**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. In Canada, the majority of these infants are born still or die during birth, and families most often face 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 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; Dickson, 2017; Limbo & Wool, 2016). During labor, delivery, and the recovery (LDR) period, it is often nurses who rise to the challenge of providing and coordinating this care (Leuthner & Lamberg Jones, 2007; Limbo & Wool, 2016; Ramer-chrastek & Thygeson, 2005). To date, the behaviors that nurses engage in to provide PPC, particularly of those nurses who are recognized by their nurse peers as being exceptionally skilled at providing PPC, have not been documented.

**Purpose.** 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 is: (1) to 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) to describe what factors promote or impede the ability of nurses to develop and carry out these behaviors; and (3) to describe the consequences of being able or not being able to enact these behaviors when providing care.

**Design.** Utilization of interpretive description, a qualitative research methodology that, by design, places emphasis on yielding knowledge for application in clinical practice (Thorne, 2016), will facilitate the development of this description. Benner’s Novice to Expert Model (Benner, 2001) and the discipline of nursing will provide the scaffolding for the theoretical forestructure of this study.

**Setting.** This study will include two participating tertiary care sites in Winnipeg, Manitoba each with one participating LDR unit.

**Sample and recruitment.** A purposive sample of 10 registered nurses will be identified and recruited through a two-step process. First, all registered nurses working on the participating units will be invited to anonymously participate in the nomination process by identifying up to three colleagues they deem experts at the provision of PPC by filling out a simple nomination form and returning that form to a locked ballot box conveniently located on their unit. Second, peer nominated nurses meeting study inclusion criteria will receive a letter of invitation to participate in up to 3 face-to-face semi-structured audio recorded interviews each approximately 60 minutes in duration.

**Data collection.** Once informed consent is obtained, participants will be asked to provide some demographic information. Next, the semi-structured interviews conducted by the researcher will be arranged at a place and time that is suitable for both parties. These interviews will be audio recorded and transcribed verbatim for the purposes of data analysis. During these interviews, nurses will be asked to
recollect a time they provided care for a family experiencing a perinatal loss. They will be asked what their experience providing that care was like, and how caring for a family experiencing the death of their infant is different than caring for a family anticipating a well infant. Other questions will be posed to engage them in a conversation about what they believe constitutes expert nursing care for families receiving PPC, and what factors promote the ability for a nurse to develop and carry out this care. Questions will also be asked about what makes it difficult for a nurse to develop or carry out this care. Finally, participants will be asked about the impact that achieving or not achieving expert PPC care has on themselves, their healthcare team, and the families they care for.

Data analysis. Demographic data will be analyzed utilizing descriptive statistics in order to portray the population of nurses who participated in the study. Thematic analysis as outlined by Braun and Clarke (2006) will be used to guide analysis of the interview transcripts.

Ethical Considerations. Ethical considerations have been made for this study given the delicate and sensitive nature of the topic of perinatal loss. Prior to an interview the researcher will invite participants to take a break or stop the interview at any point should they find the interview upsetting. The researcher will be attuned to any verbal or nonverbal cues that the participant may be feeling distressed or upset and will be sure to check in with participants during the interviews to ensure they are comfortable to continue discussing their experiences and thoughts about this topic. Additionally, nurses will be provided with contact information for counselling and support services should they find themselves in need of further support. This contact information will be embedded in the informed consent forms for this project and will be reviewed as part of the consenting process.

Dissemination. Upon completion of this project, mechanisms of dissemination and knowledge exchange will include the following: (1) Publication in scholarly journals such as Journal of Obstetrics, Gynecology and Neonatal Nursing or the Journal of Perinatal and Neonatal Nursing; (2) Findings will be presented at participating research sites, Winnipeg Regional Health Authority Palliative Care Rounds, and conferences such as the International Congress on Palliative Care, the Canadian National Perinatal Research Meeting, the Canadian Association of Perinatal and Women’s Health Nurses Annual Conference, or the Manitoba Pediatric Health Conference; (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.

When the findings are shared with the participating sites, a simple anonymous evaluation form will be administered to solicit feedback from the healthcare staff about those findings. 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.

Significance. The death of an infant can result in deep and lasting suffering for women and the families they are a part of. The aptitude, confidence, and tenor of care families are met with during this time of life matter (Wool, 2013), and nurses can help to enhance their healing processes though acknowledging and responding to individual families based on their particular needs (Cole et al., 2017). Despite this, little is known about the behaviours expert nurses engage in during their care.

There is a growing demand from the Canadian government and Canadian healthcare organizations that healthcare practice across disciplines and healthcare settings be informed by evidence. At present, how nurses might develop and provide expert nursing care in this context has not been thoroughly investigated thereby hindering the ability of nurses to provide expert care informed by research evidence. This project aims to close that gap, to serve needs of Canadian women and their families during this delicate time of life, and to support the nurses who aim to provide them the best care possible. Furthermore, conducting and disseminating research in the milieu of perinatal palliative care promotes equitable opportunity for healthcare that is informed by evidence for women and their families.
Acknowledgements. This study is supported by the Manitoba Centre for Nursing and Health Research and the College of Nursing Endowment Fund Graduate Student Research Grant.

Title:
Expert Nursing Care: Perinatal Palliative Care During Labour, Delivery, and the Recovery Period

Keywords:
Expert nursing practice, Interpretive description and Perinatal palliative care

References:


Abstract Summary:
Some infants are expected to be born still or only to live for minutes to hours after birth. This presentation will provide a description of a qualitative research study investigating the expert nursing care of families who experience perinatal loss and receive perinatal palliative care during labour, delivery, and recovery.
Content Outline:

- **Statement of the problem**
  - Perinatal palliative care (PPC) is the care of families from the time of learning of a life limiting diagnosis for their fetus into the bereavement period after the death of their infant
  - In Manitoba, families often face these losses on a labour, delivery, and recovery (LDR) unit
  - In this setting nurses provide 1:1 care for families and rise to the challenge of coordinating PPC
  - Nurses skillfully weave the tenets of palliative care into the complex tapestry of LDR care
  - The behaviors that nurses engage in to provide PPC, particularly of those who are recognized by their peers as being exceptionally skilled at providing PPC, have not been documented

- **Purpose**
  - Describe 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
  - Describe what factors promote or impede the ability of nurses to develop and carry out these behaviors
  - Describe the consequences of being able or not being able to enact these behaviors when providing care

- **Design**
  - Interpretive description, a qualitative research methodology that places emphasis on yielding knowledge for application in clinical practice
  - Theoretical forestructure:
    - Discipline of Nursing
    - Benner’s From Novice to Expert Model (1984)

- **Setting**
  - Two participating tertiary care sites in Winnipeg, Manitoba, Canada each with one participating LDR unit.

- **Sample and recruitment**
  - Purposive sample of 10 registered nurses deemed as experts at the provision of PPC by their colleagues
  - Identified through an anonymous nomination process
  - Nominated nurses will receive a letter of invitation to participate in the study

- **Data collection and analysis**
  - Participants will take part in up to three semi-structured face-to-face interviews
  - Audio recorded interviews will be transcribed verbatim
  - Data analysis:
    - Demographics: Descriptive statistics
    - Qualitative data: Thematic analysis

- **Dissemination plans**
  - Scholarly journals (e.g., Journal of Obstetrics, Gynecology and Neonatal Nursing)
  - Conferences (e.g., Canadian Association of Perinatal and Women’s Health Nurses Annual Conference)
  - Online platforms (e.g., perinatalhospice.org & Canadian Virtual Hospice)
  - Participating sites and WRHA Pediatric Palliative Care Team
    - Voluntary anonymous evaluation form to solicit feedback and identify priorities for future research
• Ethical considerations
  o Perinatal loss is a delicate and sensitive topic for some people
  o Check-in with participants during interviews and welcome to stop or break from interview
  o Participants provided with contact information for counselling and support services

• Significance
  o Growing demand from the Canadian government and healthcare organizations that healthcare practice across disciplines and settings be informed by evidence
  o How nurses might develop and provide expert PPC in LDR setting has not been investigated
    ▪ Hinders ability of nurses to provide care informed by research evidence
  o Project aims to close that gap, to serve needs of Canadian women and their families during this delicate time of life, and to support the nurses who aim to provide them the best care possible

• Acknowledgements
  o Supported by the Manitoba Centre for Nursing and Health Research and the College of Nursing Endowment Fund Graduate Student Research Grant

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