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Reframing US Maternity Care: Lessons Learned From End-of-Life Care

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Frameworks guiding care as one nears death have evolved significantly during the past century. Emerging trends in US maternity care may signal the need for similar evolutions in frameworks guiding care during labor. Recent US palliative care health system changes, poised to effect meaningful shifts in delivery of health care for those nearing death, may be used to inform potential directions for birth care health system change.

In November 2015, Medicare authorized reimbursement for clinical discussions with patients regarding end-of-life health care preferences.[1] Prior to that, in 2014, the Institute of Medicine (IOM) released end-of-life guidelines emphasizing patient autonomy, person-centered care, honoring of individual perspectives and preferences, and the importance of social support as an individual nears death.[2] These changes signal an evolution in our nation's approach to end-of-life health care, representing, among many things, systematized inclusion of patient autonomy and definition of person-centered care. Health care autonomy can be framed as a shared decision-making process, supporting an individual's ability to, in the words of Atul Gawande, "keep shaping the story of their life in the world—to make choices and sustain connections to others according to their own priorities."[3]

When first introduced more than a century ago, this approach seemed radical, and the evolution from concept to framework has been slow. Widely criticized when it was published in 1899, Simon Baldwin's *The Natural Right to a Natural Death* may be the

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CONFLICT OF INTEREST

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earliest critique of care favoring the physician's duty to prolong life regardless of the preferences or suffering of the dying person.[4] Baldwin proposed that people should be able to share in decisions about their care, including evaluating some care to be unnecessary (ie, overtreatment) and declining that care. Baldwin writes that modern medicine "reflects a spirit of altruism but its zealous attempts to prolong life often only prolong a parody of life."[4]

Differences between the processes of dying and birth might understandably dominate comparisons, with death involving one individual and a known outcome, and birth involving the intertwined woman and fetus with separate processes and uncertain outcomes for each. While acknowledging these differences, care at the end and at the beginning of life occurs at the most fundamental of human transitions—the shared cultural, social, emotional, and spiritual dimensions of these phenomena as life transitions cannot be ignored. There is also evidence of parallels in approaches to care of those during birth and those nearing death. Work in the palliative care literature has described the need to stay close and do nothing,[5] and nurse-midwifery literature has described the importance of the art of doing nothing well. [6] Both articulate the humanistic and diagnostic value of attentive presence. Both stress how heightened judiciousness with intervention may improve process and outcomes during what are predominantly uncomplicated, although intense, physiologic processes. Both focus on responsiveness to the cultural, social, emotional, and spiritual needs of the patient. However, approaches to care also diverge, with the palliative care movement using a framework that blatantly values patient autonomy and shared decision making and that acknowledges spiritual and social aspects of dying. Birth, in the dominant US maternity care system, is still primarily viewed as a phenomenon requiring intensive medical supervision and focused on separation: getting the fetus safely separated from the woman.

With the emergence of effective interventions to both prolong life as an individual nears death and also to save life during childbirth, our challenges have shifted from understanding whether an intervention is possible to understanding when an intervention should be performed and appreciating the consequences to the participating individuals and families as well as to the professionals, organizations, and institutions that provide care. The palliative care framework advocates for attention to approach. In widening the clinical lens beyond outcome to include process, the palliative care movement has successfully advocated for systems-level changes both to protect time for shared decision making and patient autonomy and to provide guidelines for person-centered care. In doing so, palliative care ascribes meaningful, quantifiable value to patient experience beyond cursory or marketing-driven measurements of patient satisfaction.

We propose that the evolution in how we care for people nearing death might inform reconsideration of how we care for women and their neonates during birth. We suggest that if maternity care adopted the palliative care framework, maternity care systems would more objectively value patient autonomy and shared decision making and would acknowledge the emotional, spiritual, and social aspects of birth. Using the IOM report[2] regarding improving quality and honoring individual preferences as a road map for birth, we believe that maternity care systems should 1) place high value on women's autonomy in the context of well-informed shared decision making; 2) prioritize a style of care that is able to assess and

support women's physical, emotional, social, and spiritual well-being; 3) develop care practices that are responsive to management of emotional distress; and 4) create a health care environment that pays attention to women's social context and social needs.[7] We advocate for changes in maternity care that would bring the patient's experience, values, and perspectives more to the forefront, alongside objectively measured and traditionally studied health outcomes, and we advocate for policy that would codify these changes.

There is evidence that a shift in the framework guiding maternity care may be needed. Tension regarding the when and how of medical intervention during low-risk labor are evident in the rapid rise of women choosing out-of-hospital birth[8,9] and the emergence of women organizing to address nonconsented intervention during labor.[10] Both point to a broader cultural critique that asks whether US maternity care offers women the chance to birth safely as well as with dignity and respect for autonomy. There may be a small proportion of women who would choose to give birth outside of a formal maternity care system regardless of how that care was structured, and certainly there will be urgent medical emergencies with less time to evaluate women's wishes for autonomy due to the need for immediate lifesaving intervention. Using a palliative care framework to inform maternity care will not serve in every birthing circumstance. However, excluding these extraordinary examples, it is possible that evolutions in end-of-life care can be used to conceptualize and propose new ways of evolving maternity care systems that aim simultaneously for safe processes of care leading to optimal outcomes and person-centered care for the majority of childbearing women.

Given historically high rates of both neonatal and maternal morbidity and mortality, it is not surprising that enthusiasm for seeking safe passage during birth may have erred on the side of overintervention. Obstetrician Dr. Neel Shah rightly points out that during birth our "tolerance for the possibility of catastrophe at a moment that's expected to be pro-foundly joyful is understandably low."[11] This impulse emerges from compassion, the means emerge from great ingenuity, and Western society is the privileged inheritor of astonishing medical advances that have advanced safety during childbirth. In spite of and likely driven by these excellent intentions, US propensity toward intervention in maternity care has led to substantial evidence of overintervention.[12]

If the palliative care framework is used to guide changes in maternity care, several challenges must be addressed. The first challenge is our uncertainty regarding where the boundary of childbearing safety lies. Those of us caring for pregnant and laboring women know that while there are some care decisions that are well supported with evidence dictating a clear course of action, there are many situations that are less black and white. Clinical decisions and the advice we provide to women and their families are often in a gray zone of statistical probabilities, shaped by our personal clinical experiences and beliefs. In addition, most of us use technologies that provide a wealth of information with less-than-ideal diagnostic criteria or standards for evidence-based care on the basis of that information (eg, continuous fetal monitoring). Birth attendants who have only uncertain information for determining where the boundary of safety lies may become naturally conservative in their estimation of this boundary and err on the side of intervention. Clinical conservatism also is informed by awareness of how the birth process may affect the fetus and its lifetime. This

differs in important ways from palliative care; when an individual's outcome is certain, as in approaching death, the value of increased attention to process is more easily embraced. Certainly, safety for a woman and her fetus should remain the primary goal of maternity care, but health care systems and individual clinicians might simultaneously aim to improve childbirth processes through an application of palliative care principles adapted to childbirth.

A second challenge is the unique enmeshment of a woman and her fetus. Unlike any other arena of health care, pregnancy and birth engage a delicate balance between a woman and her fetus, with many areas of common benefit (eg, good nutrition) and, less frequently, true tension between fetal well-being and maternal well-being (eg, delaying birth in a woman with preeclampsia to gain more fetal maturation). The fetus matters and is frequently the focus of interventions in childbirth, but the pregnant woman's health and her experience matter as well. Importantly, this is not an argument to decrease the quality and safety of care for the fetus or to discount the ethical consideration of fetal well-being. Rather, this is an acknowledgment that our health care system can do better in recognizing women's preferences, autonomy, and needs during birth and an argument that it is unacceptable to disregard women's autonomy in the birth process. In particular, we reject the reasoning that can be used to justify any medical intervention by emphasizing that a woman should simply be glad that her newborn is alive. Such arguments, fueled by a rhetoric of shaming, belittle women's autonomy and preferences, and may collectively have a chilling effect on a woman's full participation in informed decision making and collaborative care.

These challenges can be addressed. Indeed, the process of addressing them will both enlighten the current US maternity care framework and how US maternity care might achieve the dual goals of safety and person-centered care. We advocate for reimbursement of clinical time devoted to maternity care, shared decision making, and identification of maternal health care preferences. We also advocate for a US maternity care framework that strives for the same values articulated in the US palliative care framework. This means prioritizing maternal autonomy in the context of well-informed shared decision making; a style of care that is responsive to women's physical, spiritual, and emotional needs; and care within an environment attentive to women's social needs and context.

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