

**The Periviable Infant: The Implementation of a Standardized Perinatal/Neonatal
Outpatient Consultation Program**

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Abstract

Common ethical principles are the foundation for why we ask parents for informed consent before proceeding with their infant's care. Respecting parental decisions in periviable resuscitation can benefit from adopting a new practice. This evidence-based practice project detailed the identified needs-based practice change for a standardized perinatal/neonatal outpatient consult concerning the periviable infant. Initiating early consultation of high-risk deliveries provides an understanding of parental wishes and satisfaction in decision-making, care of their infant, and bereavement support through a shared decision-making model. The project aligns with value-based care delivery, designed to improve healthcare by focusing on outcomes. Larrabee's Evidence-Based Practice model served as the guiding framework. Appraisal and synthesis of the literature necessitate recommendations to employ a shared decision-making model for developing and communicating a well-designed birth plan following the delivery of the periviable infant. A validated survey, the Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU), evaluated parental stress following the perinatal consult and delivery of a periviable neonate admitted to the neonatal intensive care unit. Eight participants were recruited (four women and their identified support person). Parents who received the perinatal/neonatal consult had less critically unstable infants however reported less stress in two of the three subscales.

Keywords: counseling, extreme prematurity, palliative care, periviable, periviable birth, PSS: NICU, shared decision-making

The Periviable Infant: A Standardized Perinatal/Neonatal Outpatient Consult

Each week in the United States, an average of 72,068 babies are born, of which 7,366 are preterm, and 1,144 are extreme preterm, requiring intensive care and life-sustaining measures (March of Dimes, 2021). Premature birth and its associated complications result in complex and ethically challenging decisions. In recent years, the viability of extreme premature infants has been debated in neonatology, as some offer trial resuscitation at 22 weeks gestation. More significant concerns are the management of care and long-term outcomes of those extreme preterm infants resuscitated. The long-term implications for infants who survive resuscitation, admission to the neonatal intensive care unit (NICU), and final discharge can be devastating. Specifically, those infants born at 22-24 weeks of gestation. The decision-making for resuscitation, trial resuscitation, or supportive care following the birth of a 22-24 week gestation infant is complex. Initiating early consultation with high-risk obstetrical women about viability will allow a better understanding of parental preferences, resulting in higher decision-making satisfaction and improving the care provided to the women and their extremely preterm infants. Periviable birth is defined as a delivery occurring between 20 0/7 to 25 6/7 weeks of gestation (Ecker et al., 2016).

The limit of viability, defined as the stage of fetal maturity, is not feasible at less than 22 weeks of gestation anatomically, given fetal lung maturation. Preterm birth is defined as infants born alive before 37 weeks of gestation, and extreme preterm infants born live before 28 weeks of gestation (Blencowe et al., 2013). An infant's gestation is the most significant predictor of survival and subsequent health. Infants born prematurely have higher mortality and morbidity rates than infants born at full term or 39-40 weeks of gestation. Mortality rates of infants fall with each increase in a gestational week (Mathews et al., 2015).

In 2019, the United States (U.S.) preterm birth rate was 10.2%, remaining the highest among developed countries. The Southeast region of the U.S. continues to have the highest preterm birth rates and disparities throughout the country. Premature births and complications are the leading cause of infant deaths in the U.S., accounting for 35% of the world's 3.1 million deaths annually (March of Dimes, 2021). Traditionally, birth weight and gestational age are predictors of fetal outcomes and the criteria for offering resuscitation or supportive care (Ecker et al., 2016).

Optimal decision-making regarding initial management is achieved through joint discussions between parents, obstetrical, and neonatal providers (Cummings, 2015). Seminars in Fetal and Neonatal Medicine in 2018 discuss the National Institute of Child Health and Human Development (NICHD) Extremely preterm birth outcomes tool to aid in the outcome prediction for infants born at the margin of viability. The NICHD calculator utilizes epidemiologically derived outcomes provided through a database that can be somewhat modified and individualized for prognosis (Guillén et al., 2019). Continued discussion aligns with previous statements emphasizing that family values are the framework shaping their perceptions of their infant's outcome. Family perception of their infant's birth and care is relevant to shared decision-making (Kukora & Boss, 2018).

Neonatal providers are asked to counsel pregnant women threatening preterm delivery on viability, morbidity, and mortality according to the gestational age. Pregnant women are provided all options, outcomes, risks, and benefits associated with delivering their preterm infant, while knowing the comprehension and retention of the information supplied is limited (Haward et al., 2017). A decision is made among uniquely diverse conditions, including culture, religion, technology, and prior knowledge and comprehension (Kaempf et al., 2009). The women

and their families are then asked to decide resuscitation versus supportive care if their pregnancy is within the periviable gestation. For an imminent preterm birth, minimal resources and education are provided due to the surrounding circumstances of a high-risk admission and stabilization of the mother's labor. The decision's impact has lasting physical and psychological symptoms for women, their partners or family, and the fetus.

Methods

Project Design

The purpose of the project was to provide a proactive approach, initiating perinatal/neonatal consults preferably before the periviable period, 20 0/7 weeks of gestation to 21 6/7 weeks of gestation. The project's goal was to improve the delivery outcome for families through identified parental goals, preferences, and perceptions surrounding delivery and resuscitation goals.

Larrabee's Model for Evidence-Based Practice (EBP) guided this evidence-based practice project's development, implementation, and evaluation (Larrabee, 2009; Rosswurm & Larrabee, 1999). The evidence-based practice process serves as a problem-solving framework for decision-making. The EBP model combines "the best available evidence in conjunction with the professional's expertise" and patient's values and preferences (Levin et al., 2010, p 119). The model provided a systematic approach to problem-solving. A focused clinical question presented in the population, intervention, comparison, and outcome (PICO) format was developed to guide the search through the body of evidence. Appraisal and synthesis of the evidence supported the PICO question. After acquiring evidence, defining the practice change through a pilot project allowed for continued evaluation, feedback, and minor adjustments throughout implementation.

Larrabee identified the final step as integrating and disseminating the project results, ultimately supporting the practice change (Melnik & Fineout-Overholt, 2019).

The Johns Hopkins Nursing Evidence-Based Practice critical appraisal tools were utilized to appraise and assign each research article's level and quality grade. Most articles identified were qualitative studies with additional systematic reviews or position statements from nationally recognized professional organizations (i.e., American Academy of Pediatrics and The American College of Obstetricians and Gynecologists). Given the abundance of qualitative research retrieved, similarities and differences were extrapolated, highlighting consistent themes reinforcing the project's recommendations. Themes included a shared decision model, timing of the consultation, resources provided to parents during a consultation, and the overall communication approach with parents. Findings from the review of the literature consistently accentuated the provider and parental preference for using a shared decision-making model (SDM). The SDM model allows adequate time to identify and clarify parental values and the importance of resuscitation or supportive care. Findings from the research recommended optimizing key communication strategies with a SDM approach. Critical communication strategies, such as consistency of providers and the information delivered were emphasized. The consistency of communication and providers will help enable a trusting relationship between the parent and provider.

Additional recommendations for a semi-structured consultation with the family include devising a predelivery plan incorporating parents' preferences and goals guiding the management of the periviable infant. Although most of the literature discussed prenatal consults occurring while the women were inpatients, the research did allude to parental importance for adequate time (and potential request by parents for multiple consult sessions). Given the sensitivity of

periviability, a recommendation for the consultation to begin on an outpatient basis was made to meet the women and their support person at a regularly scheduled obstetrical appointment.

A validated scale, the Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU) developed by Dr. Margaret Miles (Miles et al., 1993) evaluated parental stress two weeks after receiving the perinatal consult and delivery. During the initial implementation phase, the proposed project ran as a pilot. Piloting the project afforded performance to occur on a smaller scale to allow continuous improvement or feedback on what was working and what could be improved.

Data Analysis and Results

The project was implemented in a Level 3+ NICU averaging some 6000 deliveries per year, with approximately 600 admissions to the NICU annually. The NICU has access to pediatric surgery and many other subspecialties and is surrounded by three Level 4 NICU centers that are easily accessible. During implementation, 163 infants were admitted to the NICU, of which six were <26 weeks' gestation.

Descriptive data were analyzed using SPSS v28. Reliability of two of the three PSS: NICU sub-scales were acceptable to good ("sights and sounds," $\alpha = 0.74$; "baby looks and behaves," $\alpha = 0.91$) with questionable reliability on the "relationship and parental role" ($\alpha = 0.59$). As predicted, "relationship and parental role" provoked the most stress ($M = 2.7$, $SD = 1.2$) following how "baby looks and behaves" ($M = 2.04$, $SD = 0.95$) sub-scale. Parents reported less stress on the "sights and sounds" scale ($M = 1.63$, $SD = 0.57$). Parents who received a perinatal/neonatal consultation ($n = 8$) had less critically unstable infants than parents who did not receive the consult. Table 1 displays the characteristics of the sample.

Table 1*Characteristics of Project Sample*

Characteristics	Perinatal/Neonatal Outpatient Counseling (n=4)	Perinatal/Neonatal Inpatient Counseling (n=4)
Sex		
Female	2 (50%)	4 (100%)
Male	2 (50%)	0 (0.0%)
Maternal age		
20-29	2 (50%)	1 (25%)
30-39	0 (0.0%)	0 (0.0%)
>=40	0 (0.0%)	1 (25%)
Gestation age at delivery		
22-23 6/7 weeks	0 (0.0%)	0 (0.0%)
24-25 6/7 weeks	0 (0.0%)	1 (25%)
>=26 weeks	2 (50%)	1 (25%)

Implications for Practice

The literature's findings encourage using a shared decision-making model recommending a semi-structured consultation with the family at risk of delivering a periviable neonate. The consultation includes devising a predelivery plan incorporating parents' preferences and goals guiding the management of the periviable infant. Preemptively beginning the perinatal/neonatal consultation earlier in the woman's pregnancy, the shared decision-making model will allow

adequate time to identify and clarify parental preferences and values regarding resuscitation or supportive care.

A shared decision-making model's success hinges on the provider, family involvement, and the support from the organization to aid in implementation. Findings from the project identified parental preferences anticipating a periviable delivery by developing a well-communicated birth plan. In addition to improving communication between inpatient and outpatient teams caring for high-risk obstetrical women, education and resources were provided to mitigate social determinants of health that impact pregnancy outcomes. Social determinants of health have recently been reported as having the most significant impact on pregnancy outcomes within the project's county and state, identified as having some of the highest preterm delivery rates (Guildford County Department of Health and Human Services, 2021).

Conclusion

A significant barrier to implementing the perinatal consult program was the lack of sufficient time between meeting with identified high-risk patients and time to delivery. There was limited time to establish a rapport and communicate patient preferences with the neonatal team. The project lead made modifications to provide all patients with the same resources and follow-up after delivery and admission to the NICU despite if they participated in the project consult. The purpose was to continue the shared decision-making process as the infant's condition warranted.

An additional barrier was the overall volume of high-risk patients, specifically those known and at risk for periviable delivery. As previously stated, 163 infants were admitted to the NICU between October 1 through December 31, 2021, with a total of six infants delivered at less than 26 weeks' gestation. The two women who were provided the perinatal/neonatal consultation

beginning outpatient and followed through delivery, infants were not as critically ill and had a relatively benign NICU course. Positive feedback was provided by all families stating that additional resources, continuity of care providers, and the relationships developed were welcomed throughout the NICU admission. Continuation of the project will occur following the project's findings and evaluations presented to the identified key stakeholders within the organization.

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