did grieve about it in her own way. And then I guess that just – I don't know, the wheel started turning in my head and I just thought, I want to learn more about this, because obviously the parent – that one dad at [site name], just made me realise how much we really do need to care for these families. (S07-1 line 36)

Family experiences truly sensitized nurses to think about the impact of their care during bereavement. They became especially attuned to how their care during the LDR period may alleviate or exacerbate grief once a family in their care leaves the hospital setting. One nurse in

particular, implemented a program at the hospital that paid homage to the same void in care her own mother had experienced after perinatal loss.

> Yeah, my mother having that loss, and when I was young – I was, like, in grade school when this happened, and I remember her losing the baby. And somehow in my mind, I believe that I had a sister. I don't think we ever did find out the sex of the baby, but in my little mind ---I had a baby sister that we lost. And so when I took this course in the States, it was called the [name of program], because they didn't feel like any mother should leave the hospital with empty arms, yeah…It was. The last time we started talking, she said, she never got any mementoes of this baby, so the only opportunity to remember this baby is -- our memories, yeah. They're not always exactly as they happened and your memories fade over time…. And so here at the hospital, we give them this little miniature teddy bear. (S07-1 line 266)

Addressing gaps in knowledge and practice. Participants were driven to develop their expertise in PPC after noticing gaps in clinical practice knowledge. This nurse remarked on the knowledge gaps she noticed unique to nursing practice.

> "You kind of have to…figure out how to do that for that patient because that's what that patient needs and you need to be, you need to…fill those gaps… as their bedside nurse. (H03-2 line 45)

Nurses also noted a lack of available resources for learning about perinatal loss to inform their care.

> "…thinking like, 'this is somebody's experience and there's gaps here that I'm missing because I don't know what I'm supposed to be doing.' You know? So that really was

> kind of unsettling to me and that made me want to be… to learn more and to get better at it. (H04-2 line 931)

Further, study participants noticed and commented on the paucity in literature on the topic of PPC as it pertained directly to nursing their care during LDR.

> I think it has been more of a journey, like I honestly didn't find much in relation to that stuff and like what is out there… I like kind of answers to things and stuff like that there's not a lot of, like publications and stuff about this topic, so what was out there, what I did find was kind of very just it could be applied to any situation, like it wasn't very helpful, you already know that kind of stuff. I think most of it just came… a lot of it came from other experiences and the patients themselves, seeing what they need or what they are kind of… yes, those gaps. (H04-2 line 1030)

Together, these gaps had a direct implication on their ability to provide the best care possible, further activating their concerns about the clinical care for families experiencing a perinatal loss.

Sense of responsibility. Some nurses described having a profound sense of responsibility toward families in circumstances of perinatal loss. This sense of responsibility toward patients was something they chalked up to the way they provide all nursing care. They described how their intrinsic characteristics as a person and as a nurse afforded them the strength to step up to do all they could to relieve suffering when situations of perinatal loss arose. One participant illustrated this when she stated "I just felt a really big obligation to those people and to their experience" (H04-1 line 13). This was further emphasized this when she remarked "I think of that as a big responsibility. In these scenarios or not, you have a responsibility to your patient and to yourself in our own practice too." (H04-2 line 69)

This sense of responsibility meant that nurses were infallibly committed to providing the best care possible. This is sometimes manifested itself as feeling protective of families and their experiences.

> I've been with the mom for seven hours and she delivers just before I go home, I've become often very protective of them and their environment and I want it to be the best experience that they can have in a really bad situation for them. (S06-1line 1251)

As a result of this sense of responsibility, nurses were inclined to weather the challenges of providing PPC even when they did not particularly want to.

> And I never shy away from doing like a [neonatal] death or a stillbirth, because I feel like I'm good at it. You know what I mean, I feel like even if I don't want to do it, I want to make sure that they have really good care and so I feel like if I can do that then I should. (H02-1 line 518)

In order to thoroughly fulfill their own expectations of the quality of care families ought to receive, many nurses shared stories about staying past their scheduled shifts.

> Some parents don't want that to be alone and then you would just have to reorganize your time so that somehow you can fit it in. I have stayed late at work many times to finish the keepsakes because it's important to them. (S05-1 line 378)

Beyond the responsibility participants felt for their patients, some also articulated a sense of responsibility towards their nursing colleagues. Expert nurses were at the ready to step in and take over when their colleagues needed them most.

> I think [nurses] are emotionally strong in different ways, so there might be something that I can't do one day and I'll need someone to step in, so if I can do this, I feel like I should. (H02-1 line 533)

Developing expertise. Developing expertise was the act of becoming both acutely aware of essential considerations for PPC and highly proficient at anticipating and executing the actions required for provision of the best PPC possible. Once nurses had a vested interest in PPC, they actively developed their skills. Nurses were best suited to hone expert PPC practice once they had established a solid foundation of knowledge and experience in the area of usual labor and delivery care. They then shaped their practice based on mentorship they received from other nurses, or learned what 'not to do' by example of others. In some instances, it was the lack of mentorship altogether that encouraged nurses to forge forward in seeking alternative ways to build their aptitude for PPC. This meant participants depended on other resources to develop their expertise such as, learning through repetition in clinical encounters, learning from the families they cared for, and appreciating how skills they had developed in other situations may be transferable into circumstances of perinatal loss.

Foundation of standard labor and delivery care. A deep knowledge of standard labor and delivery care was considered an antecedent to developing expertise in PPC.

> If you feel like, "Wait a minute, I hardly know how to do a delivery, I'm not the right person for that." That's okay to say that… if you're really, really new and uncomfortable enough with basic tasks, then maybe you're not the right fit for that, and that's okay. You will be eventually with experience, all that stuff kind of comes. (H04-1 line 1470)

Another participant explained how this foundation of standard care allows a nurse to have greater situational awareness in instances where perinatal loss is concerned:

> I think all of it… I don't know how it is in other places, but you know how they talk about, two things, how earlier practitioners are really focused on one thing. Like, they're doing a chart or they're taking care… it's very segmented kind of care. Then as you progress you

> have situational awareness…I don't need to be looking at the [fetal heart rate] monitor, I can hear that the fetal heart rate is wrong somehow, so then I can do something about it. I don't have to be focusing my attention to be gathering information, but I don't think you can do that as a [new nurse]. I think that only comes with time and practice and that when we expect to be able to do that when they're new, it's an unreasonable expectation. It just does take time, it's appropriate for patients in these types of situations, in perinatal loss situations, to have an experienced nurse because they'll be able to do that more easily. (H03-2 line 93)

Expert nurses depicted having a great deal of comfort in standard deliveries, in some instances even describing their abilities beyond the scope of nursing practice. One nurse illustrated this through her comment "…and I'm most of the time confident in a room by myself, even if a delivery happened, right?" (H01-2 line 386)

Mentorship. Study participants described the importance of mentorship from their colleagues as being integral in developing their own knowledge base for PPC, especially given the lack of formal or vocational training available in PPC. A 'buddying system' was frequently cited as a means by which to receive mentorship. This occurred when a nurse with expertise in PPC took on a mentee who had little experience in providing care to patients experiencing perinatal loss.

> But so yeah, you just kind of learn on the unit and from other nurses when you see it on the board one day. You're like what's IUD stand for, and that's kind of how it's done…Honestly, it's four days' worth of orientation [for new hires] and palliative care doesn't get the attention it deserves… you are expected to learn on the unit with a buddy nurse. (H02-2 line 169)

Most mentors were recognized as being passionate about the topic of PPC and as having a great deal of experience in caring for these patients and families.

> …she was very, very passionate about perinatal loss and it was known that if she was working on the unit that she would be assigned to the patient who was experiencing the loss always. That was her thing… (S05-1 line 79)

Expert nurses reflected on how their mentors helped them to prepare for providing PPC by describing what to expect in experiences involving perinatal loss,

> What then I think, what often happens on the labour floor is that people are buddies. If you've never done this, you're doing this with a person who has done this before and that kind of mentorship is what… I can remember one of the first times that I [cared for a family anticipating perinatal loss]… one of the experienced nurses [was with me], and I remember that I went to wash a baby and she said, "Sometimes they'll move and it's just a muscle reacting. Don't be surprised if they move." It was just a small thing and the family wasn't there. It was just having someone there basically kind of guide you and tell you what to expect. (H03-2 line 113)

and by providing guidance around the particulars of required tasks and documentation.

> …but just knowing that there's someone to help…with certain decisions. Simple things like what blood work to I draw? Are these reqs filled out right? Stuff like that, they were able to answer. (S05-1 line 91)

Mentors, who often rose to the occasion of providing mentorship informally without prompting from others, made themselves readily available to answer questions and share the wisdom they had cultivated through their own experiences.

> Specific co-workers almost became mentors in that area because they took it upon themselves to be a mentor. They were great and if you had any questions about how to approach a patient in these situations they would give you advice…. (S05-1 line 60)

Over all, one-to-one mentorship was a primary means of learning about PPC. As much of PPC is delivered in a private fashion, behind closed doors and pulled curtains, some mentees had the opportunity to see the necessary behaviors for expert care modelled in intimate situations. During these opportunities, mentees took careful note of the disposition of their mentors, and of just how absolutely central the needs and preferences of their patients were to their decision making during direct care provision. These opportunities gave insight into what best practice looked like for patients anticipating perinatal loss, and mentees strove to develop their own practice in these circumstances to reflect that of their mentors.

> And this particular nurse, she was amazing. She just always had open communication. Whenever she spoke with [patients experiencing perinatal loss] she was always down on their level… and let them, you know, decide on what the day would look like and what the plan would be. And at the delivery she was very ... she was a very good emotional support. And this particular baby was born alive and it was trying, you know? And so the parents... every time the baby had moved they kind of looked at her and being a little bit hopeful when, in reality, there was no heartbeat….So watching that, she asked do you want me to listen again, even though she had already listened and knew the outcome would not be good. But she had kind of given the power to the patient, whatever goes is up to you, and she just held her hand. She was very supportive, yeah….I learned from her. Like, I watched her and I, you know, thought to myself I'm going to be like that. (S05-2 line 144)

Sometimes, the opportunity for mentorship during direct care provision was not available. In such cases, study participants sought out mentors and looked for casual opportunities to ask questions and engage in conversation directed at learning more about PPC.

> Yeah, I think a lot of it is self-directed. There was a couple of nurses on the ward that were really good who don't work there anymore, but not so much seeing what they did because lots of it is one-to-one care, right?...So just really looking at the type of people those people [nurses] were and seeing their personalities and asking questions… But we just talk about, "Hey, how did you do this?" or "What happened here" or "What do you think of this?" (H01-2 line 899)

Experiences with mentorship were not all positive. Study participants recalled experiences when an assigned mentor had taken an approach to facilitating learning that did not align with their learning needs, or level of comfort and confidence with PPC.

> The first time I had experienced a [perinatal loss] situation like that it felt very unsettling because if felt like I didn't know how to provide care, like provide good care or like what my role was, or what I was supposed to do in the situation at all. I was with… like my first experience with it happened in my practicum. I had another nurse there with me, the nurse that was advising me, but the way that she facilitating that experience for me wasn't great. She made me do all the care. She made me give the baby to the parents, like all of this stuff that made me feel so uncomfortable. Where it would have been so much more helpful to have seen her do that and to further show me how you do this. All that kind of stuff and kind of guide you through it. (H04-2 line 914)

Where there was an absolute lack of mentorship, the emotional consequences and feelings of regret about the care they provided without sufficient knowledge or support stayed with study

participants for years. This nurse describes being thrown in to care for a family with another nurse who was also brand new to PPC. Fortunately, years later she took it upon herself to ensure other nurses would never experience the detrimental impact of such a paucity of mentorship by becoming a mentor and facilitating positive learning experiences.

> Part of this with me comes from my very first experience with an intrauterine fetal death…and a woman came in, she was 28 week loss, and the charge nurse said to me, oh, well you and L are going to do this. And I'm like, oh, I've never done this before. "Read the book" [she said]. And she handed us the binder, which was the perinatal loss binder, and said, "read through that. It's all you have to do." The two of us got sent for break in case she delivered and she'd gone to the bathroom and you know what happened, she had that baby in the toilet while we were on break….her husband and had just put the baby in this basket and left it on the counter back there for L and me to deal with when we got back from break. And we're like, what do we do? So we opened up that binder, step one, and step-by-step-by-step and we're like okay, so is this the right swab. In the meantime, this was a couple that didn't want to see the baby, they didn't want to hold the baby, they didn't want to touch the baby. And we're like, okay, so we're trying to figure out, you know, do what we had to do for her, for the recovery but still get the stuff done with the baby. And what I always wish someone had told me was when you have gloves on and you touch a baby that young, your glove will probably stick to their skin. And good luck with that. Because that was the most horrifying thing that happened to me that day was we had our gloves on, we were trying to get this baby dressed just in case the mom changed her mind. And I remember looking at L and saying, my thumb is stuck to the baby's chest. I said, the glove is stuck. And she's like what? I said, I can't get the glove off, it's peeling the skin off. And I was horrified... And

> when the whole thing was said and done, I was so angry when I went home that they felt that this was the right thing to do to L and me was to just hand us this book and tell us, just read it you'll be fine. We were of no value to those parents at all, whether they wanted to see that baby or not. We did nothing for that couple. And I had no idea what 28 week baby looked like. I had never seen one. I had no idea how cold it would be, how heavy or how floppy. And the fact that - that my glove was stuck to that baby's skin. And nobody told me. Nobody told me. I was so angry when I went home…Fast forward how many years… I always remember, and I still say this to this day, I will never, ever, ever put a nurse through that experience. And I've had a nurse say to me, "well the new perinatal loss binder makes it so simple, anybody can do it", I'm like, I don't give a shit. I will never hand that book to a nurse who has not seen a dead baby or who has never touched a dead baby and say, "oh, just read the book, you'll be fine." And that's why I defend the fact that …everybody needs one or two buddy shifts because I swore back then that I would never put a nurse through what L and I went through that day. It was horrifying. Absolutely horrifying. And now I look back on it and it's just like - you know, like the things that we could have done for that couple that we didn't do…And we just carried on right? So. It's funny how many years later, like, I remember that day it was yesterday because it was the worst thing that ever happened to me as a nurse. (S06-1 line 986)

Seeking educational resources. In addition to gaining clinical experience and receiving mentoring, expert nurses sought out other resources attending courses and conferences.

> I went down and took this course down in the United States. That was probably eight, nine years ago I went down there. It was quite a while ago. And I brought back the binder

> that they gave us at this workshop, and had lots of great ideas for taking pictures and things to say and not to say to the families. (S07-1 line 54)

However, nurses encountered barriers in accessing resources owing to the scarcity of resources on the topic of PPC in LDR. And, where resources did exist, their content was more often generic versus context specific.

> I honestly didn't find much in relation to that stuff and like what is out there… like kind of answers to things and stuff like that there's not a lot of, like publications and stuff about this topic, so what was out there, what I did find was kind of very just it could be applied to any situation, like it wasn't very helpful…(H04-2 line 1030)

Nurses also turned to non-academic search strategies on the internet in hopes of locating answers to their many questions. In doing so they reported finding little clinically appropriate information.

> …and looking online at resources and research and stuff and just seeing what other people [are saying] from all over, right?... sometimes if you don't understand a certain situation or a certain culture, you try to look that up and To be honest I Google lots of it. Yeah, you've got to filter what's appropriate and what's not. And I mean sometimes it's even reading what's not appropriate to see. Oh my goodness, this is what people are actually talking about, reading blogs of things and saying, "Oh my goodness, no, this is not factual". (H01-2 line 914)

One factor that made taking time to access resources difficult was the sheer magnitude of daily clinical demands.

> Then as far as being a… like reading journal articles, I feel like the staff nurse, and maybe it's kind of the culture that we have on our unit, but we are not good at that. We

> are not good at, what's the best practice in this area? I think all the time just trying to keep our heads above water. (H03-2 line 296)

Repetition of clinical encounters. Given that literature, conference opportunities, and courses pertaining specifically to PPC in the context of LDR were limited, nurses relied significantly on learning from having repeated clinical encounters with families anticipating perinatal loss. While all nurses tailored their care to each particular patient and family they cared for, they took the opportunity to notice how different patients and families responded to their caring behaviours. They took forward into the next encounter the approaches to care that received the best responses and refined their practice in this way.

> I think a lot of it is kind of just repetition, as awful as that is, like having experienced more of the situations [of perinatal loss]. (H04-2 line 937)

Participants attested that the acquisition of expertise required active involvement in and reflection about the care of many families who experienced perinatal loss over the course of time. It was with certainty that this expert nurse acknowledged this when she stated:

> So yeah, I mean, I've kind of grown, over the years, just by seeing what the families want and need [in situations of perinatal loss]…. But it's learning from the families. I don't know if you can teach that in textbooks, and I don't know if I can teach that to somebody. I've had nurses watch me do things, and they commented, wow, you seem so comfortable with it. Like, it took me almost thirty years to get here, to learn this. (S07-1 line 182)

Learning from repeated clinical encounters helped nurses to identify their learning needs related to the components of care they sought to improve. On her pursuit of providing the best care possible, one participant emphasized the role of her mentor in validating where she exceled in the provision of PPC, and in challenging her to focus her learning to refine other aspects of care.

> I can remember a nurse saying to me okay you're really good at this like the paperwork and charting piece like let's move on, you know. So maybe it was like someone telling me like chin up, you know, like look at the bigger picture, which I think that is a process of time as a nurse, like you can only - I think that just takes time and experience. But how do you get there? I don't know I think maybe like having an awareness that it is there, you know, that that is like an important component of your nursing care. (H03-1 line 70)

Study participants understood that nurses feeling a lack of confidence and emotional unpreparedness to provide PPC served as formidable barriers to effectively learn from repeated clinical encounters. Without appropriate guidance and support, nurses are not well positioned to learn from the clinical encounter and as a consequence, may avoid situations of perinatal loss. This avoidance in turn results in the nurse having fewer clinical encounters from which to learn.

> I feel like when we send someone in who's not prepared for that - I think particularly emotionally prepared for it is the biggest piece, because in terms of clinically prepared, that's not as much of an issue typically, right? So that part isn't the part that concerns me. It's the emotional side of it and being present for the patient…. I think it's traumatic for the nurse. The family might not realize it as much, but I think for the nurse that's traumatic because you shouldn't put someone in that position - And you can't expect that from someone who's brand new…Or, you can have the angry family who's looking for things to go wrong and piling that on top of the - like I'm focusing more so on the nurse because that's the perspective I have in the situation. But putting that on top of already trying to learn how to navigate through this situation emotionally, you throw in all of the paperwork that they never see on top of that. It's - I could see how someone would never want to do that again if it wasn't introduced in the right way. (H02-2 line 360)

Families as teachers. During clinical encounters, participants described seeing the families they cared for as perhaps their most valuable teachers.

> And again, I just – as I did more and more, I learned more and more. I learned from the families, more than I ever learned from the books and the stuff here. I learned from the families I dealt with. (S07-1 6 line 60)

In many ways, participants described becoming expertly attuned to the emotional needs and preferences of families during PPC from the words and actions of the parents for whom they cared.

> Back when I was even a junior nurse, I used to work at (site name), way back in the early – well, late 1990s, I guess. And I can remember this one dad – and I was assessing this newborn, lifeless baby, in, like, a very clinical little soiled utility room, which was very awkward. And I can remember him saying, you know, treat it like it was your own. And it was actually the dad that encouraged the love and kindness for this baby. He made me realise how much we really do need to care for these families. (S07-1 line 17)

Transferability of skills from other nursing experiences. Participants called upon skills from their nursing experience in general to inform the care they provided during PPC. In doing so, they demonstrated how some of the skills required for PPC are not unique to only these circumstances. These particular skills, perhaps honed during other nursing experiences, do in fact have transferability to caring for patients experiencing perinatal loss.

> I think that a lot of it, it's not that different, like the situation itself is different, but the way you're relating to your patient and your care is not that different from regular care. It's still… it's very human and you're still trying to connect with them and stuff like that. If you take the negative experience out of it, there's a lot of similarities within your… what you already do in your normal care, hopefully. I think you get stuck on the negative

> of what is happening and the gaps in knowledge and then you can automatically assume that you know nothing about this situation. That you, yes you do have a lot of those tools already. I guess it seems kind of mysterious or unknown at first, and it is, but the biggest things that you do for people I think is just listening and being there, which you can do without knowing anything, like do you know what I mean? Those are just aspects of your caring. (H04-2 line 1046)

Enacting expertise. Nurses enacted their expertise was through implementing the specific insights and abilities they had developed for PPC during the direct care provision of patients experiencing perinatal loss. The actions and considerations expert nurses engaged in while enacting expertise have been organized into two broad categories: (a) those that apply across all stages of LDR, and (b) those that are particular to each of the stages of labor. These categories presented as substantial themes themselves and will be discussed in detail in a subsequent section of this chapter. In addition to the actions and considerations required when enacting expertise during direct clinical care, enacting expertise occurred when study participants formally or informally mentored other healthcare staff to develop the necessary insights and skills for PPC.

Mentoring other staff (formally or informally). All expert nurses described enacting their expertise in PPC by sharing their knowledge and insights through mentoring other staff. In some instances, this mentorship was delivered formally by creating clinical resources or educational materials for other healthcare staff. Their mentorship was also made available formally during direct care provision through a nurse buddying system which provided experiential learning for more novice staff. Expert nurses also made themselves available to staff as informal mentors,

simply stepping in to help with clinical care, or by providing advice when questions were asked of them by their colleagues.

For some, formal mentorship meant developing educational materials for staff nurses. One of these nurses, for instance, had a vested interest in bolstering information received during the orientation process to LDR.

> There is a piece on [PPC] in the overall labour and delivery orientation…There's definitely a piece there and I think we talk some practical things about this is where people go if they're like 12 weeks [gestation], then they go to the Emergency Department, those kind of guidelines about allocation. Then we do talk about what we offer people as far as keepsakes and I think offering holistic care. We're working now to sort of overhaul some of those things so that they're more learner friendly in a way. (H03-2 line 168)

For others, it was the creation and upkeep of clinical resources for other staff nurses.

> …a really good reference binder… an example of the package [of necessary paperwork for perinatal loss] highlighted and with a big arrow, don't forget about this one little, whatever. That is like a practical resource…and it does seem like those details change quite a bit …so it's a handy resource to check. (H03-2 line 235)

Much of the formal mentorship described by study participants was delivered during clinical care in a prearranged fashion through a 'buddying system'. This meant that when a patient came to the unit to deliver an infant who would be born still, or only live for minutes to hours after birth, an expert nurse and a nurse who was less experienced in PPC but confident in standard LDR care would care for them together. It is of note that this buddying system used by expert nurses acting as mentors seems to be modelled after their own experiences as mentees in developing their own expertise in PPC as outlined previously.

> Well, we don't want to put a brand-new nurse into those situations. We give them a few months working before we put them in. And myself and [name of a nursing college], who is one of our CRNs [Clinical Resource Nurses] we've both agreed that no one should ever just be thrown into one of those situations and never have any training. So we always try to buddy them either with me, or one of the ex-LDRP nurses, because they were the staff that always did it [cared for families experiencing perinatal loss]. (S07-1 line 319)

Study participants repeatedly discussed the importance of assessing the readiness of nurses to be mentored by them or by their other expert colleagues. Many of the expert nurses interviewed had experience being in charge of their unit and creating nurses' patient assignments for the shift. When acting in the capacity as clinical leaders and charge nurses, study participants were highly mindful of which nurses had the necessary foundational skills in providing standard labor and delivery care before assigning them to a patient requiring PPC with or without a mentor. This was illustrated when one expert nurse described what she looks for in a nurse who is ready for her mentorship in PPC.

> The labor nurse should be knowing what to do with the [standard] labor patient. So I'm not needing to teach them what to do with these laboring patients and can focus on teaching about perinatal loss. (S07-1 line 337)

Even when study participants were on shift as a general duty nurse and were not in charge of the patient assignment that day, expert nurses advocated for new nurses to ensure they first had foundational skills and a degree of emotional readiness before being expected to provide PPC, especially when the opportunity formal mentorship through the buddying system was not available.

> I was on the unit a couple - maybe a couple of months ago. And there was a nurse who - she was working in labor and delivery maybe two months…And I saw that her name was beside a stillbirth. She had never even been buddied with anyone for a loss ever in her life. And like I said, I don't think she's figured out where she stands in this whole nursing thing yet... So I said to the charge nurse, do you think this is a good assignment for her? And she said, well I had no choice. I have no one else who can do it, so she's got to do it. That's how I learned she said. I said, but did you like that experience? Like, how was that for you when you were thrown in and she - she didn't really have much of a response. (H02-2 line 391)

Inappropriate timing, or putting nurses in the position to care for patients without appropriate foundational skills, support, and availability of mentorship could result in creating avoidant behaviours toward PPC on their unit. This was a significant barrier to providing the best care possible, and to mitigate this, expert nurses offered themselves as informal mentors and resources whenever they could when these situations arose.

> I said to the nurse. I said, okay, well [the charge nurse] is not willing to change your assignment, please come get me and I'll help you with everything. And we had a little chat…. So the impact, like when care doesn't go well, when you're thrown in as a nurse - is that you're not going to want to do it again. That's huge. And then no one gets good at it. No one gets good at it. And then that's a disservice to the patients. Right? (H02-2 line 406)

When mentorship was delivered in an informal manner, mentors helped newer nurses through direct hands-on care experiences, operational processes, and documentation. Mentors provided guidance for mentees in navigating their own emotional terrain both during the care experience and afterwards.

> …so a lot of it is kind of informal. First of all, just knowing that they're supported by you… after the baby is born and you're showing them how to move the baby, wash the baby, touch the baby, do all those things. Normalizing it… And not, I mean it's never normal, but just kind of guiding them through that because it's traumatic and it's not, I don't think it's something that you should be doing on your own, especially the first time because it's awful and you have haven't seen that before necessarily… trying to explain things and answer questions that they have and then kind of down to simpler things, like helping them with the paperwork or whatever. Also, just kind of being in tune with what their emotions might be that they might put this workday in and leave the unit and just break down. You know what I mean, like following up with that or whatever it is. I think it's huge if you can be able to support people that haven't experienced that before, so that they have the confidence to do it on their own as well because there won't always be somebody there. (H04-2 line 980)

Overall, mentorship, whether formal or informal, was aimed at preparing newer nurses to anticipate what would happen during a labor both physically and emotionally.

> I would say that that kind of mentorship, like working with another nurse so that… and it's also for the new nurse, it's a buffer for the intensity of the experience. That someone is there role modelling how to be a good nurse for these people, right, and also demonstrating the tasks that need to happen. Not only there's the physical task, but also the emotional care kind of tasks and then the caring of the baby tasks. (H03-2 line 127)

Mentors were calculated about how clinical teaching might impact the patient experience, and as a result expert nurses were thoughtful to keep focus on the patient during care and kept their teaching somewhat discrete. This meant that sometimes learning coupled clinical observation with

discussions outside of the room. This allowed mentees to be present during a delivery while ensuring any teaching being done was conducted in a respectful and discrete manner that did not disturb families during incredibly difficult moments.

> And I get that it's teaching but is this really time to talk about, "well you need to do this and you need to do that" you know, the moms don't want to hear it. Like the moms, they often don't want to hear any talking during the birth. And I think that's one of the hardest parts too, and you can add that too. What do you tell - like you know, aside from the oozing, when the baby comes out, it's so quiet. Like the room is quiet. Because it's a somber moment. We know there's not going to be a cry, there's not going to be an attempt at breathing. And it's just there's this hard work and the tears and the crying and she pushes that last push out and the baby comes out and there's just silence. And then there's usually a gut-wrenching sob that follows that silence, which is really hard when you haven't been in that situation before. But I always find that's the worst part is that initial point of delivery where everybody is quiet. And it's heavy. (S06-1 line 1221)

There were a few circumstances in which mentors exercised caution around the opportunity to provide mentorship during direct care provision through the buddying system. Mainly, nurses speculated that the presence of numerous clinicians could be intimidating for certain families.

> We don't – buddy people [nurses] up because it's too intimidating for the families to send two staff in there or whatever. (H01-2 line 904)

In those cases when a patient (or family) experiencing perinatal loss was particularly inconsolable, expert nurses acting as mentors understood that having so much as one extra person in the room could be highly distressing to patients/families. In these situations, the presence of additional staff was discouraged.

> …and in my heart of hearts I hate it. Because I don't think that - I don't care if this is a teaching hospital, these are not the [families] to learn that from. (S06-1 line 863)

This was especially true when it came to mentoring clinicians who were not permanent staff on the unit such as medical students or other trainees who were present only as a requirement of their degree. In these situations, nurses understood and valued the importance of learning but were careful that opportunities for learning were never carried out at the expense of the experience of their patient.

> Sometimes residents can get really pushy, and really nosey because we're a teaching hospital, so they want to be in everything, and they don't really realize some things aren't teachable moments. Like they're not – you don't have to witness everything. Sometimes you have to respect the patient. So we don't – I don't really let those clerks and interns and everybody in the room…it's not a checkbox. So some people really have to be told that. I think sometimes their program is so – like there's so much anticipated from them, and they're very task-oriented, that they just want to see everything, and do everything. And you just have to respect that this is a person, and this is their situation. So no, you can't come in…If we have like palliative kids, or like some strange anomaly that we've never seen or something, it becomes like this interest to see these, whatever, events…. Yeah. It's just kind of, yeah, protecting that moment. Because if you really need to see the baby, or there's something you need to learn, then you could see the baby when they take it out to shroud it, or whatever. Not 20 of you, but one or two people, can come and take a look, or see whatever you're wondering about, or learning about, or whatever. But yeah, this – it's not always the time or place. (H01-1 line 1043)

Sustaining expertise. The provision of PPC can be quite demanding, especially emotionally for nurses. After giving so much of themselves to the families they cared for, participants underscored the absolute importance of engaging in behaviour(s) that would recharge them. This included a variety of self-care behaviors, seeking support from colleagues, family, or friends, and taking time alone. It was also imperative for nurses to acknowledge their needs and advocate for themselves in order to have the opportunities to engage in these sustaining behaviors and activities.

Self-care activities. Various self-care behaviours offered participants an important opportunity to recharge so that they had the emotional reserve to continue caring for families experiencing perinatal loss. This was exceedingly important in the broader context of their lives as many were caregivers for children or parents outside of their role as a nurse.

> And so like I would think like for nurses who are often women, who are often mothers, who are like caregivers in their workplace and at home and also who are like notoriously bad at taking care of themselves in like a recovery way, like exercise and self-care and like I don't know massage whatever, relaxation, that those are like so essential to being emotional available to your patients whatever the situation is. (H03-1 line 352)

Many self-care behaviours were described and included healthy lifestyle choices directed at maintaining a sense of wellness.

> I think kind of nourishing your body, like eating well, sleeping. Maybe you're doing yoga or you're exercising or something like that to kind of do something outside of working, but if can be taking care of yourself in some way as well, that's huge. (H04-2 line 824)

Support from colleagues. It seemed enough emphasis could not be placed on the value of support from colleagues during PPC, and in its wake. Colleagues offered a place of

understanding that could not be replicated from relationships outside of the context of care, nor by the inner terrain of an expert nurse herself. Overall, support from colleagues provided a reservoir of emotional strength both during and after care experiences and were seen as preventing a feeling of emotional burn out. When challenging situations arose, colleagues could provide support directly by stepping in to assist with or take over care, mitigating the level of stress experienced by the nurse.

> And I think that in the situations where those patients are very upset or very angry, you don't have to face that alone. (H02-1 line 107)

At other times, collegial support was provided by simply being present and available from arm's length.

> Even though you're the person in the room with them. You know when you're stepping out of the room there's people there to lean on. (H04-2 line 148)

Colleagues offered reassurance to one another, and built each other up, and helped one another to look forward to their next shift after caring for a family with perinatal loss, sometimes planning something special as a small incentive.

> I think we're all really hard on ourselves, wanting to do the best we can, and when we don't feel like we did that we really self-judge a lot. So just providing support to our peers, "Hey, remember when you did this? This was awesome." (H01-2 line 636)

This was especially valuable because colleagues understood one another in a way that family and friends could not.

> We talk a lot about work family and sometimes your work family is the only people that understand what you're going through, because your home family you can't expect them to understand that. So I think it just – always at the end of the day we try to say, "Hey, you did

> this good and you did that good," and try to provide support. It hopefully lowers the stress for those new people to say, "This is a bad situation but I can do it because my peers are here to support me." So to try to set an example for the new people too to say not everything is great and exciting and a happy situation, but everybody is here to help you. (H01-2 line 819)

The gestures they provided each other may have been small, but they were packed with meaning.

> So just to provide that moral support, and it makes you want to come back to work the next day, even if your day was really bad. You say, "Hey, don't worry, I'll see you tomorrow, right?" Yeah, I'm going to be here, we'll be here, we're going to get doughnuts or whatever. We always do something stupid like that just to provide support and hopefully send you home on a better note. (H01-2 line 788)

Knowing that colleagues were there to support one another also made facing life demands outside of the workplace a little bit easier.

> Because when you go home you still go home to your family that knows nothing about your day, and you still have to function. Like for me I'm a single parent. I go home and I'm in the door, and I don't have my shoes off and it's "I have this homework" and "I need that thing" and like… Yeah, sometimes it would be nice to go home and just crawl into bed and go to sleep and wake up when you need to wake up, right? But it doesn't always work like that so just providing support to your peers to say, "Okay, this is our day" and a little debrief at the end of the day to kind of make sure people come back tomorrow, yeah. (H01-2 line 803)

Furthermore, seeking solace in colleagues encouraged the feeling of closure after challenging care situations.

> …where you have to kind of seek out that support from your team and other people that were there might have experienced it and talk about it so that they know they're not alone

> and that kind of stuff brings you a kind of closure to something, where you might not be able to ever change what happened, but yes, and I guess that's more of the healthcare side of it. (H04-2 line 746)

Even for those with extensive support networks outside of the workplace, the role of their colleagues in understanding their experiences and feelings was unmatched, as such, it was difficult at times for participants to relate with or feel understood by individuals who did not have a healthcare background.

> I have one friend in particular who works in a bank and will just go on and on and on about how terrible her day was and just complaining, and I won't say anything, and I'll say I'm sorry you had a bad day. Like that sounds tough. Meanwhile, I might have dealt with pregnancy loss that day at work. And not that I'm comparing…But we are able to normalize those experiences after a certain point in time. And I don't think that's unhealthy. I think we have to, to kind of save ourselves and guard our own emotions. But it's a fine balance between guarding your emotions and hiding your emotions. (H02-2 line 249)

Time alone. The emphasis on time with colleagues was balanced with a value of time alone. Interestingly, it was often the support from colleagues that enabled a nurse to spend this time alone during their scheduled worktime.

> Allowing myself to feel those emotions is important. If I ever need to step out, co-workers are there to allow me to… for example, that palliative care baby I had, I went for a walk after, just took my break, took one that a was little longer than normal, went for a walk outside because I just needed to cry and debrief by myself. (S05-1 line 883)

Several of the participants discussed taking breaks alone, a quiet time to process the experience.

> …but then just really analyzing your feelings after that moment has passed. So honestly, usually when I go on break, I - people always make fun of me because I'll go on break by myself. I never take breaks with other people. And that's not because I'm antisocial but it's because I need to emotionally recharge. I need to kind of analyze what I'm feeling and just be present and accept those feelings. Because if you try to push them down for too long they're going to bubble eventually. ..So really just having that time to reset. And then afterwards I think it helps if you have someone who really understands. (H02-2 line 214)

Time alone was also seen as beneficial during days off to recharge.

> I definitely take all my losses home with me. Be gentle with yourself. Like, just take care of yourself when you go home. Don't ... if you're upset don't push yourself to, kind of ... I don't know, just take time for yourself and mentally ... I don't know, the day after I experienced that most recent loss I actually took the whole day to myself. That one's going to stick with me. It was really difficult. And I just had a me day. I didn't do much. Just stayed home in bed. (S05-2 line 956)

Another nurse described her need for time alone when she stated:

> Yeah, and sometimes just to acknowledge that you need to take a day not to function, right? You need to take a day to lie on the couch and watch TV and not talk to anybody, and that's okay. (H01-2 line 584)

Understanding from family and friends. Understanding from family outside of the workplace was important. Nurses were impacted by situations of perinatal loss and it was important to them that their loved ones knew where they were coming from.

> …you know, when I go home too, you know, without giving any details, I'll let my partner know I had a loss and he knows that he needs to be gentle with me and he needs to give me

> that time, you know, and that's also very helpful. So to have open communication with the people that you live with at home, so that they know. (S05-2 line 980)

Although nurses could not share details of private health information with their families, family was nonetheless a source of comfort and support, even if they did not understand the situation fully.

> I mean I could talk to my husband and he'd be sympathetic. But he wouldn't really be able to feel what I felt. So thankfully my sister's a nurse. She actually was an ICU nurse, now she's in public health. But that's someone I can talk to about my day, and who would really understand what the experience was. (H02-2 line 221)

This nurse described the value of support from her family, even when they did not know particularly why she was in need of support.

> My kids are big, but when I started nursing they were very small, but I would always tell them, "I can't talk to you about my job and some days I'm going to come home and I'm just going to hug you and you can't ask questions." And my one daughter hates being hugged, but I said, "In those days where I come home and hug you I just need you to hug me back. That's just life," you know? (H01-2 584)

Reflecting and debriefing. Part of the support colleagues offered was being able to engage reflectively to debrief a situation together. On the other hand, much reflection occurred alone. The purpose of reflecting to sustain expertise was focused on assuring oneself they did the best they could and on letting go of the stress related to the experience so that it did not carry into other aspects of their life. In this way, nurses engaged in reflection in order to cope with and sustain practice around perinatal loss. In contrast, the self-reflective traits nurses described that were linked to activating expertise paid attention to fostering personal and professional growth.

> And I think the more that you do, the more self-reflection you have. You can look and help others and talk with other people about how maybe they've managed those days or the after-effects of those days. And the more you talk about it the less it builds up in you. You're never going to forget all the people you cared for, but the more you talk about it and the more I guess you reassure yourself that you've done what you could, it makes it easier. Because if you don't, it just keeps bottling up and bottling up and bottling up, and then all of a sudden it comes out in some weird avenue that doesn't even maybe relate to your job or relates to your home, you know? The price of your oil change goes up and you yell at the car guy because whatever, all of these things accumulate. (H01-2 line 433)

This nurse further emphasized the types of things she noticed during her own reflections when she stated:

> I think just learning from each experience and every time or every situation that didn't go well or does go well, just to put that in your pocket and say, "Okay, this is good, this is what I'm going to do next time," kind of reflecting back on past experiences. (H01-2 line 871)

Debriefing was really seen as a mechanism of engaging in reflection together. Debriefing validated the experiences of participants and mitigated the possibility of the nurse avoiding situations of perinatal loss in the future.

> And I think that debrief piece…I try to really express how important that is. Because if you don't deal with it right after while it's still fresh, it's just going to live in the back of your head. And then, I mean I think if you don't deal with those feelings, that's where that hesitancy to do it again comes from. (H02-2 line 228)

Advocating for and protecting one's own needs. In having significant experience in caring for families experiencing perinatal loss, nurses could predict that this care would likely

take an emotional toll on them. As a result, they learned to advocate for their own emotional needs in the moment. This often meant making clear to their colleagues that they needed a moment to step out of the care environment and take a break. Sometimes they pushed the team to come up with creative or unconventional solutions in order to meet their need for a break. The inability to take breaks when needed impacted expert nurses' ability to do their job moving forward.

> I went through a really bad loss and there was nobody to give us a break, and the family was probably the most vocal and just exhausting emotionally. And like six or seven hours in I didn't get a break, and finally I just said, "You know what? You have to find somebody." If you go stand in there for ten minutes – and what it ended up being was one of the other attending doctors that wasn't even in the room, she said, "I'll go sit in there for fifteen minutes and you go take a break." And I went and sat outside. But just trying to find some resources, right, if you can to just – Yeah, to just say, "Hey you guys, I need a moment," to not be afraid to ask for that. Because if you don't, then down the road you're not going to be providing any care for anybody, useful to anybody, so just being able to speak up, yeah. (H01-2 line 491)

In some instances, expert nurses even went as far as to opt not to accept an assignment to care for a family experiencing perinatal loss if they sensed it would exceed their capacity to cope emotionally.

> The charge nurse that we had at the time wasn't warm and fuzzy at all and I had a loss the day before. I actually cared for two ladies early, two losses at the same time, and then one ended up delivering so somebody else took the first patient about halfway through my shift. Then the next day I came on, she gave me another family. And then the third day I

> came on she wanted to give me another one, and I said, "You know what? I can't do it three days in a row." No matter how families cope, you still go home and you still think about the process. Somebody needs to take it, you know. And then she said, "Oh, but you're so good at it. You've had so much experience." And I go, "Well somebody needs to take some experience because it's just too taxing." Even though you're great at something doesn't mean you have to immerse yourself in it time and time again, you know? (H01-2 line 133)

Summary. This section has offered a description of a conceptual model depicting the actions and considerations expert nurses engaged in during the non-linear process of cultivating expertise. The following related sub themes of cultivating expertise were described in detail: (a) activating expertise; (b) developing expertise; (c) enacting expertise; and (d) sustaining expertise. The next section of this chapter will focus on the outcomes of enacting expert nursing care when PPC is indicated during LDR.

Outcomes of Enacting Expertise during PPC in LDR

Introduction. Enacting expertise through the provision of mentorship has been previously discussed. The definition of enacting expertise also encompasses the implementation of the skills and abilities nurses developed in order to provide the best care possible for PPC during the LDR period. As such, it is of particular importance to understand by what outcomes expert nurses determined whether they had sufficiently enacted expert practice and achieved the best care possible. Outcomes of having achieved expert nursing care during direct care provision have been interpreted as being accomplished when: (a) emotional harm experienced by patients and families was mitigated; (b) negative maternal health outcomes were prevented; (c) staff members were adequately supported clinically and emotionally; (d) all necessary tasks and

documentation were thoroughly completed; (e) all infants, whether born still or alive, received love and respect; and (f) in the case of live births, neonatal pain or unpleasant symptoms were adequately managed if present.

Only in describing *how* nurses actualized their expert practice during direct care provision of laboring patients and their families can these outcomes be fully comprehended. The actions and considerations nurses engaged in that apply broadly throughout the entire process of PPC will be described. Additionally, and more specifically, the particular actions and considerations unique to each of the stages of labor will be portrayed.

Table 7
Outcomes of Enacting Expert Care during Perinatal Palliative Care

Outcome	Definition
Emotional Harm Mitigated	The experience of perinatal loss was seen as inherently causing emotional challenges for patients and their families. As such, this outcome was achieved when laboring patients and families receiving PPC did not experience any emotional harm as a direct result of the actions of or interactions with healthcare staff.
Unanticipated Negative Maternal Health Outcomes Prevented	This outcome was achieved when nurses were able to provide high quality standard LDR care for the laboring patient *while* integrating the tenets of palliative care.
Staff Adequately Supported	This outcome was achieved when not only the patient and family receiving PPC were supported, but also the healthcare staff involved. In this way, undue emotional stress of healthcare staff was mitigated. Clinical support must also have been available throughout the process of PPC for this outcome to have been achieved.
Necessary Tasks and Documentation Thoroughly Completed	This outcome was achieved when all medical tasks and charting were comprehensively attended to while meeting all other patient needs during perinatal loss.
Love and Respect Received (Infants)	This outcome was achieved when infants, born alive or still, were treated with tenderness and reverence. Nurses facilitated opportunities for patients and families to engage lovingly with their infant should they choose to do so. Nurses themselves treated infants in this way and encouraged colleagues to do the same.
Neonatal Pain and Symptoms Managed	In the case of live births, this outcome was achieved when nurses assessed infants for pain and unpleasant symptoms, and coordinated to have necessary orders and interventions available to address same. This required nurses to assess the effectiveness of interventions and respond accordingly.

Emotional harm mitigated. Perinatal loss was repeatedly described as being emotionally arduous for patients in labor and also for their families. Expert nurses recognized that, by its very nature, the experience of perinatal loss could result in emotional harm for laboring patients and their families, no matter how excellent their care. With this in mind, study participants aimed to relieve emotional suffering to the best of their ability, and in doing so, exercised particular caution not to exacerbate the difficulty of the experience of perinatal loss. Study participants understood expert care to have been achieved when laboring patients and their families did not experience any emotional harm as a direct result of the actions of or interactions with healthcare staff.

Overall, expert nurses did not hesitate to lean into the emotional realm of care in order to achieve this outcome, no matter how challenging. Attending to the emotional needs of their patients to the best of their ability was a central outcome of enacting expertise.

> …I'd say that doing a good job, I'd say like basically being a nurse, if you're not willing to emotionally engage with people, then this is maybe not the best profession because that is what is valuable to people. It's valuable to people to have good clinical care, of course, but that's not the extent of what people are needing in their nurse…it just has to be that you are present with people…Basically, the idea is that people are looking at you and if you're not looking at them, you're missing an opportunity. That connection is… that's humanity and if you're a nurse, you are working with people in their most human state. In sickness and in health… Being willing to engage with people is essential in nursing. I'd say when it's hard, then it's more important. (H03-2 line 722)

This required nurses to be in tune with the emotional trajectory of each laboring patient experiencing perinatal loss. Study participants emphasized how both the emotional experience and

the presentation of emotions were unique to each patient and family during this time. As such, expert nurses were particularly sensitive to those nuanced differences in their needs. However, given their extensive experience caring for families with perinatal loss during LDR, study participants did indeed note some commonalities in the emotional experiences and expressions of the families they had cared for overtime.

> …but I do find that as the labor progresses, the distress increases, even though they're coping with labor, they're breathing, they're doing everything they practiced to do to have a normal healthy labor, but that emotional aspect of it can sometimes - it's gut wrenching to be in a room when a mom is in transition and there's just - she knows the end is coming. And it's not normal crying, it's that heart wrenching sobbing… And some of them don't shed a tear until that baby's out. I mean we're all different right? But it can be such an emotional time that it's really, really hard to - you - it tears at your heart, right? (S06-1 line 530)

Awareness of the emotional experience of laboring patients and their families enabled nurses to tailor their approach to care in a way that was as supportive as possible and that did not intensify the nature of emotional pain already present. In particular, it was seen as important that families did not have a lasting negative impact after hospital discharge.

> And there is… such a mix of so many emotions happening at once…those are big life moments that people remember forever. It's not about me, it's not about any of that, it's just about … the space you can make for them… around what they might need. It is not something that they ever intended to happen, so I think if they had a more negative experience, or were unhappy with [their] experience, that weighs on [their] memories of it, [they] will carry that with them forever in some way. Not that I can ever know what that is to people, or what they're experience would be after I see them, but by providing that space

> and addressing what they say they need, or what you feel that they're not saying they need…they will have a better memory of it and not a negative experience of it. (H04-2 line 544)

Whenever possible, nurses did everything they could to elevate the emotional experience of families, but did not necessarily hold on to the expectation that families would classify their experience as positive. When families did find positivity in their situation, study participants reflect contentedly.

> –lots of people said, "I really thought this was going to be a worse experience but these were some really great things that happened to me here." Sometimes it's even connecting them with resources to go home, so they have – they can't cope now but they'll cope down the road because these are the people that are involved. Yeah, sometimes it's really surprising when you think of the bad outcomes that people have, and then they come back and just say, "Oh, this was really great" or "These people were really great." (H01-2 line 831)

Study participants continued to emphasize the likelihood of families experiencing difficult emotions despite their expert care, but described their ceaseless efforts to make the experience as positive as possible despite this.

> Again, there obviously there will be sadness and anger towards it [the experience of perinatal loss], you can't take that stuff away, but those small little things can be good, like you can impact small positives in their memory of such a tragic thing. Yes, it could be talking about the baby's smile or nose or anything, they'll remember that you said that, maybe. I don't know if they will, but you feel like you can kind of find those little bits of joy in it because there is happiness and joy in it somewhere… and I guess in general, that's the difference between bad memories and good memories. You have to find positives in

> things that are even awful in order to keep going. I feel like if you can facilitate that in their experience, that that's something you're giving to them to move forward and hopefully, they will remember that. I honestly don't know if they do, but to me I guess that's back to the good experience if it feels like you have impacted them in that way, then that's like a resolve for my experience as a healthcare professional, that they have a little bit of that and that it would maybe be a little bit easier for them in the future, do you know what I mean? (H04-1 line 575)

Their efforts were especially notable in the unfortunate instances when the care actions of another healthcare provider were insufficient, incomplete, inappropriate, and possibly exacerbated the stress of their patient and family. In these situations, expert nurses stepped up to compensate for any emotionally detrimental effects influenced by the actions or inactions of their colleagues. In one situation, a nurse described how her colleague did not pay an appropriate amount of attention to a family receiving care, and left the situation abruptly. Instead of working together to mitigate the emotional challenges inherent in the experience of perinatal loss, this expert nurse now had the additional responsibility of explaining the actions and choices of the other provider in order to see this outcome attended to. This particular situation did not demonstrate behaviors supportive of the patient and family, nor of their colleague. As a result, expert care was more challenging to achieve.

> In my one instance where I had a bad outcome, the physician basically just walked away, didn't talk to the family, didn't talk to the patient, just left. And then that puts us in an awkward position. (H01-2 line 568)

Several nurses described anecdotes such as this one. In response to these circumstances, study participants did due diligence to assuage any negative impacts that arose by utilizing their own expert skill set to address the issue.

> Unfortunately, the doctor was very rude, very, very rude, so I felt like I sort of had to fix that. I was extra supportive after that. Doctor did not introduce himself, he didn't say anything, he came in, listened, and said, "Baby's dead" and left. (S05-1 line 672)

Nurses truly strived to attend to their patient's emotions and cultivate a positive relationship, but tempered this expectation by demonstrating understanding that in these extremely challenging situations of perinatal loss, a patient and their family may simply not be open and receptive to this. Even when these situations arose, study participants did not necessarily see this as having failed at providing expert care.

> I mean you just know when you leave a patient whether you cared for them in the proper way and if you didn't. I think forming a rapport or a relationship with the patient is probably the best indicator that you did something right. That being said, you don't always feel connected to patients because they… and they may not be able to connect with somebody in that moment, which I totally get as well. In those circumstances, you just have to understand. (S05-1 line 729)

Unanticipated negative maternal health outcomes prevented. Participants consistently underscored the importance of monitoring maternal health and ensuring maternal medical needs were met. This integral outcome of expert PPC nursing was a direct result of investing time and energy in behaviours and actions that would ensure those experiencing perinatal loss did not confront any unanticipated and preventable negative health consequences.

The provision of PPC by no means replaced the need to provide high quality standard labor and delivery care that was concerned with promoting and preserving maternal health. One nurse put this rather plainly when she stated "We're still monitoring mom to make sure she is healthy" (S05-1 line 546). As in any LDR situation, nurses were conscientious to avoid negative

preventable maternal health outcomes. While doing so, study participants did iterate the simultaneous need to attend to the emotional aspects of care during PPC.

> I keep kind of relating it back to like a regular, healthy labour with no negative outcomes, it's the same kind of thing. It's all those worries, hesitancies, vulnerabilities, uncertainty of what's going to happen in those situations too, you're still providing that reassurance. You're doing a good job, you're doing exactly what you should be, you're still guiding them through something. It's [perinatal loss] just something, like it's just a little bit more…sensitive and that kind of stuff. (H04-2 line 469)

Expert nurses kept maternal health at the core of their care. Sometimes this meant taking care to display patience with the natural progression of labor and negating the impulse to intervene with medications to augment the frequency, duration, and strength of contractions as is sometimes done during deliveries when a healthy infant is expected. Medical augmentation of labor was certainly considered if it was medically indicated for the health of the laboring patient.

> We still worry about the maternal health, so you still worry about, like, chorioamnionitis and Mum getting septic. You still worry about it being a prolonged process. If Mum is coping with it, even if she's making slow progress, there's no need to intervene if she's contracting on her own. (S07-1 line 696)

It was important to expert nurses that women in labor fully understood their own health was of upmost importance, even when the health of their infant was compromised. Expert nurses diligently conducted assessments and partook in actions that were aimed at preserving optimal maternal health throughout the process of delivering an infant who would be born still or only live minutes to hours after birth, and were sure to provide explanations to their laboring patients along the way.

> I do have to tend to Mum, and I have to explain to her that, okay, I am so concerned about you, you're at high risk of this or that. I still need to be checking your vital signs and checking your bleeding and doing all these things. (S07-line 765)

More than one nurse emphasized precisely the same point.

> …do their checks, make sure they're good, if there's other issues, then yeah, we've got to talk about that, you know? "We've got to watch your blood pressure," or "you had a postpartum haemorrhage, so we got to keep you, and make sure you're healthy", and whatever. (H01-1 line 745)

Expert nurses recognized that the unnecessary medicalization of birth during perinatal loss had potential to interfere with their ability to provide privacy and to deliver care that was sensitive to the grief related needs of laboring patients and their families. Over all, providing medical intervention and monitoring that was not indicated was seen as possibly contributing negatively to the experience of those receiving PPC overall.

> … like it's just such a sad experience for them, and to make it more medical than it has to be is so difficult. I mean it's one thing if a woman is sick, or if she's had a previous section it has to be a little more medical. But if it's a 'normal birth', can we normalize it as much as possible? But can we also respect the fact that these parents are grieving? (S06-1 line 902)

Staff adequately supported. One aspect of enacting expertise was through mentorship, and as previously described, experts iterated how they made themselves available to support other staff both clinically and emotionally who were the primary caregivers in situations of perinatal loss. Additionally, study participants had also discussed the importance of the role of their colleagues in sustaining expert practice through supporting one another, lessening the emotional toll of the care they provided. Whether during the act of mentorship or not, an

important outcome of expert practice was that all members of the healthcare team involved in providing care during perinatal loss received adequate emotional and clinical support. Simply put, support for staff was required during and after the process of PPC in order to provide the best care possible, and without it, it was not possible to have enacted expert practice. When study participants were confident that staff were well supported by one another during the process of PPC, they expressed greater certainty that expert practice was achieved for the family they cared for. In this way, adequate support for staff was both an antecedent and an outcome of expert practice.

With adequate support, healthcare providers were able to reconcile their own emotions in order to provide the best care possible. They could mitigate any undue emotional stress, balance their own needs with the necessary tasks of PPC, and feel successful in the care they provided.

> Because whenever those situations [of perinatal loss] arise, people [healthcare providers] get flustered and they have to identify their own emotional needs and take care of someone else's emotional needs, and on top of that there's a medical aspect and documentation and yada yada. So, it can be overwhelming. I think that another key piece to having that positive experience is having the support of your colleagues. So, working well as a team and having that support, it makes those experiences better, but I think it also facilitates a better sort of camaraderie in general. When you face a tough situation and make it out to the other side you feel accomplishment and - like I said, solidarity with your coworkers. (H02-2 line 123)

When staff were supportive, direct care providers, experts or not, knew that they could ask for help and others would respond.

> But even more experienced nurses will need help, so they need to know when to be humble and to say “can someone help me?” (H02-1 line 112)

Support came in many forms, be that giving the opportunity for a colleague to have a break or to talk through their experience and emotions,

> Just being there and verbalizing if you need any help and if they see you're having a tough time, they'll step in, just like I would step in if I saw a co-worker struggling. Offer them a break, take a 10-minute break to yourself, or even if you're included in that break, to have a conversation about why they're having such a hard time with it. (S05-1 line 596)

or having timely assistance with a delivery.

> My co-workers, in particular, are amazing…We were always checking on each whether it be live baby or stillbirth, we're always… poking our heads in and seeing if everything is okay. I felt 150% supported yesterday [while caring for a family experiencing perinatal loss]. I had [another] nurse helping me the whole way. I called for help at delivery and [she] was there within two minutes. (S05-1 line 486)

When adequate support was readily available during the process of PPC, care providers knew they would have extra hands when they needed them for the tasks of care, but also that their colleagues would be available for emotional support afterwards.

> I think…for the healthcare team when care goes well, it maybe isn't so isolating for the person that's providing that care. Again, whether that's…knowing that people are there for you in that experience to help with care or being able to debrief with people afterwards about what that delivery was like. (H04-2 line 654)

Being attuned to and attending to the unique needs of a particular family is central to providing the best care possible. Often, it was only with the support of colleagues to assist with the tasks of care, even at arm's length, that the space and time could be created for the primary nurse to fully turn her attention to the particular needs of a patient or family experiencing perinatal loss.

> Yes, and it wouldn't even be necessarily be me going into the room and meeting the patient. It might be just me helping from the outside whether that be with post-keepsake-type things. That's actually my favourite thing to do and it helps the person, so doing the handprints and the footprints and stuff, I really love doing that, so I will often do that for other nurses so that they can focus on the patient. (S05-1 line 833)

Expert nurses acknowledged barriers to being able to see that members of the healthcare team were able to support one another during PPC and lobbied for additional resources in these situations in order to see that their patients received the best care possible. Participants described situations of perinatal loss as requiring more attention and time from staff, and as a result, requiring more personnel.

> I was the charge nurse…and remember bringing like a work overload form to my manager at the end of the shift [during which a family was experiencing perinatal loss]. And, you know, like having situations where you're like it's unsafe like you don't have enough people to keep eyes…on all of the patients, and on each other. And I remember bringing her the overload form and she said well we do try and replace the staff or she said something like almost like of mathematical and I just thought, you know, I feel like my problems aren't your problems and they should be…. Like if management isn't sensitive to the fact that like you're looking somebody in the eyes and like they're in their worst moment of their life and you're not resourced appropriately, like what toll does that take on you as a provider and how can you then provide care in the next room or afterwards. (H03-1 line 204)

Documentation and tasks thoroughly completed. Expert nurses were able to look beyond their tasks and seamlessly integrate the principles of palliative care during the LDR period, but this did not diminish the importance of seeing those tasks and associated

documentation to completion. Expert nurses recognized that meeting this outcome of their expert practice alone would not be sufficient to provide the best care possible from the perspective of the patient.

> When you are new I guess the temptation is to really focus on the tasks, to avoid the terrible - but that's not what really matters to…the patient themselves because like they're scared, they're in pain, all of those tasks things that we'll address, those issues for them like solving the health problem, those aren't the things that are *most* important to them. But I mean here's a problem [perinatal loss] that can't be solved, right? So, I think that people always talk about how like they had a nurse who like she held my hand and of course as a nurse that's just one piece of all of the things that you're doing but to patients it's often the most important piece, right? (H03-1 line 45)

Nurses had a realistic expectation of balancing all they hoped to do for a family receiving PPC with what was realistically attainable given other work obligations, the workflow of the unit, and the availability of their colleagues for support. Whether or not nurses were able to fulsomely provide the emotional attention they deemed best for their patients, they recognized that the completion of necessary tasks and documentation was an important part of the expert care they provided.

> And with the busyness of the unit… you kind of have to get your job done and do the 'extras' when you can, but you don't always have time to do the 'extras', which is unfortunate. And as nurses, you have certain policies and guidelines you have to follow, and if it's not documented, it's not done, right? So, you have to make sure all the required stuff is documented because all of that psychosocial support that you provide is nice, but it doesn't really get accounted for anywhere. It doesn't discredit it, but it doesn't account for

> the time that you spend in there when you don't have specific tasks, you know, tasks that you're writing down. (H01-2 line 79)

The completion of the tasks of care while attending to other patient needs often required calling on the support of colleagues.

> And some nurses don't feel like they need [help/support] and that's fine, if you don't need it, you don't need it. But if you do, I think that we should make sure that there's the option and then that alleviates that problem [of seeing tasks to completion]. Someone working behind the scenes and the other stuff and you get to just kind of focus on the patient and do that. (H02-1 line 606)

Many nurses iterated how this outcome was frequently facilitated by involving their colleagues.

> If they have decided that they want the baby to be taken and kind of washed up and first. Maybe I would take the baby to the door and just press the call bell and the other nurse would take the baby just to the other room while we're finishing up the rest of the stuff [assessments, documentation etc..]. (H04-1 1109)

Many nurses described accomplishing these tasks, which are often the focus of care, as something external or in addition to the core of providing palliative care in this setting. As such, these tasks, such as thorough documentation and necessary medical assessments, were sometimes viewed as detracting from their ability to focus on the needs of their patient. Nonetheless, thorough completion of documentation and medical tasks remained an integral facet of providing the best care possible.

> You want to make sure you're documenting everything, so you know you're doing your charting and then your patient's left there… (H02-1 line 682)

Many nurses described the needs of their patient and the necessity of completing certain tasks as being two very separate things, pulling them in different directions.

> But also, there are so many tasks that we need to accomplish. It's like there's a fog of sadness and [sur] reality and then there's this other piece of like very realness. (H03-1 line 12)

Another nurse described this dichotomy when she discussed being in her 'palliative nurse mode' and/or her 'obstetrical nurse mode', and how in certain clinical situations she could not be both at once. The 'palliative nurse mode' was understood as attending to the more emotional needs of the patient, while the 'obstetrical nurse mode' was understood as attending to the physical needs during the LDR process.

> But I mean there are times especially if it's an emergency situation, that you have flip into this full obstetrical nurse mode. (H03-1 line 610)

This was further iterated when she described three domains of tasks in addition to documentation; the maternal physical care, the newborn physical care, and the emotional care.

> Not only there's the physical task, but also the emotional care kind of tasks and then the caring of the baby tasks. (H03-2 line 132)

To lessen this divide, expert nurses took opportunities to focus on the tasks of care when their patients did not need them to be directly engaged emotionally, but described being conscientious of always remaining present with their patients to a certain degree, even when in the midst of completing necessary tasks.

> …you're explaining what you're doing as you go and depending, is the baby still in the room? Is the baby on the mom? That's okay. They're totally focused on that stuff and

> you're doing your things and still being present in what they're experiencing, but still able to get your medical tasks done. (H04-1 Line 1097)

Additionally, nurses made every effort to be respectful when they were required to carry out a task or assessment by being transparent about the reason for their care action and by completing medical tasks promptly and efficiently. Study participants also described being discrete about tasks once explained and agreed to by the patient. In this anecdote, a nurse described the way she approached necessary postpartum maternal assessments during the few precious moments a mother would have to spend with her deceased infant.

> Well, I think like trying to like I think like who likes a fundal check, right? I think it's really just like "I'm sorry, I know it's uncomfortable". Sometimes I say to people "just give me three seconds and, you know, I just - I want to keep you safe". And trying to keep those subtle components to the whole picture, you know, like the blood pressure cuff, whatever. Trying to make those like this is happening in the background but it does actually need to happen. (H03-1 line 647)

In order to be able to expertly carry out palliative aspects of care that must occur in addition to the provision of standard LDR care during perinatal loss, it was seen as acceptable to defer certain tasks and documentation related to the LDR process so long as these tasks were still seen to completion eventually. However, it was imperative that in choosing to defer a task or documentation, the safety of the patient would not be compromised.

> And also if I can defer something I will, like if I don't have to do whatever it is like any type of work and also if there are no risk factors… Yes, then like you can stretch out those time frames [of assessment protocols] for their emotional safety. (H03-1 line 665)

Infants received love and respect. All infants, whether born still or alive, were

treated with respect and were met with loving actions by all those who were involved in their life and in their care. In order for this outcome to be met, expert nurses not only paid mind to the need for loving and respectful actions toward infants, but also to who was best positioned to provide love and respect. Expert nurses promoted opportunities for parents to interact with their infants in loving and respectful ways, they themselves engaged in loving and respectful behaviors towards infants, and they encouraged other healthcare staff to do the same whenever interacting with an infant.

One way this was facilitated for healthcare providers was through the use of visual indicators. Visual indicators were posted outside of the patient's room to alert facility staff that on the other side of the door, there was a family experiencing perinatal loss. This was intended to serve as a prompt for all hospital staff, including those not involved in direct care provision who do not have access to health information and would not otherwise know this information. This knowledge would allow any healthcare staff the opportunity to respond to situation sensitively and respectfully.

> And then we talk about the rose card, and right now, perinatal loss or the spiritual care team is redoing the logo. So it's going to go from, right now, to rose card, and then we're going to be switching the picture – I believe it's a butterfly sitting on a flower, I think, is the new logo – but I explain to the parents that we put this card on the outside of the door, and I said, it's just for staff to be aware that we have a loss in this room, so that they can be respectful to you and your family. I said, it's not labelling you, it's just so we can be respectful. (S07-1 Line 373)

In some instances, parents took the lead to express love, kindness, and respect toward their infant naturally and independently, welcoming nurses to do the same.

> And I can remember this one dad – and I was assessing this newborn, lifeless baby, in, like, a very clinical little soiled utility room, which was very awkward. And I can remember him saying, you know, treat it like it was your own. And it was actually the dad that encouraged the love and kindness for this baby. (S07-1 line 19)

At other times, nurses initially modeled behaviours of love and kindness toward infants in order to normalize expressions of love toward them. This served as an invitation for parents to do the same. However, nurses remained mindful not to push these actions as an expectation.

> …and they might not have wanted to initially hold [their infant]. They might not have wanted to initially see it …you have to feel it out. If they say, "No, absolutely not," they want to see nothing, then you shouldn't do any of that you're not forcing it on them at all, but if they seem interested or unsure… I think that that's a way to normalize it. Then you know, you're like, "Look how cute your baby is, look at its cute little nose. It looks like its mom." It's okay to have those conversations because it's still a baby to them and it's a real thing in their life and it's okay to do all that stuff. (H04-1 line 867)

Parental expressions of love and respect for their own infant were seen and valued by nurses as acts of parenting. Expert nurses encouraged parents to make the most of the short time they had together with their infant in this way if that felt right to the parent. Expert nurses never coerced families to see or hold their infant, but it was seen as best practice that they make every opportunity available to families to express love and respect through interactions with their child.

> So what I said to this dad was, and I said, so this is your opportunity to be her dad. Like they knew this was a girl. And I said - and if it's for an hour or if it's for four hours, however long you decide to stay here, this is an opportunity for you to be her dad. And I said, this is an opportunity for her to be mom. You can hold her, you can look at her, you can touch her, you

> can have pictures, you can have keepsakes. I said, but in the end, you have to leave her here. I said, and you can't get that back once you go and I don't want you to go home with regrets. (S06-1 line 323)

Nurses were highly mindful of the physical placement of an infant after the birth, especially if not in the arms of their parent. Nurses preferred to keep the infant with the immediate circle of care providers who were familiar to the family, and this was seen as being respectful toward the family and their infant.

> I really am aware of the baby once it's out. Don't want to put a baby that has passed in a bassinet and cover it up and put it in the corner… Because although baby is going to be by itself for a little bit, it's the idea of it, like I am respectfully caring for your baby…then it is not passing it off to a stranger too, unless there is somebody else… another nurse involved in the care already. I feel like that's often what I'll end up doing. (H04-1 line 1114)

When a parent chose not to see or hold their infant, nurses valued their decision and took it upon themselves to honour and cherish these infants by demonstrating love and respect through nurturing actions.

> I took the baby into the nursery and I was just sitting there holding this baby and looking at this baby and just thinking "no one has seen you, your parents haven't seen you". You know, I was thinking the love that babies feel when they're first born and I was thinking about … A long story short, I was singing this little baby lullabies, because I just felt so … And he was looking at me, I don't know how much he could register and what the condition was at all, if any. But I just remember in that moment just thinking no one's giving you love right now, so I'm going to do that, I'm going to do that, right. (H02-1 line 454)

Neonatal pain and symptoms managed. In the context of LDR when perinatal loss was concerned, study participants described having more frequently cared for families experiencing stillbirth than early neonatal death. In instances of live births however, nurses emphasized the importance of adequately managing infant pain or unpleasant symptoms if present. Although this did not apply to every instance of perinatal loss, it was nonetheless viewed as an important outcome of expert practice and required nurses to anticipate the need for symptom management, to have orders available for intervention.

> Even in the middle of the night I've talked to some people in the middle of the night to get the orders, yeah. (S07-1 line 1043)

If nurses anticipated that an infant might be born with pain or distressing symptoms and had obtained necessary orders for administration, they were sure to have the intranasal fentanyl necessary equipment for administration at hand prior to the birth. Having the medication available prior to the delivery was of utmost importance to expert nurses, for without having immediate access to the medication post birth nurses described a missed opportunity to provide the best care possible.

> [If the infant born is] gasping and all that and then [the parents] are like, "Help me," and then now you tell them about the intranasal fentanyl and then you have to go get it and maybe passes away in that two minutes and you've missed a huge part of their experience. Those are the opportunities that you have to kind of make it a little bit better for them. Because you know a little bit about what outcomes will be, so if you've had that conversation with them and you think it's getting close to delivery, maybe you're grabbing a syringe of intranasal fentanyl, you're just having it at the bedside, the same way that you're grabbing your delivery cart. (H04-1 line 1429)

Expert nurses were sure to discuss the use of intranasal fentanyl with parents prior to the delivery, and provided them with choices about using the medication.

> We have intranasal fentanyl on our unit. It's all premixed in syringes ready to go, so that's another thing you talk to them about. If the baby is born alive, is that something that you want us to give baby right away to help the baby if we think it's in any distress or anything? Do you not want anything if baby doesn't look like it's in distress and its peaceful because often that's what happens, right? Do you want us to give it no matter what? Do you want nothing unless baby is giving us signs that they might need it? That's also a conversation that you have to have [with parents]. (H04-1 line 1415)

Expert nurses had the ability to carry out an assessment and to make decisions about the need for medication for pain or unpleasant symptoms. In some cases, even with orders available and medication at hand, administration of medication was not necessary.

> This particular experience, I actually never had to [administer medication], but I would give intranasal Fentanyl…but the baby didn't seem to be in pain at all. Baby just slowly changed and passed. (S05-1 line 692)

Other times, their assessments determined a need for administration of medication. Utilizing medication to ease pain or unpleasant symptoms required nurses to provide education for parents, and to assess the effectiveness of the intervention. It was important that enough medication was administered to relieve symptoms, but no so much as to render the infant more unresponsive than necessary. The use of opiate analgesia via intranasal administration was the dominant intervention discussed to address pain and unpleasant symptoms.

> Yeah, well, if it's a known palliative baby, say it's got Potter's Syndrome or whatever, there's usually notes on the chart, and the doctor will leave us orders for intranasal fentanyl

> for the baby…and we had a baby, we didn't know how long it would live for, and we did the intranasal fentanyl. And so we wanted the mums to know that we were giving the intranasal fentanyl– not to drug the baby, but we wanted the baby to have, like, sort of a quality of life and just be comfortable. And you want to be able to spend time with your baby and not worried about if my baby was in pain or not. And we weren't giving it enough so that it was going to be drugged out. (S07-1 line 1015)

Summary. This section has offered a description of the outcomes of having achieved expert nursing care during direct care provision. Outcomes of having achieved expert nursing care during direct care provision were interpreted as being accomplished when: (a) emotional harm experienced by patients and families was mitigated; (b) negative maternal health outcomes were prevented; (c) staff members were adequately supported clinically and emotionally; (d) all necessary tasks and documentation were thoroughly completed; (e) all infants, whether born still or alive, received love and respect; and (f) in the case of live births, neonatal pain or unpleasant symptoms were adequately managed if present.

Actions and Considerations for Enacting Expert Care during PPC

To understand the critical behaviours nurses engaged in in order to provide the best care possible, participants were asked about the sorts of things they think about when they interact with and care for a family anticipating perinatal loss during the different stages of labor. They were also asked to describe, in detail, how they provided that care. They were asked about what the impact of their care was when it went well, and what happened if it did not go well. Overall, what expert nurses described has been interpreted as a series of actions and considerations imperative for expert care during PPC. First, a description of actions and considerations that apply across the entire LDR period will be described. Next, actions and considerations that are

specific to each of the stages of labor will be outlined. It is of value to note that by no means are the findings presented intended to be prescriptive for clinical practice. Given the tremendous variation in which perinatal loss can present in the context of LDR, this information is instead meant to provide fodder for practice considerations and examples of the types of actions that may be indicated for PPC during LDR.

Considerations have been understood as the concepts and concerns nurses kept in mind while gathering information and evaluating a particular healthcare situation with the intention to make decisions about which action(s) to take in order to provide the best care possible. In some instances, considerations did not necessarily have an accompanying physical action, and instead the consideration shaped or altered an expert nurse's perspective or approach to care. As a result, actions have been interpreted as having occurred in response to the considerations made by expert nurses and refers to both carrying out particular nursing skills and to how a nurse decided to conduct oneself. In other words, considerations were the thought process which resulted in rationale for electing to engage in any particular action, be that a physical task or a moment of emotional engagement.

Table 8
Actions and Considerations for Enacting Expert PPC across LDR

Topics for consideration	Considerations	Actions
Knowing and responding to the person	○ Patients will have their own unique hopes, needs and preferences ○ These can shift and change during the course of LDR ○ Patients need an empathetic approach to care tailored to their own experience ○ Patient experiences prior to the clinical encounter shape their response to their loss ○ The clinical encounter can influence their response to the loss during and after the clinical encounter	○ Be attuned to changing needs, preferences, and hopes ○ Base all actions, as much as possible, on how a patient is responding to their situation in any given moment ○ Allow knowledge of the person to serve as a compass for all care decisions
	Sub-themes	

	Connecting and contextualizing	○ Approaches to connecting with a patient will vary
		○ Ability to connect with patient is influenced by their progress in labor
		○ Patients may give subtle verbal or non-verbal cues as to their willingness to connect or to exchange information
		○ Prior experiences with the healthcare system and healthcare providers may influence willingness to share information
		○ Understanding the context a patient is coming from will enable offering the most appropriate information, reassurance, or solutions to issues
		○ When patients feel understood it is easier to arise at meaningful solutions to issues
			○ Approach patients with an open and adaptable attitude
			○ Allow silence to create space for sharing
			○ Use discretion when and how condolences are offered, there is no standard approach
			○ When possible, take time to sit with patients and their support people if present
			○ Ask questions to understand who your patient is as a person
			  ○ Can start with general questions (i.e., do they have other children?)
			  ○ Once some trust is established can ask more personal questions (i.e., hopes they had related to their current pregnancy)
			○ Make social observations to gauge readiness and willingness to connect, or to make plans for the birth

	○ The needs of patients who are in the company of support people may vary from those who are laboring without the presence of support people
	○ Many of the conversations that will take place during PPC are sensitive in nature
		○ Prioritize allowing space and time for patients and families to process their emotions over exchanging information
		○ Create a safe an non-judgmental environment by taking an authentic interest in the patient experience
		○ Different approaches are acceptable to drawing out information, history, or how the patient understands the situation:
		  ○ "What do you know about what is going to happen today?"
		  ○ "Has anyone told you what our plan is for the day, or what this process might be like?"
		○ Use straightforward language when addressing the infant's prognosis or wellbeing
		○ Conduct conversations in a private environment
		○ Use a gentle tone of voice when speaking
		○ Meet patients with patience regarding their readiness to converse or share information

Understanding and responding to difficult emotions	○ Patients and families experiencing perinatal loss may have feelings such as anger or frustration
	○ Patient feelings about perinatal loss may be misdirected at their healthcare providers (i.e., looking for someone to blame)
	○ Some people experiencing perinatal loss may feel despondent or disconnected
	○ Support people may demonstrate anger related to feeling powerless to help the patient in labor, or not understanding the grief of the patient in labor
		○ Acknowledge loss and emphasize willingness to provide support
		○ Give space by providing patients and their families with privacy in their room as needed
		  ○ Ensure they have access to the call bell if and make support and availability known
		  ○ Provide patient with timeframe of planned return (e.g., time of next medically necessary check)
		○ Display patience with those who seem despondent or disconnected, be accepting of these responses and continue to provide supportive care
		○ When tension arises between laboring patient and support people:

		○ Acknowledge, normalize, and validate different responses to perinatal loss ○ i.e., a pregnant woman may experience a deep connection and with her unborn child and the loss experience is profound while a support person may or may not feel disconnected from this ○ Provide resources for support after discharge from hospital
Tailoring care to anticipated or unanticipated losses	**Anticipated** ○ Patients may have known the infant prognosis for hours to months prior to admission to LDR ○ May have had time to process initial emotions ○ May have had time to make decisions relating to pre and post birth care ○ Specialty services may already be involved in care ○ May have been placed on a waiting list for induction with an unpredictable wait time **Unanticipated** ○ Patients learn the infant prognosis upon arrival to hospital ○ Nurse may be involved in identifying initial concern (e.g., cannot locate fetal heart rate) ○ Prognostic information will be shared with patient ○ Patients can experience a variety of responses to information (shock, grief, disbelief)	**Anticipated** ○ Acknowledge loss and offer condolences as appropriate ○ Determine what decisions have been made regarding pre and post birth care ○ Determine what supports are available to the patient ○ Are support people aware of the prognosis? ○ Contact any services involved to date ○ Be aware that the wait time to an induction may have been longer than the patient had hoped for **Unanticipated** ○ Be aware that patients will likely not be receptive to detailed information related to prognostics immediately upon diagnosis ○ Provide necessary information in straightforward language ○ Determine whether the patient would like anyone to be called in for support ○ Be present to provide emotional support, or provide privacy for a patient and their support people as indicated ○ Provide condolences as appropriate

	○ Patients may require time to process emotions prior to receiving detailed information about the prognosis	○ Assist with decision making related to pre and post birth care ○ *Prepare to attend to a host of emotions at the time of delivery whether the perinatal loss was anticipated or unanticipated

Demonstrating Presence	○ Demonstrating presence enhances the comfort of the patient
	○ Demonstrating presence opens the door to connection with a patient in order to know them as a person
		○ Prioritize time to be present without distraction
		○ Offer full attention when interacting
		○ Be aware of body language
		  ○ Sit on edge of bed or on chair or crouch at bedside
		  ○ Listen actively (e.g., make eye contact)
		○ Allow silence
		○ Offer small acts of compassion (e.g., bring tissue, dry tears)
		○ Use physical touch when appropriate (e.g., hold hand or offer hug)

Knowing the support people	○ Support people are impacted by perinatal loss and have their own unique hopes, needs and preferences ○ Support people may think they should behave a particular way during labor, and during perinatal loss that may or may not allow them to express their own feelings ○ Not all people who accompany a patient in labor offer a supportive presence	○ Attend to support people when present ○ Invite their questions, identify and address their emotions, provide reassurance (e.g., “you did not cause this”, “you are doing a great job supporting her”) ○ Look beyond gender or role based societal norms and expectations ○ Create an environment that welcomes questions and the expression of emotion for all present ○ Normalize a range of responses to the experience of perinatal loss ○ Include support people in the process of supportive labor care

		○ Invite support people to participate in infant care and involve in infant care as applicable
Influence of culture, spirituality and religion	○ Informs beliefs, values, and preferences for care (e.g., meaning of loss, which community or family members should be present, use of ceremony or ritual, handling and care of deceased infant) ○ Can serve as opportunities to learn about and connect with patient and community of support ○ Individual people are impacted uniquely by their cultural, spiritual, or religious lens	○ Approach learning about culture, spiritual, and religion with a spirit of inquiry ○ Be attentive to nuanced differences across cultures, religions, or spiritual affiliations ○ If religious or spiritual community leaders are involved for support or ceremony, ensure they engage in a way that is centered on the patient's particular beliefs and preferences ○ Ask patients with an open attitude about the appropriateness of planned or possible care actions such as those involved the creation of various keepsakes (e.g., cutting a lock of hair for a keepsake)

Exploring and supporting the role and experience of the parent	○ The meaning a patient ascribed to the loss of their infant and how they perceive their role as a parent should frame care decisions
	○ Many parents have a need to express their role as a parent through caring for their child while others do not
	○ Some parents will be forthcoming about this while other will be less candid, or even uncertain and may need encouragement or permission
		○ Determine the patient's perception as their role as a parent
		○ Validate the role as a parent as appropriate:
		  ○ Tell them they are a parent, mom, or dad
		  ○ Tell them parenthood is not dependent on a timeframe
		  ○ Encourage their participation in infant care (e.g., bathing)
		  ○ Notice and commend their love for their child (e.g., "Your baby is so lucky to have you as a mom")
		  ○ Validate any feelings of anger or jealously toward parents of well infants that may arise during their hospital stay, or that could arise after discharge
		  ○ Acknowledge that perinatal loss can be a taboo or hidden subject from society, and encourage

		them to share their story once they are home if they so wish ○ Give permission to tell people they are a parent: (e.g., "Yes, I am a mom, I had a daughter but she died, but I named her Julia")
Involving and informing colleagues	○ Sharing information about the patient as a person will facilitate the ability of other healthcare professional to provide the best care possible ○ Sharing important information about the patient as a person can avoid care actions of others that do not align with the values and preferences of the patient ○ The opportunity to share this information may not always be included during formal reporting or transfer of care	○ Take informal opportunities to connect with other healthcare providers to brief them on information pertaining to who the patient is as a person as well as their current emotional state ○ e.g., make a point of meeting with other healthcare providers before the enter the room when feasible ○ Invite colleagues that you suspect will be involved in the patient's delivery to come and greet the patient ahead of time ○ Share information with colleagues about the patient hopes, preferences, and needs for best care, making the plan for care clear and known ○ e.g., it is important to the mother to have her infant placed skin to skin immediately at delivery ○ Advocate for patient hopes, needs, and preferences especially if another colleague is going to carry out an action that does not align with what the patient wants
Reallocating control and providing choices	○ Perinatal loss involves a loss of control and power for the person experiencing the death of their infant, and for their community of support ○ Patients are often unfamiliar and sometimes uncomfortable in the hospital environment contributing to a sense of powerlessness	○ Be aware that patients did not choose to experience perinatal loss ○ Familiarize patients with the care environment and how staff can be of service to them ○ Provide choice whenever possible, choices can be provided about:

	○ The physical process of labor can contribute to the sense of loss of control ○ Making assumptions about care can perpetuate feelings of powerlessness ○ The provision of choice provides a sense of control ○ When providing choices, patients may make decisions that contradict one's own beliefs ○ Experiences of loss of control and powerlessness can cause feelings of fear ○ External factors such as patient flow, bed utilization, and infection control may limit the ability to provide choice around particular issues	○ Care decisions for labor (e.g., method of pain management; consider patient controlled analgesia when appropriate) ○ Selecting which care activities would take place (e.g., which investigations to conduct or not or creation of particular keepsakes) ○ Nuances of infant care (e.g., how they would like their infant presented to them post birth) ○ Where selected care activities would occur (e.g., creating keepsakes in the room or take infant to different location) ○ The level of participation in infant care activities (e.g., to partake in infant bath or not, or do themselves) ○ Support the choices patients make ○ Take inventory of own assumptions, biases, and comfort with particular patient decisions ○ Do not limit choices based on own comfort, assumptions or biases
Recognizing the role of one's own emotions	○ Nurses experience their own range of emotions during PPC ○ Nurses make decisions whether to demonstrate or withhold their own emotions ○ Expressing emotions may allow foster emotional connection with some patients ○ Outward expression of emotions is not required to provide best care ○ Repressing the outward display of certain emotions may be preferable for some providers	○ Demonstrate emotion during direct care provision if a patient would feel supported by this action ○ It may be prudent to withhold the outward expression of emotion in the moment if it is going to detract from the ability to provide best care possible

Considerations and actions across LDR. In general, expert nurses described a degree of fluidity between their considerations and actions through the anecdotes they shared. What they described also illustrated the aptitude with which they were able to move through a comprehensive and targeted series of considerations and actions aimed at meeting the outcomes of expert care previously described. Study participants described a host of considerations they kept in mind throughout the LDR process as illustrated by this nurse:

> Considering the broader context and think about their present state. How old they are. Who is with them, their support people, whether they have support people or not. Their social situation. You always want to inquire about how they're taking it. How have they been acting? Did they already know or just found out in triage or whatever? How are they coping now? What are their plans? We usually talk about that beforehand, and like what conversations had the prior nurse talked about? (S05-1 line 126)

The sequence of actions throughout the process of LDR varied and were not carried out in a prescriptive or stepwise manner.

> It's so difficult to put caring into words. You want to be able to say, "Step one, step two, step three, step four," but there isn't that obvious order and what I do might be totally different from what somebody else does, yet they [the care providers] are fulfilled by that care and the patient is as well. (H04-1 line 1109)

The order of their actions in any given scenario were based on the physiologic process of labor, and what their patient and their family needed from them in any given moment.

> …but just letting her kind of guide the process, and, you know, not so much worried about the order of things, but just what you can do for the family. (H01-1 line 52)

This nurse iterated much the same point when she stated:

> I just do so many things automatically, I don't really think of the steps that I'm doing. So it's hard, because I have to kind of think, like, okay, what do I do? It just - I just sort of roll into that role and do what feels right and it works…I don't actually think at the time, I don't analyze what I'm doing or about the order that I do things in. And a lot of it's based on the two most important people, which are the mom and dad, right? (S06-1 line 602)

Broadly, the considerations expert nurses kept in mind across all stages of the labor process during perinatal loss have been understood as being based on knowing and responding to the person they were caring for and reallocating control and providing choices. These considerations guided nurses in making decisions about which actions were most appropriate for the situation at hand.

Knowing and responding to the person. Considerations were consistently centered on and tailored to who the expert nurse understood their patient to be as a person, and who the people were, if present, that comprised her community of support. In order to know and respond to the people they were caring for, expert nurses took inventory of their own biases and assumptions by bringing awareness to their own emotions and life experiences prior to engaging with their patients.

> And I think just going into those situations and being aware of your own feelings and history before setting foot [in the room]. (H02-1 line 100)

The actions of expert nurses were rooted in this knowledge and it allowed expert nurses to explore and anticipate the hopes, needs, and preferences of the families they cared for in the deepest and most connected way they could. This meant that nurses were attuned to the shifting emotional tides of labor, and of the experience of perinatal loss, and could adapt their own actions accordingly.

> There's definitely not a one size fits all approach to it at all and there's a certain fragility to the situation for sure, but yes, it's not a standard approach that you could say, "You do this, this, and that when this happens" because a lot of it is, just with nursing in general, is feeling out the situation and seeing who those people are and what those people needed at that time. Being present and anticipating and reacting to what people might need from you in each moment is key and it might change drastically in the course of five minutes, you know, what that is that people need. (H04-1 line 34)

Every interview was imbued with the notion that each specific patient, who they were as a person and what they made of their experience, was at the centre of how an expert nurse constructed each element of their care in any circumstance of perinatal loss. One nurse put it rather simply when she stated: "What I do is based on how they are." (S06-1 line 611). Study participants described a level of trust in this as the compass by which to dictate their approach to care.

> I think every time is a little different. It kind of depends on the patient. Maybe because I've done it numerous times already, my kind of fear that "what are we going to expect?", or "what's going to happen?", is – it's not gone, but it's kind of in the backburner, and you just need to think, "what can I do for this specific person, or family, or whatever the situation is?" (H01-1 line 7)

Overall, it was knowledge of the person that drove the empathetic approach to care ubiquitous across interviews.

> I always try to kind of put myself in what they would be experiencing. You never truly know what people are experiencing inside, but just to try and empathize with their specific situation and it's not always you saying, "I'm so sorry for your loss," because that is not

> always the right thing to say to people, right? Especially when you first meet them, you know? (H04-1 line 160)

Acknowledging the person, as mentioned above, considered the nurses' experiences prior to the clinical encounter, but also took into consideration that these individuals would inevitably be impacted by their care experience in the wake of their hospital stay. Providing the best care possible meant minimizing emotional harm, and this could only be achieved through an empathetic approach:

> I mean, it all comes down to empathy, really. I would just hope that going into a room you just have to remember that these patients are going to remember this situation for the rest of their life, most likely, and what you do in there really can make a difference or ... you know, make a good difference or make a bad difference. So I would just hope that people would think that before going into the room… (S05-2 line 234)

Connecting and contextualizing. In order to become acquainted with their patient as a person, expert nurses needed to consider how to best connect with and approach a particular woman in labor as well as her support people. The ability to assemble this information often depended on the progress of labor and how an individual was responding to the experience of labor at that particular moment. Nurses took great care to understand this about their patients by sitting with their patients and asking questions that would help them to best understand their patient.

> Sometimes they come in and they're in induction and you get time to spend with them…be in that room and sit and talk with them and get to know them, what their likes and their wants are. And yeah, just the talking with the families. Some are spiritual, some are not spiritual. Just getting to know them, yeah. And it's probably very hard for them to open up to somebody they've never met before. So I usually start with just getting to know them

> and their family and their partner, and then if they have other children. And you start talking about those things, and then as the trust and the bond between you and the family has developed, then they start opening up to you. And then it just – yeah, it goes from there, the things that they wanted for this baby and… get to know them human-to-human, and their background, where they come from and, you know … (S07-1 line 71)

They also made social observations to gauge the readiness of families to talk about the plan for labor and delivery, and gave people the time the needed to process their situation before piling on the information and requests for decision making.

> So a lot of it is just done by watching them. So you get the dads that are, really, they're just grieving just as hard as the mom. And so again, if they're sobbing you're not going to sit there and just going into this spiel about, so when your baby's born we're going to take the swabs and we're going to do this. And the mom and the dad are crying, they're not hearing a word I'm saying. You know. So I will acknowledge that they need some time and that we still need to talk about what's going to happen when the baby's born. So I'm just going to leave for a bit. So you need to acknowledge to them that they need some time, because sometimes they don't recognize that. And that when you're ready to hear more I'll come back and we'll talk some more. (S06-1 line 665)

Prior to first interactions with their patients, expert nurses typically did not have insights about their patient as a person beyond what was in their medical chart. They approached first greetings with their patients with an open and adaptable attitude and were able to swiftly discern whether actions such as offering condolences, allowing silence and space for their patients to share, or displaying their own emotions were appropriate.

> Walking into a room… it… I don't know where to start with this, but I would just tell people, "I'm so sorry that this is happening to them" and it's not what they expected the situation to be. You just have to anticipate what… that conversation is so different and it might not be saying things, it could just be silence. I have had so many times where you just, you're just sitting with the mom and you're crying and you just met them and that's okay and if… the mom might be there all by herself. She just came in because her partner is at work and she feels like something is weird and the baby is gone and that's a whole other experience too. (H04-1 line 184)

Nurses were thoughtful to understand the context and concerns of their patients, this enabled them to offer the most appropriate information, reassurance, or solutions to any issues that were identified when possible.

> This particular girl, she had been in labour - we had been inducing her for quite a while, started two days prior, so it was already tough when I came into the picture because I'm sure she just wants it to be over with. I guess when I came on, that's when she started laboring, so she was very quiet and reserved, which may have been related to her culture, so it was very difficult to have in-depth conversations with her …she was also quite young, so discussing her feelings and stuff may have been out of her comfort zone. In the beginning it was tough. I just do what I normally do, which is just to make sure that they know that I am here always for anything at all. She started to progress later on in the evening, or contractions getting stronger. Pain relief was, I guess the biggest issue…she was also not coping in that situation. It was hard for me because she just is so young and to see someone sobbing at so young and going through an experience like this is tough, but I just sat down with her… sat down beside her. I asked her first of all why she was crying, whether it was

> emotional or physical? She confirmed it was more the physical pain and so I just asked her questions and explored pain options with her…That seemed to calm her down, she stopped crying, and I was able to make the situation a bit better. (S05-1 line 178)

Expert nurses understood that their patients' previous life experiences, including prior encounters with the healthcare system and with other healthcare providers, informed their willingness to share information. All nurses highlighted the significance of striving to understand their patient as a person by learning about their particular situation leading up to the experience of perinatal loss and about how they were responding to the situation by creating an emotionally safe and non-judgmental environment and by taking an authentic interest in their experience.

> It's always letting them share what they're comfortable with I find that I think just because it is… it's a setting where people know that you have experience. It's the same as how I was saying before, people confide in nurses because they know that they have been through things or they've seen things and they're not going to be judged. I think that sometimes when people come into contact with healthcare workers there's just like a release of all that because they know that they are in a safe place, sometimes, not always. When you just are talking, those little bits will come out and it won't be exactly how easy I just made it, you know Tuesday this happened, Wednesday… you're not going to get a timeline like that, but you definitely will get little pieces. I also think it's okay to ask in a caring and empathic way. Obviously, you don't have to sit down and be like, when did this happen, what day did… It's all your approach, but I think if you are doing those things, like how I was saying, at first, you're being genuine and you're being honest that shows and people will receive your questions as… like you are genuinely caring and interested in what they are going through and they will give you those answers. (H04-1 line 256)

Sometimes this could be difficult, especially if the patient had not had a positive experience leading up to the event of perinatal loss.

> …some people are more accepting of hospital care. Sometimes they blame us for whatever reason. This makes your job really hard. You know, if they were on the induction list and they were healthy, and then all of a sudden they're 41 and 5 days and they come in and there's no fetal heart, then that's our fault, and it makes providing care very hard for them. Because even though you're not at fault, the person who's providing the care or the system itself maybe, or maybe it is our fault and we still have to provide care, right? It makes it hard to build that connection with them. (H01-2 line 353)

Nurses had various approaches to drawing out the stories and experiences of their patients in a way that was sensitive and attuned to what would feel respectful to that particular patient. Expert nurses first needed to connect with their patient in a way that allowed them to share comfortably, which sometimes meant not expecting them to divulge any information. Once a connection was established, nurses were open to the stories their patients shared. This allowed them to contextualize the meaning of their loss in order to provide validation about their feelings and experience.

> I think I… like one way of getting some of the story out of the patient without directly asking or waiting to kind of feeling it out a little bit might be asking them, "What do you know of with what's going to happen today?" or "Has anyone told you kind of what our plan will be or what the process will be like?" Again, there's so many variables and so many situations, but that would be kind of any easy way to start it and then you're not just directly saying like, "When did your baby die?" Then "How long have you…?" like, whatever not that I… you should never ask in those ways that's not sensitive. It is a way of

> approaching the situation that is kind of putting your feelers out and letting them give you… It will suss out kind of what they're willing to share with you. People will tell you nothing or they'll tell you everything and then you can kind of go with that in the conversation too, but like I was saying before, I don't think that people are looking for answers from you, they're just looking for validation of their experience and you can easily give that to anybody. (H04-1 line 290)

As a part of contextualizing their care to the person, nurses used their skills to evaluate how their laboring patient was comprehending the situation pertaining to their infant's prognosis and wellbeing and then were able to respond in a way that conveyed compassion while being straightforward with the information at hand.

> …in that you're always trying to read the patient. I did [name of course and agency] …and one of the parts was health literacy and I did just that one piece. Just that whole idea of being able to… titrate information, but give people something they can understand and I don't know…you have to frame this is a way that's gettable for you or else my message won't get across…I don't know, maybe it comes down to language and communication, trying to make sure that you're giving people what they need. (H03-2 line 32)

Another nurse iterated this point through the following anecdote:

> It was a young girl from a northern community and there was a little bit, not necessarily a language barrier, but maybe some misunderstanding at times. Baby was born with anomalies and was not to… was going to pass, but the mom maybe had accepted or maybe there was something preventing her from acknowledging that was going to happen. She knew, but she didn't know. For example, in a situation like that I like to point out the good things in the baby or like the beautiful things, especially with ones with anomalies, so I

> remember saying, "Look at your baby's hands they're so perfect and beautiful. In that moment, she looked at me and she said, "So, my baby is going to be okay?" So, gently you have to fill in that gap and explain to her that, "No"... That was very hard. (S05-1 line 633)

Study participants acknowledge that many of the conversations they had with their patients were indeed challenging and delicate in nature. As such, nurses were very thoughtful in how they engaged during these conversations, by promoting privacy and being sensitive in how they were speaking.

> …just being gentle in how you're speaking to them and approaching the situation. I always… I like to close the door so that it feels more private and all that kind of stuff. (H04-1 line 452)

They also demonstrated patience when those they cared for were not ready or did not want to engage in these conversations, instead they met them with acceptance.

> And some of the parents are like, I can't think about that yet. And that's okay too. (S06-1 line 217).

Understanding and responding to difficult emotions. If differences did arise between themselves and their patients during these conversations, or if their patients were experiencing emotions such as frustration or anger and were directing that at those providing their care, expert nurses focused on being truthful and typically were able to resolve conflict through this means. They were also respectful to give patients the space they needed, while still making themselves available.

> So yeah, there's lots of variables but I guess 95% of problems can be fixed with communication, so you just have to be honest with people. But just to be open and communicate with them and say this is the position that we're in and we're here now so how

> can we make this the best for you? And sometimes people have been very angry and I'm going to say, "Okay, I'm going to leave you be. Here's the call bell. This is what I'm required for my job to do, and if you'd like my help you can call, but I'm going to be in at these times to check up on you and this is what's required, you know? So you kind of have to get the vibe of the people. Yeah, I think I've experienced all kinds, from people throwing things and kicking me out to people hugging you and not wanting you to leave and you to go home with them. So you kind of just have to communicate. (H01-2 line 331)

Expert nurses were sure to make their support and availability known to their patients, especially in the face of anger as this approach seemed to help dissipate those emotions. Although many nurses spoke about this, one nurse in particular broached the subject of anger on several occasions:

> I mean there are some people who like I said are angry and they're looking for someone to blame. And for those situations I think it's really important to let them know that you're here to help them, you're here for their comfort and like I said to express the sorrow that you feel for their loss and that goes a long way….(H02-1 line 65)… I think that it's making the best out of a bad situation for them. I think that they need to see that we're doing everything that we can for them. Because just personal experience, when things - when they're faced with an adverse situation like that, sometimes people are looking for someone to blame or they're looking for something to be angry about. So I think if we let them know where we stand and how we're here to support them and really having that up-front discussion, acknowledging their loss, I think that goes a long way in allowing them to not feel that anger. At least for the time that they're with us. I mean not completely but I mean - If they know that we're on their side and that we're here to support them, I think that that makes things easier. (H02-2 line 278)

Every nurse described facing anger and denial as making it especially challenging to forge a connection with their patient. In these instances, expert nurses described having a great deal of patience and a malleable approach to their care. They worked diligently to meet their patient where they were at emotionally in any given moment.

> … I guess it could be partially what the patient has experienced sometimes too. If there's a lot of anger and denial and stuff, they might not be ready to hear a lot of those things or they might not be as accepting of maybe the supports that we have to offer in the hospital and stuff like that. That could be, I mean, that's…You can't change that, but you can… you just have to change the way that you're caring or the way that you're offering those resources to people. (H04-1 line 329)

Perhaps even more exigent than facing anger, was facing disconnect or despondence. Nurses described being particularly concerned about those who were withdrawn. Again, study participants talked about taking their time with these individuals, and not expecting them to be open to connecting immediately. This nurse spoke generally about patients with these emotions,

> I think well you still always have to play off like the patients' cues, like I said you know if they're despondent, if their affect is flat, if they are angry, just really … It's hard to say how to act in those situations, I think it's kind of somewhat instinctual, you have to tread lightly with those people. I think it's your basic supportive care that we all do and we have those abilities and those open-ended questions and you're not really validating their feelings. But I think a difference that it really makes is how the nurse feels in that situation, that's a big thing I think because obviously if someone's come to grips with it, it's much easier for you to cope than it is for someone who just found out, right. And I think that … I personally feel like it's okay to be upset if you're in that situation… (H02-1 line 86)

and also shared a specific clinical encounter that really stuck with her as being particularly challenging.

> And then there's some people … I remember there was this one girl, she was 13 and she was acting like nothing had happened, like nothing at all. You know and I think that that's concerning too, because she will have to deal with that if not now, later, so having that conversation, you know just to help them heal too, but really you have to take it based on their lead … You can't force your ideals upon them at all. And the thing about when you're caring for a loss typically there's more time, there's more time to have those discussions to have that really supportive care, especially since it's usually an induction, right. So it's a slow process, there is that kind of front-end time to talk about things. (H02-1 line 65)

Expert nurses also talked about the tension that could exist between the laboring woman and her partner, and how anger could play into that. Expert nurses saw a role for themselves in helping to diminish the divide by helping them to understand one another's perspectives. They understood that this difference in emotional response to perinatal loss could require support after their time in hospital and provided resources as appropriate.

> Often what we see are angry dads. And not angry at any of us. They're angry that it's happened and they're angry that they can't do anything about it. They're angry that they can't help. They don't know what to say to their wives. And they're grieving too but you know, I've had a dad say to me, well I'm not the one who was pregnant, I wasn't feeling the baby move. Or sometimes they're not as sad as the moms and they feel bad about that, especially if it's an early loss, like 20, 22, 24 weeks, mom might just be looking pregnant. And he kind of doesn't get her grief, right? So you have to sort of look at the dad and so those are ones I tend to focus on, like, do you have questions? Do you understand, you know, well I had a

dad say to me once, well I don't understand, like you know, she was only five months pregnant. And what I said, you know…you have to understand that she's felt the baby move. She may have gone through morning sickness, which makes you angry at your foetus that you really didn't like that. But then that resolves and then you start to get a belly and then you start to feel pregnant and you start to plan and you start to make future plans for your baby. And what are they going to look like?...I said, a mom plans for her baby almost from the day she finds out she's pregnant, so for her that loss is greater because that baby has lived inside of her and she feels that she has failed. And it's totally normal to feel the disconnect from that, because you didn't experience any of that. She wasn't big enough to feel the baby move so you didn't have those opportunities, but it doesn't mean that you can't support her in other ways. And I tell the dads too that you may find that a week down the road is when you're going to realize that you have had a loss, and I said if you never do feel that connection that's okay too because that is normal. But it can sometimes cause a rift between parents, right? Oh, it's destroyed marriages. Especially for women who can't - if they blame themselves can't get past that. Or if - even if there was nothing that ever happened they may sometimes blame dad, whatever, you made me walk too far. Or she's just mad, why aren't you crying for this baby? I don't understand why you're not crying, and he said, well I don't understand it's been two years, why can't you stop crying, right? So I also tell parents that if you feel the need to talk to somebody, well once you go home there are resources out there and our spiritual care people, you can always call and talk to them and they can - no matter when. So I let them know that they can still contact spiritual care once they've been discharged from the hospital. But it's just trying to normalize and validate their feelings... (S06-1 line 617)

Tailoring care to anticipated or unanticipated losses. One of the most notable general considerations made by nurses in order to contextualize care in instances of perinatal loss was whether the death of the infant was anticipated or unanticipated.

> Well I think even within the stillbirth area, there's two kind of separate subcategories … There's those who have known for a few days and then there's those who are just finding out. And I think that if they don't have the time to deal with it, there's a lot more anger, there's a lot more just emotions in general than if it's someone who has known for a few days and had a chance to kind of wrap their brain around it. But also in terms of the care you provide for a live well baby versus someone's whose baby has either passed or will pass. (H02-1 line 9)

It is important to note, that this sub-theme reflects whether the loss is anticipated or unanticipated at the time the study participants encountered their patients. For example, if a pregnant woman were to find out her infant had died in utero during a fetal assessment as an outpatient but was then placed on a waiting list for induction of labor, this loss was not expected when she received this information in the outpatient clinic, but the loss has come to be anticipated by the time that woman is called in for her induction of labor when the expert nurses who were interviewed would have assumed her care.

> So it kind of depends, did they just find out, did they find out a while ago, and now they're coming back to be induced to deliver the baby, kind of how upset they are, or inconsolable, or have they kind of come to terms with it? So every case is kind of different. Even though the subject might be the same, it's – every experience is different. (H01-1, line 11)

This nurse discussed a few of the things she considered when responding to such a situation:

> There's so much differentiation and those people that are waiting for a long time to be induced… to me I think, like what is that experience? Who knows that this is even happening to you? Does your partner even know? Because of like how we were saying, it's not talked about, she may not have told him or have you been holed up in your house because you don't want to go outside because people can see you're pregnant and then they talk about your baby? Does anyone in your family know? (H04-1 line 244)

Nurses used this information to prepare themselves to anticipate and best attend to the emotional needs of a laboring woman, and any support people who were present. This also helped dictate their approach to providing information and education; nurses were sensitive not to overwhelm them with information, while ensuring they had the information they needed.

> For those ones that have been so recently diagnosed, a lot of it, they have not processed that at all. It is, it's a shock from everything that they thought they were going to experience. You can't throw too much at them all at once, you really have to take it slow and meet people where they're at, but also understand that they're in a state of shock where they are not going to be processing so much of what you're saying to them. They might need time just to kind of have some time together if they're with family, or they might need you in there just to sit with them and cry with them and hug them because there's nobody there and they're experiencing one of the worst days of their life. I feel like the situation can be so broad in how it would present itself. It's hard to know which way to go. That's kind of with experiences that are sudden, that have just happened before you're taking care of that patient. There are also situations with, say they've had an ultrasound and there's anomalies and they have opted for some kind of medical termination depending how far along they are, they still might have to vaginally birth that child. In those situations, obviously it doesn't make it any

> easier. The experience that they're having when they come into contact us as a healthcare professional, but they've had a little bit more time to process that. Either it was choice that they've made to not progress with the labour or it's something that they have literally… like they've been waiting. (H04-1 line 196)

Nurses discerned that when a loss was anticipated, a woman in labor may have had the opportunity to learn about and process the death and may have even been introduced to other care providers and had the opportunity to make some decisions and give input to their care plan. When the death was unanticipated when they arrived to the LDR setting, nurses were responsible to emotionally support a woman, and those in her company if present, to absorb the information about her infant's prognosis and to guide her in making necessary choices. When it came time to delivery, expert nurses had learned to anticipate that emotions would run high whether the loss was expected or unexpected.

> Like if a family comes in, and they came in because they were labouring, and they came into triage, and they're six centimetres, and they're having a baby, and then we just go to do our normal thing, and we can't get a foetal heart, or there's some kind of compromise there, our – my focus is on her emotional support, than versus if it's a family that they were being followed in foetal assessment, and they know the baby is palliative, and they've had time to come to terms, maybe talk to neonatology, understand kind of what the process is. They've had time to kind of process that, and make some choices, it's very different, because they now understand what's happening with the baby. We can focus on all the other things. They could – I mean, it's not easy for them, but I find it's easier for them to like have a thought process, and kind of cope through the situation, until you get

> to the delivery, and then of course it's devastating for everybody. But it's, yeah, focusing more like on what's important at that moment. (H01-1 line 86)

Study participants went beyond simply differentiating between these general two categories of losses, but truly empathized with what a patient and their family might be feeling. Expert nurses acknowledged that, in certain ways, the current healthcare system is not well designed to accommodate the unique experiences and needs of those faced with perinatal loss. This nurse shared her particular concerns around the somewhat unpredictable waiting period some women experience between diagnosis of an intrauterine fetal demise and induction of labor.

> I feel like the situation can be so broad in how it would present itself…. That's kind of with experiences that are sudden, that have just happened before you're taking care of that patient. There are also situations with, say they've had an ultrasound and there's anomalies and they have opted for some kind of medical termination depending how far along they are, they still might have to vaginally birth that child… they've had a little bit more time to process that. Either it was a choice that they've made to not progress with the labour, or it's something that they have literally… like they've been waiting. I feel so awful for these people because if people have a loss and then they're not in labour they get put on our induction list and they just keep getting bumped and bumped and bumped because there's not a process for that…it's prioritized every day, so people that are at higher risk or if the mom is not sick… they're going to be waiting a long time. Then you think about what that experience is like for people. (H04-1 line 207)

Not only did study participants deeply empathize with the range of situations that may be encountered, but they also anticipated the varying considerations and actions that could arise as a result of whether the patient presented with an intrauterine fetal demise or an infant who was

expected to be born alive but die shortly after birth. For instance, when an infant was born alive, nurses needed to provide infant care and anticipate and prepare for their death. In some cases, nurses were present at the moment of death and were responsible for pronouncing the death of the infant and providing supportive care to their parent throughout those moments.

> With a palliative baby, like I said, you're still caring for the baby, so you need to make sure that pain is under better control, you wouldn't have to that with a stillbirth. You're still feeding the baby, so yes, it's a mixture of both stillbirth and a normal live delivery with a bunch of emotional stuff. In this situation, I had just come on shift and baby was lasting, or alive, a lot longer than we had expected and baby had fed and we weren't expecting baby would feed and I was about to give baby a bath and mom was looking at baby and I kind of unwrapped and I noticed that it was changing colour. I left the room to get the bath stuff, I came back, and mom was just sitting with baby in front of her on the bed and you could tell in that moment that she knew and I knew it was coming fast and I just went beside her, I actually went on my knees. I always like to be on their level or lower because it… no-one wants to have someone looking over them. I wasn't able to hear a heartbeat and so, I explained to her I'm not hearing anything and she already knew. You could tell, she just was silent and I just sat there with her a little while and made sure she was okay and gave her some time… (S05-1 line 650)

Demonstrating presence. Making time to listen and not being distracted by other tasks facilitated their ability to know their patient as a person. Expert nurses made a concerted effort to prioritize moments to be present with their patient, to offer them their full attention and to engage in discussion and listen actively during discourse.

> But I think if you're staring at their chart and you're like, check, check, check. When can I get out of this room, this is making me uncomfortable? They're not going to open up and they'll put that wall up and maybe not share things with you. I think, it's so hard to put into words, but I think, I guess I always start off just being present in the room and taking it from there, like sitting down on a chair, sitting on the bed if that's acceptable and you're not in their space too much, depending. If they're alone, it might be sitting closer to them, if there's a 100 million family members, but just sitting down so they know you're there. You're not busy, you're not going to check on another patient, you're not going to do this, like you are there's and you are there for that experience and addressing their needs. (H04-1 line 281)

Demonstrating presence and engaging in active listening were frequently cited as means by which to get to know their patients but also allowed them to gauge the intensity and nature of emotional support their patients required. This nurse highlighted some of the physical actions and emotional approaches she utilized when providing care in situations of perinatal loss such as allowing silence, holding hands, offering condolences, and small acts of compassion when she stated:

> Sometimes – I think most of the time it's just having a physical presence, not running away, not being scared of the situation, but holding their hand, or giving them a hug, or sometimes picking them off of the ground. Like treating them like I treat every patient, or trying to treat every patient like they're my family. How would I want my family to feel, right? Not everybody comes in with a big group of family, or like good support people, or even good situations prior to coming in, so just being physically present. Sometimes you don't have – you can't say anything. Sometimes you don't know what to say, but it's not so much of what you said, but how you make people feel, right? Just sit there, hold their hand, like tell them

> you're sorry, give them a hug, bring them Kleenex, like those kinds of –- just listen, emotional support, yeah. (H01-1 line 110)

Nurses described a variety of ways they used non-verbal communication to demonstrate their presence, and that this allowed them to most deeply connect with their patients. This included things like sitting or crouching at the bedside, and using touch when patients seemed comfortable with and responsive to it.

> Body language is super important. I mean, I'm pretty aware of my body language, with every patient, because I think it's really important as a nurse or, kind of ... you know, you're looked at as a professional, and that could be scary, and I don't want to be a scary professional in a situation like that. So I try and humanise myself as much as possible. Getting down to their level. I never stand at the bedside and look down at them. I think it's important to look them in the eye, face-to-face. Sometimes crouching. Sometimes pulling up a chair, sometimes sitting beside them on the bed, if they're okay with that, yeah, depending on the situation, what's around. But I do think of it a lot. Touch is also very important. I mean, depending on your patient and what kind of ... how you're reading them. They may not be as okay with touch but it could make a difference, showing them just, you know, how much you care. And just talking to them like a human being. You know, asking them how they're doing and just trying ... trying to ask it like you're just another human being, not a nurse. I don't know how to describe that either. Just making them feel comfortable so that they ... you know that they're open enough to be honest with you about how they're feeling and what they want or what they don't want or what they don't like. Like, I want my patient to be able to tell me all of those things because it's important. (S05-2 line 429)

Knowing the support people. Study participants were conscientious to get to know those involved beyond the laboring patient herself and this required attending to her support people, if present, in this manner. Nurses prioritized creating a climate where support people could also express themselves fully, should they wish to do so. Study participants acknowledged and challenged societal norms and expectations and looked beyond them. Doing this enabled expert nurses to begin to know the individuals in front of them in a way that enabled them to best address their emotional needs.

> I don't know, maybe there's a sensitivity to the male… you know how men in our culture are discouraged from having feelings basically. Was I saying to you that I felt like sports was a way for men to have the full range of feelings? Yes, like that's okay to cry when your team loses, but it's not okay to cry when your baby is not going to live for very long, so I think just normalizing that for people and making a safe place for them to have feelings. (H03-2 line 661)

In considering the essence of each individual present during perinatal loss, nurses responded to the needs of each individual through their actions toward that particular person, thoughtfully taking into account who would most benefit from their care actions, such as through physical touch or by providing verbal reassurance, in any given moment.

> Sometimes I'm hugging the dad, because the mom is okay, but the dad is falling apart, or the grandmother is falling apart, or, you know, just trying to give them kind of reassurance that they didn't cause this. (H01-1 163)

When support people were present, study participants described making efforts to include them in the process and saw that most often they were there to help. This meant inviting their questions and providing them with opportunities to care for the infant once it is born.

> I make sure that they're - if I'm - of course if I'm explaining something to mom and dad I'm focused on them. But I'll also turn and look at them and say, do you have any questions about that? So that they're a part of it too because they may have questions and feel like they can't ask. So, I think that's really - especially the grandmas, right? Because first grandchildren, grandmas, you know what it's like right? So I do try to make sure that they can come to us for questions too, like to not think that they can't ask questions. Like that's so important letting them know that I consider them to be a part of this whole process too. If the parents have invited their family to be here then we need to make them part of the process because obviously it's important. So same thing by clarifying, you know, do you have any questions about what I just told her, or you know, or sometimes they do. It's like, well will you take the baby away to bath and I said, only if the mom wants. If she doesn't want - I had a grandma ask me not too long ago, well if whatever her name was doesn't want to bath the baby can I bath the baby? I went absolutely you can bath the baby. You can bath the baby here in the room or we can bath the baby in another room, you know, that we have. (S06-1 line 582)

On the other hand, nurses were also attuned to the fact that occasionally, the people who accompanied their laboring patient did not necessarily offer a supportive presence. Nurses invested time in observing and getting to know the support people to determine what their role would be and if they would be helpful for their patient in labor.

> Yeah, because not everybody who comes to the hospital with somebody is emotionally supportive. Sometimes they’re there for the event, sometimes they’re there because they’re all 16 years old, and that’s the thing to do, and, you know? Or sometimes they were driving to Wal-Mart with their kids in the car, and now they got to bring them because they don’t have a babysitter, or they don’t have support, or their partner’s

> abusive, or, you know? So it kind of depends. Sometimes it's a small timeframe to kind of get the vibe of who the people are, and what they do. (H01-1 line 143)

Overall, nurses acknowledged that some support people would require more attention and reassurance than others, and they did their best to personalize care for support people as just as they did with their laboring patients.

> …you will provide them with support too as needed. Typically they're being the strong person, so they might not necessarily need as much from you, on occasions they do, like they have questions…you get support people, the nervous partners who want to know everything that's going to happen. The only thing that I think that might be different in terms of the care provided to them, is if they're feeling a sense of like animosity and anger about the situation. So just kind of seeing what language they're using and how they're interacting with other staff members and yourself and just kind of tailoring how you communicate with them based on how they're acting. (H02-1 line 393)

Considering the influence of culture, spirituality, and religion. Culture was frequently cited as a means by which to gauge the beliefs and values of the individuals they cared for.

> Culture is very important as well. Finding out what culture they're from, any sort of specifics that they would like to do or not do in the delivery. (S05-1 line 144)

Expert nurses understood culture, spirituality, and religion to be in relationship with one another, together informing the lens and perspective of their patient and the family they belonged to. They saw these factors as opportunities to learn about and connect with their patients.

> Because everybody's different, right? You know, people who are very religious may have a different way of approaching things and if the family supports or other nurses that they too are very religious then there might be a connection there, right?... And of course, now

> with so many different cultures too, we get so many different religions, right? (S06-1 line 701)

Nurses recognized that some similarities exist within or across cultures and approached learning about cultural practices with a spirit of inquiry. However, they were attuned to differences in how each individual person might be influenced by their culture and find support in cultural practices in situations of perinatal loss.

> I think you got to look at – you have to look at the family, and not just stereotype the family, but different cultures look at death in different processes, right? So we – I had an Inuit lady that had a loss, and it was probably the best day of my career. We sat in her room, we laughed, we joked. We never really got that vibe that this was a horrible, terrible, life-changing moment that some other people would. She just had accepted this is – I come from a harsh climate, we know people don't survive, like this is a way of life. This baby wasn't meant to live, the next one will, you know? It's a different culture. Where lots of aboriginal people will look at the whole process, the cycle of life, and want to talk to, you know, spiritual care, or different environments. And they bring in lots of family with them, and it's a family moment, and it's okay for the kids to be there to see that process. And then other cultures don't want the kids there. Like so every time it's a little different. Not every culture is the – not every group of people from the same culture is the same, but that's kind of the, you know, the gist of it. Most of the time just kind of these are the things to kind of look out for. (H01-1 179)

Nurses also shared anecdotes about the nuanced differences across religions, and made efforts to connect with religious community leaders who could engage in religious ceremony in a way that

was centered on the particular person's beliefs while meeting their emotional and religious needs related to the death of their child.

> There's one priest…and he is the only priest that will do a conditional baptism…So Catholics believe that you cannot baptise a dead baby, you can only baptise a baby that is alive. So if a baby has passed, then we do a blessing. So if a baby is born alive, like, the nurses can baptise a baby, because you might have seconds where it takes its first one or two breaths, and then you baptise. He said, you never truly know when the soul has left the body. So he will do what's called a conditional baptism, and he will provide the families with a certificate of baptism, and I thought that is so wonderful…Because that's what that family needs. (S07-1 line 1012)

Nurses acknowledged the importance of asking families about the appropriateness of any of their care actions, and were aware that culture, spirituality, and religion were several among many factors influencing how their patient would perceive the care actives they engaged in, such as providing different types of mementoes,

> You know, some of our Middle Eastern people or African, probably maybe Muslim, but they don't do a lot of what we do... But I always - and again I encourage people to not just assume it's okay to cut off that lock of hair, like make sure you ask. Would you like a lock of your baby's hair for later, like for our term babies, they - some even will have some hair that you can cut from the nape of the neck and put it in the little box- so that's always kind of nice for some. (S07-1 line 26)

Or engaging in therapeutic touch.

> And culturally too, like not everybody – you can't hug everybody, or you can't touch everybody, right? So kind of just trying to get the feel of the people. (H01-1 line 151)

To help nurses on the unit be attuned to cultural, spiritual, and religious domains of knowing the people they care for, one site included information on cultural and religious practices in their perinatal loss resource binder.

> We've got some readings in the perinatal loss binder as well. And different cultures and religions deal with it in different ways, so we've actually started putting some cultural things into the binder as well. (S07-1 line 962)

Exploring and supporting the role and experience of the parent. Ultimately, knowing a patient as a person allowed nurses to ascertain the meaning their patient ascribed to their loss and how they perceived their role as a parent. This was another important consideration to frame decision making across the care experience. Expert nurses aimed to support the values and preferences of their patients in a way that aligned with patient's perception about their role as a parent. Some patients viewed themselves this way, and occasionally, others did not. For those who did, some patients clearly expressed their parenthood and when they did, expert nurses supported them fully.

> I remember saying to a mom whose baby had had anencephaly, but she was like just like holding the baby and loving the baby so much. And I remember saying to her like your baby is so lucky to have you for a mom, you know, because it's such a like a weird thing that they baby in a way isn't there but still the mom is loving the baby so much, and being a mom. (H03-1 line 862)

While descriptions provided by other nurses seemed to elude to the fact that certain parents needed some measure of permission to express their parenthood in the context of the hospital, and that their care providers could make or break this opportunity.

> You validate, you make them parents for the little bit of time. (S06-1 line 734)

The patient's perception of their role as a parent shaped, for instance, how an expert nurse would start a conversation about whether a family wished to see or interact with their infant after the birth. Validating the parent experience was seen as having a paramount impact on their care experience in the moment, and after discharge from the hospital. This was especially important as expert nurses understood perinatal loss to be an experience that is not openly accepted by society at large.

> So I'm always hoping that if I can validate their experience in the hospital and say to them, yes, you are a mom, and it may not be for the same length of time that I'm a mom, but for this period of time you are a mom. And it doesn't matter if your baby looked at you or didn't look at you, you were still a mom, you were still a dad. And this is your time. This is your time. So I'm always hoping that when they go home they realize that yeah. That's my goals, that they go home knowing that they were parents and that I was able to make the best of a bad situation for them. And so that they can enjoy their baby, and that they can feel that, at least for a little bit, it wasn't all for nothing. Right? That's all you can do for them. And you hope that when they go home that that they're going to know that they got the best care that they could get and that their feelings were validated. That's the hardest thing is just saying it's okay to be sad and it's okay to be angry and it's okay to hate people, right? And it's okay to look at people with babies and be jealous and be angry. And those feelings will probably always be there. And I have to have these conversations with some moms. Some people don't want to talk about it, but I do talk about when you go home, you are still - you're still a mom, you still had a baby, you can't ever erase that. So I hope that they take that home with them and that they can tell people, yeah, I have a child, I'm a mom, but my child died. Because I think it's sad that that is still hidden so much from society. Yeah, I had a daughter and I - she died, but I named her Julia, or whatever, right? And it just makes that baby real

> for them, and that's my goal is to make that short period of time of being a parent as real for them as possible, if that's what they want. (S06-1 line 745)

Involving and informing colleagues. Participants highlighted the importance of sharing any information they had gleaned to inform their knowledge of the person they were caring for with other healthcare providers involved in their care. This promoted their ability to see patient needs and preferences best attended to in an effort to provide the best care possible. This nurse, for instance, described how she makes every opportunity to share knowledge of the people in the room with her colleagues.

> I walk down the hall and enter the room with the physician every time as possible… like I make a point of going in there with them every time. And that walk down the hall is usually when you kind of say, okay, heads up. They are very weepy or - like whatever it happens to be so they're not - so they don't get blindsided" by the family's state or the tenor of the room. They haven't been with the patient. Help them to understand how to provide good care for this family. (H02-2 line 512)

Expert nurses facilitated, when possible, having other care providers meet the patient prior to delivery. When possible, they clearly outlined the specific hopes, preferences, and needs they had learned about their patient with the members of their team that would be involved during the different stages of the LDR process.

> Sometimes that initial meeting is when the baby is coming out that that's a different relationship, so if you can, again advocating for your patient and catching that person in the hallway, "My patient is this. This is her experience, just want you to come and hi." You can even have that little bit of a conversation again, like this is what we're hoping for the delivery. We're going to have the lights turned down low. Mom wants the baby right on

> the skin or we don't want to see the baby when it comes out, so we're just going to take the baby away for a second. You can get everybody on the same page about what's happening. That's just a way to facilitate a better birth for them. Less frantic, just so we don't decide a plan of what's going to happen and then somebody comes in and does something totally different. Right. And you don't get that moment back, you can't change it, this has happened. (H04-1 line 1005)

In instances when other care providers did not know the patient to the same degree as the expert nurse caring for them and were going to provide a care action that did not align with who they were as a person, expert nurses took it upon themselves to be sure the needs and preferences of their patient were known, even it made them uncomfortable.

> These are things we cannot control…if the doctor is abrupt or in appropriate in some way… there is one specific doctor who does this sort of thing where they come [into deliveries when infants are born still or expected to die shortly after birth] and turn the lights on and just act like it's every normal full delivery. But just saying, you know, speaking up even if it is scary to say, you know…we would like you to leave the lights down if that's okay. Or she's really comfortable in this position so we're hoping to deliver in this position. You've got to stick up for your patient. And that was - that's tough for me. Because I don't like confrontation. That's something you have to do if necessary. (H02-2 line 481)

Reallocating control and providing choices. There was an assumption across interviews that the experience of perinatal loss inherently involved a *loss* of control and power for the person experiencing the death of their infant, and for their community of support because they had no control over the fact that their infant had died or would die shortly after birth.

> **…**really just be cognisant of the fact that this isn't the situation anyone wants to be in.

(H02-1 line 58)

Adding to the sense of powerlessness inherent in perinatal loss was the unfamiliarity of the hospital environment to patients. Expert nurses recognized that while the hospital setting is comfortable for clinicians, it may not be for a woman in labor who is experiencing perinatal loss. Study participants were sensitive to help their patients feel more comfortable by providing them with choices and making known how they can be of service.

> …because they're coming into my environment, and it's not the environment they know. So just saying these are the things that we can help, or if there's anything else that you think of that you might need, big or small, we'll try to work with it, and, you know, get everything, just trying to make them feel like they're in control, and they're kind of responsible for their care. (H01-1 line 72)

The physical process of labor itself was an additional factor that could contribute to a sense of loss of control and this was something expert nurses understood even their patients expecting a healthy infant experienced.

> like the idea that like when you have some control over what you're doing, that is very different psychologically than when you're on the receiving end and I feel like labor and delivery is kind of like always on the receiving end. (H03-1 line 396)

Study participants alluded to the fact that making assumptions about what was best for their patients was an approach to care that could perpetuate the sense of loss of control and powerlessness in the face of perinatal loss,

> But then I just feel like that's her choice and like supporting people's choices is the most important thing that we can do because it's their experience. Like the idea that we would know best for those - for patients is just so bonkers, right? (H03-1 line 615)

and that any actions that did not promote providing choice could further intensify the experience of losing control by coming between what the patient thought was best for themselves and their infant.

> But I feel like, just these kinds of situations, I don't want to be the person who got in the way of what you thought was right for you. Also, I want to offer the thing that I think is helpful, which it's such a delicate balance. (H03-2 line 329)

In response to this multifaceted and inherent powerlessness and loss of control their patients experienced, expert nurses felt it was imperative to *give* their patients as much power and control over their care situation as possible. It was principally through providing choice whenever possible that expert nurses believed a sense of control could be supported for a patient experiencing perinatal loss. As such, choices were presented about fundamental care decisions. This approach to mitigating powerlessness also trickled down to nuances of care, and as a result, expert nurses offered choices at every opportunity throughout the entire process of PPC in the LDR setting. This nurse, for instance, provided an example of how she integrated those smaller opportunities for choice in the care she provided:

> …if the baby still has a heartbeat they'll usually want the baby, but most of the time people want the baby gone just for a minute and then you can bring them back, like you can put a little hat in them, you can wrap them up and just…Then they can choose what to experience out of that situation. They see their cute little face and you have a way to kind of control the situation that's not so blatant. (H04-1 line 830)

While this nurse was conscientious to frame the standard practice of garnering consent to use a palliative care visual indicator as an opportunity to provide a choice.

> but I explain to the parents that we put this card on the outside of the door, and I said, it's just for staff to be aware that we have a loss in this room, so that they can be respectful to you and

> your family. I said, it's not labelling you, it's just so we can be respectful. And I need their consent to put that on the door, and it gives them some control, you know, that they have some control on their situation still. (S07-1 line 377)

Another nurse was sensitive to how usual care activities for standard labor care, such as how analgesia was administered, could be leveraged to influence and promote the sense of control for women experiencing perinatal loss.

> Exactly, so it's hard to gauge when to get that epidural for those ladies, so if you have a PCA [patient controlled analgesia] going, unless pain starts to become uncomfortable, they can push their button and get themselves to that kind of gives them a sense of control. (H02-1 line 238)

Other examples included choices about which care activities would take place, where those care activities would be carried out, and in what capacity the parents themselves would like to be involved in infant care.

> And so talk about that and I tell them that there are specimens that we do have to send because we are trying to determine why your baby didn't survive. So we talk about the nasal swabs, and I said that's really the only invasive ones that we do. And we take some blood from the baby's cord and - but I tell them too, I said if we can't get the blood from the cord we do have to try to take it from the baby's heart. And I tell them that that is not done in the room. Like we will not do any of that - in fact we don't have to do anything in the room if you don't want to. Some of them do, and some of them don't. Even the swabs they don't want. And we talk about once that's done we can bath your baby and I said if you'd like to be a part of the bath we can do it in the room, and I tell them some - and I know that a lot of times they're thinking, and I've had moms say, well what do other moms do? Right? So rather than leave that I tell them we have moms

> that want to participate in the bath. They want - in fact if it's not - if their first baby they often want to bath the baby themselves, but some of them don't want - they're afraid to touch the baby or to bath in case something happens to the baby so they choose to watch. Or they don't want the baby in at all. I always offer a choice so that they're part of the process because the choices become important to the moms, right? (S06-1 line 377)

Nurses reflected on how it was difficult to provide choices to laboring women and their families when they were new to providing PPC, and it was through experience that they began to not only appreciate the importance of choice in these circumstances but also of what sort of choices they could provide. This ability was an undeniably a distinguishing feature of expert practice.

> it gives people control in an uncontrollable situation, but it's definitely… I think of being a new nurse and I think of these conversations and exactly like I was saying before, I feel like, how do you know what to say? What do you say? What's the script? What am I supposed to say to people? (H04-1 line 1344)

Expert nurses demonstrated awareness about the bounds of their own comfort zone regarding the types of choices about care they would provide for their patient, but never let their own comfort get in the way of providing parents with opportunity to make choices of any sort.

> If baby comes out and its breathing, what do we want? Do you want to hold baby? Do you want me to hold baby? Do you want baby in the bassinet? Because it's their choice and I don't want to take that away from them with what I feel comfortable doing… (H04-1 line 1329)

Another challenge expert nurses faced when promoting choice for their patients arose when parents made choices that do not resonate with their own beliefs and preferences based on personal

perspectives and clinical encounters. Expert nurses were able to reconcile this to some degree, but found these circumstances challenging nonetheless.

> And I'll admit, I struggle with the parents that don't want any - because I just don't understand it. Like I understand it but I don't understand it. Because thinking from my perspective if it was me, like when a parent - they decline autopsies, and that's fine, that's their choice. But I guess when they're laying there afterwards and they're like, oh, what happened, I don't know why this happened and they're sad, I don't know why this happened. And I always think, well if you agree to the investigations then maybe we'll know. And for me that's closure. But even if you do everything possible, the swab, the bloodwork and the autopsy and they don't come up with an answer, at least you can say, well I don't know why my baby died, but at least I tried to find out. So my struggle is with the parents who don't want anything, or they don't want the keepsake package, which I understand too because they don't want that memory, and I kind of wish that palliative care - or not palliative care, spiritual care would still - we could still make packages and hold them and I was really upset if they say no, it's no. And I said, well parents often aren't in the right frame of mind to say no. And that we used to have parents who would - they'd say no, I don't want it, don't want to take it home. We'd make one anyway, and they would either change their mind before they left, you know what? I think I will take that package. Or they would come back, sometimes four or five months later for their packages. And now we're told, no, if they say no, they say no. So that's one of the things I struggle with too, right? (S06-1 line 776)

Even in the face of such challenges, expert nurses persevered to promote choices and reallocate power, for without such attention to this element of care feelings such as fear would intensify and prevail.

> Just reiterating that this is their experience and everything that I do is for them and if they want to change anything at all we can. I always make it very focused on them so that they know they're in control, because I feel like in this situation most people can feel out of control and that is a very scary feeling. (S05-1 line 155)

There were factors, beyond the influence of expert nurses, that limited the ability of expert nurses to provide choices to their patients who were experiencing perinatal loss, and some of these included issues that arose related to patient flow, bed utilization, and infection control.

> And I think - and - what bothers me the most is there's this mentality that they're in the hospital so we have to do something right away. And now she's taking up a labour bed, and now I'm feeling more pressured for them to make a decision sooner. And I don't like that feeling because they shouldn't have that pressure at all. If she wants to go home for a week, that's her choice. Mind you they're going to be discouraged from that because we don't want infection, right? (S06-1 line 229)

Recognizing the role of one's own emotions. The role of emotion was acknowledged as important in the provision of expert PPC. It was undeniable that participants experienced their own range of emotions when providing PPC. The choice of whether to demonstrate those emotions with their patients was important to consider while enacting expertise and was addressed by many of the participants. In most instances described by study participants, the demonstration of emotion furthered their ability to connect with patients.

> I do allow myself to cry with the patient, like I cried in the delivery yesterday. I feel like patients usually respond well to that and when they see their nurse crying with them, they feel supported in a way and they feel like they're being cared for. If you're about to show emotion with them, it's kind of like you're in it together. (S05-1 line 877)

While some expert nurses described that in some circumstances expressing their emotions fully detracted from their ability to provide expert care.

> …it was sad. It was hard and probably it's the only time I've ever cried for an IUFD [intra-uterine fetal demise], because personally for myself I can't do my job if I am letting myself be that emotional. I'm not saying that I'm hard or cold, but I have to turn that off in order to support the mom, support the dad and whatever other family people are there and support the baby. And I can't do it if I'm weeping along with the parents, which they actually appreciate when they see a nurse cry because they know we have feelings. But I can't do that. (S06-1 line 291)

The choice to express or repress emotion was dictated by the needs of the particular laboring woman and her family. Nurses were aware of and in control of their emotions. If the nurse determined that emotion would elevate the care they provided, they would allow their emotions to be seen.

> I mean, it could mean anything from ... I mean, that last delivery I balled my eyes out. Like, I think when you show emotion, whether it just be, you know, your eyes watering or full on crying with a patient. It shows them that you care and I think that when they see that you care makes them ... I mean, how is that not going to make them feel better? It's going to give them a little bit of comfort, you know? So I do think it's very, very important to show emotion when you're in rooms like that. (S05-2 line 494)

While the actions and considerations described above transcend across all stages of LDR, expert nurses also discussed a host of actions and considerations that were specific to each of the stages of labor. These will be described in detail in the following section.

Considerations and actions during each of the stages of labor. To follow is a description of the actions and considerations expert nurses engaged in during: (a) the admission process; (b) the first stage of labor; (c) the second stage of labor; and (d) the third and fourth stages of labor.

Enacting expert nursing: actions and considerations during admission. Patients experiencing perinatal loss can be admitted to the LDR unit during any stage of their labour. For those who are admitted in the earlier stages, or even before labor begins when an induction is indicated, expert nurses will be able to accomplish more of these actions upon their patient's arrival to LDR unit. For those who are admitted in active labor, a nurse will need to swiftly consider which actions are priorities, and whether they are feasible to undertake given the progress of the labor.

Table 9
Actions and Considerations for Enacting Expert PPC during Admission

Topics for consideration	Actions
Initial interactions	o Make nursing role known o Provide timeframe you are on shift to provide care o Describe how you will be able and available to care for the patient o Share condolences as appropriate o Invite questions openly o Assess patient understanding of situation o Determine which decisions regarding pre and post birth care have been made o Share information about anticipated infant condition o Provide options for pharmacological and non-pharmacological pain management o Emphasize that any decisions made can be re-evaluated, altered, or retracted o Take inventory of patient plans for visitors and support people
Paperwork	o Bring awareness to the necessity of paperwork o Provide timeframe in which completion is expected o Be transparent about necessary tasks and documentation particular to perinatal loss
Investigation and autopsy	o Investigation and autopsy might be a sensitive topic for some patients/ families o Take a straightforward, honest, and thoughtful approach to broaching these topics o Temper any expectations of definitive results o Describe tests and procedures in plain language o Provide choices where possible o Initiate checklist to organize work if available within organization
Consults	o Consult services for involvement as clinically indicated at earliest convenience (e.g. allied health such as social work and spiritual care or specialist services such as genetics, neonatology, or palliative care) o Review prenatal health records to see what services were involved in care, and follow up for their continued involvement

Shaping the physical environment	Prior to admitting patient to labor room: o Remove equipment intended for live infants as applicable o Remove signage promoting activities parents anticipating perinatal loss will not be able to experience with their infant o Prepare seating for support people if expected to be present o Admit to most private and quiet space available During admission: o Keep a calm environment o Avoid bright lights when possible
Managing people in the environment	o Communicate with patient and offer self as gatekeeper to manage which support people they want present and when they want them there o Take a flexible approach to visitor restrictions, allow additional people in accordance with patient preference o Use visual indicators when possible to notify healthcare staff of perinatal loss before entering room o Safety permitting, minimize number of healthcare staff and make preference for compassionate staff members to contribute to care

Initial interactions. At the time of admission to the LDR unit, regardless of the stage of labor a patient was in, expert nurses were always sure to make themselves known to their patient. They shared information about their role, about the duration they would be providing care, described what they could do to help in the situation, and shared their condolences.

> For somebody with a loss, it might just be… "I'm so sorry you're having to go through this. I'm with you here for 12 hours, we're going to get through this together. Any questions you have? All that kind of stuff. It's so much reassurance, but also allowing space for questions from them, for them to share, and kind of seeing what they're comfortable with. (H04-1 line 308)

In addition to these things, expert nurses did their best to invite questions with a great deal of openness.

> Basically, for me, like I start off saying, telling them I'm very sorry for their situation, and I'm here to help them, so anything they need, there's no wrong question, there's no don't feel bad about asking anything, or just making them feel comfortable as much as I can in that situation, I think, kind of is the more important thing. Kind of explaining my role, and what I'm there for, and then letting them ask questions. (H01-1 line 61)

Nurses assessed what their patient understood to be happening, and determined whether they had made decisions about their care. This information provided the basis for their considerations moving forward. Once they established an understanding about what the patient was anticipating, with time before delivery permitting, they shared additional information such as what condition they might expect the infant to be born in, and provided choices around post birth care. Study participants integrated gestures that demonstrated compassion throughout the admission process to set the tone.

> Ask them about the process, like when they found out and like how are they feeling and maybe about supports that they have and, you know, like sort of basic things, getting them to let us know if they need anything… Do they need Kleenex, like those kind of small things. Also like talking about the process, just like this is what's going to happen and this is what you can anticipate and when they baby is born what do you want that to look like? You can do this, do you want to spend time with the baby, do you want to see the baby right away, do you want us to bath the baby, like sort of talking about these details when the time is right so the less like surprises there are and the more things that they can maybe have anticipated before.... So, I mean if the baby has been gone for a while, I might talk to them about how the skin will look, like if the skin might be like peeling. Yeah, I guess it really depends on the situation, like you might see blood, the head might not feel as firm as you would think it would feel. Yeah and that piece about after the baby is born, do you want to see the baby right away or do you want us to give the baby a bath? Who do you want to be in the room with you, what else? (H03-1 like 269)

This nurse described some of the other points for discussion she approached early in her interactions with her patients such as the topic of pharmacological and non-pharmacological pain management during labor. By doing so, she put decision making power in the hands of her patients at her earliest convenience. She also used this opportunity to highlight that any decisions made could be retracted, revaluated, or altered at any point during the process of LDR. In addition to this, this nurse described how she provided reassurance to her patients about her availability and willingness to provide care during their hospital stay, and took inventory of the patient plans for visitors or support people.

> I tell them who I am, and this is where you are, and, you know, we're here to help you, and you're - you have a lot of good support here, and those kinds of things. The plan is either you're going to labour, if they're naturally labouring on their own. I don't know if you've talked about something for pain control, if that was in your plan at all. I always tell people I'm not a big pusher of drugs and kinds of things, but there's lots of interventions, lots of things we can do, the shower, the birthing ball, those kinds of things. Anything that you want, you ask me. If there's something you want for pain, you let me know. So there's always a time, unless we're physically pushing out a baby, there's always a time for something. So you can change your mind, because you never did this before. So if now you say, I don't want anything, and two hours from now you say, I want every drug you have in your cabinet, that's okay, we don't judge. At the end of the day we just want to help you through the process. So that's something I tell everybody. And then kind of once that's all out of the way, then I just usually tell them, you know, anything you need, you let me know. You can have as – I usually kind of ask who's in the room if they're expecting more people, depends on where we are, how big the room is. But we can really allow as many people, or as little people as you want. (H01-1 line 256)

Paperwork. Nurses took the opportunity during the admission process to bring awareness to the necessity of particular paperwork that would need completing, and provided a timeframe for their patients in which completion was expected. It was through such actions that nurses did their best to make transparent their obligations in terms of necessary tasks and documentation that is particular to perinatal loss.

> and then I always tell them there's a few paperwork, and technicalities we have to do, so at some point we have to talk about these things, but not right now, kind of just before you go

> home, we have to get all the paperwork done, or by the end of my shift, kind of, whichever comes first, right? Because if we have a delivery, we don't want to leave all of that paperwork, and all of that information we know to the next nurse, so that they have to ask it again, or whatever. So we try to tie up things kind of at the end of our shift. With a healthy baby, they get a birth registration form, and then before they're discharged, they have to fill that out. It names the baby, and basically tells the government that this baby was born in the province. And then we send that off to vital statistics. When they have a stillbirth, or a neonatal death, we have a package of paperwork that we get from admitting. And so sometimes we know ahead of time if it's going to be one or the other, we can request that package, and then kind of start filling it out as we go. In there, there's different things, like a request for autopsy, that as a nurse we need to talk to them about. (H01-1 line 297)

Investigation and autopsy. With these necessary tasks and documentation under way, nurses took a straightforward, honest, and thoughtful approach to broaching particular topics with their patients that may be sensitive for some such as investigations into the cause of the infant's death.

> It's hard. It's hard to do that, but kind of dependent on the situation, again. Sometimes they know, sometimes I just say to them, I need to ask you these questions. So, there's an autopsy available, if you want to know more information, and then they go, no, no, no, I don't want them to cut up my baby, whatever, right? And then I say, no, I said there's other options. They can look at the baby, they can draw blood, or they can do a full autopsy. I said, you have total control. If you don't want anything, you don't have to do anything, right? So kind of putting that ball in their court to make that choice. So I kind of tell them there's all these investigations we can do. So we can do as little or as much as you want,

> but this is kind of, you know, where we're at. But there's no guarantees to the outcomes of the information, right? (H01-1 line 318)

Study participants tempered expectations of definitive results from autopsy and other investigations into the cause of death at the outset. They described in plain language what tests and procedures would be required for investigation into the cause of death and how various samples would be taken. Expert nurses kept patient choice at the centre of any plans regarding investigations.

> …then I'll discuss with the mum, okay, we want to try to find out what's caused this. And sometimes we don't always find a reason why, sometimes there's no reason. But we try to look for answers, and one of the ways we look is by taking some of your bloodwork to see if we can find any anomalies. So then I explain that I need to do a lot of bloodwork. And they know – or I let them know – that they have the right to decline anything. And so then we take it from there, and then I do all the bloodwork and we send it off. Most people want to know why.…and they don't always find out, sometimes they never find out.…but I think that they feel good knowing that at least we're trying, that we'd like to find answers for them. I've never had anybody decline the bloodwork, never. Yeah. Then I usually explain to them that once the baby is born, there's going to be other tests and stuff that we need to do, and again, they have the right to decline, but this is what we do and why we're doing it. The only one they're not usually too keen on, is the cardiac blood for the baby, but I do let them know that we try to get it from the cord first. I don't think they like the idea of a needle going through the baby's chest, you know, to the heart.…But more often than not, we don't get that sample anyways. The baby's been gone for a couple of days, we're not going to get it. And they're usually okay with the swabs and the samples But I let them

> know that ahead of time, before the baby's born, if we're going to do those things. (S07-1 line 441)

Given the volume of tests, swabs, and samples, a checklist was derived and was intended to improve communication between providers and to streamline the workflow between shifts to facilitate the necessary and thorough completion of tasks particular to perinatal loss. This checklist was initiated during the admission process.

> Then I have developed a checklist for the nurses, as they do things, I sign it off, so when we do transfer to, say, the next shift coming on, they know what's been done and what's not been done. There's about eight tubes of blood that we need to draw from the mother prior to delivery, and I mean, I show the paperwork to the nurse, I show her my way of making sure I don't get the tubes and the blood mixed up. You've got eight tubes to draw. (S07-1 line 429)

This checklist was a part of a broader resource binder. Both sites had some version of a resource binder for perinatal loss and most study participants described it being as instrumental in keeping them organized pre-delivery and post-delivery. This resource binder facilitated the ability of expert nurses to thoroughly complete their tasks and documentation.

> Well, there's the perinatal loss binder. It has everything that you could probably need in the situation from instructions to examples of the reqs you need to fill. If I'm not mistaken, I think they even have the tubes in there, so that you…know what tubes… yes. We have premade buckets on our unit as well, you just take one bucket. It has the pre-blood work already filled out, or the reqs filled out with all the tubes stapled together. It's separated for post-delivery and pre-delivery, which is nice. Then the list of instructions, it's about two or three pages long and it's right from the get-go, what you do pre-delivery, what you need

> to draw, and then post-delivery, like who you need to call, what needs to be done, what needs to get signed. It's all detailed in… it's very easy to follow. (S05-1 line 698)

Consults. Expert nurses coordinated services for their patients throughout the duration of the LDR process,

> Lots of times we're like the liaison between social workers, spiritual care, or neonatology, if it's a palliative baby, or a palliative care team for the baby, or kind of the liaison between all of those people. (H01-1 line 382)

and whenever feasible, consulted services for involvement or follow up at their earliest convenience to ensure all parties who needed to be involved in care were able to engage as necessary. These consults may be for allied health,

> Once we have all that out of the way…I talk to the family about the consults, which is usually – like, the one for spiritual care.…And…sometimes either social work or aboriginal services, so we'll put those in. (S07-1 line 472)

Or for specialist services such as neonatology, depending on the gestational age, diagnosis, and condition of the infant at the time of admission.

> …are we planning to do any kind of resuscitation? Is it an anomaly that we're thinking maybe there's a surgery for and we're going to have full resus on this baby? That stuff, that is usually known before. They've usually made that decision, but I still talk about it with people because things change. If it's viable to do resuscitation, especially if the baby is close to the borderline of a viable infant, maybe they're just in really, really pre-term labour and they're 23 weeks, like go for that [consult] now, so they know their options. You might not be the person to give them all their options, but you can start that conversation and if

> they want to know more, maybe you're getting Neonatology involved, I mean in that situation you would be. (H04-1 line 785)

Participants from one site discussed a process that had been in place in the past which included bringing together health records for pregnant women who had received a diagnosis of a life limiting condition for their fetus during pregnancy and having those records available on the unit prior to admission. This had allowed nurses to be aware of these patients who were anticipating perinatal loss and to be prepared for their care by being up to date with their plan of care prior to their admission. However, due to restructuring of their program, this process had fallen by the wayside but had been considered to be quite valuable in promoting their ability to provide the best care possible by facilitating their ability to be up to date with the plan of care.

> …their fetal assessment, a copy of the prenatal sheets, and whatever consults they'd had, and it would all be attached together in a package. And we had an envelope that we kept in one of those drawers for future admissions, and would say, you know, like this baby has fatal anomalies, it may be born alive, and if it is they've had a consult to paediatric palliative care and so the plan is that they will stay here with the baby, and so the information is here, try to read it in the next couple of weeks in case she comes in. And since the amalgamation almost a year ago we never get any of that anymore. So I kind of - I miss that because it gives everybody a heads-up and - because nobody likes the surprise and it's like, you know, when these women come out, I mean if we have that information we're – it gives a different way to talk with them- like you've got that information so you're not probing. You can go in there and sit there and talk and I understand that this is the plan. I've - you know, I've read the consult - and I would say to them I read the consult from Dr. whoever, and so I just want

> to check with you that we are still following this plan, right? That's why that information is nice to have before they came in. (S06-1 line 49)

Shaping the physical environment. Expert nurses recognized that the labor and delivery environment was set up, by default, for a population of patients anticipating live infants in a variety of conditions. Nurses saw opportunities to shape the environment in a way that catered to the unique needs and perspectives of patients and families experiencing perinatal loss. Although they did not expect their efforts to ease the pain of loss itself, they did presume shaping the environment to lessen the presence of items that might be unduly emotionally triggering. This meant removing equipment intended for live infants and signage promoting activities these parents would not be able to experience with their infants. This also meant adding things like additional seating if extra support people were expected. Nurses often did this pro-actively before they received their patient on the unit.

> …there are definitely things in that perspective that I think of too and how the room is set up as well before I even get the patient in, can even think of that. If the baby is already passed, there's no indication for monitoring fetal heart rate or anything, right? I take the monitor right out of the room, like take that out of the room. Sometimes even, we have in some rooms, signs on the wall like, "Breastfeeding is best" with a picture of a mom breastfeeding her baby. Take that down if you can. Just try to… not that you want, again, you're not trying to hide the experience and make it not like it's happening, but there's things that you can do… maybe add some more chairs for people to sit and all that kind of stuff, different places to move around. But yes, if it's a loss I would take the fetal monitoring machine and the [baby warmer] right out of the room just because we don't

> need them and it's just that subtle reminder. In that way, we can change the environment and adapt to what they need to make it a little bit more comfortable. (H04-1 line 479)

In addition to these considerations, expert nurses were attuned to the fact that sounds and sights of other women in labor and live born infants could prove to be distressing. With this in mind, study participants were sensitive to minimize these sights, sounds and interactions whenever feasible.

> …but you can also advocate for maybe having your patient over there, away from all that sound, like away from all that other stuff so that it's more private and it's more… Like you're not hearing babies crying and all that excited happy everything, you know… (H04-1 line 445)

Managing people in the environment. Expert nurses also described their approaches to managing the people in the environment helped to shape it in favour of the needs and preferences of the laboring patient. Expert nurses supported the woman in labor by acting as a gatekeeper for who could be present during labor, delivery, or afterwards. Expert nurses did this on behalf of their patient to lessen any social burden that the woman in labor may be feeling that conflicted with her actual needs and preferences in any given moment.

> And then I say, if there's a time that you don't want any of the people in here, you just look at me, and tell me, and I have no problem kicking everybody out. Because it's not my friends or family, and you're the key person here. So if you want everybody out, then everybody's going out. So kind of to give them that control, because lots of people have a hard time telling their mother, or their mother-in-law, or whatever. And then I don't make it personal, I just say, you know what guys, we can't have this many people, you need to leave now, blah, blah, blah, and then the onus isn't on them to make them [visitors/support people] feel bad. (H01-1 line 287)

Study participants were not overly pedantic in abiding by visitor restrictions and exhibited a degree of comfort with flexing the usual hospital rules around the number of visitors typically permitted during LDR.

> Yeah. So then I - yeah, I tell them if they like to have more people, that's totally okay, as long as we can kind of function in the room, they can have many as – as many people as you want. (H01-1 line 285)

In some cases it was through the absolute disregard of visitor restrictions that expert nurses believed their patients would be best cared for.

> …so with these families, there are no rules. There are no restrictions. They can have as many people in there as they want because they know how they're going to feel the most supported. (S05-1 line 528)

If the woman in labor preferred additional people of her choosing to be present during any point of the LDR experience expert nurses advocated for what they believed to be best for their patient, even in the face of disagreement with their colleagues.

> I remember being in a situation where…a woman had tons of her family in the room. And this nurse…she's like what are you doing in there? Like why are you letting so many family members in there? And I was like - like I was really taken aback. I don't really get it either, like I wouldn't want my cousins to be in a room with me while I'm delivering a baby but she does. So like who am I to get in the way of that? (H03-1 line 620)

When larger, and more private rooms were available, nurses made efforts to admit their patients to those spaces to promote privacy, and to accommodate larger numbers of visitors.

> It depends where they are. We like to keep them on the old side where there's private rooms, the bigger rooms and then that way they can have whoever they want in there. We're a lot

> more lenient I think with that rule, generally it's as long as you can stay out of the way of the doctors and the nurses and the job that they're doing, we're okay with whomever. (H02-1 line 341)

Overall, study participants attempted to keep LDR environment as calm as possible. Things that contributed to this were keeping lights low, using visual indicators outside of the room to ensure those entering are aware of the circumstance and responding appropriately without the sense of urgency sometimes required with live deliveries.

> So I would say like if it's - like the idea of like keeping a calm environment is important even if it is - if the baby's delivered. I would say that like the lights being low or at least not all on, like I'm not saying dimness but I think low lights is good. And, you know, like if the woman has her baby - usually people will know what's happening in our rooms. Like they know there's like a stillborn baby. Like yeah just the idea of like keeping a calm environment I think because like the focus is on the patient who's like experiencing this and we're just doing all of the things around. (H03-1 line 537)

Other study participants described going to lengths, safety permitting, to avoid particular healthcare providers from entering the environment if they perceived them to have a lack of compassion toward individuals experiencing the death of their infant and would be disruptive to the tone of the environment.

> Yeah, and if there's a doctor on I don't like I'm not going to call him [for the delivery]. So there. Fire me. You know. I often feel like that right...and for some of them, I think sometimes they're glad that they don't have to go to it. And they don't have that compassion. There's one that doesn't have a lot of compassion. I've never seen compassion come out of her mouth. And then there's one with fake compassion, which makes me just as angry be I

> can here in her voice that's not sincere… Like I read all my doctors very well and I know which doctors are really good with IUFDs [intrauterine fetal demises] and I know which ones aren't. (S06-1 line 1254)

Enacting expert nursing: Actions and considerations during first stage. To follow is a description of the actions and consideration nurses engage in when enacting expert care from the onset of regular uterine contractions until the cervix is dilated adequately for delivery of the infant. This is an important differentiation from the definition offered previously for the vaginal delivery of a full-term labor of a healthy infant when typically, the end of the first stage would be demarcated when the cervix to be fully dilated. Also of note, is that some of the actions and considerations in this section reflect the care expert nurses undertake when a medical induction of labor is indicated. These actions and considerations may then, in some circumstances, precede the onset of active labor.

Table 10
Actions and Considerations for Enacting Expert PPC during First Stage

Topics for consideration	Considerations	Actions

Solidifying the birth plan	○ Given the variance with which perinatal loss can present itself in LDR, a patient may or may not have a birth plan, or have made decisions around pre and post birth care
	○ Infants can be born in a variety of conditions depending on their gestational age, if and when the infant had died in utero, and whether physical anomalies were expected
	○ Physical appearance of the infant can be distressing to the parent(s) depending on infant condition, especially if they did not receive information about what to anticipate
	○ The parent(s) may base their decisions about post-birth care on the condition the infant is expected to be in
		○ Determine what decisions the patient has made
		○ Provide specific options for remaining decisions to be made, for instance:
		  ○ See, touch, or hold infant or not
		  ○ Skin-to-skin immediately
		  ○ Clean and bundle infant first
		○ Provide examples of what other patients who experienced perinatal loss had done to help frame decision making
		○ Invite questions and concerns
		○ Describe, in plain language, what the infant is expected to look like at the time of birth
		  ○ Anticipated size
		  ○ Overall colour (e.g. red skin, dark lips)
		  ○ Skin integrity (e.g. friable, possibility of skin tears)
		  ○ Discharge from eyes, ears, nose
		  ○ Soft or crinkly skull
		  ○ Details relating to known anomalies

Recognizing and responding to the experience of total pain	○ Pain during labor is multidimensional ○ Emotional, psychological, and spiritual pain related to the death of a child may catalyze and magnify the physical pain of labor and vice versa ○ There is variation in how patients experience pain ○ There is variation in how patients elect to treat their pain ○ Some pain experiences cannot be treated with medical intervention ○ Some patients elect not to treat physical pain and want to fully experience the sensations of labor	○ Acknowledge the gravity of the loss ○ Provide emotional support ○ Arrange to have orders for pharmacologic pain management available early in the process of labor for those who choose ○ Reassure the laboring patient that physical pain will be treated by whichever means they choose ○ Reframe thinking around timing of administration of narcotic analgesia, it can be utilized near delivery without risk of harm to a deceased infant

	○ Opioids cross the placenta and enter the fetal nervous system resulting in respiratory depression and sedation in live born infants ○ These symptoms are not of concern for the neonate when they are expected to be born still and additional options can be considered for maternal pain management	
Fetal heart rate monitoring	○ Fetal heart rate monitoring is not indicated when an intrauterine fetal death has occurred ○ Approaches to fetal heart rate monitoring vary when the likelihood of an infant surviving labor is unknown ○ Some patients may elect to listen for the fetal heart rate intermittently, it may be important for them to know whether their infant will survive labor ○ Monitoring the fetal heart rate can be a source of distress for some patients anticipating the death of their child ○ The presence or absence of fetal heart rate monitoring and documentation impacts workflow	○ Do not attempt to monitor the fetal heart rate when an intrauterine fetal death has been confirmed **When fetal heart rate monitoring is indicated:** ○ Acknowledge when findings are favorable ○ Do not provide false reassurance about the viability or prognosis of the infant **When fetal heart rate monitoring is not indicated:** ○ Listen intermittently only at the explicit request of parents ○ Make clear that the findings of the fetal heart rate assessment will not dictate altering the plan of care
Vaginal examination	○ When labor is medically induced or augmented, vaginal examinations are required at regular intervals ○ Maternal health is the focus of the purpose of vaginal examinations	○ Do not conduct in response to concerns about infant health ○ Conduct only when necessary to promote maternal health ○ Thoughtfully explain why a vaginal examination is indicated ○ Provide notice ahead of time that a vaginal examination will be conducted

Solidifying the birth plan. If a plan had not been solidified about infant care at the time of admission, nurses worked with their patients to provide specific options about what could be done in terms of their care and the care of their infant. Study participants described proving examples for their patients of what other women had done after their infant was born in similar circumstances to frame options and assist with decision making. Expert nurses considered what condition they expected the infant to be in especially in terms of the integrity of the skin and any physical anomalies that may be present. They shared information with parents about what their infant might look like at the time of birth, and this helped them to inform their decisions about care immediately after birth such as to place the infant skin-to-skin immediately, or to clean and wrap the infant first.

> What do you want us to do with baby once baby is born? Do you want to see baby right away? Do you want baby on your skin? It's okay to still do skin-to-skin if you want. It's whatever you need to "get through" and to normalize that experience. You obviously don't want to do that to people that are not interested at all and that's why it's good to have that conversation. I will give people different situations because we can really normalize it and we have the ability to talk about it. It's really… this is what other moms have done, this, this, and this. Here are your options that are available to you. Do you want the baby right on your chest? Are we doing cord clamping in any way if there is a heartbeat? Do you want to see baby right away? If there is lots of anomalies sometimes that's really hard and sometimes it's taking baby away for a couple minutes after the delivery and just kind of making baby a little bit more presentable for their experience, all depending on what it is. Because sometimes stillborn babies come out really cute and they're 40 weeks and it just

> looks like a baby, but sometimes they're quite macerated and that's a whole other thing as well. People do not expect that. (H04-1 line 806)

Based on their previous experiences, expert nurses were aware of a host of physical features to expect when an infant had died in utero and they reassured parents that they had experience with same. Expert nurses really invited patients to share any questions or concerns that they have and they drew of their knowledge from previous instances of providing PPC to help their patients make decisions regarding care immediately after birth.

> …do you have questions? Like is there questions about maybe how the baby will look when it comes out, or, you know, what you want to see, or don't want to see, or that. Can I answer questions? I've done this a few times, and let me see if I can kind of help you make a decision, right? (H01-1 line 592)

They themselves recalled wishing they had been briefed about what an infant might feel like and look like at the time of birth, and this sensitized them to the need to share this information with their novice colleagues and also with the patients themselves.

> …sometimes when you pick up babies and they've got that crinkly skull they've been gone for so long it just feels like broken papier mache and again, knowing that goes such a long way. And the very first time I ever felt that I was like, I wish somebody had told me sometimes skulls feel like this. (S06-1 line 1113)

This nurse recalled being particularly alarmed when, an infant born with very fragile skin had a forceps delivery that caused quite severe skin tears.

> and so the delivery itself can cause... you know, you can get tears and rips in places you wouldn't normally expect, like the underarms, the neck, if they're more of a difficult

> extraction. I have seen that, and that was very shocking; mostly the delivery itself, because it's just not a pretty thing to watch. (S05-1 line 753)

Some of the features expert nurses made a point to describe in addition to friable skin, a softer skull, the overall size and colour of the infant, and any details relating to a prior known anomalies, nurses were sure to counsel their patients around anticipating discharge from the nose, mouth, and ears.

> I do talk to them about the desquamation and the peeling of the skin, yeah. And you want to try to keep the skin as intact as you can, so try not to rub or wipe it off, because it'll just make it break. And that baby often oozes sanguineous discharge from any orifice, like… if you lay the baby on the side, you might have bleeding of the nose, through the nose. So they just have to be very careful [in how they] handle [the baby]…I do, I let them know ahead of time that this might – and it's not to be afraid of, to just be prepared for it. (S07-1 line 540)

Expert nurses acknowledged that these features could be distressing to parents, especially if they had not been prepared for them. When parents had been briefed about what to anticipate, they could take the situation in stride and be gentle and caring to their infants in response to these features.

> So you need to [talk to them]- because when you walk out of that room to give them privacy with their baby and then you get a call bell put on and the mom's crying because now there's stuff oozing out of the baby's nose, often once they know that for some of them it's normal, they'll take a Kleenex and they'll dab it themselves. (S06-1 line 416)

This nurse provided detail about how she communicated information with parents prior to delivery about how they might anticipate their infant to look. She spoke with plain language and was straightforward with what she described in order to adequately prepare parents for the experience.

> I don't know, just explain to them that the baby's been passed so you can break it down a little bit and sometimes babies look a little bit different….I just explain pretty, like basic, like their skin could be peelie and if it's peeled off a little bit, you know, your baby might look a little bit red and sometimes I'll explain sometimes the lips are quite dark in colour. The head is very soft so you have to be very careful with it. You know, stuff like that. Yeah, I don't really sugar-coat that very much. I don't think you really can…Just that they're going to be very small and they're probably going to look very red. The skin will be very thin and friable. I may not use the word friable but - Just thin and can easily break. And, I mean, there are anomalies sometimes as well. Usually the parents are aware of what that could look like, but it doesn't hurt to, you know, kind of enquire about what they think. What they think the baby might come out looking like, yeah. Or, like ask them what they've been told by their obstetrician. I think the most important things would be the skin and the colour. Those are the more shocking things. (S05-2 line 811)

Recognizing and responding to the experience of total pain. Total pain is a concept first described by Dame Cicely Saunders in 1964 (Clark, 1999), highlighting the multidimensional nature of the pain experience by recognizing physical, emotional, spiritual, cultural, and spiritual layers to the experience of pain. Nurses in this study were profoundly attuned to the notion that pain during labor was multidimensional, and this was especially true during labors where death was concerned. They described how the emotional, psychological, and spiritual pain resulting from the death of a child had a catalyzing and magnifying impact on the physical pain of labor and vice versa.

> No matter how much people have processed or expected what is going to happen to them, when you bring the physical pain of labor into it, it changes everything I find. People can

be like, “Okay, my baby… I’ve been waiting on the induction list. My baby has been gone for week.” They’re coming at you from a fairly stable way, or seemingly. They’ve had some time to process what’s happening and all that kind of stuff. But when you add pain to it, it changes everything. It makes it real and unfortunately… and different from other loss and palliative care, it’s like the two hardest days of your life; labor is like the hardest thing you’re going to have to do and losing somebody is the hardest thing you’re going to have to and it’s literally combining those things. On top of all that grief and expectation and loss, then you start feeling pain and it opens up a lot of that grief again and those expectations again and everything. Pain tolerance might be lower just because there’s a lot of emotion involved in it. …like experiencing cramps to a person… if someone was just in labor with a healthy, well infant, when someone is having cramps, you’re like, “Okay, here’s what to anticipate. It’s going to going to get a lot worse and awful.” But in their experience, those cramps might be it’s not that much pain, maybe it’s like 0.5/10 on the scale if you want to rate as pain like we always do, but it’s much broader. It’s what that pain means about what they’re going to have to experience and the reality that they will lose their baby. There’s a lot of fear in that too I would imagine because …in pregnancy in general your baby is inside and it’s all very exciting and you get to meet it and see that baby for the first time, right? They are going to have to go through all that, all the pain and all the labor still in the same way and it’s really hard and it’s really awful, but they are not getting that same reward at that end. That’s going to be the first time they ever see their baby and it’s going to be a dead baby… How do they prepare for that? How does anybody ever prepare for that? I think once the pain and once labour starts…There’s just all those

> expectations and your reality and your grief are all kind of combining. It's a reminder of all those things to come and everything that you've experienced. (H04-1 line 561)

In response to total pain, expert nurses talked about this with their patients and were prepared treat the physical pain of labor whenever and however their patient felt best. In order to streamline the process of treating physical pain, nurses arranged to have orders for pharmacologic pain management options available early in the process of labor.

> I think that one of the big things that I like to have a discussion with my patients is pain management … Because labour is hard work, but usually you get a baby at the end. So when there's not that incentive it can be like excruciating, so I think having that discussion with them … Not only with them, but with the doctors, getting those orders pre-emptively and talking them through that process is really important. **(**H02-1 line 185)

In other instances, expert nurses also needed to be prepared *not* to treat the physical pain with medical intervention. As this nurse discussed, it was important to some patients to feel their labor fully. Even in instances when patients opted to treat the physical pain of labor with medical intervention, their pain and suffering in its multidimensional nature, persisted.

> Their interpretation of pain is often escalated as opposed to a normal labour patient, right? And they always have that option of an epidural and it seems maybe 50/50 some will take, some won't, some just want fentanyl, some want PCA. And I - some moms want to feel labour because they don't know if they can get pregnant again. They don't know if they won't get pregnant again, or if this was the last baby, don't really want to try another last baby. So they want to experience the whole thing. So they'll cry during their labor and nurses interpret that as sometimes nurses will think, oh well, she's suffering, she's in pain, she needs an epidural. But it's what they want…they want to feel that pain all of these complicated things

> are part of that pain, right? And you can't treat them - No, you can't. You can't even treat that with an epidural sometimes. Like they may go to sleep for a while, but I find they startle awake a lot. Right? It's like, oh yeah, I'm having this baby, but now they're not physically feeling any of it. (S06-1 line 464)

Along with many other study participants, this expert nurse drew attention to differences in the pharmacologic pain management options available for women anticipating perinatal loss from those receiving standard care for an infant expected to live. These differences were described as being related to the ability of opioids to cross the placenta and enter the fetal nervous system resulting in symptoms such as sedation and respiratory depression in live born infants. When these symptoms are not of concern for the neonate, such as in instances when infants are anticipated to be born still, additional options can be considered for maternal pain management throughout the process of labor and delivery.

> …First, I would say have you thought about your pain management throughout the labour and you see what they know, because if it's their first baby they might know nothing, if it's their third, they might have been through this a few times and know kind of what they want to do. So just seeing that their knowledge base is and then I like to tell them that we want to keep them as comfortable as possible, so there are a few different options. So I typically talk about kind of from least invasive to most invasive, so nitrous oxide gas, the morphine, just about how that … You know it doesn't take all the pain away, but it can really lessen it. And then something that we offer here is patient-controlled analgesia (PCA), so they have the option of like a morphine PCA, which is something that we don't offer usually in labour, because of the fact that baby will be [dead or anticipated to die shortly after birth]-Yeah, when we typically know that the baby is compromised… Even if it's palliative really, it's not

> our goal, our goal is mom's comfort. So we don't tend to think about that, like for a normal healthy laboring woman, you usually offer the morphine like once … You know once they hit that certain point, you now like usually five centimeter mark or something, it's not offered again. But we don't have to worry about that. Some of them still do get epidurals. Often times I feel like the PCA is the more likely to be used, especially since they typically go fast… Especially for the earlier gestations from nothing, nothing, nothing and then suddenly the baby's coming. And I also let them know that if they try something and they don't like it, we can try something else. So if they want to try morphine and they decided that it's not for them or it's not doing as much as they wanted it to, they could still move on to something a little stronger if need be. Yeah, I think that's probably the main differences through the discussion I have. Like I said especially a patient like what do you know … Tell me what you know. (H02-1 line 201)

This nurse illustrated a similar point about the timing of administration of opioids during labor when the infant is anticipated to be born still or die shortly after birth when she stated:

> If their pain is getting worse, I mean, with a live baby, you don't want to give fentanyl too close to the end [i.e., time of delivery]. But again, the nurses need to be reminded that giving a mum fentanyl when she's fully dilated is not going to hurt anybody. You just have to stop, take a minute and think about what you're doing or you're not doing. Why am I not giving fentanyl when they're an anterior lip- like, why don't we do that? Because it's going to be hard on the baby, and the baby might be compromised and not breathe [at the time of birth]. Okay, it's a dead baby, it doesn't matter. (S07-1 line 730)

Fetal heart rate monitoring. Much of the care during a delivery of a live born infant is organized around monitoring (either intermittently or continuously), assessing, and documenting

the fetal heart rate throughout the first and second stage of labor. In instances of intrauterine death, fetal heart rate monitoring is not indicated as there is no fetal heartbeat. When an infant had a diagnosis of a life limiting condition, medical approaches to fetal heart rate monitoring varied. This being said, there were situations described in which patients with infants who may live through the delivery elected to listen intermittently for their infant's heart rate.

> But they also need to know that we don't have to be listening for the fetal heart rate if, like you say, we know the baby is going to pass, or if we know it's a palliative care baby, to be constantly listening to the fetal heart rate, is unnecessary. Sometimes the mums want to hear it, they want to hear, like, we'll listen for it, but other than that, we don't. We don't have them on the monitors. (S07-1 line 340)

When fetal heart rate monitoring was indicated, expert nurses acknowledged when the findings were favourable in any given moment, but did not provide false reassurance about the overall viability of the infant.

> In situations… we also have… there's lots of different variations of how this could present, but maybe there's a baby with a lot of known anomalies and the baby is still alive, but there's not much expectancy at birth, maybe the baby they were expecting at birth… the baby to live for minutes, for hours, or anything like that. In those ways, we do have to monitor the baby ['s heart], but that's okay and I find in those situations, that's… it can be reassuring like, "Listen to your baby, it sounds really good right now. We can get through this bit of time because listen to what's happening. You're doing so well, baby is doing so well. We're going to take it as we go." There are times that we have to monitor and that's okay too. (H04-1 line 527)

Some nurses reflected on the stress that fetal heart rate monitoring could cause for some patients anticipating their infant to die during labor or shortly thereafter, but despite this some patients did request to hear their infant's heart beat intermittently and nurses abided.

> Usually we get direction in that regard from the physician, typically we don't [monitor]… even for a palliative baby, because it can cause some stress and anxiety for the patient if they see that that number of picking up and then it stops. It could be as simple as the baby moved, the patient moved, but we don't want them to feel that sense of distress. So sometimes the patient will ask if there's a heart rate and then the nurse might do a listen to see. Yeah, but as a general rule it's not something that's typically done with a palliative baby, no. (H02-1 line 254)

This nurse described why some patients may have had a preference to monitor the fetal heart in situations where the likelihood of the infant surviving the labor process was unknown. She understood that it may have been important for these patients and families to know whether or not their infant would be alive at the time of delivery. When the fetal heart rate was monitored in response to the patient preference, it was of utmost importance for nurses to communicate that the findings of the fetal heart rate assessment would not dictate altering the plan of care.

> And I think that we like, like it is kind of a touchy subject with sometimes patients, sometimes doctors about whether we're monitoring, how much. But I think just having that conversation, like do you want us to monitor. Sometimes like people will say it doesn't matter, like if the baby is palliative then it doesn't matter. But sometimes it matters to the family - Yes, like is the baby going to be alive when the baby is born or not, because sometimes they're not going to survive the process. So, I think yeah and I think doctors are flexible too, like that sort of thing, if the family wants the baby to be monitored than we do.

> But also having that express discussion like if the baby's not doing well in utero then like we're not going to do a C section, like those kind of things. Like it's okay if the heart beat is low or whatever the case might be but making sure we're all on the same page about what we're doing and how important. And I guess the why if we were monitoring is to know how the baby is doing in the process but not for the purpose of adjusting the course of care, but yeah. (H03-1 line 449)

The presence or absence of fetal heart rate monitoring did indeed impact the workflow during PPC. When it was not indicated, nurses were more easily able to provide patients that wanted time alone or with their support people. This also allowed nurses more time to complete the necessary documentation and tasks associated with the death of an infant.

> It all depends on the patient, because there's times when that means that your workload might be lessened, because we're not as focussed on the [fetal heart rate] tracing. I mean we're still doing our vital signs and depending on which method of induction they may be using, we might still want to be monitoring contraction pattern, that sort of thing, but it's not as dire that we are in the room all the time at that point. And some people don't want you in the room all the time, because if they're in really early induction, they might need a good sleep, so we should just be poking our head in you know once an hour to check in on them and then that's it. But there are people who need you, in which case you might not leave your room except to go to the washroom and come back. So it all depends, it really does, it's hard to say. In terms of the actual paperwork I'd say it's a trade-off, because you have the stillbirth and the [neonatal death] packages which are you know extensive package of paperwork that most people are familiar with, so it takes a little bit more concentration to get that part done. But then you have less in terms of continuous monitoring. So it's a trade-off, it all depends

> on what shift you're on, because you might be on the shift where nothing's happening and then you know your colleague comes on and then they have to do the birth, the shrouding, the paperwork and you know take care of the mom postpartum as well. (H02-1 line 268)

Vaginal examination. Expert nurses performed vaginal examinations infrequently unless labor was medically augmented or induced. In such cases, vaginal examinations were indicated at regular intervals.

> I wouldn't say we do them – we don't do them as often... We try to keep them to a minimum. We still worry about the maternal health, so you still worry about, like, chorioamnionitis and Mum getting septic. You still worry about it being a prolonged process. If Mum is coping with it, even if she's making slow progress, there's no need to intervene if she's contracting on her own. But a lot of the times it's inductions, and it's inductions with vaginal misoprostol, so the doctors are coming in and doing vag exams to put the misoprostol in. (S07-1 line 721)

When perinatal loss was expected, expert nurses described being particularly thoughtful to thoroughly explain why the examination was indicated, and to let their patient know well ahead of time when they could expect an examination.

> It depends if they're labouring on their own or if they're being induced. If they're being induced obviously there's different points where we would have to check to see if what we're doing is working, if we need to do another option, all that kind of stuff. Yes, so I would say, I mean it's a little bit different than a regular labour because if people are wanting something for pain when they're just laboring you would often check to see what is the appropriate thing to give them at that time, so in that way there might be a little bit less checks, but there are still kind of those check-in points of making sure that you're

> providing the right care. I think with most of this stuff the recurring thing is just… it's communication and easing people into it. Like, "The medication that we gave you, it's been going for 6 hours now," 12 hours now, 24 hours now, whatever that is, "so it's the time that we do an assessment down below just to kind of see what's happening. I know that can be hard, but it will just inform our care." Again, it's just explaining. You definitely don't want to come in and be like, "Oh, it's time to do the check" and in and out goes the doctor or whatever. Sometimes that happens, but I think your role as a nurse, you are that person that's guiding them through and you often know when that's going to happen, so you can even have that conversation an hour before and just say, "Coming up," maybe tell them a little bit earlier too, you know, "At 12:00 we're going to reassess okay and that's going to involve this, that, and this and at that time we'll know what the next step is." Give them a little more of a head's up. (H04-1 line 674)

Enacting expert nursing: actions and considerations during second stage. The actions and considerations outlined in this section reflect care from the time the cervix is adequately dilated for delivery until the infant is born.

Table 11
Actions and Considerations for Enacting Expert PPC during Second Stage

Topics for consideration	Considerations	Actions
Dilation at delivery	○ Infants who are not full-term gestation or who have growth restrictions and can pass through a cervix that is not fully dilated ○ Such deliveries can occur quickly or suddenly ○ Be prepared for expedient delivery ○ Be prepared to deliver infant independently if medical staff does not have time to arrive ○ Expedient delivery can be distressing to the patient and support people ○ Sometimes patients may feel afraid	○ Let families know that the delivery may be fast ○ Place hat in toilet to prevent infant from being born in an undesirable location ○ Have necessary equipment for delivery at hand ○ Place call for assistance for delivery early ○ Provide support to family by acknowledging any feelings that arise ○ Provide reassurance about the process during an expedient delivery, in an effort to help the patient feel safe
Demeanor at delivery	○ Infants who are full-term may have a longer second stage ○ The physical stress of labor is not a concern for infants who are deceased ○ Consider the emotional readiness of the patient to engage in pushing ○ Consider words of encouragement thoughtfully and centre on who the patient is as a person and what meaning they make of the experience of perinatal loss ○ Consider whether comments on meeting the infant or soon becoming a parent would resonate well with the particular patient as a source of encouragement or not	○ Second stage is not an ideal time to focus words on the loss or on offering condolences ○ Focus words of encouragement on commending patients for making it through the physical demands of labor ○ Provide coaching around the physiological process of pushing if appropriate ○ Provide reassurance around the physiological process of labor ○ Notice and commend physical and emotional strength ○ Allow more time for second stage because there is no cause for concern about stress on the infant ○ Work with the patient's physical response to labor, do not rush to initiate pushing, wait for the urge to push ○ Allow for breaks as required or preferred ○ Use physical contact and non-verbal communication to convey support as appropriate

Caring for the support people	○ Support people often feel responsible for caring for the laboring patient ○ Support people are processing their own emotions	○ Involve support people in supportive care in labor ○ Commend their involvement ○ Acknowledge their emotions and provide support
Reframing risk	○ Consider whether particular events have the potential to cause harm to maternal health ○ If maternal health is not at risk, often no intervention is required	○ Take a moment to determine whether the issue presenting poses an actual risk in the situation and whether the intervention is in fact required ○ e.g., In the event of a shoulder dystocia, patience can be displayed in resolving the issue safely to the tolerance of the patient in labor ○ e.g., In the event of breech presentation, the delivery of the infant can take as much time as needed without intervention to the tolerance and safety of the patient in labor ○ e.g., Narcotic analgesia may be safely utilized up to the time of delivery for maternal comfort in the event of intrauterine fetal demise
Care in the operating room	○ The patient has been removed from the calm environment that had become familiar to them ○ The nursing role in the operating room may limit opportunities to attend to social and emotional aspects of care ○ The type of analgesia received will impact the patient's ability to interact with their infant after a caesarean section ○ The support person may or may not be permitted in the operating room	○ Take time to reorient the patient to the space ○ Promote the opportunity for skin-to-skin, or for seeing and holding the infant if patient preference ○ Include support person in experience and ensure they have adequate support ○ After surgical recovery, reorient to decisions made for post-birth care of the infant

*Dilation at delivery***.** Expert nurses reported that many of the deliveries requiring PPC were for infants who were not at term gestation or who had significant growth restrictions. This meant that the infants were relatively small and as a result, laboring women did not necessarily need to be fully dilated for the infant to deliver. This also meant that the delivery could occur suddenly and quickly when compared to deliveries of full-term infants.

> For someone earlier, again to see exactly that, they might not need to get to the 10 cm, … I think in those situations because it can happen quite fast, depending on how you're inducing, but say hypothetically, they're 27 weeks or something like that, like small baby probably only needs to get to 6 or 7 cm maybe. (H01-4 line 731)

In response to this, nurses took precautions to ensure the infant was not born in an undesirable location.

> …these babies can deliver at less than less 10cm dilation. So I mean, you still have to look at the hospital side of it; when they get up to the bathroom, you have to put the little hat in the toilet, because a little twenty-two-weeker could slip through the cervix and into the toilet, so you have to be cautious of those kinds of things. (S07-1 line 346)

Nurses also prepared for these expedient deliveries by having the necessary equipment at hand.

> … it can be 0 to 100, so …I think in that way if it was somebody who has had a baby before or it's an early gestation that you think it's just going to go quickly for whatever reason, you can be… one step ahead of what's happening, as you are in any situation, but yes, just so that it's not as stressful of a delivery. …you could have that kind of stuff ready too. Maybe not in the room, because again, it's one of those triggers to what's to come, but maybe outside the door you have your bassinet so that when mom starts pushing and it's

> going to go quickly, it's right there or your delivery cart or whatever it is, if you think it's going to be that fast. (H04-1 line 744)

It was exceedingly important to have equipment at the ready, because in many instances, nurses described delivering these infants themselves. Being so quick, there was not always time to call for the physician, or if they were able to place the call, the physician may not have been able to make it in time for the delivery.

> at the delivery it's really nice to have a bassinet there with a couple of blankets just to cover and… there's so many pieces. Even if on the inside I'm feeling terrified myself, because those deliveries do happen very quick, so chances are the doctor might not make it. (H02-1 line 325)

Expert nurses were sensitive that the pace of labor and delivery of preterm infants could be overwhelming for their patients, and did their best to acknowledge any feelings that arose and provided support when they were able.

> I think she was shocked with how quickly it went because she had said, "It's time already?" and you could sort of see some fear in her eyes, very scary of course, so I just kind of sat there with her on the bed…(S05-1 line 277)

Nurses often recalled these fast deliveries viscerally and in great detail. They took great care to provide reassurance to their patients throughout and worked with the woman in labor to safely deliver her infant, in many cases without the presence of the physician.

> She was twenty-one weeks [gestation]…. but she wanted to go to the bathroom. And she got up to go pee, and a foot fell out. So she – for whatever reason, they had gloves in the bathroom, so she put gloves on and she just held herself, and got back to bed and she lay down in bed, and she wouldn't let her hand go. And that's when the husband or partner

> was hugging her and talking to her. And through coaching, I encouraged her to let her hand go, it was okay, she was safe, you're going to be okay. And finally, she let her hand go so I could see, and I had my buddy nurse with me at the time, and we called for the doctor right away, but he was in the OR. And so I ended up just waiting for this baby to deliver all on its own. (S07-1 like 703)

Demeanor at delivery. Not all deliveries requiring PPC were as expedient as those described above. In some cases, women anticipating perinatal loss were delivering full-term infants and as a result, their second stage of labor was much longer than those previously described. During second stage, some expert nurses described focusing less on the loss than during the other stages of labor. Instead, they turned their attention toward supporting their patient to make it through the physical demands of labor and in doing so, nurses drew on similar skills used in deliveries of healthy live born infants.

> I tell them you know you're almost there, we're almost through this, you can do this. I try to not say things like I'm so sorry you're going through this, because I want to give them encouragement that they can get through this point, right. Keeping it almost like taskful, because it's not the time to have that discussion about I'm so sorry for your loss, this must be so hard, because we have to keep them focussed so they can get through this. That can come before and after and I think just remembering those principles of supportive care. So, in the moment it could be as easy as just a cool facecloth… (H02-1 line 310)

When liveborn infants were expected, nurses described how the words of encouragement they offered to their patients often focused on meeting the infant and soon becoming a mother. These topics were understood to serve as motivation to persevere through the birthing process. When perinatal loss was concerned, these sentiments might not be perceived as helpful.

> I think when we're expecting a healthy outcome, it's kind of like kind of giving them that boost of energy, like that you waited 40 weeks for this, and you're at the end, and you have control, and you have to find that strength and motivation, and – because usually at that point, they're just exhausted. Like they're tired, right? Just to kind of give them that morale boost, the power boost to say like, you're going to meet your baby, you're going to be a mum, it's going to be so awesome, right? But you can't do that when they're going to push out a stillborn baby, and it might be the worst day of their life ever. (H01-1 line 458)

However, nurses did not entirely shy away from talking about the moments their patient would share with their baby, but nurses placed significantly less emphasis on this than in the delivery of an infant who was expected to live.

> Not that you try to avoid the "meeting your baby", because you're still meeting the baby, and there's still maybe that moment of time, or that hour or two hours of time where that baby could live. And that's the most precious time, right? So – but kind of not making that the sole focus of [what you say to them]. (H01-1 line 537)

As expert nurses were not necessarily concerned about the impact of the stress of labor on the infant in circumstances of perinatal loss, they demonstrated patience and felt little need to rush the physiological process as they might have in the case of a live born infant.

> So usually we kind of just wait until they can't not push anymore, right? So if people are feeling a bit of pressure, and a bit of urge to push in a healthy baby, we'll say, if you -- want to do it, give her – get it done, right? In this aspect we say, just wait for your body to do it. Your body's going to take over, you know, just wait for it, there's no rush, we don't have to hurry. Just listen to your body, and work with it, and when it's time, we're going to push out a baby, you know?... So we kind of plan for that moment, but just kind of we're not as

> aggressive, I guess, in the whole situation, so just kind of letting them push. (H01-1 line 466)

Once the woman in labor had an undeniable urge to push, expert nurses demonstrated patience with the process and encouraged their laboring patient to work with her body's natural responses and take breaks when she needed. During this time, expert nurses turned their language toward commending the hard work being done by the patient and provided reassurance and encouragement around the physiological process.

> And sometimes still, as a nurse, it gets frustrating, because you know this could be over in half an hour, and like in the long-run it's better for her if it's over quick, but you're not going to force her to do something. So it's just having patience in that moment to say, this is normal, you know? Everything that you're doing, your body's just doing it. So -- let's just get through each contraction, and work with it, you know? When we're pushing in that moment, I just tell them the most effective way to push, is to push until you need a breath, and then take a breath, and then do it again. If you can do three, that's fantastic. If you can do one, that's okay, too, you know? Let's just kind of make each contraction work with us, and we'll get there, you know? And then sometimes people freak out, and they say, I can't do it, I can't do it, and then you go, okay, we're just going to take a moment, like we don't have to rush. If you want to take a break and not push, we can do that too. So you tell me what you want to do, right? Because there's no hurry. I mean, we can push for 12 hours if that's what she wants to, or every, you know, half an hour, if that's what she wants. But kind of really trying to make them still feel like they have some control over part of the situation. Yeah, positive reinforcement, you know? You're doing great, this is hard work, like just take it one contraction at a time. (H01-1 line 481)

Nurses also displayed a great deal of patience around the woman's emotional readiness to face the moment of delivery, and understood that sometimes this delayed their engagement in pushing until the physical process of labor took over.

> I've had women afraid to push, because they know as soon as they push, that baby's gone. As long as the baby is still inside of them, that baby is still with them, and yeah, I've had women that are afraid to push, they're just not ready to let go. Yeah, and you just – what's the rush to push, really?... there is no rush. Like, her body will eventually do it. Any pregnant woman, if you just left them alone… have baby, or just, yeah, it would come. (S07-1 line 641)

Study participants repeatedly underscored the significance of reassurance and encouragement during the second stage of labor during perinatal loss in response to the fear they often observed these mothers to experience. Sometimes this reassurance and encouragement came in the form of coaching, and guiding with words, and often focused on the physiological process of birth.

> I think there's a lot of encouraging in that moment because again, that's another one of those times that makes it a reality, all the grief and the loss. All of a sudden, they're pushing and they're going to meet their baby right away and people get really scared and that's normal, but I think…So, you're still coaching them and you're guiding them about what to do in the same way that you would be with a healthy well baby, but I think there's more reassurance, more… just to reassure that they can do this, that they are doing this, that you know… like to validate because a lot of people will get really scared and they maybe won't push because they don't want to meet that, and they just want to keep their baby in there because it feels safe in there and they don't have to confront that reality. I think it's a lot of encouragement and I don't know, I just… I always try to tell the moms how strong they

> are for having to do this and that they can do it and they're doing it, to listen to their body when the time comes to push and it's going to be okay, you've had that conversation with them about what to expect already, so you can kind of tie all of that stuff in. But I think there's a lot more of encouragement in labor …but definitely I would focus on that and really kind of building the mom up a little bit just so that she knows she's not alone and she knows she can do it and that her body can do it and all that kind of stuff. (H04-1 like 964)

Other times, this reassurance was provided through physical contact and non-verbal communication.

> And it's hard, because you know, it's not a good outcome, right? But they need that reassurance, and usually that's really if there hasn't been a lot of connection up to that point, that's when often the connection will occur is when she grabs your hand because I have yet to have a mom that hasn't grabbed my hand at that point of delivery. And even if you don't say anything to her she's going to look at you and you're going to look at her, and she's going to know you've got her back, right? That's the only way I can describe it is that there doesn't have to be words sometimes, there just has to be eye contact and that means everything. So yeah. (S06-1 line 1347)

Caring for the support people. Study participants recognized the challenges that the second stage of labor during perinatal loss presented for support people. Support people, often felt responsible for caring for the woman in labor but were also processing their own emotions. Expert nurses provided encouragement for those present in support of the laboring woman and helped them to be involved in providing comfort measures.

> Like supporting the dad, because the dads feel helpless in that situation - In general. They always want to be the helper, and the strong person, and the supporter, and now here like they're probably not holding it together either, but they have to support her, or hopefully they're there to support her. But just telling them like, oh, you guys are such a good team, and you're doing such a good job supporting her, and here you can hold her neck, or do this, or get a cloth, or kind of making him feel involved, or whoever that support person is, involved in the actual moment, makes them kind of, I don't know, disassociate from the actual event that's going to happen, but just being involved in the moment in supporting her. (H01-1 line 511)

Reframing risk. Providing PPC required nurses to reframe how they thought about common obstetrical risks and the accompanying interventions that would be considered standard care for live born infants. In many cases, these interventions were not indicated as the infant was not at risk and they would not be of benefit for maternal health. Expert nurses were sure to respond with urgency to any medical issues that would compromise the health of the mother. This nurse shared an anecdote about not necessarily responding with a sense of emergency to shoulder dystocia,

> …we had one that was a shoulder dystocia, and they were ready to pull the emergency bell, I'm like, no, no, no, just let it – like, it's okay. And you don't want to say it, but you're like, the baby's dead, shoulder dystocia is not going to hurt the baby, and it's just going to scare the mother. So then the nurse is just – she'd step back for a second and went, yeah, you're right, we don't need to do all of that. But we're like Pavlov's dogs, as soon as there's a shoulder dystocia, let's jump on the bed, but you don't need to do that. And they [nurses] just needed to be reminded, and once they'd thought about it, they were, like, yeah, you're right, there's no emergency, and that would just scare the mother, and she's already scared

> enough, you don't need to add to it. So as far as second stage going, yeah, their body will instruct them when to push. You don't need to do the emergencies, unless Mum is haemorrhaging, then that's more a maternal thing. (S07-1 line 653)

and another about taking a breech delivery more slowly than if the infant had been living.

> And so I ended up just waiting for this baby to deliver all on its own. And it took seventeen minutes, because it was breach and it had got stuck, and I sat there with baby in my hand for seventeen minutes, waiting for this head to deliver, while he talked to her and told her about wedding plans. (S07-1 line 719)

Care in the operating room. Expert nurses acknowledged that providing PPC in the operating room environment was inherently challenging. First, this took their laboring patient out of the calm environment expert nurses had sought to create.

> It would definitely change the care though. Yes, most definitely because just even they're relocated; going to the operating room, then coming back and going to the recovery room. That in itself is probably not the best thing mentally for a patient…For someone who is experiencing a loss to go through that, I feel like it would…be disorienting. Having a home base, one room where they can feel safe, that's theirs, or as safe as possible, I think is important. (S05-1 line 508)

Second, their role during a caesarean section required expert nurses to pay mind to the tasks required during surgery and detracted from their ability to attend to the social and emotional aspects of care.

> Yeah, it's very different, because in the OR, like depending on what role you get, usually like we have a scrub nurse, and we have a circulator. Usually if it's your patient, you're the circulator. So it gives you a little bit more human contact with the patient, but it's still very

> much a task-oriented place, right?... I'm doing a lot of computer work, charting in the OR. There's a lot of timing for counting of instruments, and marking down times, and all those things. And yeah, you're focused on what's happening for a surgery, right? So sometimes it's hard – or it's easy to lose track of the situation. That emotional contact with the patient, because you're not even seeing that. My back is turned towards the patient, I'm charting away on the computer. And, yeah, still trying to do your role, but try to, you know, peak behind the curtain, and kind of say a few things to the patient. But it is very different… So you kind of lose control of that social aspect of it… (H01-1 line 896)

The effects of various medication utilized for surgery impacted how involved a mother could be with her infant immediately after birth. When spinal analgesia was utilized, expert nurses helped their patients to reorient back to the birth plan and they could be involved with infant care, whereas the use of general anesthetic made this more challenging.

> If they've had a spinal or something, and they're more, you know, able to react and stuff, then yeah, we can kind of regroup that kind of hopefully bond, or something, that we've had, and kind of just talk about what happened, and talk about, you know, the same postpartum stuff where we go from here, you know? We talked about maybe going home, but now unfortunately you've had major surgery. Like we have to keep you, and this is kind of what you can expect, and… In a general anaesthetic the dads aren't in the room if the mom is intubated. But otherwise the dad they could be in there, we could give the dad the baby. She could still do skin to skin…if she wants. So we talk about that. But it is a very different medical environment. (H01-1 line 1008)

Enacting expert nursing: Actions and considerations during third and fourth stage.

The actions and considerations expert nurses made during the third and fourth stages of labor

particular to PPC were not demarcated clearly based on the delivery of the placenta. As such, the description of the care during these stages has been combined and will be outlined to follow. The fourth stage of labor is typically referred to as the recovery period, and medically is considered to last approximately two hours. It is of note, that many of the anecdotes nurses shared about their care during this time, exceeded the two hour window. Although LDR patients who delivered live born infants were typically transferred to a mother-child-unit for care, patients who had experienced perinatal loss often stayed on their unit until they were medically stable and until they had spent several hours with their infant if they had wished to do so. The actions and considerations outlined in this section sometimes span several hours after the fourth stage of labor and come to an end when the infant has been sent to the morgue or other setting as appropriate and the labor patient, so long as was medically stable, was discharged from the hospital.

Table 12
Actions and Considerations for Enacting Expert PPC during Third and Fourth Stage

Topics for consideration	Considerations	Actions
Seeing and holding the infant	○ Patient preference regarding how they would like to receive their infant at the time of delivery varies ○ The initial responses of a patient to their infant at the time of delivery varies ○ The duration of time a patient and family spend with infant varies ○ Consider use of a cooling mattress for longer infant stays ○ Taking the infant from the parents to the morgue can be an emotionally charged moment ○ Patients may opt for their infant not to go to the morgue and prefer to take their infant to an alternative location such as directly to the funeral home, or to their own home	○ Place infant skin-to-skin as per patient preference ○ Wipe, dry, and/or bundle infant before handing to patient as per their preference ○ Observe parental response to their infant ○ Offer comments admiring infant features as appropriate ○ Inform patient about availably of a cooling mattress for those who plan a longer stay ○ Be aware of any organizational policy regarding expected timeframe to send infant to morgue ○ Advocate for patients to have the time they need with their infant ○ Prepare parents to take infant to morgue by giving ample notice ○ Be thoughtful when choosing language to label and describe the morgue ○ Coordinate plans when an infant is not going directly to the morgue
Opting not to see or hold the infant	○ Some parents and/or support people may have never held a newborn infant, let alone one born still or actively dying ○ Parents and support people likely have preconceived notions about what it would be like to hold a stillborn or dying infant, those assumptions may or may not be accurate ○ Parents or other support people may have opposing views about seeing, touching, or holding their infant ○ Many patients will change their mind after having initially opting not to see or interact with their infant	○ Offer the opportunity to see, touch, or hold the infant to any support people present ○ Conduct an assessment on liveborn infants at the time of delivery before bundling ○ Dry and bundle infants before setting them down in a bassinet so they are presentable for a patient who may change their mind ○ Do not sent the infant to the morgue immediately when a parent(s) opts not to interact with their infant should they change their minds ○ Inform parents that they are welcome to change their mind about the decision not to see, touch, or hold their infant at any time

	○ Some parents need time and information before they are ready to consider seeing, touching, or holding their infant
	  ○ These parents might find it helpful to ease into seeing or interacting with their infant
	○ The opportunity to see, touch, or hold an infant is time limited
	○ Some liveborn infants who are not expected to live for more than minutes to hours will not be held by their parents or family
		○ Describe what interacting with the infant might be like for the parent and explore their fears or assumptions with an open mind
		○ Be attuned to piquing interest in interaction with the infant
		○ Tactfully offer the opportunity to see, touch, or hold the infant on multiple occasions
		○ For parents who seem interested, help to ease them into the experience of seeing or interacting with their infant:
		  ○ Offer specific descriptions of the infant
		  ○ Show parents parts of their child, just feet for instance
		  ○ Demonstrate comfort holding and being affectionate toward the infant
		○ Provide help and encouragement to parents and support people when holding or considering holding a stillborn or dying infant
		○ Inform parents before the infant is being sent to the morgue and provide them another opportunity to see, touch, or hold their infant, let them know their decision is quite final at this point
		○ Demonstrate respect regarding a parent's decision not to see, touch, or hold their infant

Balancing maternal medical care	○ Maternal medical is dictated by protocol and the mother's physical well-being must be attended to
	○ The time a parent(s) has to spend with their infant is time limited
	○ Maternal medical care and monitoring can interrupt valuable moments but is a priority nonetheless
	○ Some patients will prefer to have the nurse present throughout, while others will prefer privacy
	○ When no maternal risk factors are present, privacy may be easier to accommodate
		○ Plan for efficiency
		○ Group necessary tasks together to minimize interruption
		○ Provide privacy between mandatory medical care
		○ Inform the patient that you will give them privacy but will remain readily available
		○ When an infant is expected to be born alive:
		  ○ Ensure adequate orders have been obtained and necessary medication is available
		  ○ Assess infant for pain or unpleasant symptoms and if present, provide appropriate treatment

	○ Some infants will be born alive and may present with pain or other symptoms	
Infant care and creating keepsakes	○ A variety of keepsakes can be prepared for and given to the parent(s) (e.g., hand/foot prints or moulds, locks of hair, photos, infant gowns or outfits etc.) ○ The condition of the infant can impact the creation of keepsakes ○ Approach to involving the parent(s) and support people in infant care and creating keepsakes can vary ○ Activities such as bathing an infant gives a parent or family member an opportunity to enact their role as a parent, grandmother, aunt etc. ○ Infant care and the creation of keepsakes can occur in the presence of the parent(s) and support people, or in an alternative location ○ A parent may decline creating keepsakes ○ Some parents may regret their decision to decline keepsakes at a later date	○ Welcome the parent(s) and support people to participate in infant care such as the bath, and in the creation of keepsakes ○ Inform parent(s) that other families have participated in infant care and the creation of keepsakes ○ Inform parents that they can participate by observation or by being hands-on ○ Demonstrate respect for and accommodate their preference participate or not ○ Give the parent(s) warning that the condition of the infant can impact the creation of particular keepsakes ○ E.g., if the infant's skin is friable, place an addition layer of clothing under any clothing the parent(s) wish to keep to prevent staining ○ Create and store a few keepsakes if a parent(s) declines keepsakes should they return at a later date in hopes of retrieving a memento

Seeing and holding the infant. At the time of delivery, if mother had opted to see and hold their child immediately, nurses placed her infant skin-to-skin. These moments were seen as being monumental because of the time limited nature of the opportunity for these families to be together.

> If the mothers want, I put the baby skin-to-skin with Mum and I leave them to bond, I don't take baby away. I leave them together, because that's the only time that mother's going to get, and she needs to get as much of it as she can, so I'll leave. (S07-1 line 756)

Depending on the patient preference that had been previously determined, nurses either placed the infant directly with their mother, or took a brief moment to dry and wrap the infant before placing her/him into the arms of their parent.

> If they do want to see the baby… sometimes they want them cleaned up first, but otherwise we'll put the baby on their chest just like we would otherwise, wipe their face off, so that they can see the baby. (H02-1 line 416)

Expert nurses gave space and for families to experience their organic reaction(s) to the situation at the time of delivery. Nurses observed the responses of the mother and her support people if present, and based her actions to follow on this. When parents expressed adoration of their child, nurses might for instance admire the infant's features.

> And usually I don't say anything right away, I let them have some time and that also helps me to gauge what I should say… And I mean depending on their reaction, you know if they say oh he's beautiful, I'll say look at those precious little hands or those beautiful eyes or you know that sort of thing. And I think that again acknowledging their loss at some point is important too. That might not be the perfect time just then, if again just see what the patient's reaction is. (H02-1 line 419)

The duration of time families would spend with their infant before the infant was sent to the morgue varied. This variation was a result of the individual preferences of families, the practices of expert nurses, and the policies in place at the institution. Some families elected to stay with their infant for hours to days after the delivery. In these cases, availability of a cooling mattress was helpful in accommodating a longer duration of time together. However, some families did not prefer the sensation of their infant being cool to touch.

> So if Mum wants to have the baby in the room with her while she's in the hospital, she can have the baby on the [brand name of cooling bed]. Some choose to have the [cooling mattress], some don't. I had one mum that did not want the mattress. We brought the [cooling mattress] into the room, and she did not like it, because she said her baby always felt cold, so she brought the baby into bed with her, and she would sleep with the baby – that's another real big break, I mean yeah, sleep with the baby in bed. And we let that go, because she was only there for, I think, two days, and anything longer than that, then the baby would start to break down and start to smell, which is the whole purpose of having them in the cooling cot, so that they don't. (S07-1 line 862)

Some nurses reported the duration a family spent with their infant was solely up to the family. Especially since their unit now had the benefit of the cooling mattress to stave off the process of decomposition.

> Well, it's all up to the patient when the baby goes down, within reason of course. We have a [cooling mattress] now, a family donated it a couple of years ago. It's a cooling bed, which has been amazing because it allows parents to spend the night with their baby in their room without the baby starting to decompose and start to smell and stuff, so that's been a real blessing. It's been awesome... I remember a mom who didn't want to go home

> without spending one night with her baby because that was important to just have one night with her baby, for whatever reason, so we just accommodated it. At that time, we had the cooling mattress, so it was good. (S05-1 line 419)

However, nurses did acknowledge some barriers to families staying with their infant for a longer duration such as if available beds for laboring patients were limited. In these cases, nurses could look at transferring the family to another unit within the program.

> that being said, if there… if we're really short on beds, that may change, but I've never felt pressure… they would move to a post-partum room. (S05-1 line 447)

This nurse reported variation in the support from the charge nurse, some understood that some families needed more time, while others were more reactive to constraints pertaining to bed utilization and patient flow.

> It depends on who you work with, really it does. There are certain charge nurses that are more focused on time, like, you have to finish this recovery up, you have to finish up, because there's more patients coming. And then there's other charge nurses who are, no, take as much time as you need, I understand IUFDs [intrauterine fetal deaths] take more time, and so then we don't rush them. (S07-1 line 784)

Nurses reported other barriers for families spending extended time with the infant such as stipulations set out from other hospital departments such as pathology, infection control, or the morgue itself.

> It's typically like they want the body delivered to the morgue within two to four hours along with the paperwork, I don't feel like that's enough time sometimes. Usually I will give them a little extra time. I've actually called admitting and said okay what is the maximum amount of time that I can give this family… But at the same time, pathology needs to have that body.

> Yeah, if there are investigations. But infection, prevention and control are the ones who say that the body can't be at room temperature for too long. (H02-1 line 725)

When the time finally arose for the infant to go to the morgue, expert nurses gave families warning when they would be preparing to take the infant.

> so I'll say you know what you know in another hour I'm going to get baby ready to go. So I'm just letting you know so you can have this last little bit of time and just giving them that heads-up, so you're not just going…okay, I'm taking the baby away. (H02-1 line 738)

Throughout care, expert nurses were consistently straightforward with their language and descriptions about their care. This differed around the topic of taking an infant to the morgue. This nurse described taking the infant to the morgue was the one topic around which she softened her language.

> I would say that … the baby [is] going out of the room like are you ready for me to take the baby out? And I don't think that, maybe this is a place where I'm vague with people but I don't think I say to people the morgue. I feel like that's too real. It's already real to them, I don't think I've ever said the morgue. (H03-1 line 758)

Sometimes families had other plans in mind to meet their needs such as taking their infant home, to a more private location such as a hotel, or directly to a funeral home. Nurses did their best to accommodate these requests but it involved quite a lot of logistics that were not familiar to all staff. Although it was possible to do, it wasn't offered as a standard of practice.

> there was like a cord accident, but otherwise healthy baby and they actually let the mom and dad take the baby to the [name of hotel adjacent to hospital] … Like the baby was a living … But as it passed, they took baby to [name of hotel] and they just spent time with the baby there. Outside of the hospital. I know that by law they have that opportunity to take the baby

> home now, providing they can meet certain criteria … And I know that we have body bags now that are suitable…I know that it's an option, but it's not something we want everyone to do. (H02-1 line 770)

Despite the challenges inherent in the process of opting for something different than a direct transport to the morgue, expert nurses worked diligently to see their patient's preferences met when taking the infant to an alternative location was of great importance to them.

> It is not common, it's not recommended, don't ever suggest it, is the words that we've gotten from people. It's really a technicality thing…Like it is a human remains, and it has to be, you know, dealt with through the proper channels. I don't think it's a lack of support for the patient, or the family's wishes, or anything. It's really the hospital following hospital policy. So all – not always - 98% of the cases that I've dealt with, the baby at some point goes to the morgue, or goes to pathology, and is released to the funeral home that week. I did have only one case ever where the family – this mum was just distraught that her baby, a stillborn, would have to go to the morgue. That was just a horrific experience for her. And social work was involved, and there was a bunch of parties involved, and it was afterhours, so like the regular people aren't there to make this easier. But we did go through a lot of higher-ups at the hospital, and we were able to release the baby to the funeral home from the ward. It was a big choreographed thing, and it was not well received by the staff, by administration. The family was adamant. The family was taking the baby from there, whether we let them or not, you know? That was just how strongly they felt about it. So that was really like I guess advocating by me, and advocating by my nursing supervisor, who was like my next-up, I guess, at the time, that we really like not fighting the policies, but finding the loopholes in the policy to say, we got to do this for her. Like this lady's going to have a nervous

> breakdown here in the hospital. Like what can we do? Why can't we do it? Challenging, you know, professionally, but challenging people to say like, you know, how can we make this happen? (H01-1 line 813)

Opting not to see or hold the infant. If a mother expressed a preference not to see or hold her child immediately, nurses offered the opportunity to the support people if they were present.

> If Mum does not want the baby, then I'll encourage Dad to hold Baby, or Grandma to hold Baby, or somebody in the room. (S07-1 line 756)

Study participants noted that for many new parents, even with a live born infant, holding a brand their brand new baby could be an overwhelming experience, especially given that some parents may have never held an infant before. There were sensitive to this fact, and acknowledged that parents would need additional support in situations of perinatal loss.

> Like some guys have never held a baby before they come there, and the now all of a sudden you're going to give him this dead baby, and just say, you know? It's awful. Like you shouldn't be alone in that moment, I feel, like regardless of who you are, right? (H01-1 line 995)

If all family present elected not to see or hold the infant, the infant was wrapped up and placed in a bassinet.

> …if nobody wants to hold the baby, then I will wrap the baby up and put the baby on, say, the basinet, because often we take the warmer out of the room. (S07-1 line 756)

In most instances when infants were live born, study participants reported that the majority of parents wanted to be with their child at birth.

> If they're born still living then I've never had an experience where the patient - the parent didn't want, to hold their baby. (H03-1 line 610)

In the occasional circumstances when parents did not want to see or hold their liveborn infant who was not expected to live for more than minutes to hours after birth, nurses conducted an assessment before taking the infant from the labor room.

> If it's a palliative baby, obviously we want to listen to heart rate and do that sort of assessment, even if the parents don't want to see it, we do that first. And then it would go into what we call like our snuggery or our nursery. (H02-1 line 412)

Nurses were sure to dry and bundle an infant so that should a parent decide they did want to see their infant after all, that they were presentable. Then, the infant would be taken to a separate room.

> And then having like warm blankets nearby so that if they don't want to see the baby right away that we can like bundle the baby and sometimes take the baby out of the room, to the utility room here, that's sometimes what people want. Or being able to like dry the baby off so if they do want to have a look at the baby that that can be done easily without too much fuss. (H03-1 line 601)

When parents were reluctant to see or hold their child, whether they were born still or alive, nurses encouraged the parents to consider seeing or holding their child. The majority of study participants held a belief that it would beneficial to the wellbeing of their patients to interact with their infant. As such, nurses stressed the importance of offering parents the chance to see their infant on multiple occasions.

> Well, I think the bottom line is that I'm going to do for them what they want. But sometimes like I might say something like, you know, it might be important for you to like to process this to do this, you know, like it might be easier for it not to be so

> mysterious, yeah… Yeah. Because I feel like there will come a point where it's not an option [to see or hold your child] but it is an option now, right? (H03-1 line 743)

Nurses described these beliefs being cemented by their experiences with patients who after initially thinking they did not want to interact with their child, inevitably decided to do so after being encouraged by a nurse. This nurse described one such interaction with a father:

> he said, and I'm so glad I had that opportunity to hold my daughter because the hardest part after I got home was I - he said he wrote - and he said to me too, I don't know what I would have done now knowing what I know if I had gone home and I hadn't held my baby. (S06-1 line 339)

Sometimes parents had opposing views about seeing, touching, or holding their baby. This nurse was quite up front with her patients and their families with sharing her strong beliefs about the necessity of interacting with the child after the birth in the interest of the mother's wellbeing moving forward.

> Yeah, I do encourage every family to at least touch the baby. Some are ready to hold it, some not. I had one family… and he did not want her to hold the baby. He didn't want her to touch it, to see it, and to just pretend like it didn't happen. And that was a full-term baby. And I had to explain to him that she needs this as part of her grieving process, she needs to be able to let go, and to be able to let go, she has to hold it first. And the baby was born, and she just cried, my baby, my baby, and you knew she wanted to hold the baby and he was saying no. (S07-1 line 540)

Nurses had experiences when parents had indeed changed their minds about seeing and holding their infant. With these experiences in tow, expert nurses were sure to make it clear to parents that they could change their mind.

> And that's okay to change your mind, that is so important, because they might say they don't want to [see their baby], but they're allowed to change their minds. So just keeping that door open for them is a big deal. (H02-1 line 481)

Knowing that many parents changed their mind about seeing or touching their infant, expert nurses kept these infants on the unit for a while before sending them down to the morgue to allow for this change of heart. This study participant made a point of checking back with parents that they were ready for the infant to go to the morgue if they had not seen or held their infant, as this would be their last opportunity to see do so.

> If I were to have a patient like that, I would… I feel like I would want to gently push them to maybe consider looking or touching, but in no way would I try and force them. I don't know…I mean I would also reassure them that they can change their mind because they can and if there's a family who doesn't want to see the baby, we usually keep the baby on the unit for a while in case they change their mind. Sending the baby down to the morgue is a very final decision, so at that point we make it very clear that this is a final…Once baby goes down, it's very difficult for baby to come back up, just so that they know. If they're having any sort of doubt… (S05-1 line 400)

Expert nurses understood that sometimes parents needed time before they would be ready to consider seeing or holding their infant. Nurses stayed attuned to peaking interest and described various techniques they used to ease their patient into the experience of seeing and holding their infant. This nurse had her patients see or touch parts of their child to start, just the feet for instance.

> I went back and I talked to the mom and she was asking questions. What does the baby look like and I said to her you know as you know facially there's some deformities, but he has perfect feet … He has perfect feet, so if you change your mind and you want to see

> them, I'll bring the baby to you. So she did change her mind and she said I don't want to see his face, I just want to see his feet. So I held the baby and I had like a little receiving blanket over here and she saw the feet and then after that she wanted to see the baby. And then after that she wanted to hold the baby. You know so she was starting to go through that process and that baby actually ended up living for two weeks and she was there for that baby… And it wasn't in a pushy way, you know just letting her - (H02-1 line 456)

This nurse offered descriptions of the appearance of the infant to the mother with her words, helping her patient to know what to anticipate in seeing her child after the birth.

> She was afraid to hold the baby when it was first born, she was afraid to look, because it was premature… and she was afraid to look, because she didn't think it would look like a baby. And so I delivered the baby and just through my words, and literally describing exactly what that baby looked like to her, as if you were reading in a book, she was able to finally look at the baby and realise, it does look like a little baby…And then she held it, skin to skin, and checked out all the little fingers and toes. But I just told her how absolutely perfect it was, two little eyes, two little hands, two little feet, and it was perfect. It was a perfectly-formed little baby, it was just tiny, just so tiny. (S07-1 line 525)

This nurse eased her patients into the experience of seeing and holding the infant by demonstrating comfort with holding and being affectionate towards the infant herself, and through her actions parents felt welcome to do the same.

> I think it's modelling behaviour too. If they see that you're holding their baby, they… …it invites them do the same. you're not forcing it on them at all, but if… I think that that's a way to normalize it for sure. Then you know, you're like, "Look how cute your baby is,

look at its cute little nose. It looks like its mom." Like, it's okay to have those conversations. (H04-1 line 862)

Balancing maternal medical care. After the birth of an infant, expert nurses were required to follow a maternal monitoring protocol. This required regularly checking vital signs, monitoring bleeding, and assessing involution of the uterus. They also needed to clean up equipment, measure loss of blood, complete their charting, administer necessary medications, clean up body fluids, and help the mother get cleaned up and comfortable. In short, this was a very busy point of the LDR process yet nurses were adamant to protect the time families had to spend together, and interrupt them as little as possible.

> You do, but a lot of times family members want time to themselves afterwards. Yesterday, for example, she… we finished suturing, I cleaned the room out very quickly, I did a set of vitals, checked mom's bleeding, and then I gave them time. I gave them 15 minutes, just enough time for me to come back and do my next check, but just time for them to talk, say good-bye, and grieve without a nurse staring at them. It's moments like that where you can leave the room and do the other tasks that you need to do. (S05-1 line 365)

Expert nurses were able to achieve this except in the event of a maternal medical emergency.

> … there's a little bit of space in those checks too, like if you're waiting for the placenta, do your quick blood pressure and then you can take the baby out of the room and come back and it's still okay. You have those minutes you can find unless they're hemorrhaging and it's going bad, but yes you can find the little moments. It might just be a little bit different, but I would definitely not just leave the baby in the bassinet in the corner. It could be easy to do and get focused on your tasks as a new nurse. (H04-1 line 1167).

The described efficiently planning to perform necessary tasks together and minimizing interruptions. Expert nurses were sure to let families know that this is the plan and remain available to them at their request in between.

> Grouping you work together, so not doing a temperature and then coming back in five minutes and saying hey do you want something to eat and then coming back and doing a fundal check. You know really putting all of that together so you can limit your interaction. I think that that could change if they don't want you to leave, then you're going to stay, but most of the time I think that they do need that time to forget that they're in a hospital, to just be with the family. So doing that … So grouping your care and just not stopping to small talk unless they want to talk with you, so just being upfront. So I'll say you know I'm going to give you as much time as I can, let me know if you need me, so you know if your bleeding is getting heavy, if you have any questions or concerns about baby, otherwise I'm just going to come in and do my checks that I need to do and then I'll leave you alone. So just being upfront, so that they don't wonder hey where did she go, they understand what we're doing. (H02-1 line 700)

Some nurses felt comfortable stretching out the timeframe between checks when there were no maternal risk factors present.

> If there are no risk factors I miss a check no big deal. Now I wouldn't tell a new nurse to do that because I feel like it's easy to miss stuff when you don't even know what you're looking at in a way. Yes, then like you can stretch out those time frames for their emotional safety. (H03-1 line 666)

When infants were born alive, study participants described assessing the infants for pain or other unpleasant symptoms and treating those symptoms as indicated. Then remained available while families spent time together.

> Well I mean for the palliative infants … we're not going to be doing a full resuscitation, at most intranasal fentanyl, if there is respiratory distress witnessed, but other than that just stepping back and giving them that time with their while they still have the baby. That's important, so I feel almost like in those situations like I'm a ghost, I'm there, but I don't want to interrupt what they're doing as a family. (H02-1 line 691)

Study participants described most physicians being proactive in planning for treating possible pain and symptoms for infants who were anticipated to be born alive but only live for a short duration. Nurses did recall experiences where they found they needed to advocate to prepare for possible pain and symptoms. A specialist pediatric palliative care service was noted on numerous occasions as being a valuable resource in situations of uncertainty.

> So what happens is sometimes we have a couple of our doctors who will write orders for the intranasal Fentanyl for the [babies] that are suspected to be palliative. So there's a few who will still take on that role and then otherwise sometimes the nurses have to advocate a bit, to say you know can I have orders for fentanyl for the baby in case we need it, that sort of thing. But I think most of the time they know what to do to a certain extent or they're aware of the limitations and will consult palliative care if need be. (H02-1 line 797)

Nurses noted that it was particularly helpful to have their service available around the clock, and that they were typically involved with anticipated losses. When the specialist service was involved, the plans for birth and post-birth care were well laid out, alleviating the need for nurse to guide their patients through making so many decisions during the labor process.

> So they're very helpful … They're always available for any questions we have just regarding the process in general, often times if they're present they'll talk to the family about things that normally would fall on the nurses' shoulders. So those planning for after the baby is born and that sort of thing, they typically have to handle that, which is great. And I think if it's known, if there's time to put that contact in place before delivery, that's when it's done. So if it's a known anomalies and that sort of thing, you tend to see them involved more … For like your cord accident, not so much. (H02-1 line 787)

Infant care and creating keepsakes. Both sites stocked a variety of materials for nurses to create keepsakes for families including hand and foot prints and/or moulds, sachets for locks of hair, props and cameras for photos, baby gowns, and necklaces and charms to name a few. This was a component of the care they provided completely unique to perinatal loss and took time to create and organize.

> We do a lot of keepsakes, so that can be very time consuming. We do footprints, handprints in clay. We will give as much as we can bands, measuring tape, a lock of hair, anything. That's definitely different than your normal care that you would provide to a family with a live baby. (S05-1 line 356)

Expert nurses had experience in creating keepsakes, and planned for some of the challenges they knew could arise. This nurse for instance, described the considerations she made when working with and dressing an infant with friable skin.

> I will take two boxes [handpainted by volunteers to keep mementos in] in. No more than that because they can't make a decision, but I do pick out the two boxes that I think suit the parents' personality or what they feel that the baby's personality may be, and I give them the option of picking whichever box they want. And then they're more of a part of it, and I'll do

> the same with the outfits. And now more and more people are doing that too. But we've also had a donation of angel gowns given to us right? Which are made from wedding gowns. And not everybody likes them... But the parents appreciate it. So I talk to them about angel gowns versus clothes, a lot of them have brought their own clothes. And again we have to broach that subject, well if I put your baby in your own sleepers, and I talk to them and this is the hard part is talking to them about sometimes the skin gets moist and weeps through it. And I said - so if you want to keep the sleepers I can put another outfit on over the baby that won't soil your own sleepers and then that can be part of the keepsake box. Because I find that if you don't, and as hard as it is to tell them everything, if you don't, and now they see, you know, blood from the baby on a measuring tape or blood from a baby on the sleepers - It's very distressing, right? (S06-l line354)

The approach to infant care and memento making varied between providers. All expert nurses involved parents and support people in infant care at their wish, but some openly and regularly offered the opportunity, while others let patients take the lead to make their desire for involvement known. This nurse welcomed patients to participate in bathing their infant by letting them know that other families had done the same. She knew that even in doing so, some would choose to participate by watching, others by touching, and some not at all.

> And we talk about once that's done we can bath your baby and I said if you'd like to be a part of the bath we can do it in the room, and I tell them some - and I know that a lot of times they're thinking, and I've had moms say, well what do other moms do? Right? So rather than leave that I tell them we have moms that want to participate in the bath. They want - in fact if it's not - if their first baby they often want to bath the baby themselves, but some of them

> don't want - they're afraid to touch the baby or to bath in case something happens to the baby so they choose to watch. Or they don't want the baby in at all. (S06-1 line 387)

Some of the expert nurses also described offering support people the opportunity to participate in infant care, whether that was bathing or creating keepsakes.

> …there was a mum, a dad, a grandma, a grandpa, an aunty, everybody was in the room, and they all participated in that baby's first bath. Everybody had a washcloth, everybody was touching and washing the baby, everybody helped do the hand print – like, they were all involved in it. Like, it was just warm to see them all. I wanted that mum to feel like a mum and do the things that mums do. You kind of you get the sense that, if all these people are there in the room, supporting the mum, then maybe they want to be a part of it. So I offer, and if they decline, they decline, but at least I've offered them the chance to do it…But I figure they're there for a reason, they want to be supportive, so give them the chance to do something. Every family is so different. I've seen so many different ways, it can go so many different things people do, yeah. (S07-1 line 174)

This nurse took a different approach and she described how she typically made keepsakes in a separate room, unless the family themselves specified wanting to participate in these activities.

> I have never made - I made hand and footprints quite a bit and we don't usually do that with the family. I've never done it with a family. We usually do a bath. I almost always do it without family but the last family that I worked with we did it together because they wanted it. And so yeah, we just did it together, yeah. (H03-1 line 687)

This expert nurse believed strongly in the value of keepsakes for parents in their grieving process after discharge from the hospital. In response to this belief, even if a parent had explicitly stated they did not want mementos, she prepared the keepsakes in the event they changed their mind.

She described several cases in which parents had in fact come back at a later date in search of them.

> So my struggle is with the parents who don't want anything, or they don't want the keepsake package, which I understand too because they don't want that memory. And I said, well parents often aren't in the right frame of mind to say no. And that we [had] parents who would - they'd say no, I don't want it, don't want to take it home. We'd make one anyway, and they would either change their mind before they left, you know what? I think I will take that package. Or they would come back, sometimes four or five months later for their packages. (S06-1 line 787)

Summary

This fifth chapter provided a description of the characteristics of the nomination process and study sample. The study findings were presented and were organized around three overarching topics: (a) how expert nurses cultivated expertise in PPC in the LDR setting; (b) the outcomes of expert nursing care when PPC was indicated in LDR; and (c) the actions and consideration nurses engaged in to enact expert PPC in LDR. The final and sixth chapter will present a discussion of the findings of this study within the context of existing evidence, review the study limitations, and pose recommendations and for nursing education, practice, and research.

Chapter Six: Discussion and Conclusion

Introduction

This sixth and final chapter will present a discussion of the findings of this study within the context of existing evidence, review the study limitations, and pose recommendations for nursing education, administration, practice, and research. Each theme and subtheme of the findings of this study will not be touched upon individually in this discussion. Rather the focus will explore more deeply aspects of particular findings which informed the recommendations made for nursing practice, administration, education, and research.

Discussion

Given the vital role of the nurse in circumstances of perinatal loss in the context of LDR care and the gap in literature describing expert nursing care in these circumstances, the purpose of this study was to: (1) develop a description of the critical behaviors required for the provision of expert nursing care for those families expecting a stillborn infant or an early neonatal death during the LDR period; (2) describe what factors promote or impede the ability of nurses to develop and carry out these behaviors; and (3) describe the consequences of being able or not being able to enact these behaviors when providing care. During data analysis, it became evident that in order to describe the expert behaviors nurses engaged in, it was valuable to first situate how their expertise came to be through articulation of the process detailed in the fifth chapter regarding the cultivation of expertise in PPC (Figure 1) that included obstetric nurses: (a) activating expertise; (b) developing expertise; (c) enacting expertise; and (d) sustaining expertise.

What became evident, is that without in-depth, timely, and context specific education on the topic of perinatal loss during undergraduate or diploma preparation, or during their orientation to the specialty area of obstetrics, expert nurses relied on other means to develop their

expertise. This included activities such as seeking out the mentorship of other nurses, learning from repeated clinical encounters involving perinatal loss, learning from the families they cared for, and transferring nursing skills from other situations to suit circumstances of perinatal loss. In these ways, much of the development of their expertise was self-guided.

Overall, the non-linear process of cultivating expertise cannot be characterized as an easy or simple journey as it required nurses to first activate their interest in the topic by noticing gaps in clinical practice and realizing they have a set of intrinsic characteristics that would enable them to provide families experiencing perinatal loss with the best care possible, often evoking a calling or deep responsibility toward these families and their care. Even when nurses had achieved expertise in the area of PPC their work was not done. They engaged in activities to sustain their expertise on an ongoing basis such as those which promote self-care. In order to do this, they garnered support from their colleagues and understanding from their family and friends. In addition, expert nurses found time to reflect, debrief, or to be alone. All of these activities to sustain expertise required nurses to acknowledge their own needs and advocate to see them met. These findings have significant implications for the nursing profession.

Situating the model of cultivating expertise in PPC in the context of common and contemporary discourse. In order to explore implications of this conceptual model related to cultivating expertise for the nursing profession, it is of value to understand how its main concepts are similar to current or common discourse on nursing expertise and PPC, and how they are unique.

Congruencies with Benner's Novice to Expert Model. Many works that examine the concept of expertise in nursing practice look to Benner's model to inform their understanding (Hutchinson et al., 2016). In this study, Benner's (2001) from Novice to Expert Model served as

a helpful sensitizing framework. Many aspects of the conceptual model of cultivating expertise from this study align closely with Benner's from Novice to Expert Model (1982), while several aspects are distinct.

Benner (1982) asserts that novice nurses are highly task oriented when compared with their more experienced counterparts. This is echoed in the theme of developing expertise where a foundation of standard LDR care is described by study participants as being an absolute prerequisite to developing expertise in PPC. Only with a firm grasp on the usual tasks of LDR care can a nurse carry them out while at the same time having a degree of situational awareness, allowing her/him to simultaneously make considerations central to expert care such as the impact of their patient's culture, religion, and spirituality on their needs and preferences, or how the context of their patient's life outside of the hospital shapes the care decisions they make and the supports they need. Study participants recalled themselves as novice nurses where the need to focus on the standard tasks of LDR care detracted from their ability to attend to more holistic aspects of care such as the emotional support often needed during perinatal loss, and interfered with their ability to adequately incorporate the additional tasks required during perinatal loss (e.g., particular paperwork, bloodwork, or assisting families in decision making about post-birth care). Expert nurses shared similar anecdotes from their standpoint as experts about assessing the readiness of a potential mentee based, in large part, on their comfort with the standard tasks required for LDR care of patients who are not experiencing perinatal loss. Further to this, expert nurses described the negative impact of being assigned to care for families experiencing perinatal loss before having mastered tasks of standard LDR. This resulted in a negative experience for the nurse who had not mastered the standard tasks of LDR, as well as concerns that their patients received sub-standard care as a result of their lack of preparedness. The need for LDR nurses to

have a foundation of standard LDR care prior to receiving mentorship for PPC or being expected to provide PPC has critical implications for nursing practice when considering how patient care assignments are devised, and when opportunities for mentorship during clinical care are presented to more novice nurses.

Other consistencies with Benner's findings (2001) about the characteristics of experts and their course of developing expertise were identified throughout data collection and analysis. For example, similar to Benner's (2001) description about nurses having a difficult time articulating precisely what it was that made them experts, participants in this study too grappled to find words to describe the development and enactment of their own expertise. An important step in understanding quality care in any milieu of care, is illuminating the knowledge embedded in the clinical practice of expert nurses (Benner, 2001), but the challenge expert nurses face in being able to articulate what is expert about their practice can be a potent barrier to eliciting sufficient depth of information when investigating this topic from a qualitative standpoint. It was helpful during interviews to employ different strategies to encourage experts to find words to illustrate more clearly their behaviours while providing care such as asking expert nurses to imagine they were watching themselves provide care from an aerial view and to describe what sorts of things they saw themselves doing or heard themselves saying. Researchers may need to consider different interviewing strategies when investigating how nurses enact expertise during direct care provision in order to support them in finding ways to articulate details about their care in order to understand the knowledge embedded in the practice of experts and make it both tangible and accessible to those aspiring to deepen their knowledge and ability in a particular context of care.

The findings from this study support Benner's (2001) assertion that expertise is not gleaned merely by the passage of time in the profession or practice context, but rather through

"the refinement of preconceived notions and theory by encountering many actual practical situations that add[ed] nuance or shades of differences to theory" (Benner, 1982, p.407). For example, the results of the nomination process identified experts with as little as four years of LDR experience, and as many as 36 years. All expert nurses reported having a minimum of 10-30 clinical care experiences with families anticipating perinatal loss, and some recalled having greater than 50 clinical experiences. The model for cultivating expertise generated from this study suggests that it is neither the number of years of experience in the clinical context, nor the number of clinical encounters particular to PPC, but the importance of thoughtfully reflecting about each clinical encounter involving perinatal loss that enables the development of expert practice. This feature of reflective practice resounds across much of the literature on expert nursing practice and speaks to the self-directed nature of the development of expertise in nursing across healthcare settings as noted by Morrison and Symes (2011) in an integrative review on the topic of expert nursing practice. Experts in this study were candid in noting their own intrinsic traits of being self-reflective. During repeated clinical encounters nurses noticed and examined how different patients and families responded to their caring behaviors, then took forward what they had learned in order to further refine their practice. This finding highlights the value of including opportunities to learn about and engage in self-reflection and reflective practice during nursing education in order to adequately equip nurses with this important ability to refine their practice in the clinical context.

On a more granular level, numerous other congruencies were noted between the outcomes, actions, and considerations of expert nursing practice during PPC in LDR from this study and the seven domains of nursing practice identified by Benner (2001) which include: (a) the helping role; (b) the teaching-coaching function; (c) the diagnostic and patient-monitoring

function; (d) effective management of rapidly changing situations; (e) administering and monitoring therapeutic interventions and regimens; (f) monitoring and ensuring the quality of healthcare practices; and (g) organizational and work-role competencies. Though the examples of congruencies between domains of these models are numerous, perhaps the most poignant connection is illustrated in relation to an aspect of Benner's (2001) helping role. Benner (2001) describes this aspect of the helping role as providing comfort measures and preserving personhood in the face of pain and extreme breakdown whereby:

> …nurses must face the fact that there is little they or others can do to prolong the life of a patient. On the other hand, there is often some room to enhance the quality of life, short though it may be… While the nurse must be able to give up on trying to save a patient's life, she or he must not avoid the patient and must still find ways of providing comfort for him and his family" (Benner, 2001, p. 55).

This was certainly a quality exhibited by expert nurses in this study, who remarked on this shift in their practice during their own evolution toward expertise. Expert nurses described putting the fear and pain of their patients above their own insecurities and temptations to avoid difficult interactions by focusing on tasks as they may have done when they were less experienced in dealing with perinatal loss. Expert nurses truly leaned into addressing the comfort of their patients through their expert ability to, for example, understand and respond to difficult emotions.

Another rather literal intersection occurs between Benner's (2001) domain of the helping role where the ability of expert nurses is described as allowing them to "interpret kinds of pain and select appropriate strategies for pain management and control" (Benner, 2001, pg. 62) and the ability of expert nurses in this study to recognize and respond to the experience of total pain.

Through examples such as these, it is evident that many of the observations and descriptions Benner offered through her Novice to Expert Model (1982), remain relevant in understanding the development of clinical nursing expertise as well as the characteristics of experts in contemporary nursing practice.

Where the model for cultivating expertise in PPC in the LDR setting most clearly departs from Benner's (2001) Novice to Expert Model is around the aspect of sustaining expertise. Although Benner (2001) indeed remarks on the need for "meaningful incentives and reward systems" (p. 199) such as providing nurses with entitlement, recognition, and rewards, the focus of such initiatives is geared toward increased job satisfaction and retention of nurses. The model for cultivating expertise in the current study is less concerned directly with nursing retention, although this may be a positive consequence of the activities outlined which sustain expertise, but sustaining expertise is linked to the ability of nurses to see their own emotional needs met in order to provide PPC in their work setting on an ongoing basis. This model does not assume that simply because a nurse has developed expertise in their ability to provide expert care that the nurse will not require supports in order to maintain their willingness or ability to provide that expert care. This is of particular importance given similar findings reported in the literature about nurses' experiences in providing PPC (Willis, 2019). Willis (2019) reported that nurses struggle with their own emotions such as fear, panic, anxiety, sadness, and grief during and after the care of those experiencing perinatal loss, and that in response to this, nurses must engage in self-care and have the opportunity to debrief with collages to prepare to return to work after providing PPC. The importance and value of debriefing after caring for those experiencing perinatal loss has been recognized and is further emphasized by organizations such as the National Association of Neonatal Nurses in their recent position statement on palliative and end

of life care for newborns and infants (Catlin et al., 2015). It would be in the interest of nurse administrators to foster opportunities for nurses to debrief with their colleagues and to have access to other support services within the organization such as counselling services to work through difficult emotions. The health care facility should also promote the importance of self-care activities for frontline healthcare staff and create opportunities for self-care when possible.

Another departure between the findings of this study and Benner's work is around the aspect of activating expertise. Benner's (2001) model perhaps contains an assumption that, although not all nurses will move from proficiency to expertise in nursing, those who do have a "vision about what is possible" (p.35) in nursing care. However, Benner (2001) does not elaborate about what characteristics or experiences shaped their ability to conjure such a vision. In the model for cultivating expert nursing practice in PPC in the LDR setting, activating expertise involves a vision that there is a need for expert PPC, that the nurse him or herself has the capacity to become an expert, and that the nurse can see them self being committed to learning to provide the best PPC possible. In this study, conjuring the vision to activate expertise is further driven by noticing gaps in practice and by having clinical or personal experiences with PPC where more knowledge would have benefited care. Ultimately, when nurses in this study had activated their decision to cultivate expertise, they reported a strong sense of responsibility toward families experiencing perinatal loss. Nursing educators in both nursing education programs and in hospital settings, might in future, play a role in sensitizing nursing students and less experienced LDR nurses to the crucial need for expertise in PPC. In addition, mentors in clinical practice can model positive nursing behaviors to generate and harness passion in less experienced nurses (Hale, 2019). Together, this would place less reliance on individual nurses to activate their interest in developing expertise through experiencing difficult situations such as

those involving deficits in the healthcare system or crucial gaps in evidence with which to inform their practice. Though the role of mentoring in cultivating expertise will be discussed in detail later in this chapter, (Hale, 2019) suggests that "mentors can model positive nursing practices and create a sense of enthusiasm that harnesses the raw passion new nurses often have for practice" (p. 183).

Situating in existing discourse: The role of knowing and responding to the person in enacting expertise. Given that during the development of Benner's (2001) From Novice to Expert Model, knowing the patient as a person emerged as a recurrent theme of expert practice (Tanner, Benner, Chesla, & Gordon, 1993), that knowing the patient as a person has persisted as a key characteristic of expert nursing practice across time and practice settings (Hutchinson et al., 2016; Morrison & Symes, 2011; Tanner, 2006; Zolnierek, 2014), and that aspects of knowing and responding to the person in this study are reflected also as key features in several models, frameworks, and pathways for PPC across the healthcare trajectory (Cole et al., 2017; Dickson, 2017; Murdoch et al., 2013), it is perhaps no coincidence that the expert nurses in this study placed a great deal of emphasis on their ability to know and respond to the person they were caring for. In the conceptual model for cultivating expertise in PPC, perhaps the most prolific series of considerations for enacting expertise which transcend the entire LDR process are those related to the expert nurses' ability to know and respond to the person they are caring for. In order to achieve this, nurses were able to: (a) connect with the patient, and understand the context the patient is coming from; (b) understand and respond to difficult emotions that arise; (c) tailor care to anticipated or unanticipated losses; (d) demonstrate presence in a way most appropriate to the patient; (e) know and respond to the support people present; (f) acknowledge the influence of their patient's particular culture, spirituality and religion; (g) explore and support

the patient role and experience as a parent; and, (h) help their colleagues to also have an appreciation of the patient as a person by involving and informing them about the person receiving care.

In this study, knowing the person required time and an ability to articulate and communicate aspects of the knowledge of the person they cared for with other colleagues. Additionally, knowledge of the person positioned nurses particularly well to respond to them when providing direct care, and given their intimate understanding of the needs, preferences, and hopes of their patients, to advocate for their patient within the broader context of their LDR unit.

Existing literature recognizes knowledge of the patient as a person to be central in the provision of PPC and has been discussed by others. For instance, the importance of care being personalized was an essential finding in a recent mixed-methods study that investigated maternal perspectives of perinatal palliative care including an analysis of focus group data from nine participating mothers (Kamrath et al., 2019). Other authors have identified nurses as the providers within an interdisciplinary context of PPC provision to be best positioned to have an intimate understanding of their patient and an exceptional ability to recognize and take action on the unique needs of their patients during PPC (Leuthner & Lamberg Jones, 2007; Limbo & Wool, 2016; Ramer-chrastek & Thygeson, 2005). Another instance where the importance of knowing the person that arose in the literature is in relation to PPC concerns quality indicators to predict parental satisfaction of care during PPC developed by Wool et al., (2016, 2018). A number of these quality indicators closely align with considerations for knowing and responding to the person identified in this study. For example, several of the quality indicators posed by Wool et al., (2016, 2018) that directly address the parents' perceptions that nurses knew and responded to them as people included: "nurses took time to talk with me" (Wool et al., 2018, p.

278); “health care team worked with me to identify my needs” (Wool et al., 2018, p. 278); “healthcare team helped me cope with my emotions” (Wool et al., 2018, p. 278); “healthcare team assessed and supported my cultural, spiritual, or family traditions” (Wool et al., 2018, p. 278).

In this study, what most often posed a challenge in achieving adequate knowledge of the person was a lack of time to connect with, make social observations about, and converse with the patient. Not having sufficient time to get to know the patient has been identified repeatedly across time, geographical regions, and contexts of care as a significant barrier to knowing the patient as discussed in an integrative review of the literature examining the concept of knowing the patient with 21 studies meeting inclusion criteria (Zolnierek, 2014). A lack of time for focus on the person in this study was related to the tremendous workload requirements to thoroughly complete the innumerable necessary tasks and documentation for standard LDR care in addition to those necessary in circumstances of perinatal loss, and was exacerbated in the absence of support or availability of other nursing staff to assist in the completion of these tasks. Lack of available staff or support was dictated by a combination of constraints caused by demands on the LDR unit at large, and beliefs held by nurses in charge of unit assignments that caused them to underestimate or undervalue the amount of time and resources that were required to provide the best care possible for families experiencing perinatal loss.

Given the challenges identified by expert nurses around having adequate time to achieve knowing and responding to the person receiving care, even with their ability to expediently anticipate and carry out necessary tasks, it may not be reasonable for individual nurses to assume the responsibility of procuring additional resources for ‘creating’ more time in individual care scenarios. Other authors have asserted that there may be a limit to the ability of individual

healthcare providers to influence practice change in order to enhance the quality of care provision and that organisational support should be garnered (McCormack & McCance, 2006; Zolnierek, 2014). A key implication of this for nursing administration is that organizations should endorse models of care on their LDR units that enable nurses to know and respond to their patients as people, especially during instances of perinatal loss. This means ensuring nurses have adequate support and time during PPC to form relationships that allow for trust and connection as well as sufficient time to engage with their patients in order to gather information about their needs, preferences, and hopes, and to integrate the information they glean about the person into the plan of care. There must be a recognition that additional nursing time and staff support are required to achieve all of this while carrying out necessary tasks and documentation associated with the LDR process and perinatal loss. Whenever possible, staffing levels and nursing assignments should reflect the time needed to achieve this during PPC in the LDR setting to support the ability of nurses to contribute to patient satisfaction and quality outcomes through their expert practice.

Situating findings in existing discourse: The role of mentorship in developing and enacting expertise. Another significant concept contained in the model of cultivating expertise was that of mentorship. Mentorship was integral in the development of expert practice in PPC, and was also one significant way in which study participants enacted their expertise in PPC.

Mentorship was viewed as the central means by which study participants received information about perinatal loss in order to build their skillset. Essentially what nurses described in this study is that without mentorship, they were left to cross a chasm void of educational opportunities and context specific resources with little more than a trial and error approach during repeated clinical encounters in order to learn about and hone their expertise in PPC. Most

mentees entered the mentorship relationship without having had much more than a brief introduction to the concept of perinatal loss during their orientation to the LDR program, and some had not even had this brief introduction as a foundation to preface their first clinical care experiences. Mentorship was of incredible valuable to the participants in this study and had great influence over their ability to develop expertise.

Once nurses had developed a degree of expertise, they extended their own skills by taking on a role as mentor to other nurses with less experience with perinatal loss in both formal capacities through nursing leadership roles, and informally as colleagues who would make themselves available to assist in care for families experiencing perinatal loss, to provide advice or demonstrate skills, and make themselves available for emotional support to any of their colleagues who were providing PPC. This phenomenon is not unique to this study and has been previously referred to as "mentoring beneficence" (Hale & Phillips, 2019, p. 169), and is a component of a recently developed grounded theory "Mentoring Up" (Hale & Phillips, 2019) that is described as when a mentee becomes proficient in their area of care, in large part due to the mentorship they received, and develop a desire to contribute to nursing by engaging in mentorship relationships with more novice nurses than themselves.

In the late 1970's and early 1980's mentorship was described in disciplines outside of nursing such as in psychiatry (Levinson, 1978), and business (Kram, 1985), and first appeared in the nursing literature in the late 1970's (Stewart & Krueger, 1996; Vance, 1977). Since that time, the concept of mentorship in nursing has been the topic of inquiry on numerous occasions. To illustrate, in a review of evidence on the topic of mentorship relationships in nursing, Hale (2018) identified eight literature or integrative reviews and four concept analyses published between 1994 and 2018, with each noting a lack of conceptual clarity around mentorship in

nursing. The purpose of a mentorship relationship is to enhance professional growth and requires mentors to exhibit characteristics such as being accepting, competent, knowledgeable, and caring, and to do more than simply share information but also to provide support to their mentee as a coach, advisor, counselor, and facilitator (Hale, 2018). Some studies have even referred to mentors as exhibiting qualities of friends (Bray & Nettleton, 2007), or mentors and mentees developing a "familial affection and devotion" (Hale & Phillips, 2019, p. 165) toward one another. Although there is no one universally agreed upon definition of mentorship, Eby (1997) provides a definition based on the earlier work by Kram (1985) that broadly applies to the descriptions of mentorship experiences in this study:

> Mentoring is an intense relationship whereby advice, counselling, and developmental opportunities are provided to a protégé by a mentor, which, in turn, shapes the protégés career experiences… this occurs through two types of support to proteges: (1) instrumental or career support, and (2) psychological support (p. 126).

Distinctions have been made between formal and informal mentoring opportunities in this study, but also in previous research. In this study, formal mentorship often meant that less experienced nurses may have been 'buddied' with an expert nurse in a clinical leadership role for the opportunity to observe expert care in action, or for the opportunity to have the mentor present as a resource for guidance and clinical and emotional support when the mentee was new to providing PPC. Informal mentorship occurred when expert nurses informally made themselves available, without being assigned to do so, to share information, to help out with tasks, or provide emotional support to their mentee, and often did this while they had their own patient assignment. These characterizations align with models of formal and informal mentorship previously described in the literature. For instance, Chao, Walz, and Gardner (1992)

characterize informal mentorships as being neither "managed, structured, or formally recognized by the organization. Traditionally, they are spontaneous relationships that occur without external involvement from the organization" (p. 620). Further to this, Tourigny and Pulich (2005) further specify that informal mentorships are based on "mutual identification and personal development needs" (p. 71). Formal mentorships, on the other hand, are characterized as being "managed and sanctioned by the organization" (Chao et al., 1992, p. 620), and involve "establishing objectives, selecting and matching mentors and proteges, and helping them develop realistic expectations" (Tourigny & Pulich, 2005, p.69).

Over time, numerous models of mentorship, be they formal or informal, or in one-on-one or group scenarios, have appeared in the nursing literature and differ from organization to organization (Hale, 2018). Although mentors in this study may have taken on more than one nurse mentee, they typically provided mentorship on a one-on-one basis, especially during direct clinical care, as mentors were conscientious to limit the number of extraneous healthcare providers caring for a patient experiencing perinatal loss in an effort to promote privacy for the grieving family. To date, there is little evidence to endorse the utilization of any one model of mentorship over another (Hale, 2018).

The impact of mentorship has indeed been emphasized as an integral means by which nurses developed expertise in PPC in this study, but mentorship in nursing (or other healthcare disciplines) in relation to PPC has not otherwise been studied. Mentorship, however, has been investigated in the context of Canadian perinatal nursing (Ryan, Goldberg, & Evans, 2010). In their qualitative study using feminist phenomenology, the analysis of the perspectives of a purposive sample of five perinatal nurses concluded that "expert perinatal nursing knowledge develops within positive mentoring relationships between perinatal nurses practicing

with birthing women" (p. 183). Although not particular to the tenets of palliative care in this setting, the study findings provide further evidence that mentorship is indeed an effective and familiar strategy for developing nursing expertise in the perinatal setting. Ryan et al. (2010) characterize mentorship as a form of relational learning that occurs in context and in the mentor/mentee relationship, but also with the birthing woman. This all occurs within a "complex health, social, and gendered context" (Ryan et al., 2010, p,186) and the impact of these contextual factors on the individual they learn about and care for must be considered. Also important to relational learning is what the mentor or mentee bring to the situation based on their own life contexts (Ryan et al., 2010).

Mentors in perinatal nursing modelled behaviors, particularly those highlighting interactions with a birthing woman that foster authentic connection, physical presence, and intimacy in the nurse-patient relationship (Ryan et al., 2010). Mentees in this study described having an appreciation for learning new skills but most valued learning ways to build relationships with women in labor (Ryan et al., 2010). Mentors felt they had succeeded in fostering the development of a perinatal nurse once the nurse could integrate necessary skills such as titrating an oxytocin infusion *while* engaging with the woman in labor. In this way, the study findings presented by Ryan et al. (2010) and those presented in this study accentuate the utility of mentorship in facilitating a transcendence from simply carrying out tasks to masterfully completing those tasks while maintaining a level of engagement and presence that is dictated by the multidimensional needs of women during the LDR process.

Though the effectiveness of mentorship in developing expertise is important, data suggested that not all mentors are created equal. Expert nurses in this study discussed the experiences wherein their mentors had been ineffective in their role, including instances where

their formal mentors who avoided PPC altogether. And, although benefits for mentors such as pride, satisfaction, and an enhanced reputation in the workplace have been documented (Hale & Phillips, 2019), not all expert nurses are motivated by these benefits, nor do all expert nurses have the skills that make them excellent mentors. Studies across disciplines have identified the necessity of bolstering organisational support and recognition for mentors in order to enhance their willingness to engage in mentorship relationships and to be effective in their role as a mentor (Ghosh, 2014). Various mentorship workshops and development programs have enhanced the self-reported perception of competence for mentorship of those who participate (Lau et al., 2016) and organizational support for and recognition of mentors enhances the likelihood of achieving positive outcomes within mentoring relationships for mentors and mentees alike (Hodgson & Scanlan, 2013). A commitment from institutions to support structures for mentorship has been reported to result in organizational benefits such as improving patient outcomes (Race & Skees, 2010), and enhanced retention of nurses (Greene & Puetzer, 2002) to name a few. A critical implication for nursing administration and education then, is to ensure nurses with expertise in PPC have educational opportunities to build their competence for mentorship and have support and recognition from the organization to take on mentees in order to foster the growth of other nurses in PPC and build capacity for the quality care of families experiencing perinatal loss within the organization.

Given the reliance on mentorship as such an essential, and in some instances the nearly singular means by which to develop expertise in PPC as demonstrated in this study, it is also prudent to consider whether this level of reliance on mentorship is the most efficient way to cultivate expertise in the sub-speciality of PPC in LDR in the healthcare system. Considering that studies exploring healthcare professionals' experiences in providing PPC universally stress

the need for formal and vocational training on the topic, it is time to heed and act upon those recommendations (Gandino et al., 2019; Shorey et al., 2017; Willis, 2019). This is not to diminish or degrade the impact and importance of mentorship, only to emphasize that mentorship ought to be supplemented as a means by which to cultivate expertise with other educational opportunities. In recent years, evidence relating to PPC has indeed amassed. Although still limited in many respects, there is more evidence with which to inform nursing education on this topic than ever before. Additionally, there is a novel and valuable survey with which to assess healthcare provider competency, attitudes, and knowledge about PPC (Stenekes et al., 2018) that could facilitate the identification of priority educational needs amongst staff at an organizational level. Given the documented unpreparedness of healthcare providers entering the LDR workforce to care for families experiencing PPC (Gandino et al., 2019; Shorey et al., 2017; Willis, 2019), and some specifically sharing a perception of having not been trained to manage perinatal loss in formal preparation for their profession (Martínez-Serrano et al., 2018), undergraduate and diploma programs should, at the very least, introduce concepts of perinatal loss and PPC in courses pertaining to obstetrical care and the health of women and infants. To date, little is known about the extent to which undergraduate or diploma programs for nursing (or other healthcare disciplines for that matter) include content related to perinatal loss or palliative care for fetuses and infants, or about pedagogical strategies (e.g., role play, lectures, concept-mapping, simulation) nursing students find most engaging and effective for learning about PPC. These may also be valuable topics for research moving forward.

Outcomes of enacting expertise during PPC in LDR. Given the scope and purpose of this study, the six outcomes identified of enacting expertise were: (a) mitigating emotional harm; (b) preventing negative maternal health outcomes; (c) adequately supporting staff; (d) thoroughly

completing necessary documentation and tasks; (e) providing love and respect to infants; and, (f) managing neonatal pain and symptoms if present. These outcomes are reflective of how nurses understood their care to impact their patients and colleagues, and are representative of how expert nurses distinguished whether care had gone well or not. Though not exhaustive, these six outcomes are valuable to assist nurses in clinical practice in framing their goals of care when facing perinatal loss in their work on an LDR unit.

Mitigating emotional harm. Several of the six outcomes could be perceived as having application beyond instances of PPC in the LDR setting, such as mitigating emotional harm. Mitigating emotional harm is arguably a very worthwhile outcome for consideration for any healthcare provider meeting a patient experiencing perinatal loss during any point of their care trajectory. Even more broadly, the outcome of mitigating emotional harm is reflective of the ethical principle of non-maleficence which applies generally to medical sciences in all healthcare settings (Canadian Nurses Association, 2017). However, what makes this outcome of striking importance in the LDR setting is first related to the perception of expert nurses that perinatal loss is an inherently emotionally difficult and incredibly challenging experience, and that not all healthcare experiences in the perinatal setting are perceived by nurses this way or to the same degree. Expert nurses in this study certainly expressed a desire to relieve emotional suffering, but recognized that it may not be feasible to entirely alleviate emotional suffering given the magnitude and intensity of negative emotional experiences for parents in circumstances of perinatal loss.

Evidence to substantiate the recognition of the emotional challenges faced by parents experiencing perinatal loss as described by participants in this study appears in the literature on numerous occasions. For instance, a systematic review exploring the psychological effect of

stillbirth and neonatal death on fathers inclusive of seventeen studies, concluded that fathers indeed experience anxiety and depression after the death of the child, and that guilt, shame, loneliness, emptiness, and anger are a few of the difficult emotional experiences that have been reported by fathers after perinatal loss (Badenhorst, Riches, Turton, & Hughes, 2006). There have also been reports of posttraumatic stress disorder after the death of an infant in both fathers (Turton et al., 2006), and in mothers, where posttraumatic stress disorder is often accompanied by a major depressive disorder (Horesh, Nukrian, & Bialik, 2018). In a mixed methods study investigating the psychosocial implications of stillbirth which included perspectives from twenty five women who had experienced stillbirth within the last six to eighteen months, 28% reported having considered suicide after the death of their infant, with 12% of the study population actively thinking about it at the time of the study (Human et al., 2014). To further emphasize the known impact of perinatal loss on the emotions and wellbeing of parents and families, a recent systematic review and meta-analysis examining the psychosocial impact of stillbirth included 144 studies of both qualitative and quantitative methodology published between 2000 and 2016 that concerned the experiences of parents, siblings, future children, and grandparents in their analysis (Burden et al., 2016). Burden et al. (2016) concluded that negative psychosocial symptoms were present post bereavement, and also in subsequent pregnancies after stillbirth. Burden et al., (2016) identified that negative psychosocial symptoms such as incongruent and disenfranchised grief were present in parents of the infant, but also in siblings of the deceased infant and their wider family members (Burden et al., 2016). In parents, psychological and emotional disorders such as "depression, anxiety, social phobia, agoraphobia, negative cognitive appraisals such as a sense of failure and long-term guilt and other posttraumatic stress disorder symptoms, and suicidal ideation" (p. 4) were present after stillbirth. Overall, Burden et al.,

(2016) described stillbirth as having profound and long-term negative impacts for families experiencing stillbirth be those physical, social, financial, or psychological in nature. In a more recent cross sectional quantitative study Kokou-Kpolou, Megalakaki, and Nieuviarts (2018) predicted just how 'long' can be meant by long-term grief/depression when they utilized a hierarchical regression model with a sample of ninety-eight mothers who had been bereaved for an average of forty months to predict the duration of symptoms of depressive disorders related to perinatal loss. They determined, based on factors such as whether the loss was anticipated or not, the presence of negative cognitions about self, world or future, and whether they had other living children, that for some mothers, depressive disorders could persist for greater than ten years after perinatal loss (Kokou-Kpolou et al., 2018).

The second thing that makes the outcome of mitigating emotional harm in the LDR setting of particular significance is that healthcare providers caring for families experiencing perinatal loss have expressed feelings of guilt (Gandino et al., 2019; Shorey et al., 2017) and self-blame (Farrow, Goldenberg, Fretts, & Schulkin, 2013; Shorey et al., 2017) about the care they provided, as well as concerns about how and whether their care may have impacted families emotionally after their discharge (Thornton et al., 2019). Nurses recognize the emotional challenges parents inherently face in relation to their perinatal loss, yet they continue to blame themselves or feel guilty about those parental responses. This poses a junction where a lack of confidence in their ability to provide the best care possible seems well justified. We know nurses lack comfort and confidence in providing PPC (Wool, 2013), and have even expressed the need to avoid, or opt out of providing it (Gandino et al., 2019; Shorey et al., 2017). In order to prevent nurses from feeling guilt, lacking confidence, and potentially avoiding PPC, the outcome of mitigating emotional harm has implications for nursing practice by providing a reasonable

benchmark toward which nurses can strive. This outcome fosters nurses' ability to maintain reasonable expectations of themselves in these care scenarios as total relief of emotional suffering during and after perinatal loss is likely not possible. Of course, expert nurses do all they can to take a terrible experience for their patient and soften pain and suffering as much as possible, but they should not be burdened with an actual or perceived responsibility to bring resolution to the negative emotional experiences of parents. In nursing education, framing an outcome of PPC as *mitigating* emotional harm, expectations of care become far more approachable, especially for those who are new caring for families during perinatal loss. In nursing practice, this outcome allows nurses to prepare for inevitably facing these challenging emotions, and thinking about strategies to validate the feelings and emotional experiences of their patients as opposed to resolving them.

Evidence clearly demonstrates that perinatal loss results in challenging and lasting difficult emotional experiences for families, and that healthcare providers in this study worry about the impact of their care on exacerbating those experiences. What is less known about is the degree to which the actions and interactions with healthcare providers impact the emotional experiences of parents after perinatal loss.

Although nurses inferred that their actions and interactions with patients had an impact on their emotional experience, without contact with families after discharge from the hospital they could only speculate about whether the impact of their care had a lasting effect on parents after discharge, and if so, whether the care they provided could make a lasting impact on parents' emotional experience during bereavement.

This sentiment was echoed by King et al., (2019) when they stated "While we have some idea of the multidimensional effects of stillbirth, we do not understand much about how

healthcare providers factor into those effects" (p.2) (M. Q. King et al., 2019, p.2). It is clear that the degree to which interactions with healthcare providers impact the experience of parents after perinatal loss after discharge from care is unknown and warrants attention in future research. The role of bereavement follow-up practices and programs in mitigating the negative emotional experiences of parents would also be valuable to consider in future research.

Managing neonatal pain and symptoms. This study considered perinatal loss broadly, and included findings which pertain to the care of infants born still, and infants who were born alive but only expected to live for minutes to hours after birth. Study participants reported having more experiences relating to perinatal loss with families of infants who died before birth than those who died in the early neonatal period. Expert nurses reported what made their care unique for the care of infants who were born alive from those who were not was the need to prepare for, assess, and manage infant pain and symptoms of distress.

One such way nurses achieved this was by obtaining orders for pharmacologic treatment of pain and distressing symptoms, and by having necessary medications at the bedside prior to birth. The recommendation to have intranasal fentanyl pre-drawn before the birth and accessible to use immediately upon detection of symptoms was described by Harlos et al., (2013) and has indeed made its way into practice at the participating study sites. Nurses in this study identified that the consequence of not doing so was a missed opportunity to provide the best care possible.

Pain and symptom management is a hallmark of PPC (Balaguer et al., 2012; Catlin et al., 2015; Dickson, 2017). In a review of evidence that was conducted in an effort to summarize the evolution of the concept of PPC, Balaguer et al., (2012) identified infant pain relief was the earliest foundation of PPC. Later, and in large part from borrowing concepts from the adult and pediatric hospice movements, an approach to palliative care during perinatal loss that was

centered around management of pain and symptoms only later became supplemented by the importance of multisensorial comfort, maternal bonding, family-centered care, and a comprehensive and integrative approach to care starting at the time of diagnosis of a life limiting condition (Balaguer et al., 2012). The importance of providing analgesia via the least invasive route has been noted (Catlin et al., 2015), and is particularly important in the delivery room setting as to not impede bonding and attachment between parents and infants (Durrmeyer et al., 2017) thereby supporting the contemporary aspects of PPC as identified by Balaguer et al (2012). Since the publication of their study on the use of intranasal fentanyl in the palliative care of infants and newborns (Harlos et al., 2013), this intervention has been described by others as the most suitable and least invasive option for pharmacologic pain management for palliative care in the context of the delivery room (Garten & Bührer, 2019).

In addition to recommendations for pharmacologic symptom management by the least invasive means possible, non-pharmacologic symptom management has also been emphasized in the literature for infants receiving palliative care (Carter & Brunkhorst, 2017; Catlin et al., 2015; Dickson, 2017; Garten & Bührer, 2019). Although non-pharmacologic pain management for acute or procedural pain in the neonatal intensive care unit has been researched at length, particularly regarding the use of non-nutritive sucking in combination with oral sucrose (Stevens, Yamada, Ohlsson, Haliburton, & Shorkey, 2016), less is known about the efficacy of non-pharmacologic pain management for prolonged pain in infants receiving palliative care. Nonetheless, non-pharmacological interventions that have been recommended for PPC include but are not limited to: keeping lights low and excessive noise to a minimum, providing warmth, providing skin-to-skin contact with parents, opportunities for breastfeeding or non-nutritive sucking for those infants who are able, and interventions such as swaddling and facilitated

tucking when not skin-to-skin with parents (Carter, 2016; Carter & Brunkhorst, 2017; Catlin et al., 2015; Dickson, 2017; Garten & Bührer, 2019). Such interventions have been suggested for use in response to pain and unpleasant symptoms, but are also recommended as a means by which to enhance the overall comfort of an infant who is receiving palliative care and should be incorporated into the routine care of these infants no matter their context of care (Garten & Bührer, 2019).

Despite these consistent recommendations for the provision of non-pharmacologic symptom management in the literature and the expertise described in this study relating to non-pharmacologic pain management strategies for laboring patients, the expert nurses in this study never directly described the provision of pain or distress management for infants by non-pharmacologic means. Though nurses described routinely placing dying infants' skin-to-skin when parents wished to do so, ensuring infants were warm, and keeping a calm environment, expert nurses did not necessarily cite these actions as being in response to infant pain or distress but rather were seen as means by which to treat an infant with love and respect and to promote bonding and attachment.

Practices around the utilization of intranasal fentanyl in response to evidence of infant pain and distress seems to have translated well into practice. However, non-pharmacological strategies for relieving pain and symptoms of distress in infants at the end of life are possibly being underutilized or are not being recognized as a means by which to relieve pain and distress in instances of PPC in the LDR setting. Therefore, a recommendation to provide educational opportunities for nurses which emphasise non-pharmacologic pain and symptom management strategies for non-acute infant pain in the LDR setting is warranted.

Throughout the course of the interviews for this study, nurses discussed making judgements about infant pain and symptoms yet none of the expert nurses discussed the use of a validated tool or pain scale to frame their judgement about whether an infant was experiencing pain or other distressing symptoms. Where symptoms such as dyspnea are concerned, nurses relied on their subjective clinical judgement due to the lack of any validated tools to assess same. In lieu of this, Harlos et al., (2013) recommends that healthcare providers observe for "1) increased work of breathing: tachypnea, nasal flaring, grunting, use of accessory muscles, chest wall retractions and 2) evidence of distress: restlessness, irritability, crying." (p. 267). Still, symptom relief was at the centre of expert nursing care even though they relied on their subjective findings from clinical assessments to make decisions about administration of analgesia. Durrmeyer et al., (2017), reported similar findings about the pain assessments of extremely preterm infants receiving palliative care in the delivery room in their study including 73 infant deaths occurring during a one year period between eighteen participating sites in France. Pain assessments were conducted 72% of the time, but a pain assessment tool was not utilized on a single occasion (Durrmeyer et al., 2017).

Despite the increasing evidence base related to neonatal pain, particularly regarding procedural pain in the neonatal intensive care unit environment (Hatfield, Murphy, Karp, & Polomano, 2019), there is a paucity of evidence inclusive of infants with palliative care needs. The need to assess pain and other symptoms of distress in infants receiving palliative care has been noted on numerous occasions, and in each case it is recommended to use a validated assessment tool (Carter, 2016; Carter & Jones, 2013; Dickson, 2017; Garten & Bührer, 2019).

There are existing validated assessment tools for infant pain and distress, but they have their limitations. Nearly forty tools to assess neonatal pain and distress have been

developed (van Dijk & Tibboel, 2012) and only five have been recognized by the American Academy of Pediatrics (2016) as having undergone rigorous evaluation with infants serving as their own controls by measuring both physiologic parameters and their behavioral responses (American Academy of Pediatrics Committee on the Fetus and Newborn and Section on anestheiology and pain, 2016). With the majority of infant pain assessment tools focusing on acute or procedural pain, even fewer have been validated for use in circumstances of prolonged pain (Garten & Bührer, 2019). In their evaluation of evidence for pain and distress management in palliative care for neonates Garten and Bührer (2019) identified three scales that were validated for prolonged pain in neonates which included the: (a) Echelle Douleur Inconfort Nouveau-Né scale (EDIN scale) (Debillon, 2001); (b) Neonatal Pain, Agitation and Sedation Scale (N-PAS scale) (Hummel, Puchalski, Creech, & Weiss, 2008); and; (c) COMFORTneo scale (van Dijk et al., 2009). The N-PAS scale (Hummel et al., 2008) is the only assessment tool that met the criteria of having been validated for assessment of prolonged pain *and* was recognized by the American Academy of Pediatrics (2016) as being rigorously evaluated where infants served as their own controls. Another feature that separates the N-PAS scale (Hummel et al., 2008) from the others identified is that it does prompt for assessment of sedation, which was indeed a concern of expert nurses in this study.

In a systematic integrative review of infant pain assessment tools conducted by Duhn and Medves (2004), the authors asserted that any of the available scales are limited in truly differentiating the experience of pain from distress resulting from other sensations or unmet needs such as the experience of hunger, agitation from overstimulation, or the need for physical closeness and asserted that it would be more appropriate to refer to these as infant distress scales and this was echoed more recently by Garten and Bührer (2019).

The use of an assessment tool for infant pain and distress is important for two reasons. First, this population does not have the ability to tell us about their pain and it takes a particular skill set to identify signs of pain and distress. Secondly, interventions to relieve pain and distress are indeed being implemented in practice and without the use of assessment tools clinicians have little means by which to determine or communicate the effectiveness of any interventions they have implemented. Overall, infant pain and assessment tools are often utilized in the neonatal intensive care setting and although the existing assessment tools have their limitations regarding application for infants at the end of life in the LDR setting, organizations should adopt use of an assessment tool that most closely meets their needs in order to discern the need for non-pharmacologic or pharmacologic intervention, and to evaluate the effectiveness of any analgesia administered. Additionally, such a scale could be utilized in research to determine the efficacy of pharmacological and non-pharmacological treatments for infants receiving PPC in the LDR setting.

In terms of future research, there remains a dire need to assess pain and other distressing symptoms such as dyspnea in infants of varying gestational age at the end of life, and it would be a worthwhile endeavour to develop a reliable assessment tool to guide the care of infants receiving palliative care in the LDR setting.

Particular educational needs related to management and assessment of infant pain and symptoms can be determined at the organizational level with utilization of the survey to assess health-care provider's competency, attitudes, and knowledge about perinatal palliative care developed by Stenekes et al., (2018) as it is includes items regarding pain and symptom assessment and management.

Enacting expertise in PPC during LDR: Actions and considerations of expert nurses. At the outset of the study, the intent was to provide a context specific description of the necessary nursing behaviors for expert PPC during LDR. The study findings are inclusive of an extensive list of the actions and considerations nurses engage in when providing PPC during LDR. The actions and considerations that transcend the LDR process have been clearly identified (Table 8) from those that are particular to each of the stages of labor (Tables 9 through 12) and each action and consideration integral to the expert practice of during PPC in the LDR identified in this study has been plainly outlined.

Existing models, frameworks, and care pathways for PPC provide useful information about PPC from the time of a diagnosis of a life limiting condition for a fetus through into the bereavement period but fall short in providing specific considerations and actions for nurses to guide their care during the LDR period (Balaguer et al., 2012; Cole et al., 2017; Dickson, 2017; Murdoch et al., 2013; Wool et al., 2016). In addition, a valuable and novel set of quality indicators describing *what* quality care entails has been published, but falls short in describing *how* it is achieved (Wool et al., 2018, 2017). The nursing actions and considerations described in this study can be used in conjunction with the other resources available to fill in the gaps specific to LDR nursing practice to inform their care with evidence.

This description of the actions and considerations by expert nurses provides insight into how nurses think about palliative care in the perinatal setting, how they make care decisions during PPC, and how they carry out the best care possible. PPC requires obstetric nurses to shift their lens from one that is governed by preventing negative health outcomes for maternal *and* infant patients to one that promotes comfort of dying infants and their families while still maintaining medical wherewithal to ensure the wellbeing of the laboring mother throughout the

LDR process. This is no small task. This extensive description of the actions and considerations of expert nurses during PPC provides educators with an important resource to help their students understand how to integrate the principles of palliative care into the complex and dynamic tapestry of standard labor and delivery care, and clinicians with context specific evidence to inform their practice.

Although the role of the nurse during LDR and their provision of intimate often 1:1 care makes them well suited to coordinating PPC (Limbo & Wool, 2016), they alone cannot be responsible for achieving quality care. Research exploring the expert care of other healthcare disciplines involved in PPC during LDR such as midwives, obstetricians, neonatologists, social workers would provide insights into how healthcare professionals as a team can achieve the best care possible in the context of interdisciplinary and collaborative care experiences in the perinatal setting.

Research exploring parent perceptions and experiences of PPC is on the rise, in Manitoba it may be of particular value to explore the perceptions and experiences of parents from diverse backgrounds who face known barriers to accessing healthcare services, such as those of newcomers, refugees, and those living in remote locations who relocate for birth services (Struthers et al, 2014).

Study Limitations

Four limitations specific to this study are acknowledged. The first and perhaps most glaring limitation of this study is related to the study setting. Although the intent of this study was not to produce findings that are generalizable across all healthcare settings, but rather to provide a rich description and interpretation of the findings from the two participating urban tertiary care sites, the findings in the current study are representative of nurses deemed as experts

in only those two urban tertiary care settings. These centers are well resourced when compared to rural settings, and especially when compared to settings in low- and middle-income countries. Perinatal loss knows no bounds but is far less prevalent in well-resourced urban settings where standard care for pregnant woman is inclusive of prenatal care, antenatal screening, and the availability of trained medical staff who provide care and monitoring during the intrapartum period. In this study setting, all of these necessities for high quality maternal child care are in place. The Lancet recently published a series on ending preventable stillbirths by 2030 and reported that at the time of the report, 98% of stillbirths occur in low and middle income countries, and half of those take place during the labor and delivery process (De Bernis et al., 2016; Lawn et al., 2016). Many of the stillbirths that occur during labor and delivery are considered preventable with access to high quality prenatal and intrapartum care (De Bernis et al., 2016; Lawn et al., 2016). And although the resources for and bereavement care after stillbirth are not always available for populations in low- and middle-income countries, it is nonetheless recommended when a family experiences perinatal loss (Heazell et al., 2016). This limits the generalizability of findings to this urban context of care within a healthcare system, that despite its limitations, is revered around the world.

Second, this study considered perinatal loss broadly and did not always distinguish between the care of families whose infants were born still and those whose infants were liveborn but died shortly after birth. The study was intended to provide detailed evidence with which to inform practice in the LDR setting which was achieved in certain respects. With the exception of a few of the findings, the study does not differentiate between the PPC of families anticipating stillborn and live born infants with a life limiting condition who may have different needs, preferences and hopes relating to the status and condition of their infant.

Third, the researcher's personal experience working in the LDR setting and caring for families experiencing perinatal loss unavoidably contoured the study from conception of the idea through analysis and the conceptualization of implications for the nursing practice. This experience indeed sensitized the researcher to the need for this study from a clinical perspective but has also inevitably shaped the research findings.

Fourth, data collection for this study relied singularly on participant interviews. Observation was not a component of the data collection in this study but may have been valuable in understanding more deeply the social structures informing the behaviors of expert nurses, as well as the facilitators and barriers they encountered in providing care.

Recommendations for Nursing Practice, Administration, Education, and Research

The findings of this study investigating expert nursing practice in the LDR setting when PPC was indicated provided the foundation upon which recommendation for nursing practice, administration, education, and future research have been made. Implications for these various domains of nursing have been discussed throughout this sixth and final chapter and Table 13 presents a summary of those recommendations deemed most important and is presented next.

Table 13
Summary of Implications for Nursing

Domain of Nursing	Recommendations
Nursing Practice	1. Nurses should only be assigned to care for families experiencing perinatal loss when they have an adequate foundation of standard labor and delivery care, have previously received mentorship for PPC by way of observation or 'buddying' with experienced colleagues previously, and readily have access to support from more experienced colleagues during the shift for which they are assigned to provide PPC. **2.** Nurses who have a foundation of standard labor and delivery care are better suited to engage in mentorship relationships with more experienced nurses to learn about PPC than those who do not have a strong foundation of standard labor and delivery care. 3. The six outcomes of enacting PPC during LDR developed in this study can assist nurses in framing goals of care when providing PPC. 4. The resources developed in this study that provide an extensive description of the actions and considerations of expert nurses can be used in conjunction with other resources available to inform nursing practice during PPC in the LDR setting practice with evidence.
Nursing Administration	1. After nurses provide PPC, opportunities to debrief with their colleagues should be available 2. After nurses provide PPC, access for support services such as counselling must be available 3. Organizations should promote the importance of self-care activities for frontline healthcare providers working with families experiencing perinatal loss, and create opportunities for staff to engage in self-care whenever possible 4. Organizations should endorse models of care in the LDR setting that promote expert care, and staffing levels and nursing assignments should reflect the additional time needed for expert care during PPC enabling nurses to contribute to patient satisfaction and quality outcomes. 5. The cultivation of expertise in PPC relies heavily on nurse to nurse mentorship. Organizations should endorse educational opportunities for nurses to develop competence for mentorship. 6. Expert nurses should have support and recognition from the organization to take on mentees in order to foster the growth of other nurses in PPC and build capacity for the quality care of families experiencing perinatal loss. 7. Organizations should adoption use of a validated tool for assessment of infant pain and symptom management to discern the need for pharmacologic and non-pharmacologic intervention, and to evaluate the effectiveness of any interventions offered.
Nursing Education	1. Nurse educators must play a role in sensitizing actual and potential perinatal nurses to the need for expertise in PPC by providing exposure the concepts of perinatal loss and PPC in undergraduate and diploma programs for nursing as well as during orientation to the LDR area for new hires. 2. The need for formal and vocational training related to PPC has been consistently identified in response to healthcare providers reporting a lack of training, a sense of unpreparedness, and a lack of confidence regarding the provision of PPC.

There is more evidence with which to inform nursing education on the topic off PPC than ever before. Undergraduate and diploma programs should introduce concepts of perinatal loss and PPC in courses pertaining to obstetrical care and the health of women and infants.

3. In depth learning opportunities about perinatal loss and PPC should be offered during orientation to LDR for new hires.
4. Organizations can use the survey developed by Stenekes et al., (2018) to assess the competency, attitudes, and knowledge about PPC to facilitate the identification of priority education needs related to PPC amongst staff at an organizational level on an ongoing basis.
5. The six outcomes of enacting PPC during LDR developed in this study can be utilized in nursing education to explore reasonable benchmarks for goals of care, helping to make the concept of PPC approachable for healthcare providers.
6. Non-pharmacological strategies for relieving pain and symptoms of distress in infants and the end of life are possibly being underutilized or are not being recognized as a means by which to relieve pain and distress. Nursing education on non-pharmacologic pain and symptoms management strategies for non-acute infant pain is warranted.
7. Education regarding assessment of infant pain and symptoms using a validated tool during PPC in LDR should be offered.
8. The resources created for this study extensively describing the actions and considerations of expert nurses during PPC provides educators with an important resource to help their students understand how to integrate the principles of palliative care into the complex and dynamic tapestry of standard labor and delivery care.

Nursing Research

1. Little is known about the extent to which undergraduate or diploma programs for nursing and other healthcare disciplines include content related to perinatal loss or PPC, or about or about pedagogical strategies (e.g., role play, lectures, concept-mapping, simulation) students find most engaging and effective for learning about PPC. These are valuable topics for research moving forward.
2. The degree to which interactions with healthcare providers impact the experience of parents after perinatal loss after discharge from care is unknown and warrants attention in future research.
3. The role of bereavement follow-up practices and programs in mitigating the negative emotional experiences of parents would should be considered in future research.
4. Development of an assessment tool to assess pain and other distressing symptoms such as dyspnea in infants of varying gestational age at the end of life is a priority for future research. Such a tool could be utilized in further research to determine the efficacy of pharmacological and non-pharmacological treatments for pain and symptoms in infants receiving PPC in the LDR setting.
5. Research exploring the expert care of other healthcare disciplines involved in PPC during LDR such as midwives, obstetricians, neonatologists, social workers would provide insights into how healthcare professionals can achieve the best care possible in the context of interdisciplinary and collaborative care experiences in the perinatal setting.
6. Exploration of the perceptions and experiences of parents from diverse backgrounds, particularly of those living in remote locations who relocate for birth services as there are known barriers to accessing healthcare services, would provide valuable insight for healthcare providers to adequately meet the needs of individuals experiencing perinatal loss who face known barriers to accessing healthcare services.

Conclusion

This study sought to redress the current paucity in evidence regarding the nature of expert nursing practice when PPC is indicated in the LDR setting. Interviews with seven nurses deemed as experts in PPC by their colleagues led to the development of a conceptual model outlining the non-linear process of cultivating expertise in PPC in the LDR setting, a set of six outcomes for expert nursing care particular to PPC during the LDR period, and a comprehensive series of considerations and accompanying actions expert nurses engage in across the LDR process. The findings substantiated existing evidence in the milieu of expert nursing practice, and also in that of PPC, and made novel contributions to existing literature by adding specificity to how expert nursing is cultivated and enacted when PPC is indicated in the LDR setting. This sixth and final chapter situated the study findings within the context of existing evidence, reviewed the study limitations, and posed recommendations and for nursing education, administration, practice, and research.

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APPENDIX A
Disclaimer for the Study and Nomination Form

Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, Recovery, and the Recovery Period

Principal Investigator: Chloe Shindruk RN, BN, Graduate Student
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University of Manitoba

This is an invitation to you to participate in a research study being conducted on your unit titled "Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period

Purpose of the study:
The purpose of this study is to identify the important actions to take in order to provide excellent nursing care for families expecting their infant to be born still or to live only minutes to hours after delivery. This Disclaimer form, a copy of which will be left with you for your records and reference, should give you the basic idea of what the research is about, and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please feel free to ask. Please take the time to read this Disclaimer carefully, and to understand any accompanying information.

This research has been approved by the Education and Nursing Research Ethics Board, at the University of Manitoba, and approval for access has been obtained from this facility. If you have any concerns or complaints about this project you may contact me, Chloe Shindruk at (204) 474-9476, my academic supervisor, Dr. Genevieve Thompson at (204) 474-8818, or the Office of Research Services at the University of Manitoba directly at (204) 474-8418.

How the study will take place:
There are two phases to this study. If you agree to take part in phase one, you will be asked to anonymously nominate a nurse you work with who you see as an expert in caring for families experiencing perinatal loss. You will be provided a form to help you with the nomination process. It is estimated that this process should take less than 10 minutes of your time to complete. Nurses who receive a minimum of three peer nominations will be invited to participate in the second part of the study. The second phase of

the study involves one-to-one interviews with the researcher with a focus on understanding the actions of expert nurses when providing care for families experiencing perinatal loss.

You are asked not to sign your name on this form. By identifying the *name of at least one nurse* who best fits the description outlined, you will be giving your consent to participate in this phase of the study. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. The information on this form is confidential and will only be accessed by the researcher Chloe Shindruk.

Instructions for Nominating Peer Experts
Please read the following instructions carefully and indicate the name(s) of the nurse(s) that you work with who best fit the description. Please nominate at least one nurse and as many as three nurses. Please feel very welcome to nominate yourself.

1. **Nominate Peer Expert(s)**

If there was a family on your unit experiencing perinatal loss, which of your nursing colleagues would you want at their bedside?

Name of Nurse _____

Name of Nurse _____

Name of Nurse _____

2. **Describe Peer Expert(s)**

Can you briefly describe what makes these nurses/ you stand out amongst your other colleagues in terms of how they provide care for families experiencing perinatal loss?

_____

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Appendix B
Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period
LETTER OF INVITATION TO PARTICIPATE

Dear_____ (Potential Participant);

You have been nominated by your colleagues as an expert in the care of families experiencing perinatal loss during their labor, delivery, and recovery period in a hospital setting. As an expert, you are invited to participate in a study that has been designed to learn about the behaviours that expert nurses engage in when providing care for families experiencing a perinatal loss during their labor, delivery, and recovery. Nurses on your unit who received a minimum of three peer nominations are being invited to participate in this study. The knowledge gained from this study will contribute toward the development of a description about the nursing care of families experiencing perinatal loss.

If you agree to participate, you will be asked to take part in one to three digitally audio recorded interviews lasting approximately 60 minutes each with the researcher Chloe Shindruk. Interviews will be scheduled outside of work time, at a time and place convenient for you.

Please make the selection of your choice:
[___]If you wish to know more about the study prior to making a decision, please contact the researcher Chloe Shindruk by telephone (204) 474-9476, or email umshindr@myumanitoba.ca

[___] Yes, I agree to participate in this study. You can contact me with further information.
Name: _____
Telephone number:_____
Best time to call: _____
Email address: _____

Once you have marked your selection above, please:
Place the completed 'Invitation to Participate' in the accompanying envelope; stamped and marked "confidential" and addressed to the researcher, Chloe Shindruk;
Seal the envelope and drop the envelope into the mail.

This research study has been approved by the University of Manitoba Education Nursing Research Ethics Board.

Thank you for considering this invitation. A prompt reply is most appreciated.

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Appendix C
RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
Individual Interview

Title of Study: Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period

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Sponsor: Manitoba Centre for Nursing and Health Research
College of Nursing Endowment Fund Graduate Student Research Grant

You are being invited to participate in a research study involving individual interviews. This consent form, a copy of which will be left with you for your records and reference, is only a part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Study
The purpose of this study is to identify the important actions to take in order to provide excellent nursing care for families expecting their infant to be born still or to live only minutes to hours after delivery.

You have been invited to participate because you were nominated by your colleagues as an "expert" in the care of families experiencing a perinatal loss. You have received a verbal explanation of the study and have had an opportunity to have your questions answered. You will be one of approximately 10 nurses participating in this study who were also nominated by their colleagues.

How the study will be done
If you agree to participate, you will be invited to partake in one to three digitally audio-recorded interviews lasting approximately 60 minutes each. These audio recordings will be transcribed by (insert name once determined) to ensure accurate reporting of the information you provide. The transcriber will sign a form stating that they will not discuss any item on the recording with anyone other than the researcher. These interviews will be scheduled outside of your work hours at a time and place that will be convenient for you. The researcher, Chloe Shindruk, will facilitate the interview discussion by asking you questions, and will interview you in person one-on-one. During the interview you will be asked to recall situations from your clinical practice when you have cared for families experiencing a perinatal loss. You will be asked questions about what things you consider during the care of families experiencing perinatal loss during different stages of their labor, delivery, and recovery period. You will be asked to reflect about times you felt care for families experiencing a perinatal loss went well, and about times the care did not go as well as you had hoped. You will be asked about how you learned to provide care for families experiencing a perinatal loss. These questions will help the researcher to better understand the actions of expert nurses when providing care for families experiencing perinatal loss. You may decline to answer any questions and you may withdraw from the study at any time.

Risks and Discomforts
The risks anticipated for participation in this study are minimal and there are no costs associated with participation in this study. The possibility does exist that recounting experiences about providing care for families experiencing perinatal loss during the interviews may be emotionally upsetting. In that event, you are free to stop the interview and discuss your feelings with the researcher, or a support person of your choosing. If you require further support counsellors will be available to you by contacting the Blue Cross Employee Assistance Program. The Employee Assistance Centre is open 24 hours a day, 7 days a week. To contact the centre call (204) 786-8880 or 1-800-590-5553 (toll free).

Benefits
Although you will derive no direct benefits from participation in this study, the knowledge gained through this study will contribute toward improving the care provided to families experiencing perinatal loss in the labor, delivery, and recovery setting.

Costs or Payment for Participation
The interview will be set up at a time and place convenient for you. There will be no financial cost to you for taking part in this study. You will not receive payment or reimbursement for any expenses related to taking part in the study.

Confidentiality
Your participation in the study is considered confidential. A list of names and contact information of participants will be kept in a secure file so we can send you a summary of the results. You will be assigned a code number, and your name will not appear on any documents or digital audio files. This will protect your identity and the identity of any colleagues, patients or families you may discuss. All information collected is also considered to be confidential. During the course of the study, the data collection forms will be stored in a locked cabinet and will only be reviewed by the research team and the individual hired to transcribe the digital audio files. The digital audio recordings will be shared with the transcriber on a password protected flash drive. That flash drive will be returned to the researcher once the transcripts are completed. The consent forms will be stored in the same manner, in a separate location. The digital audio files and coded information will be stored on a password protected computer. At the completion of the study, the data collection forms, transcripts, and digital files will be retained for a period of ten years until February 2029, following which they will be destroyed.

The results of this study will be published in the form of a journal article and may be presented at various professional conferences. Additionally, the study findings will be presented to the staff working at participating sites, and will be presented verbally and in writing as a part of the requirements for the completion of the researcher's Master of Nursing thesis project. Any excerpts, such as quotes, from individual interviews used in presentations or publications will not contain any identifying information. Instead, a unique code identifier assigned to each participant will be used. Participants will be described using the basic demographic information, and no other identifying information will be disclosed. Individual participants will not be described

The University of Manitoba Nursing/Education Research Ethics Boar and a representative(s) of the University of Manitoba Research Quality Management/ Assurance office may also require access to your research records for safety and quality assurance purposes. All of these organizations have a professional responsibility to protect your privacy.

Voluntary participation and withdrawal from the study
Taking part in this study is voluntary. You decide whether to take part. You may refuse to participate. If you choose to take part, you may withdraw from the study at any time by letting the researcher know in person, by telephone, or by email. Your decision not to participate or to withdraw from the study will not affect your performance evaluation at work.

Debriefing and Study Findings
There will be two opportunities for you to debrief, receive information about the study findings, and provide feedback. The first involves your participation in the validation portion of the interview. This is an opportunity for the researcher to ask you for your thoughts about the collective findings from all of the interviews conducted up to that point to see if they represent your experience. This will take place during the interviews themselves and does not require an additional time commitment from you. Second, once the study is completed the researcher will present the findings at your facility. At this time, you will have the opportunity to complete a brief voluntary anonymous evaluation form about the information presented that will be used to help inform future research and educational activities.

Additionally, you will have the opportunity to receive information concerning the findings of this study. On the last page of this consent form there is space to indicate if you would like to receive a summary of the study results by mail or email. Once the findings are complied, the researcher will send the summary to you directly to the address you provide in approximately 6 months time.

Questions
If you have any questions or concerns about the study, you may contact the researcher, Chloe Shindruk, at (204)474-9476 or umshindr@myumanitoba.ca. For questions about your rights as a research participant, you may contact The University of Manitoba, Education/Nursing Research Ethics Board Office and the Human Ethics Coordinator at (204) 474-7122 or humanethics@umanitoba.ca.
Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent
Your signature on this form indicates that you have read and understood all 4 pages of this consent form to your satisfaction, and that you have had a chance to ask questions and have received satisfactory answers to all of your questions regarding participation in the research project. Your signature also indicates that you agree to participate in the study. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB), University of Manitoba Research Ethics Board. The Research Ethics Boards and research access committees of the hospitals participating in this project have also given their approval. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Coordinator at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation.

Participant Signature:

_____

Date (day/month/year): _____/_____/___

Participant's printed name:

_____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed Name:

_____

Date (day/month/year): _____/_____/_____

Signature: _____

Role in study:

_____

I would like to receive a summary of the results of this study:

Yes: _____

Name:
_____

Address:
_____

_____

Email Address:
_____

Appendix D Demographic Questionnaire for Nurses Site ID#_____

Participant I.D.#_____ Date _____(dd/mm/yy)

1. Gender:
    a. _____Female
    b. _____Male
    c. _____Other

2. Age now:
    a. _____ (years)

3. Employment status:
    a. _____ Full time
    b. _____ Part time
    c. _____ Casual

4. Current place of employment:
    a. _____ Health Sciences Centre
        i. _____LDR
        ii. _____Women's health float team
    b. _____ St. Boniface General Hospital
        i. _____LDR
        ii. _____Women's health float team

5. Number of years/months experience as a registered nurse: _____ (years/months)

6. Number of years/months experience as an obstetrical nurse: _____(years/months)

7. Number of families you have cared for who were experiencing a perinatal loss (i.e., their infant was born still or only lived minutes to hours after birth):
    a. _____ 1 to 10 families
    b. _____ 10 to 30 families
    c. _____ 30 to 50 families
    d. _____ greater than 50 families

8. Most recent level of nursing education completed:
    a. _____Registered Nursing Diploma
    b. _____Register Psychiatric Nursing (Degree or diploma)
    c. _____Post-Diploma Degree in Nursing
    d. _____Baccalaureate Degree in Nursing
    e. _____Baccalaureate Degree in Midwifery
    f. _____Master Degree in Nursing

9. Have you completed a post-basic / specialized palliative care course or training?
    a. _____Yes
    b. _____No

If answered Yes, please describe:_____

10. Have you received post-basic/ specialized training in perinatal care?
    a. _____Yes
    b. _____No

If answered Yes, please describe:_____

***THANK YOU ***

Appendix E

Semi-Structured Interview Guide

1. Tell me about what it is like to care for a family anticipating their infant to be born still or die shortly after birth?

2. What sorts of things do you consider when you are interacting with and caring for a family anticipating perinatal loss during the different stages of labor?

    a. Vaginal Birth
        i. First stage: (early labor, active labor and transition into second stage labor)
        ii. Second stage: (pushing and delivery of the infant)
        iii. Third stage: (delivery of the placenta)

    b. Caesarean Birth
        i. What, if anything, is different about providing perinatal palliative care for a family experiencing perinatal loss if a caesarean section is indicated?
        ii. How does the setting of the operating room influence the care you provide?

3. What sorts of things do you consider during the recovery period?
        i. While monitoring the maternal vital signs?
        ii. While assessing or managing any symptoms if the infant is born alive but expected to die?
        iii. While engaging in any rituals around the death of the infant (i.e. memento making/ family photos/ washing and dressing infant)?

4. What kinds of things do you need to think about and do in order to provide families experiencing perinatal loss with the best care possible?
    a. Are there things that make it hard for you to provide them with that sort of care?
    b. Are there things that make it easier for you to provide them with that sort of care?

5. Can you recollect a time when you were providing care for a family experiencing a perinatal loss you feel went well?
    a. What went well about that?
    b. What impact does that kind of care have on:
        i. You?
        ii. The healthcare team you are a part of?
        iii. The family that was being cared for?

6. Can you recollect a time when you were providing care for a family anticipating/experiencing a perinatal loss you feel did not go as well as you had hoped?
    a. What would you have changed? How might you have changed those things?
    b. What impact does that kind of care have on:
        i. You?
        ii. The healthcare team you are a part of?
        iii. The family being cared for?

7. Your colleagues have identified you as being an expert at providing perinatal palliative care during the labor, delivery, and the recovery period. How did you go about learning to provide care to families experiencing a perinatal loss?
    a. What resources or people did you find helpful?
    b. Are there any resources or people that you continue to turn to for help or guidance when you are providing perinatal palliative care?

8. If you could give a pearl of wisdom about perinatal palliative care to new nurses working in labor and delivery, perhaps something you had wished you would have known when you began working in labor and delivery, what might you share with them?

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Appendix F

ATTENTION NURSES

There is a research project currently underway on your unit.
The purpose of this study is learn about expert care for families experiencing perinatal loss.

There are two parts to the study:

Part I involves the identification of nurses who are seen as experts in the care of families experiencing perinatal loss. This is done by nominating those who you work with.

If you are interested in participating, please look at the form called "Disclaimer for the study and nomination form" and complete the second page of the form. You do not sign your name on the nomination form.

Please leave any completed nomination forms in the ballot box located in the Staff Room. The researcher, Chloe Shindruk, will collect the ballot box in two weeks.

In Part II of the study, the experts, who have been identified by their colleagues, will be sent an invitation to participate which involves face-to-face, digitally audio recorded interviews with the researcher Chloe Shindruk. This interview will be scheduled outside of work time at a time and place convenient for you. All names of the staff members who participate in Phase II of the study will be kept confidential.

If you have any questions about this research study, please do not hesitate to contact the researcher, Chloe Shindruk, at telephone number (204) 474-9476 or by email at umshindr@myumanitoba.ca

This research study has been approved by the University of Manitoba Education Nursing Research Ethics Board.

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Appendix G

Evaluation Form

Today you have attended a presentation about the findings from the research study titled *Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period* that recently took place on your unit. As a part of that study, the researcher (Chloe Shindruk) is interested in collecting information from nurses in response to the study findings that have been presented. The information collected on this form might help to inform future educational activities and research projects.

It is anticipated this form will take approximately five minutes to complete. The purpose of this evaluation form is to: (1) determine whether you think the findings of the research study that have been presented might be helpful for you as a healthcare provider; and (2) to identify future directions for research in the area of perinatal palliative care.

Completion of this anonymous evaluation form is voluntary. The anonymous comments on this form may be used for teaching and research purposes. The completion of this evaluation form will be taken to mean that you agree for your comments to be used help inform future educational activities and research projects.

1. Did you learn something new during this presentation? (check one)
   _____ YES

   _____ NO

2. If you checked yes, what did you learn? (Please write in the space provided below)

3. In your opinion, will the findings presented from the research study be helpful for your healthcare practice?
   _____ YES (see question 4)

   _____ NO (see question 5)

4. If you checked yes, what do you think will be most helpful for you in your healthcare practice? (Please write in the space provided below)

5. If you checked no, why do you think the findings presented are not helpful or applicable to your healthcare practice? (Please write in the space provided below)

6. When thinking about perinatal palliative care, what would you like to know more about? (Please write in the space provided below)

Appendix H
Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period
SCRIPT FOR STUDY INFORMAITON SESSION

Hello, my name is Chloe Shindruk and I am a registered nurse and a graduate student in the Mater of Nursing Program at the University of Manitoba. I am here today to tell you about the research study I am conducting as my thesis project. It is titled "Expert Nursing Care: Perinatal Palliative Care during Labor, Delivery, and the Recovery Period".

This study is taking place at two hospitals here in Winnipeg, and your unit (LDR) is one of the two participating units.

The purpose of this study is to identify the important actions to take in order to provide excellent nursing care for families expecting their infant to be born still or to live only minutes to hours after delivery.

There are two phases to this study. Today, you will have the opportunity to voluntarily and anonymously participate in the first part of the study. If you agree to take part in phase one today, you will be asked to anonymously nominate one to three nurses you work with who (you may nominate yourself) you see as an expert in caring for families experiencing perinatal loss. You will be provided with a form to help you with the nomination process. It is estimated that this process should take less than 10 minutes of your time to complete. When I leave the room, nomination forms will be available to those of you who are interested in participating and once you have completed your nomination forms you can leave them in this locked ballot box. A locked ballot box and additional nomination forms will be available on your unit at the nursing station for the next two weeks should you elect to participate at a different time. This will also be available for those of your colleagues who are unable to be here today.

Once all of the completed nomination forms are collected (in about two weeks), I will tally the results and the nurses who receive a minimum of three peer nominations will be invited to participate in the second part of the study. The second phase of the study involves a series of one-to-one audio-recorded interviews with me scheduled outside of work time. These interviews will have a focus on understanding the actions of expert nurses when providing care for families experiencing perinatal loss. All names of the staff members who participate in Phase II of the study will be kept confidential. It is anticipated that approximately 10 nominated nurses between the two sites will participate in the study.

Once the study is complete, I will share the research findings with you and your healthcare team.

This research has been approved by the Education and Nursing Research Ethics Board, at the University of Manitoba, and approval for access has been obtained from this facility. If you have any concerns about this project you may contact me, Chloe Shindruk, my academic supervisor, Dr. Genevieve Thompson, or the Office of Research Services at the University of Manitoba directly. That information can be found on the nomination forms.

Questions? Thank you for your time.