



Ethics and palliative care in the perinatal world



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A B S T R A C T

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The perinatal world is unique in its dutiful consideration of two patients along the lines of decision-making and clinical management – the fetus and the pregnant woman. The potentiality of the fetus-newborn is intertwined with the absolute considerations for the woman as autonomous patient. From prenatal diagnostics, which may be quite extensive, to potential interventions prenatally, postnatal resuscitation, and neonatal management, the fetus and newborn may be anticipated to survive with or without special needs and technology, to have a questionable or guarded prognosis, or to live only minutes to hours. This review will address the ethical ramifications for prenatal diagnostics, parental values and goals clarification, birth plans, the fluidity of decision-making over time, and the potential role of prenatal and postnatal palliative care support.

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1. Introduction

Advancements in perinatal diagnostics and medical technology have changed the landscape of the perinatal world. The threshold of viability continues to decrease, diagnostic information is available earlier in pregnancy and more rapidly at the bedside, and overall outcomes continue to improve. In 2014, the US infant mortality rate was 5.82 deaths per 1000 live births, accounting for a total of 23,215 deaths [1]. Whereas the infant mortality rate was at a record low, neonatal mortality and morbidity remain ever present in the neonatal intensive care unit (NICU) as nearly 70% of infant deaths occur in this setting [1]. In addition, the leading causes of infant mortality are frequent diagnoses in neonatology: congenital malformations and chromosomal abnormalities, disorders related to short gestation and low birth weight, and maternal complications of pregnancy [1,2]. Graduates of the NICU experience a wide range of outcomes and represent a portion of the growing population of children with complex health conditions and technology dependence [3]. In this milieu of rapid advancements in diagnostics and interventions, continued risk for significant morbidity and mortality, and uncertainty regarding outcomes, ethical challenges are ever present. How do we counsel parents about prenatal diagnostic tests and procedures while acknowledging the

remaining uncertainties about prognosis and outcome? How do we provide parents and families the information and support they need while eliciting and respecting their own values? How do we address physiologic futility or assess the burdens and benefits of technology? How do we transition from aggressive life-sustaining measures to a focus on comfort?

2. Prenatal diagnostics and counseling

Medical decision-making depends on three factors: diagnostic certainty, prognostic certainty, and prognostic meaning to family [4]. Since the 1960s, prenatal diagnostic tools have been available and expanding the ability of clinicians to gather anatomic and genetic information about a fetus prior to birth. Antenatal ultrasound has become a routine part of prenatal care; fetal magnetic resonance imaging and advanced imaging modalities have led to more detailed understanding of fetal anatomy. Amniocentesis, chorionic villous sampling, preimplantation genetic screening, and non-invasive prenatal testing of maternal blood all add to the possible array of antenatal testing. However, the availability of exhaustive prenatal testing does not necessarily lead to diagnostic or prognostic certainty, and which tests to consider or complete remains a decision of the parents in collaboration with the care team.

The American College of Obstetrics and Gynecology Committee on Ethics and the American Academy of Pediatric Committee on Bioethics state that the informed consent process around antenatal diagnostics should involve “a thorough discussion of the risks and benefits for both the fetus and the pregnant woman. The full range

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of options, including fetal intervention, postnatal therapy, palliative care, or pregnancy termination should be discussed" [5]. Completion of this "thorough discussion" rests on the knowledge and comfort of clinicians to provide difficult information and the skills to elicit the beliefs and values of the parents.

In preparing for this conversation, clinicians have a duty to acknowledge their unique role in caring for two patients – the mother and the fetus. It is essential that clinicians provide information regarding the risk, benefit, and burden for both mother and fetus individually while acknowledging their entwined relationship. The mother is an autonomous individual and has the right to make informed decisions regarding her personal health, and to balance the risks and benefits of additional diagnostic testing. The fetus is also a unique patient but is not an autonomous being, relying on her mother to make decisions in her best interest. These decisions are framed by the beliefs and values of the parent, the fetus' surrogate decision-maker. Additional antenatal fetal diagnostic information is certainly not of direct benefit to the fetus unless met with a fetal intervention (e.g. prenatal diagnosis of a fetal tachydysrhythmia for which medication is prescribed to the mother to normalize the fetal heart rhythm), but may well be of direct benefit to the infant by virtue of it being known before birth (e.g. choice of delivery hospital, or delivery planning in terms of equipment, personnel, etc.). The simple acquisition of fetal imaging or genetic testing may or may not be viewed as beneficial, or helpful, to parents. Some parents may opt to complete all available testing as they would consider termination of the pregnancy based on their assessment of burdens and benefits of a short life for their child. Others may opt to attempt prenatal interventions – such as prenatal open neural tube surgery for spina bifida – accepting significant procedural risks with the hope that the long-term outcome for the newborn and child is beneficial. And still others may focus on embracing the experience of pregnancy, birth, and the life of their baby regardless of its duration.

There are some prognoses that can be made with relative certainty despite diagnostic uncertainty, for example presumed extreme prematurity based upon uncertain gestational age assessment or the severity of chronic lung disease and its sequelae in the child. Yet despite growing outcomes data, substantial variation exists in prognostic information given in antenatal periviability counseling, as evidenced by a recent study comparing morbidity and mortality estimates conveyed to parents during simulated periviability counseling encounters by obstetricians and neonatologists [6]. This variation is recognized by parents and adds doubt to diagnostic and prognostic information that may be already difficult to understand and digest.

In contrast, there are some prenatal diagnoses that can be made with certainty, for example trisomy 13 and 18, that leave prognostic uncertainty [7] and are laden with value-based decisions. Counseling in these situations requires providers to give balanced information, sharing the spectrum of possibilities, including stories of survival against all odds, when appropriate [8,9]. In a review of literature on communication surrounding prenatal diagnosis, parents frequently felt that information was poorly communicated, clinicians were overly fatalistic and biased in their presentation of available choices, and clinicians "stepped-back" from the continued care they provided [10].

Furthermore, there is a growing body of evidence that physicians and medical professionals consider the long-term effects of chronic illness and disability on quality of life more negatively than patients themselves do. For example, in studies looking at proxy and self-reported quality of life of adolescents and young adults who were former premature infants with varying levels of disability and impairment, patients consistently rated their quality of life higher than values assigned by their parents or clinicians

[11,12]. In addition, in studies on quality of life over time, scores from all reporters (clinician, parent, and self-report) improved from preschool to school age to adolescence/young adulthood [12]. Clinicians have a professional obligation to provide up-to-date, accurate information, and to recognize the limits of our own knowledge. In caring for patients in the perinatal world, we must be cognizant of our own experiences, biases, and framing of our counsel so that they do not overshadow the objective information we are obligated to share. Furthermore, we need to address the variation in counseling that parents may encounter.

3. Parental values and goals clarification

When difficult medical information and decisions are presented to competent adult patients, we respect their authority to make decisions based on their personal values and goals and provide tools to aid in this process. When an adult patient does not have capacity to make his own decisions, we expect surrogate decision-makers to uphold the patient's autonomy and make decisions in line with the wishes, values, and goals of the patient using substituted judgment. In pediatrics, where parents are primary decision-makers, we have traditionally held their decisions to the best interest standard, with emphasis on the individual or self-relating interests of the child, emphasizing the ethical principles of beneficence and non-maleficence [13]. This best interest standard also plays a role in the process of shared decision-making, the standard decision-making model in medicine [14].

In the perinatal world, however, the best interests of the fetus are entwined and complicated by the best interests of the mother, and the ubiquitous presence of prognostic uncertainty leads to a continuous – or often fluid – process of decision-making. These decisions often hold certain ethical principles in tension and require consideration of alternative ethical frameworks, such as relational and narrative ethics. As Walter and Ross described, "in a relational account, the best interests of the child may need to be balanced against the interests of the family" [13]. Similarly, a narrative approach allows the parents to share the story of their fetus-newborn and make decisions with this "big picture" in mind. For example, while intubation and mechanical ventilation may prolong the dying process for a child with pulmonary hypoplasia, it may allow time for family bonding and memory-making.

In order to best support parents in their role of decision-making, eliciting their values and goals is imperative. Asking questions that explore a family's values, their understanding of the newborn's meaning and quality of life, and their experience in the medical journey help build a relationship based on trust and caring. The information gathered can help clinicians provide guidance that is tailored to the family and expected prognosis, and free from the value-based judgments of the clinician [9].

Advance care planning in perinatology often comes in the form of a birth plan, or a document that spells out the wishes of the parents for the delivery and resuscitation of their child and provides additional information about their values, hopes, and goals of care. Obstetricians may value insights into the mother's desire for mode of delivery, extent of fetal monitoring and responses to any ascertained fetal distress, and choice of anesthesia in constructing her care on the labor and delivery unit and in the postpartum period. Whereas some clinicians may hesitate to spell out a plan in situations of uncertainty, a broad picture can be helpful. Parents report that completing an advance care plan ensured the best care for their child, provided them the time and information for best decision-making, helped them communicate their desired outcomes with the entire care team, and provided peace of mind during stressful situations [15].

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