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Opportunities and difficulties for counseling at the margins of viability

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A B S T R A C T

At the margins of viability, the interaction between physicians and families presents challenges but also opportunities for success. The counseling team often focuses on data: morbidity and mortality statistics and the course of a typical infant in the neonatal intensive care unit. Data that are generated on the population level can be difficult to align with the multiple facets of an individual infant's trajectory. It is also information that can be difficult to present because of framing biases and the complexities of intuiting statistical information on a personal level. Families also do not arrive as a blank slate but rather arrive with notions of prematurity generated from the culture they live in. Mothers and fathers often want to focus on hope, their changing role as parents, and in their desire to be a family. Multi-timepoint counseling provides the opportunity to address these goals and continue communication as the trajectories of infants, families and the counseling team change.

Introduction

At the margins of gestational viability, it may be tempting to view counseling as a single opportunity to impart data to a family prior to delivery. This conversation with families at a challenging point in their lives frequently centers on gestational age [1,2], and is at risk of being poorly understood. If the counseling encounter is viewed as a single opportunity to convey the right information, in the right way, at the right time, the stakes are unimaginably high. Even a seasoned counselor will face a daunting task when counseling is viewed through this prism.

One approach to counseling is to focus on data and imparting information. Facts are presented to a family so that they can understand the morbidity and mortality risks that their infant and family face in the short and long term. The hope is that this information will let the family make an informed decision. These goals can be the drivers of counseling despite beliefs, data and biases that indicate that families want and need something else [3–7]. The desire of the counseling team to impart data may conflict with the needs of families which are often not data-driven [2,6]. One of the challenges of counseling is to provide responsible and reasonable data but also to honor the needs of each individual family.

As the individual trajectories of families, infants, and care providers evolve, there are fortunately multiple opportunities to ascertain a family's goals and needs, share information, develop relationships, and change course if needed. Challenges still abound due to the complexity and uncertainty surrounding a particular family's needs and a specific infant's outcomes. A multitude of questions arise when encountering each family and infant [8]. What do families want? What information do care providers deliver? What structural biases are inherent when counseling families? What is the best way to counsel families generally and individually?

Limitations in gestational-age-based antenatal counseling

Historically, counseling has centered on the gestational age of infants. Population-based estimators have highlighted the complexity that exists at the margins of viability and have pointed out that besides gestational age, weight, antenatal steroids, gender and multiple status all play an important role [1]. Outcomes are frequently reported in the literature by gestational age, which may reinforce our bias toward counseling based on gestational age alone [9]. Fig. 1 highlights the limitation of this approach by showing outcomes with selected risk factors at 22 and 25 weeks side by side, in which the 22-week infant is predicted to do better than the 25-week infant.

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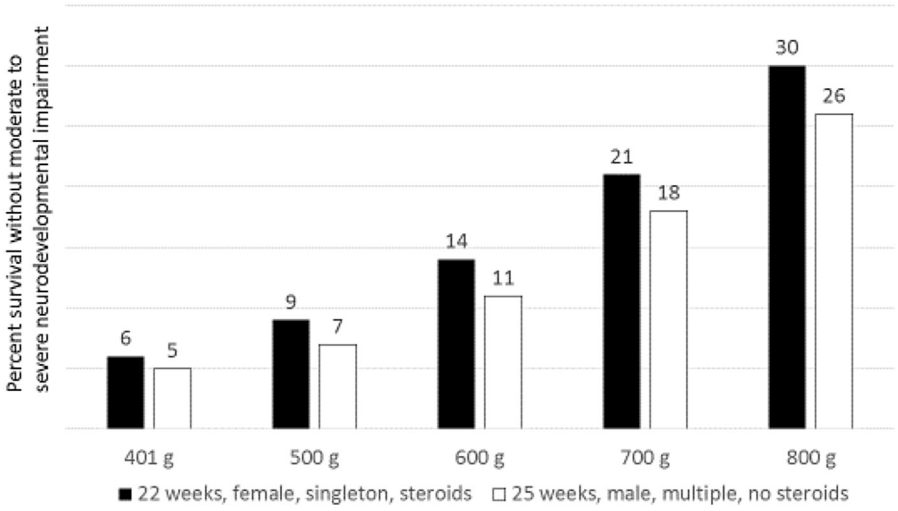

Fig. 1. National Institute of Child Health and Human Development (NICHD) Neonatal Research Network outcomes estimator comparison of mechanically ventilated infants: best case at 22 weeks versus worst case at 25 weeks [12]. When infants at the margin of viability are viewed as more than just gestational age the true complexity of infants appears. In each weight category the best-case scenario for a 22-week infant has better outcomes than the worst-case scenario at 25 weeks. If only gestational age had been considered, the aggregate prediction would support the traditional notion that gestational age is paramount.

Limitations in delivery-room-data-based counseling

The advent of population-based outcomes data sources (i.e. Vermont Oxford Network outcomes [10], Pediatrix outcomes data [11], National Institute of Child Health and Human Development (NICHD) outcomes estimator [12]) has given neonatologists multifaceted information to communicate to families [13,14]. These data are almost universally used with families during prenatal counseling [2]. The difficulty of prenatal prognostication is that it provides a time-limited version of the future that is most useful at the time of delivery. Once the infant is born, a myriad of previously unaccounted-for factors (i.e. type of ventilation, presence of intraventricular hemorrhage, the need for vasopressors, vital signs, etc.) change an infant's future trajectory. With each passing day, fetuses and infants move away from the outcome predicted by population-based aggregate and toward their own distinct path. This results in individual families having access not only to new information, but to more specific information. This should be a good thing. After all, a family is less interested in how all 24-week infants will do but rather they want information about how their 24-week, 551 g, betamethasone complete, on continuous positive airway pressure (CPAP) +5, baby girl will do. However, families and care providers who have elected for a trial of therapy are left with fewer sources of hard data and have to use experience and intuition to judge individual trajectories of infants. This may be difficult since only a few attempts have been made to better illuminate population outcomes postnatally [14,15], which may explain the finding that some neonatologists use prenatal data to provide counseling and support decision-making for infants in the neonatal intensive care unit (NICU), after the initial resuscitation [2].

An alternative approach is to embrace the NICU team's intuitions and couple these with data available early in the clinical course to better counsel families about likely long-term outcomes and support early decision-making during a trial of therapy. In conjunction with clinical data after resuscitation, Meadow and colleagues have shown that providers' clinical intuitions of death before NICU discharge have poor predictive power for the outcome of death alone, but high predictive power for either death or neurodevelopmental impairment [15–18].

Local policies affect population outcomes

Particularly at the lowest gestational ages, a delivery team's hospital policy or culture has the potential to alter how empiric data are presented and whether delivery resuscitation efforts are initiated [19,20]. The choices of either maximal intervention or comfort care will alter the trajectory of some infants, especially at the border of viability. A recent NICHD trial demonstrated the differences in morbidity and mortality among different centers in their approach to resuscitation of infants at the border of viability [19]. Intervention or non-intervention at a local level affects population survival outcomes. For the earliest gestational age, the actual population outcomes are unclear as maximal intervention is not universally offered or desired by all families. Additionally, whereas the population as a whole may have improved survival, the response of each individual is still difficult to predict, especially when preterm infants have multiple risk factors and variable illness severity [21]. Therefore, providers must make the intuitive leap that more intervention will lead to more survival, without epidemiologic support for this prediction. Some infants might die despite maximum intervention, whereas some infants will do better than expected with limited intervention (Fig. 2).

The only way to determine how many infants will survive at a certain gestational age or with a specific critical congenital condition is to attempt resuscitation on all live-born infants. But, even with maximal intervention, not all survive, and some infants who do not receive care will nonetheless survive. Survival and mortality outcomes can be altered for some infants but not for all. This uncertainty about individual trajectories makes counseling challenging for both families and physicians.

Family preferences are affected by competing framing

Family preferences for resuscitation may be driven in part by data presented antenatally and over the course of care. Although many neonatologists do not believe that empirically derived data alter families or the counseling team's decisions in the delivery room, these data are used in the counseling encounter [2]. The source and nature of these data present additional challenges to

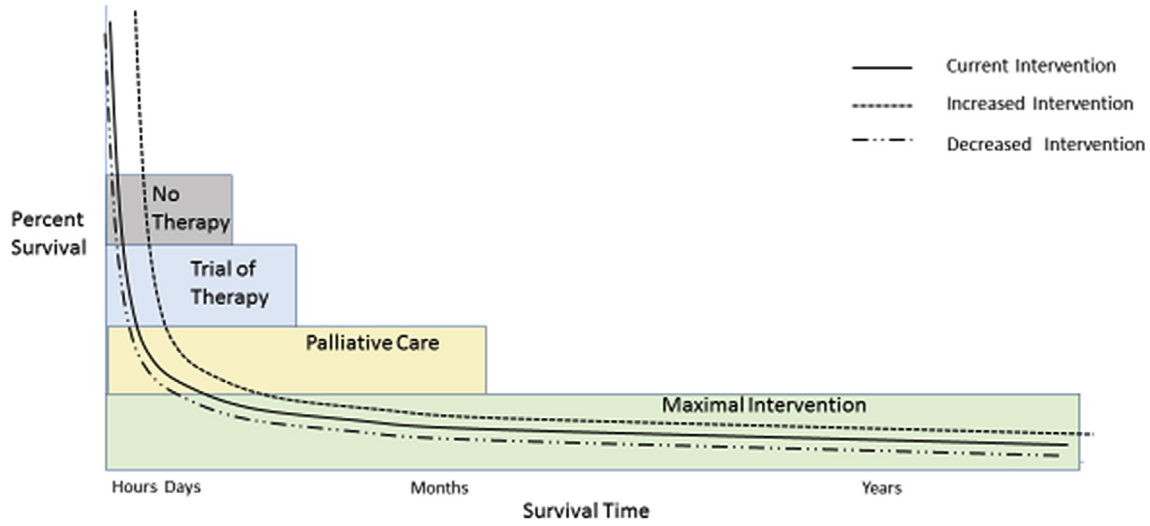

Fig. 2. Blueprint for how historical, institutional and parental advocacy change aggregate outcomes. Outcomes are dependent on three factors: the infant's individual trajectory, specific neonatal intensive care practices and shared decision-making between clinicians and parents. All three factors interact to generate a final outcome, but each factor can also undermine the other factors. The final curve for "increased intervention" may only be determined if maximal intervention was used on all patients and is likely to be different for different disease states.

values-based counseling. First, outcome probabilities at the population level are biased by differing definitions of the population of interest, the population denominator, and the outcome studied [22]. Second, practice variability among different centers impacts medical decisions and outcomes reported to larger data sets – this is problematic when these institutions then counsel using center-specific outcome data, and when these outcome data are analyzed in aggregate, multicenter cohorts. Finally, the information that families first access in contemporary care is likely to be located online; this often comes from families that have chosen to resuscitate their child.

If the completeness and validity of the data presented by the counseling team is unclear, families' interpretation and receipt of the information may be even murkier. How medical choices are framed will alter what patients hear and how they make choices [23]. This extends to the delivery room where families are more likely to choose resuscitation if information is positively framed around survival data [24,25].

The framing effect is particularly important when talking to families of infants at the margins of viability. Starting with delivery resuscitation, physicians undervalue preterm infants when compared to other groups of critically ill patients [26,27]. Physicians' pessimism about long-term quality of life is also greater when compared to both parents and former preterm infants [28,29]. Pediatric residents overestimate the chance of death, disability, and cerebral palsy among infants born at 26 weeks [30]. When neonatologists used population-based outcome tools prior to counseling, they are more likely to overstate morbidity and mortality percentiles when compared to empiric data sets [2]. As clinicians providing counseling, it becomes important to acknowledge the effects of framing on families' decision-making, and that there is a potential bias toward pessimism within the counseling team.

Multi-timepoint counseling

If counseling is viewed as a single opportunity or conversation, it is hard to overcome the obstacles to using population data. As described here, a single conversation limits the ability to understand what the family wants, turns choices into an all-or-none proposition, and does not acknowledge that individual fetal/infant trajectories deviated from population norms. Multi-timepoint counseling can overcome some of these difficulties. It provides an opportunity to meet families, physicians, and infants at different points of their individual trajectories. This creates the opportunities for families to be the most informed and involved in the course of their infant with the hope that this provides the best outcome for them.

The needs and trajectories of families, infants, obstetricians, and neonatologists evolve over time (Fig. 3) [31]. Therefore it is more helpful to view consultation as a series of opportunities to tailor the discussion to the unique needs of each individual family and continue to discuss prognosis and neonatal care plans that harmonize decision-making for both the medical team and the family.

Families of infants at the margins of viability are broadly offered four distinct choices during counseling: pregnancy termination (in some cases), comfort or palliative care, a trial of therapy, and maximal beneficial intervention. Some families will indeed be able to reach a single, final decision early in the process but other families will be helped if they are offered a full complement of options, supported in their decision-making processes, promised continued communication, and given the opportunity to change course.

Three components will ultimately dictate what happens for each family: the infant's unique trajectory, unit practice and culture [32], and the direction the family most desires. Through communication and discussion, the optimal outcome would be for all three of these components to align by having multiple conversations, listening to a family's stated and unstated concerns, and guiding the medical management appropriately. However, each factor could override the other two to alter the discussion during perinatal counseling and the clinical course. A scenario that demonstrates one factor opposing the other two factors is when both the family and unit want to provide maximal beneficial intervention to a 22-week infant but the infant is born with a trachea too small to pass any endotracheal tube (a physiologic factor).

Resuscitation or non-resuscitation in the delivery room is the next distinct point in the counseling timeframe and is historically the point where most neonatology counseling teams focus their

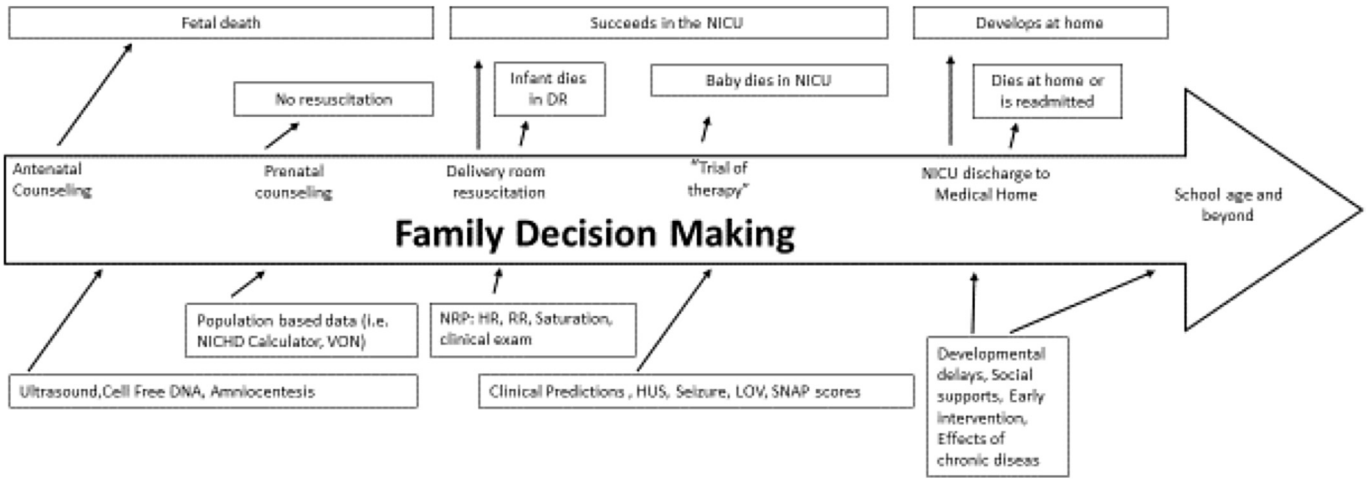

Fig. 3. Multiple opportunities during the counseling timeline. Time, individual family and infant trajectories and testing modalities all interact at different points to provide multi-timepoint counseling. Modified with permission from Meadow et al. [31]. NICU, neonatal intensive care unit; OR,; VON,; NRP,; HR,; RR,; HUS,; LOV,; SNAP,.

efforts. It is also a point where the counseling team is most likely to feel that there is a solitary opportunity for success when an infant at the margins of viability is born emergently. Historically gestational age has been the driving force behind how and what information neonatologists impart about delivery room options, but we have described the limitations to this approach.

For those families who are uncertain, especially at 22–25 weeks or when infants have a poor trajectory, the NICU team can offer a trial of therapy [18]. This is the opportunity to withdraw or withhold care that can be tailored to the family's and infant's needs while the infant is still mechanically ventilated, potentially taking into account subjective predictions of adverse outcome as well as objective prognostic data [33]. Infants will then move toward a stage of NICU care where there are fewer ethically permissible choices because the opportunity to withdraw and withhold care no longer exists.

The ability and willingness of the counseling team to revisit these decisions should be ongoing. The relationship between the counseling team and the family is healthiest in an atmosphere of respect, continued communication and a spirit of non-abandonment. While consensus will remain about the best possible outcome, flexibility in consideration of the worst possible outcome is paramount to providing empathetic, family-centered counseling.

Conflicts of interest

None declared.

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