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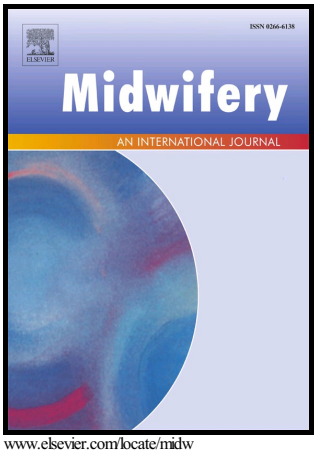

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Perinatal Palliative Care: Integration in a United States Nurse Midwifery Education Program

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Abstract

Midwifery students with perinatal palliative care education develop a skillset to provide holistic midwifery care to women and families who are experiencing stillbirth or life-limiting fetal diagnoses. This paper presents a model of perinatal palliative care in a United States midwifery education program. By utilizing evidence based practices and national programs, perinatal palliative care can be threaded through midwifery curricula to achieve international standards of practice and competencies. Most importantly, enhancing perinatal palliative care education will better prepare future midwives for when a birth outcome is not what was expected at the outset of a pregnancy.

Keywords: Perinatal palliative care, midwifery education

Background

The World Health Organization (2016) describes palliative care for the neonate as a holistic, multidisciplinary approach to the physical, emotional, spiritual and social aspects of the neonate and family, beginning at the time of diagnosis. The goal of perinatal palliative care (PPC) is to comprehensively provide quality of life to families as they await a neonate with a life-limiting fetal diagnosis (LLFD) (Wool, 2013). PPC is tailored care throughout pregnancy, birth, and the postpartum period, to meet each family's individual needs when faced with a LLFD (Hasegawa & Fry, 2017; Wool, 2013).

Midwives can utilize PPC in the antepartum, intrapartum, and postpartum practice settings. In the United States, a total of 23,595 fetal deaths at 20 weeks of gestation or more were reported in 2013 (Macdorman & Gregory, 2015). Fetal mortality occurs disproportionately in non-Hispanic Black women, and is more common among teenagers and women 35 years or more of age (Macdorman & Gregory, 2015). The PPC model of care may be beneficial for women experiencing a stillbirth, as well as those who receive a LLFD resulting from genetic disorders or congenital anomalies. With robust noninvasive genetic prenatal testing, pregnant women are receiving LLFD earlier in their pregnancies. Women are faced with decisions surrounding continuing pregnancy verses termination. In the United States, approximately 33% of women continue a pregnancy diagnosed with trisomy 21 (Natoli et al., 2012), and in Austria 22% of women continue a pregnancy diagnosed with trisomy 13 or 18 (Lakovschek et al., 2011). Worldwide, estimates are that between 37-85% of parents continued pregnancies with a poor prenatal diagnosis (Wool, 2013). Counseling of women with a LLFD should include family

education and preparation, as well as availability of adoption, termination, and PPC services (ACOG & Society for Maternal-Fetal Medicine, 2016).

The American Academy of Nurses advocates for all disciplines to be educated and collaborate on PPC (Limbo et al., 2017). For a new midwifery graduate, the thought of delivering the news of LLFDs to patients and subsequently managing their care and attending their birth can be overwhelming. Midwifery students require a safe space to rehearse these conversations, and a midwifery curriculum that includes them. The goal of PPC threaded throughout midwifery education is to best prepare students for all aspects of caring for women and families holistically, and foster a network of supports and resources for when they are independently managing the care of pregnant women with LLFD.

The Model of Perinatal Palliative Care in Midwifery Education

Content of the Model. At our institution, palliative care has been threaded throughout the midwifery program. Central to our institution is the Kanarek Center for Palliative Care Nursing Education, which was established to educate nursing students about high quality, evidenced based practices, with the aim of developing leaders ready to deliver palliative care services for patients with serious illnesses and their families (Fairfield, 2017). The Center is available to assist in PPC educational resources in the midwifery program.

As the program and curricula were developed, PPC was woven into each midwifery course. Specifically, resources and readings from internet-based bereavement sites such as Now I Lay Me Down to Sleep (2017), Resolve through Sharing (2017), End-of-Life Nursing Education Consortium (ELNEC Pediatric Palliative Care, 2016) Perinatal and Neonatal Palliative Care module and perinatalhospice.org (2017) have been infused. The primary case study adopted for

antepartum, intrapartum, and postpartum care is an exemplar by Cole et al. (2017). Content of the model includes: rights of the dying neonate/newborn; guidelines and samples of birthing plans; cultural and religious aspects of perinatal death practices; characteristics of death in the neonatal intensive care unit; perinatal loss checklist; and questions for an initial follow-up telephone call of parents who have experienced a perinatal loss (ELNEC Pediatric Palliative Care, 2016). Our program philosophy also delineates our commitment to providing PPC, setting us apart from other midwifery programs and allowing prospective students to understand this focus.

A final important component of our model is a partnership with a local agency Hope After Loss© that offers free educational outreach to healthcare professionals on best practices when working with families experiencing loss. This organization also provides emotional support and financial help for burial cost to families.

Implementation of the model. Specific examples of how PPC is infused into antepartum and intrapartum courses are through seminar discussions and simulation. In antepartum, students rehearse with one another the experience sharing a LLFD of T18 from non-invasive prenatal testing results with patients. Classmates provide feedback during the debriefing starting with the strengths of the student midwife's conversation, followed by suggestions for improvement. Largely, students have mastery with displaying empathy, but struggle with being direct in giving the diagnosis. The safe space to rehearse this conversation not only prepares students to have this difficult conversation with women and families but also allows them to process what the experience of saying these words aloud is like and the emotional sentiments that accompany these conversations.

Students then have lecture and readings associated with providing PPC and preparing

women and families for the time they have during the pregnancy with their child. Making meaningful memories during the pregnancy through pregnancy photo sessions and journaling are some examples of plans we discuss incorporating into care. We also focus on the planning for the birth. Details of who they would like to have come and meet their child, arrange for a photographer or use ideas for taking photographs through Now I Lay Me Down to Sleep (2017), creating a thorough birth plan specific to PPC from ELNEC Pediatric Palliative Care (2016), and bringing special clothing or blankets to hold their child are all incorporated into the planning. Ethical issues related to PPC, such as organ donation are discussed (Mendes et al. 2017). Students are asked to reflect on supports they have professionally and on how they will cope personally following these experiences. This reflection piece is critical in allowing students to remember to care for themselves and augments the skills they are learning in providing PPC.

Later in the curriculum we include the case study written by Cole et al. (2017) describing a 38 year old multigravida woman (G3 P1011) who receives a LLFD of Trisomy 13 at 22 weeks gestation and follows her, her partner, and their four year old son through the pregnancy, birth, and postpartum period. We use this case as the base for simulation in each of the periods so that students may actually talk through and be with this family planning PPC. We have modified Cole et al.'s (2017) case to have a certified nurse midwife involved in the patient's antepartum care, and to have the patient proceed with an induction of labor at term, ending in a vaginal delivery of a stillbirth baby attended by a midwife (in lieu of the cesarean birth of the case study). In the simulation, students are able to discuss spiritual considerations such as baptism, perform a naming ceremony, and take photos of the child per the wishes of the family.

Additionally, a local maternal fetal medicine physician and a geneticist guest lecture to students on genetic testing options. This lens infuses real world case studies into the classroom

setting. Following this guest lecture, students spend a day with the geneticist and observe counseling with families who are working through a current LLFD, or may have in the past.

The Model's Effect

Meeting midwifery competencies. The International Confederation of Midwives' (ICM, 2013) global standards for midwifery education curriculum concordance map competencies include areas that can be met with the PPC model. For example, the ICM competencies include, independent or collaborative management of intrauterine fetal death; care, information and support that is needed during and after miscarriage or abortion; community resources; normal process of involution, physical and emotional healing following miscarriage or abortion (ICM, 2013). The *ACNM Core Competencies for Basic Midwifery Practice* (ACNM, 2012) include promotion of women and family centered care, empowerment of women as partners in health care, and care for vulnerable populations, which can also be met with PPC education.

Meeting maternal health needs. Women who have experienced a neonatal death or stillbirth have identified gaps in their care and shared that they would have appreciated more sensitive communication from providers and staff, and more organization of services (Mills et al., 2016). The addition of PPC into midwifery education provides students with skills and resources to provide holistic care to women experiencing a stillbirth or a LLFD. Women who receive PPC report personal growth in the aftermath of their experience (Wool, 2013).

Challenges and Sustainability

Overall, there are a few challenges to infusing PPC into the curriculum. The first challenge is the consideration of time devoted to teaching this content in programs that are

already content heavy in meeting the *ACNM Core Competencies for Basic Midwifery Practice* (ACNM, 2012) and/or the *ICM Core Documents* (ICM, 2017). Nurse midwifery programs planning to adopt this model would benefit from conducting a curriculum revision to adequately infuse the PPC content throughout the program. Consideration of adding the PPC focus to the midwifery program philosophy is recommended. Another challenge is looking at rolling PPC out as a national model through a targeted midwifery competency.

The use of the published case study by Cole et al. (2017), which we have suggested modifying for midwifery care, provides an excellent starting point for midwifery educators to adopt in order infuse PPC in the curriculum. The sustainability of this model does rely on having either faculty members, or access to consultants or webinars, to provide PPC learning opportunities for students through classroom and/or simulation experiences. At our institution, midwifery faculty members are supported to attend Resolve Through Sharing's® perinatal death training program (RTS, 2017) or End-of-Life Nursing Education Consortium (National Hospice and Palliative Care Organization, 2017) both of which include PPC education. Another unique feature of our program is the partnership with Hope After Loss© and a maternal fetal medicine physician. Programs adopting the PPC model would look within their local communities and can refer to resources through RTS (2017) and perinatalhospice.org (2017) to form their own partnerships.

Conclusion

Midwifery education programs worldwide can adopt our model for PPC education. Utilization of local resources for PPC makes this a viable option for programs. Future updates to the model are to remain aware of advances in fetal testing, of trends in numbers of LLFDs, and

of the PPC services available locally.

PPC services are growing in response to the needs of families with LLFD. Perinatalhospice.org (2017) maintains a current listing of PPC services, and there are now nearly 300 PPC services in the United States, and services in 22 countries worldwide. Midwifery students with PPC education develop a skillset to provide holistic midwifery care to women and families who are experiencing stillbirth or a LLFD. Empowering women is always a hallmark of midwifery care, but even more so when the birth outcome is drastically different than what was expected at the outset of a pregnancy. PPC educated midwives have the knowledge and skills to provide holistic care to women and families in their darkest hours, allowing for the creation of memories and a meaningful birth.

Ethical Statement

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(1) Conflict of Interest
None declared

(2) Ethical Approval
Not applicable

(3) Funding Sources
Not applicable

(4) Clinical Trial Registry and Registration number (if applicable)
Not applicable

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Highlights:

- Perinatal palliative care (PPC) education is designed to better prepare student midwives for situations in which a birth outcome is not what was expected at the outset of a pregnancy.
- Midwifery students with PPC education develop a skillset to provide holistic midwifery care to women and families who are experiencing stillbirth or lifelimiting fetal diagnoses.
- By utilizing evidence based practices and national programs, PPC can be threaded throughout midwifery curricula to achieve international standards of practice and competencies.