The Natal Journey and Perinatal Palliative Care

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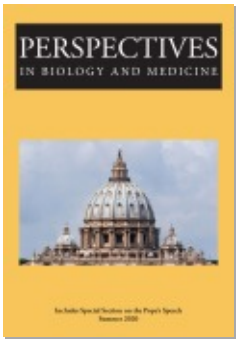

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ABSTRACT Doctors often focus on the science of medicine involved in matters of reproductive health and childbirth, at times to the exclusion of the psychosocial and spiritual dimensions of health. Pregnancy and childbirth are clothed in mystery when it comes to the question of why a pregnancy goes well or is fraught with complications. And while explanations may abound in this age of increasing genetic understanding, the meaning attached to these matters is beyond the scope of medicine alone—especially when the newborn's very survival is in question. Perinatal palliative care can bring solace to such troubling realities.

Pope Francis beautifully describes how the perinatal journey starts in mystery. Doctors may forget this. We focus on the science that may partially explain how conception and implantation occur, how the placenta functions, and the gradual development of embryo and fetus. But science cannot address that metaphysical—or spiritual—reality. The question of "why?" is never too far away from the minds of expectant parents. Why now? Why me? Why did my baby develop these terrible problems? Why is my life being challenged in this way?

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Maternal-fetal "cross-talk" is a reality that cannot be denied. It occurs both when the fetus is quiet and when the fetus is active. It may be facilitated by fetal imaging—an ultrasound of the facial profile is very reassuring and stimulates the maternal imagination. Attachment may begin or be enhanced not only by fetal movement ("quickening") but by ultrasound, which visually melds the identities of two beings into one and so gives an image that portrays what pregnant women already know.

For the past 60 years, the fetus has been recognized as a patient. Over these years, there have been many improvements in the technologies that allow us to assess fetal well-being. Pioneers like Bevis, Liley, Harrison, and Flake developed techniques like amniocentesis, intrauterine blood transfusion, and intrauterine surgery that allow doctors to diagnose and treat fetal disease in utero (McMann et al. 2014; Moise 2014). At the time of delivery, complicated cardiopulmonary conditions that might have otherwise been met with certain neonatal death can now be successfully treated (Marwan and Crombleholme 2006). Specialists in maternal-fetal medicine deploy these tools and also have mastered new ways of making labor and delivery safe. These developments provide hope for many, a hope that most pregnancies will end in the birth of a baby who will survive and thrive. That hope is borne out in most pregnancies today.

Even with these advances, some fetal disease cannot be treated, and some pregnancies end in either fetal or newborn death. There is room for continued improvements in fetal diagnostics and treatment, women's health in general, and maternal health specifically, as well as in neonatal care. In most countries, prematurity rates are too high. We still don't know the causes of prematurity, so we don't know how to prevent it. Life-limiting or life-threatening fetal conditions continue to abound. Indeed, children with physical or metabolic anomalies occupy more hospital bed days than any other diagnostic group, including prematurity (Namachivayam et al. 2012). The need for devoted clinicians, clinician scientists, and clinician educators remains. We need to continue advocating for improved women's health, children's health, and equal access to health care, and this includes advocating for perinatal palliative care services.

Perinatal palliative care (PPC) is the most humane medical practice in situations where a baby's survival is unlikely. It is a family-centered approach to recognizing the uniqueness of pregnancy and birth among all human experiences and also recognizing that not all babies survive. Clinicians are drawn to PPC from many backgrounds and for many reasons, but all honor and respect life. As health professionals, they seek to do what Pope Francis pleads for doctors to do: "establish a rapport with others, assume responsibility for other people's lives, be proactive in dealing with pain, capable of providing reassurance and always committed to finding solutions respectful of the dignity of each human life" (Pope Francis 2019). Clinicians working in PPC address psychosocial, spiritual, and physical domains of care for pregnant women and their families.

Although the detailed protocols of PPC are complicated, the moral impulse behind such care is simple. The developing fetus whose mother has chosen not to terminate the pregnancy is an unborn baby who deserves our respect, our care, and our compassion. We know that most parents name their unborn baby. PPC clinicians always refer to the unborn baby by name in conversations with parents, in documentation in medical records, and in professional correspondence. When birth comes, the new one is supported in a manner consistent with possibilities that have been previously discussed with families. Palliative care is rendered concurrent with life-extending intensive care in a neonatal intensive care unit (NICU) or beyond. It is an acknowledgement that all persons need recognition, respect, love, and accompaniment in this world (Limbo, Wool, and Carter 2019).

While treatment may be directed to the little patient, care is for both the patient and the family. We accompany the family on their journey, traversing liminal spaces, uncertain of what may be next. Our message to them is that, on this journey, they are not alone. Even at such a time as when the infant or child is perceived to be bearing disproportionate pain, harm, or suffering, the PPC clinicians will be present for symptom relief, comfort, and accompaniment of the family (Moore et al. 2019). They will be present through and beyond the death of a child to support the family in bereavement.

Pope Francis's address is inspiring. He exhorts those in technologically advanced countries, those for whom advanced maternal-fetal care, monitoring, interventions, and modern NICU provisions are within reach. But the message is perhaps even more relevant for those living in countries in which access to such technologies is out of reach for most people. Poverty complicates much of the human condition around the world (Hassan et al. 2009; Nagahawatte and Goldenberg 2008; Smith and Ashiabi 2007). Such poverty not only impacts present persons, it impacts the generation of future persons.

Women who live in poverty are at increased risk for complicated pregnancies, pregnancy loss, premature and low birth weight infants, and higher infant mortality, due to an inability to meet the requirements of maternal health, nutrition, and overall well-being noted above (Bartick and Tomori 2019). Virtually every complication of pregnancy is increased in circumstances of poverty—even maternal postpartum depression (Klainin and Arthur 2009). Yet when we look at how enhanced health-care access and technology can facilitate good pregnancy outcomes, we see that these phenomena are not equally distributed around the world. Maternal, fetal, and neonatal morbidity and mortality may all result from a maldistribution of resources. This includes access to good pain control medications and palliative care services (Knaul et al. 2015).

One must wonder if the silent cry noted by Pope Francis is not eclipsed by the many cries of mothers whose pregnancies end in dark places, with no help, in poverty and tragedy. Certainly, we should endorse the Pope's statement that "These possibilities and information need to be made available to all."

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