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Prognostic value of clinicians' predictions of neonatal outcomes in counseling at the margin of gestational viability

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ABSTRACT

Within antenatal counseling sessions at the margin of gestational viability, clinicians frequently to use population-based outcome data and statistical models to guide the decision-making process. These tools often utilize non-modifiable prenatal factors to estimate outcomes based on population averages. However, most parents prefer individualized predictions, which cannot be supported by these models. Additionally, prognostic accuracy is limited by institutional practices surrounding active management of infants at the margin of viability. Throughout the literature, parental perspectives emphasize the importance of communicating subjective information, such as providing hope and supporting personal values, over the importance of accurate prognostic information from the clinician. In this review we aim to describe the value of clinician prognoses in the decision-making process at the margin of gestational viability and emphasize the importance of addressing parental values during the counseling process, regardless of the expected outcome.

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Background

Resuscitation at the margin of gestational viability continues to be an area in neonatology that is both medically complex and confounded by moral and ethical ambiguity. The wide variety of outcomes ranging from mortality or profound neurologic morbidity to minor morbidities or no impairments, leads to difficulties in the decision-making process.¹ Despite attempts to use statistical models, population-based outcomes, and clinical intuitions, there are still gaps in prognostication at an individual level.^{2,3}

Lack of standardized consensus on management of births from 22-24 weeks' gestation imparts additional challenges to

antenatal counseling. Recent observations based on single center studies have shown that there is a trend towards increased willingness among clinicians to offer resuscitation before 23 completed gestational weeks based on changing national guidelines and data supporting improved outcomes (based on survival and survival without severe neurologic morbidity) for infants for whom active resuscitation is initiated.⁴⁻⁷

Potentially many decisions must result from antenatal counseling sessions.⁸ Statistical presentation of prognostication to families is not the sole defining factor in how parents make these decisions, such as whether to proceed with life-sustaining interventions in the delivery room and beyond.^{9,10} However, provision of outcomes information remains a

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powerful tool that can aid and impact parents' values-driven decisions about goals of care after birth.

The counseling session

Ideally, counseling sessions prior to delivery at the margin of gestational viability occur on more than one occasion and evolve to reflect changing clinical circumstances. However, due to the often-precipitous nature of such births, iterative formal counseling sessions might not be an option. Recent evidence shows that there appears to be a large gap in documented rates of neonatology consultations in both high- and low-volume birthing centers. One multi-centered study found that the documented rates of neonatology consultations were 40% for 22-week deliveries and 72% for 24-week deliveries, with short admission-to-delivery times not fully explaining consultation gaps.¹¹ In the prenatal counseling encounter, three broad ethical scenarios that strongly drive decision-making are possible. These potential scenarios are: (1) those in which there is clear benefit of intervention, (2) those in which there is uncertain benefit- the "gray zone," and (3) those in which care is determined to be medically "futile" with no benefit of intervention.¹² It is presumed in the first instance that interventions will lead to reasonably positive outcomes, as determined by both clinicians and parents. By definition, infants in this category should not be considered to be "perivable". In the United States infants born at or after 25 weeks' gestation without complicating morbidities fall into this category, and prenatal counseling generally is characterized more as anticipatory guidance than decision-making about care after birth.

In the second instance, the counselor is unable to provide epidemiologically derived prognostic information, or available information is indeterminate in that outcomes could be either positive or negative as defined by the parent. By gestational age alone, in the U.S. this category generally includes infants born at 22, 23, and 24 weeks without major complicating features, but might include infants of greater gestational age with additional morbidities. Although the boundaries around the prolifically invoked "gray zone" might change over time due to both advances in technology and evolving epidemiologic understanding, the fundamental attribute of this second category is that "reasonable people" are allowed to disagree about the morally appropriate course of action.

In the third scenario, prognostic information provided by the clinician is meant to inform, rather than ask: given the high likelihood of mortality or significant morbidity, initiation of life-prolonging interventions after birth is not morally justifiable. Again using gestational age as a single, defining characteristic, this is the basis for exclusion of infants born before 22 weeks, although this might also include developmentally older infants with complications such as extremely small size, congenital anomalies, complex maternal-fetal conditions, or other clinically relevant contextual features.

It is thus the middle category, in which reasonable people can disagree about the best course of action, that active resuscitation is neither ethically obligatory nor impermissible, that has been the focus of debate and scholarship, and fundamentally defines counseling at the margin of

gestational viability. Within the "gray zone" the clinician's role in the counseling process includes assessing risk, communicating risk and providing ongoing support to families regardless of their goals of care.¹³ At the center of assessing risks and benefits is the clinician's ability to prognosticate outcomes if full interventions are attempted. A family's acceptance of risk and uncertainty, in addition to their core values, will determine whether resuscitative efforts are initiated.

Population based outcomes and accuracy of clinician prognostication

Within the counseling session, it is up to clinicians to not only discuss specific outcomes data, but help families understand what they value and how to make decisions for their infants in a way that is congruent with their beliefs and values. In the past, neonatologists have considered their primary role to be providers of information. With this approach, the counselor provides seemingly objective information and may assess parents' understanding of information, but tend to avoid more subjective and sensitive topics such as previous experiences with death, spiritual orientations, and interpretations on quality of life.¹⁴

In a study conducted by Myers *et al* among US neonatologists, 91% stated they utilized population-based outcome data while counseling parents regarding decision-making at the margin of gestational viability. Sixty-five percent of respondents that utilized population-based outcome data indicated that they used the National Institute of Child Health and Human Development (NICHD) calculator and 14.5% utilized institutional databases. Most respondents indicated that they felt the data they presented to parents influenced their decisions.¹⁵

The NICHD Extremely Premature Outcomes Tool was generated from institutions belonging to the NICHD neonatal research network and Vermont oxford network. The tool incorporates five factors that are thought to impact outcomes: gestational age (range from 22-25 weeks), birth weight (401g-1000g), infant sex, singleton birth, and use of antenatal steroids. Based on these factors, there are three predicted outcome categories.¹⁶ They include: survival (either to hospital discharge or to one year of age if still hospitalized at this point), profound neurologic impairment, and moderate to severe neurologic impairment. The tool includes outcomes information both from patients for whom active management was initiated and whom active management was withheld (active management defined by the NICHD as intubation, surfactant therapy, epinephrine, chest compressions, bag-valve-mask ventilation, mechanical ventilation, or intravenous nutrition).

While clinicians have indicated that they utilized this statistical calculator during their counseling sessions, models like the NICHD tool are generally based on population averages. Also, most models use prenatally available factors to determine postnatal course. It is not uncommon that once a trial of therapy is initiated for an infant, their postnatal course follows a trajectory that may have not been initially empirically predicted³. While population-based outcomes

data are important in the counseling process, and utilized by most clinicians, most families do not intuitively connect with a large, anonymous population of infants – rather, they want to know what will happen to *their* child. Unfortunately – “predictor” tools are not actually able to forecast the specific outcome for an *individual infant* – they merely account for a range of knowable information and relate this information to a historical cohort of *similar infants*.

Clinicians’ prognostic abilities relative to an actual infant are thus inherently intuitive and imperfect. When attempting to predict outcomes based on individual courses after delivery, clinicians are good at predicting a “poor” outcome, defined as either mortality or survival with severe neurologic morbidity, but not mortality itself.¹⁷ Previous practices also relied upon clinicians’ assessment of “how an infant looks” in the delivery room as a prognostic tool to guide decision-making. The usefulness and reliability of such gist assessments has been repeatedly debunked.¹⁸

Based on a retrospective cohort study of infants with congenital anomalies conducted by Kukora *et al*, neonatologist prognostication during the perinatal period was fairly conservative, listing “uncertain” prognoses for most infants that survived. Delivery room resuscitation was performed for almost all infants predicted to have high likelihood of survival and those with uncertain prognosis, whether it was classified as uncertain but likely non-survivable or uncertain but likely survivable. Most infants predicted to have low chance of survival were not actively resuscitated in the delivery room.¹⁹ Of note, while this study did not focus on predictions of morbidity, it is clear that resuscitation efforts in the delivery room are affected by predictions of survival. However, the risk of mortality may not be the sole influencer of parental decision-making.

While use of prognostic information in guiding parental decisions is important, it is equally important to identify how information is framed and how implicit biases can influence recommendations. Recent evidence suggests that clinicians who have an implicit negative socioeconomic bias are more likely to recommend comfort care when counseling women of higher socioeconomic status. Also, clinician demographics can influence recommendations. Women clinicians and married clinicians showed a preference for comfort care compared to their counterparts. While acknowledging patient values is central to the decision-making process, it is also important to understand how clinician experiences, culture, and personal preferences may shape how they counsel patients.²⁰

Parent and Clinician Preferences

When it comes to the counseling and decision-making process, most parents prefer shared decision-making when considering management plans for periviable births²¹. While clinicians base their counseling sessions on assessing risk and predicting outcomes, determination of what constitutes an acceptable or unacceptable quality of life is a highly subjective endeavor. Although clinicians likely have their own beliefs and values regarding quality of life, in contemporary perinatal decision-making, parental valuations of quality (and quantity) of life are considered to be the most important to values-based decision making in the “gray zone.” In these instances, the relevance of medically informed “futility”

deteriorates, and the parents must be the primary decision makers in determining intensive life supportive treatment in the face of poor prognoses.²²

Although best interest standards are generally considered to act as boundaries around the range of decisions that parents can make to request or refuse life-prolonging interventions,²³ the term “best interest” is highly subjective, better operationalized in law than in medical practice. For example, when considering a long-odds intervention after birth, the medical team may deny parents’ request on the basis of best-interest, determining that the potential harms of the intervention outweigh the incremental increase in length of survival. However, some parents might argue that their child’s best interest are not promoted by accepting death, when there is even a remote chance of successful intervention. These nuanced valuations demonstrate that, while family-centered counseling is the ideal format for determining goals of care, clinicians’ own values may influence how information is presented and what information is presented. Additionally, clinician comfort with prognostic uncertainty has the potential to limit effective communication. In instances of uncertainty, clinicians may resort to operationalization of information while parents may need more abstract, affective elements of communication.²⁴

Parents of infants born extremely prematurely or with potential lethal anomalies have reported that they felt that clinician’s predictions of survival or disability did not strongly influence their decisions. Rather, a combination of their own perceptions of the situation and religion, hope, and spirituality guided their decision-making. Additionally, parents have reported “feeling abandoned” by clinicians who appeared to be simply following protocol rather than addressing the patient’s individual circumstance. Most parents expressed that they would have preferred clinicians to present their predictions and prognoses in a way that is optimistic and gives hope to the family.⁹

In a study conducted by Kieszun *et al*, expectant women facing preterm birth responded to case vignettes regarding preferences for life sustaining treatments or palliative care at the margin of viability. Among the women who were surveyed, most treatment decisions were based on individual values rather than reasoning through numerical estimates about survival or survival with morbidity.¹⁰ The onus is on the counselor to utilize prognostic information in a way that provides information to families without making them feel as if they have lost a sense of agency or hope and allows them space to make decisions based on their individual values.

Obstetrician and neonatologist approaches to counseling

When considering counseling at the margin of viability it is important to note that obstetricians and perinatologists are often at the front-line of communicating imminent premature delivery and counseling on delivery and management options. Professional organizations from both obstetrics and neonatology have set forth guidelines surrounding the consultation process. Emphasis is placed on concurrence between the two specialties prior to, and after, counseling.

Obstetricians and neonatologists should ideally meet prior to the counseling session to avoid conflicting information, or, even better, provide integrated counseling together. If unable to co-counsel, debriefing between both teams should occur after the sessions have occurred to confirm management plans.²⁵

A study conducted by Edmonds *et al* demonstrated that during antenatal counseling, obstetricians were more likely to discuss antibiotics, maternal risks, and the need for and risks of cesarean delivery. Neonatologists were more likely to discuss resuscitation options, possible complications for the baby, and palliative care options. It was found that with regards to counseling on use of antenatal steroids at the margin of viability, each specialty deferred to the other. Neonatologists were twice as likely to reference values, comfort/suffering, and uncertainty within their counseling sessions as compared to obstetricians. Of note, prediction of survival varied widely among clinicians, from no survival to 50% survival among both obstetricians and neonatologists.²⁶ These divergences highlight important areas of continued study and reflection.

Challenges in counseling and future directions

Current methods for prenatal counseling at the margin of gestational viability utilize population-based models that are a compilation of population averages mainly based on non-modifiable prenatal factors. After a trial of therapy is initiated, more counseling sessions must occur to determine whether to continue to pursue intensive interventions. Oftentimes, these sessions are based on limited epidemiological data.

In a blueprint generated by Myers *et al* (Fig. 1), rates of survival depend on predetermined paradigmatic plans along each stage of decision-making.²⁷ For infants in which no active intervention is intended at delivery, the survival rate rapidly declines after birth. Survival is slightly higher in infants for whom a trial of therapy is initiated, and again higher for those with whom palliative care is involved and

even higher for those with whom maximal intervention is introduced. While some infants may unexpectedly survive with little to no intervention, others may not survive even with maximal intervention. The uncertainty surrounding individual trajectories remains one of the most challenging facets of counseling sessions at the limit of viability.²⁷

Many tertiary care facilities with the infrastructure for managing extremely preterm births have attempted to generate standardized protocols, checklists, or materials to assist in the counseling and decision-making process. While these tools may help to improve parental knowledge about the potential outcomes and decisions at hand, it was found that despite increased knowledge about empiric outcomes there was little to no change in decision-making pre- and post-exposure to these tools.²⁸

While prognostic information is essential to the consultation process, it is important to be mindful of framing effects by the clinician, parents' abilities to accurately process and assimilate information in stressful situations, and the influence of emotions on decision-making. It is essential that empiric data be utilized to support qualitative discussions surrounding goals of care without overwhelming the family with data. Expectant parents will differ in terms of how they welcome, understand, and assimilate information. This requires anticipation and discernment of parental needs and wishes and is a domain that must be expanded upon in both research and training.²⁹

Summary and conclusions

In this review we explored the benefits and pitfalls of providing objective, prognostic information surrounding outcomes at the margin of viability. Although provision of such information is central to the counseling process, parents generally rely less on this objective information than on their own personal values. Additionally, accuracy of prognostic predictions of survival, or survival with severe neurologic morbidity, are challenged by the unexpected trajectories that can occur after birth. Within antenatal counseling sessions, prognostic

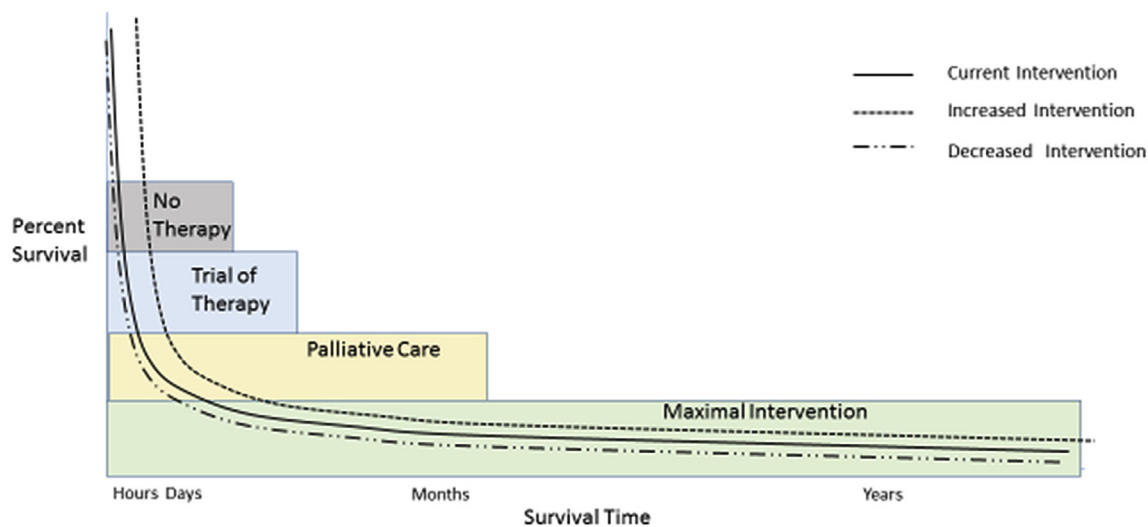


Fig. 1 – fig

information should be utilized as a supplement, with careful attention to the end user of this information, and with deliberate focus on delineation of parental values and goals of care in determining plans for management surrounding infants born at the margin of viability.

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