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Values-based shared decision-making in the antenatal period

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ABSTRACT

Despite advances in life-saving technology for critically ill neonates, challenges continue to arise for infants delivered with extreme prematurity, congenital anomalies, and genetic conditions that exceed the limits of currently available interventions. In these situations, parents are forced to make cognitively and emotionally difficult decisions, in discussion with a neonatologist, regarding how aggressively to provide supportive measures at the time of delivery and at what point burdens of therapy outweigh benefits. Current guidelines recommend that parents' values should guide these decisions; however, little is known about the values parents hold, and how those values are employed in the context of complexity, uncertainty, and emotionality of these situations. Systematic investigation of how parents derive their values and how clinicians should engage with parents about those values is necessary to guide the development of interventions to enhance shared decision-making processes, ultimately improving satisfaction, coping, and resilience and minimizing the potential for regret.

1. Introduction

Management decisions in neonatology involve unique ethical challenges, particularly in determining which high-risk newborns should be resuscitated, and how aggressively [1–4]. A myriad of high-stakes antenatal decisions surround extreme prematurity (Fig. 1a) and congenital anomalies (Fig. 1b), with expansive outcomes ranging from intact survival to significant neurologic morbidity and death. Prognostic uncertainty plagues this population, as the rarity of extreme prematurity and complex anomalies limit extensive study. Research over the past two decades has shed light on the complexities of the decision-making process in neonatal medicine, but ethical ambiguity persists about who should decide for these infants, and on what information and values those decisions ought to be based. General agreement exists that providers and expectant parents should engage in shared decision-making, and should strive to balance the best interests of the infant with the goals and values of family [1,2,5–8]. Yet meaningful specifics regarding how clinicians should effectively engage with expectant parents to share these decisions have not been well-characterized, nor have relevant patient, family, or clinician outcomes been adequately studied [9]. Characterizing the barriers impeding incorporation of authentic values in these decisions is crucial in strengthening parental coping and resilience and in minimizing the potential for regret. In this paper, we review these challenges of integrating values into shared decision-making in the clinical setting.

The American Academy of Pediatrics (AAP), and other national organizations worldwide including the Nuffield Counsel [10], offer recommendations for the type of information and options that should be provided for deliveries threatened at extremely premature gestational ages. Historically, these have emphasized communication of prognostic outcomes using epidemiologic population-based data, and discussion of ethically permissible options given the probabilities of these outcomes for the individual patient [11–13]. Likewise, guidelines for counseling regarding severe anomalies [14,15] call for disclosure of information and assistance with decision-making, though without specific prognostic thresholds at which various resuscitation options are ethically permissible. Only the most recent guidelines on antenatal counseling for extreme prematurity note the importance of considering parental values in these decisions [5], though do not

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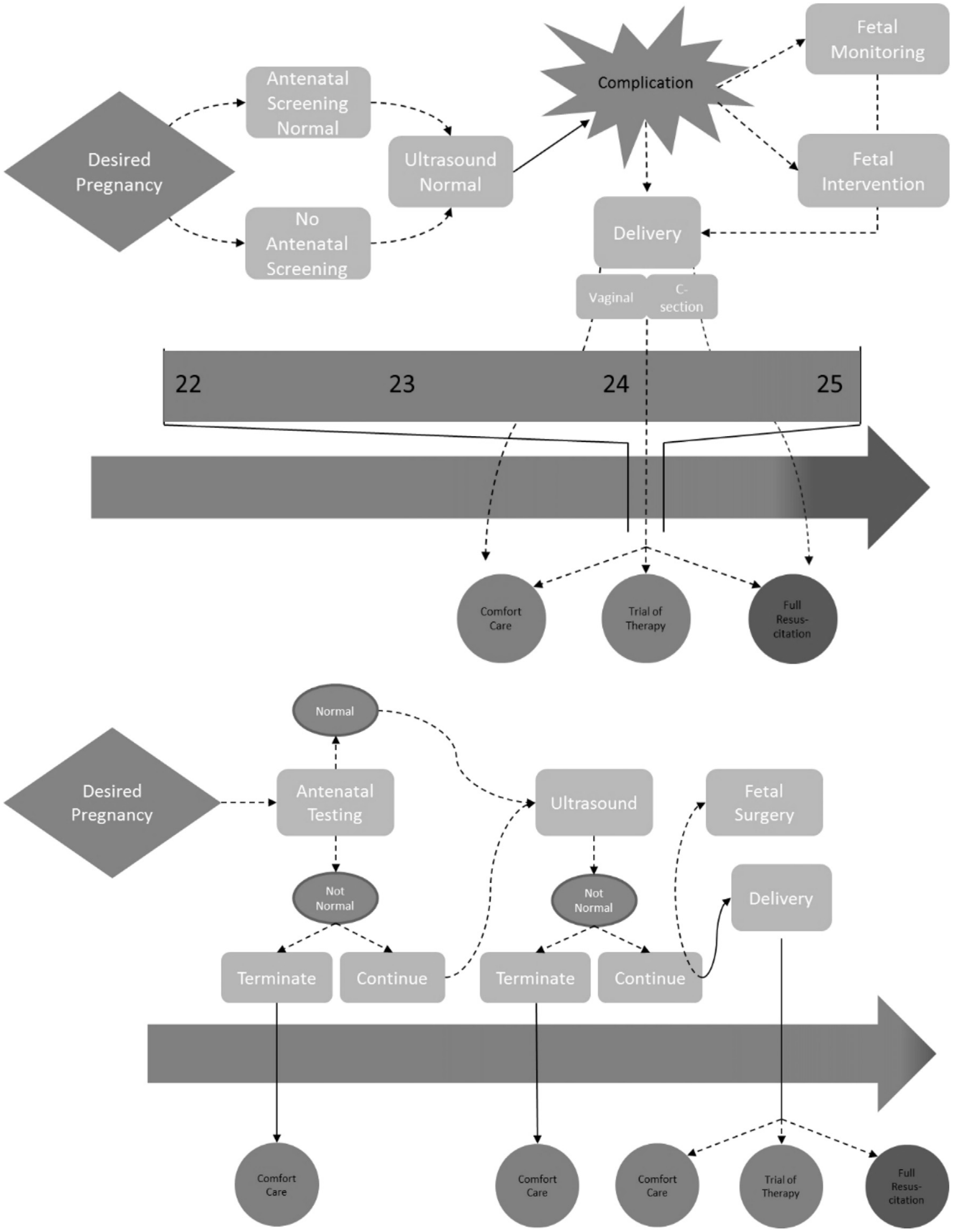

Fig. 1. (a) For those delivering between 22 and 25 weeks gestation, the “margin of viability,” prognostic uncertainty in survival, and neurologic morbidity outcomes permit a spectrum of ethically appropriate care options for the infant. These include comfort care, in which the focus is on quality of life rather than prolongation of life, a trial of therapy in which initial resuscitative efforts are provided with continued reassessment of the infant's status and redirection to comfort care if a poor outcome is anticipated, or full resuscitative interventions to preserve life at all costs. In pregnancies threatened with fetal loss near the gestational age of viability, the parents and care team may be faced with a decision of when to monitor and intervene on behalf of the fetus, which requires deliberation not only about the long-term anticipated outcome of the infant, but also about risks to the mother and her future fertility from a classical cesarean section. (b) When a severe fetal anomaly, chromosomal/genetic disorder is discovered on routine testing, termination or fetal reduction may be considered. Such choices are ethically complex, as the moral status of a fetus evolves as the pregnancy advances. Additional complexity occurs as infants with congenital anomalies have a high propensity to deliver preterm, and preterm infants with anomalies tend to have poorer outcomes than their term counterparts. Due to paucity of outcome data and variability in severity of these conditions, the gestational age at which survival becomes possible or probable is difficult to ascertain. In certain congenital anomalies in which there is anticipated benefit from in-utero correction, the mother and fetus may be eligible for an antenatal procedure which could lessen the extent of future morbidity; these procedures involve risk to the health of the mother, and threaten the pregnancy with the risk of fetal demise or induction of premature delivery.

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