



American Academy of Nursing on Policy

Perinatal palliative care as an essential element of childbearing choices

Rana Limbo, PhD, RN, CPLC, FAAN^{a,*}, Debra Brandon, PhD, RN, FAAN^a,
Denise Côté-Arsenault, PhD, RN, FAAN^a, Karen Kavanaugh, PhD, RN, FAAN^a,
Amy Kuebelbeck, MA^b, Charlotte Wool, PhD, RN^c

^a Expert Panel on Maternal and Infant Health

^b Editor, perinatalhospice.org

^c Assistant professor, York College, York, PA

Executive Summary

Perinatal palliative care (PPC) is an interprofessional model of care for parents who choose to continue their pregnancies following diagnosis of a life-limiting prenatal condition, defined as conditions with “no reasonable hope of cure that will ultimately be fatal.” (Fraser, Miller, Aldridge, McKinney, & Parslow, 2011) The Academy supports (a) development of effective models of PPC, (b) workforce development for all members of the PPC team, (c) increased awareness of PPC for the pregnant woman and family faced with a life-limiting fetal condition, and (d) endorsement of the role of the nurse as a key member of the PPC team.

Background

The number of families who experience the shock of learning that their expected baby has a serious condition has increased, given the widespread availability of prenatal testing (e.g., ultrasonography, genetic testing). These families need appropriate, informed, and coordinated care regarding their baby’s condition and prognosis, bereavement care (which begins with diagnosis), birth planning, and assistance with planning for their baby’s care following birth—all of which are elements of PPC (Kobler & Limbo, 2011). New prenatal testing practice guidelines from the [American College of Obstetricians and Gynecologists](#) and the Society of Maternal-Fetal Medicine include a recommendation that postdiagnosis counseling should include discussion of PPC (American College of Obstetricians and Gynecologists’ Committee on Practice Bulletins—Obstetrics, Committee on Genetics, and the Society for Maternal–Fetal Medicine).

Societal lack of understanding about the goals of palliative care extends to PPC and must be addressed (Wool, 2015a). Neither family members and friends nor

health care providers and their professional organizations may recognize the benefits of continuing the pregnancy, and their undesirable reactions may cause parents additional heartache and distress (Lathrop & VandeVusse, 2011). Parents report fragmented care delivery with limited coordination, continuity, and communication among clinicians, and professionals report knowledge gaps and a lack of educational preparation (Bidegain & Younge, 2015; Côté-Arsenault & Denney-Koelsch, 2011; Tosello et al., 2015; Walker, Miller, & Dalton, 2008; Wool, 2015a). Furthermore, lack of consistent funding hinders development and implementation of PPC services (Wool et al., 2015). Finally, health care systems do not lend themselves well to interprofessional teamwork (Wool, 2015a). Thus, the crucial role of nurses in PPC must be well established.

Responses and Policy Options

Standardized guidelines to support the provision of quality PPC should be developed for the interprofessional team. Workforce PPC training should be relationship based (Browning & Solomon, 2006), competency driven (c.f. HPCG, 2013), and systems focused and should include instruction in complex communication skills (Browning & Solomon, 2006). Examples of providers of education include End-of-Life Nursing Education Consortium, Resolve Through Sharing, and National Hospice and Palliative Care Organization.

The Institute of Medicine advocates that providers measure the quality of all palliative and end-of-life services, but only 41% of self-identified PPC programs conduct quality assessments (Wool et al., 2015). Measuring PPC quality is complex because the grief and emotional impact on an otherwise healthy woman requires exceptionally sensitive care. Only one available tool measures parental satisfaction and quality (Wool, 2015a, 2015b). Parents report higher satisfaction

* Corresponding author: Rana Limbo, Gunderson Medical Foundation, 1900 South Avenue, Mailstop AVS-003, La Crosse, WI 54601.

E-mail address: RKLimbo@gundersenhealth.org (R. Limbo).

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when professionals communicate compassionately, recognize their baby as a person, and give consistent and safe medical care (Côté-Arsenault & Denney-Koelsch, 2011; Wool, 2015b). Additional tools will begin to benchmark metrics that go beyond mere patient satisfaction to the emotional benefits of PPC in the long term.

The role of nurses in PPC is similar to that in pediatric and adult palliative care. Nurses can initiate referrals, be part of the PPC team, and provide care as part of a specific care team, such as labor and delivery (Boss, Kavanaugh, & Kobler, 2011; Engelder, Davies, Zeilinger, & Rutledge, 2012; Feudtner et al., 2013; Kauffman, Hauck, & Mandel, 2010). Advanced practice nurses hired as members of the PPC team often serve as care coordinators, who strive for seamless services and monitor quality (Leuthner & Jones, 2007). These nurses must be experts in collaborative palliative and bereavement care, advance care planning, birth planning, fetal surgery, family systems, culturally centered care (Chichester & Wool, 2015), decision-making, guided practice (Pridham, Limbo, Schroeder, Thoyre, & Van Riper, 1998) and, optimally, care coordination.

The Academy's Position

The Academy has a history of supporting initiatives that promote nursing's role in advancing health policy and delivery. Perinatal palliative care requires collaboration with other key disciplines including obstetrics, maternal–fetal medicine, genetic counseling, hospice and palliative care, pediatrics, neonatology, perinatal social work, family medicine, spiritual care, and others to advance PPC as the standard of care for families who wish to continue their pregnancies following the diagnosis of a life-limiting prenatal condition. We recommend the following in support of perinatal palliative care.

Recommendations

- Nursing and health care organizations should support the development and implementation of effective models of PPC that provide for ongoing communication with the pregnant woman and family about goals of care following the diagnosis of a life-limiting condition in a fetus (Bidegain & Younge, 2015; Boss et al., 2011; Côté-Arsenault & Denney-Koelsch, 2016; Denney-Koelsch et al., *In press*; Fraser et al., 2011; Kauffman et al., 2010; Kobler & Limbo, 2011; Wool et al., 2015).
- Health care organizations should allocate the resources necessary for the preparation of all members of the interprofessional team to better care for pregnant women and families who would benefit from PPC. Education should be family centered and

focused on the mother and baby as one unit, and it should include all individuals who provide care before, during, and after birth (American College of Obstetricians and Gynecologists' Committee on Practice Bulletins—Obstetrics, Committee on Genetics, and the Society for Maternal–Fetal Medicine;; Browning & Solomon, 2006; Engelder et al., 2012; Feudtner et al., 2013; Kauffman et al., 2010).

- Congress should mandate funding mechanisms to reimburse providers for PPC advance care planning services that extend beyond the physician and ongoing evaluation of individual and family outcomes that extend beyond satisfaction using reliable and valid measures of quality (Tosello et al., 2015; Walker et al., 2008; Wool et al., 2015; Wool, 2015; Wool, 2015a, 2015b).
- Health systems and nursing organizations should endorse the role of the nurse as a key member of the PPC interprofessional team and advocate for the nurse as care coordinator and advanced practitioner as a central and continuous member of the team across care settings (Côté-Arsenault & Denney-Koelsch, 2011; Kauffman et al., 2010; Kobler & Limbo, 2011; Lathrop & VandeVusse, 2011; Leuthner & Jones, 2007; Wool, 2015; Wool, 2015a, 2015b).
- Nursing organizations should establish a credentialing mechanism for certification in PPC nursing (American Nurses Credentialing Center).
- Nursing and health care organizations should increase public awareness of the role of PPC for the pregnant woman and family faced with a life-limiting fetal condition by including personal accounts from families who received PPC in media distribution and by linking and disseminating existing resources for PPC, such as Web sites, with other pediatric and adult palliative care resources (Perinatal Hospice & Palliative Care_A; Perinatal Hospice & Palliative Care_B; Pregnancy Loss and Infant Death Alliance [PLIDA]).

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