Personalized Antenatal Consultations for Preterm Labor: Responding to Mothers' Expectations

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Objective To explore prospective mothers' perspectives regarding antenatal consultations by neonatology teams for threatened preterm delivery.

Study design In a prospective multicenter study, women at risk of preterm delivery between 26 and 32 weeks of gestational age were surveyed during the 72 hours following their antenatal consultation. The questionnaire used was developed and validated during a single-center study.

Results Over 18 months, 229 mothers completed the survey (73% response rate), at a median gestational age of 30 weeks. Spouses/partners were present for 49% of consultations. Most women (90%) reported a positive experience. They found it important to discuss the outcomes of prematurity (96%), but 39% of them reported receiving too much information. Women wanted their spouse/partner to be present (71%) and wished to discuss parental concerns: their roles as mother of a premature baby (82%), their integration in their baby's care (83%), and a better understanding of the neonatal intensive care unit (NICU) environment, including antenatal NICU visits (69%). The majority (56%) wanted a follow-up consultation: this was less likely if a NICU visit had been offered ($P < .001$), if their role as decision-maker had been discussed ($P < .05$), or if the consultation had lasted longer ($P = .001$).

Conclusion Policy statements recommend a standardized approach to providing parents with child-centered information. Although clinicians follow these guidelines, mothers want personalized information focusing on their individual concerns and questions, such as what they can do for their baby, how NICUs work, and the integration of their family. *(J Pediatr 2016;178:130-4).*

Antenatal consultations by neonatology teams are an essential step in preparing parents at risk of preterm delivery. Several recent policy statements have been published by national professional organizations and focus on the importance of informing parents in this situation.[1-3] Guidelines suggest parents should have access to standardized information: providers should explain local survival rates and provide detailed information regarding potential short-term or long-term complications and outcomes of prematurity.[2-4] These important statements are considered the standard of care: they exert significant influence on clinical practices and research agendas.[5] Indeed, checklists have been proposed to ensure consultations are comprehensive, standardized, and follow a rigorous agenda so that all prospective parents receive the same accurate and homogeneous information.[2] Increasing efforts are being made to ensure parents both understand and retain information provided during the antenatal consultation.[6-8]

Have policy statements and research programs overestimated the importance of information transfer and recall? Parents and physicians remember information differently.[9,10] Studies that assessed parental perspectives have demonstrated that they seek more than factual information from neonatologists.[11,12] Furthermore, even though spirituality and hope are essential to parents at risk of preterm labor, many neonatologists view their main role as providers of factual information and inconsistently address social and parental issues.[11,13,14] Although neonatal ethics and research has focused primarily on consultations at the limit of viability, these situations occur in less than 1% of births and the majority of prenatal consultations occur later.

The objective of our study was to explore mothers' expectations, wishes, and perspectives regarding antenatal consultations for preterm labor beyond the limits of viability, between 26 weeks and 32 weeks' gestational age (GA), and their experience of this consultation.

Methods

This study was a prospective survey of women at risk of preterm delivery. The survey was developed with the use of results from our previous qualitative study

GA	Gestational age
NICU	Neonatal intensive care unit

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exploring mothers' perspectives and expectations regarding prenatal consultations for preterm labor.[15] An initial survey was constructed in French. Construct validity was verified by sending the survey back to the initial participating mothers. Content validity was then assessed by a group of health care providers (2 neonatologists, 2 nurses, and 1 obstetrician) and by a new sample of 7 women hospitalized for premature delivery. These participants gave their feedback regarding clarity of the items and ability of the tool to address the most important issues. Given women's rapidly evolving situation, reliability and test-retest stability could not be assessed. In 2008, the survey was distributed to a sample of 51 participants in CHU Sainte-Justine. After its completion, 3 items were modified for the final survey. The survey was translated in English by one of the investigators, and 2 bilingual experts in the field of neonatology back translated it. The final tool has 76 questions, taking approximately 20 minutes to complete (**Appendix**; available at www.jpeds.com). This study was approved by the institutional review board of all 3 participating health care institutions. Written informed consent was obtained from all participants.

Between April 2012 and September 2013, the multicenter investigation took place at the CHU Sainte-Justine (University of Montreal), CHU Laval (University Laval, Québec City), and McGill University Health Center (McGill University, Montreal). Women hospitalized for threatened preterm labor between 26 and 32 6/7 weeks' GA who met with the neonatologist for an antenatal consultation were invited to complete a survey within 72 hours of the consultation; only women who had not yet delivered were included. All women who met the following inclusion criteria were approached: ≥18 years of age, English or French speaking, no active psychiatric disorder, and no identified fetal anomaly. An interviewer was made available for women who reported they could not read or needed help to complete the survey. Information regarding who performed the antenatal consultation was collected, but the outcomes of the respondents' pregnancies were not.

The data were entered into an Excel database (Microsoft Inc, Redmond, Washington) to generate descriptive results. Categorical data were analyzed with χ^2 tests. Continuous data, with a normal distribution, were compared with Student *t* tests. Continuous data, not normally distributed, were analyzed with nonparametric statistical analyses, such as the Mann-Whitney *U* test, a Kruskal-Wallis *t* test, or a paired samples sign test. Quantitative data analysis was performed with SPSS v20 (IBM Inc, Armonk, New York). Subgroup analyses with Kruskal-Wallis *t* tests were performed to compare patients' answers depending on their ethnicity, country of origin, religious beliefs, marital status, primary language, and education level. The survey's open-ended answers were transcribed in full in TAMS Analyzer (Matthew Weinstein; http://tamsys.sourceforge.net/) and analyzed with thematic analysis by 2 investigators (N.G. and A.P.). Discrepancies were resolved by consensus.

In the 3 institutions, staff neonatologists, neonatology fellows, pediatric residents, and trained neonatal nurse practitioners perform antenatal consultations. None of the centers have a protocol for antenatal consultations: providers do not use checklists, standardized information, tools, or decision-aids. As reported in previous studies, providers generally use a parent-centered approach: topics discussed during consultations are driven by parental concerns and questions, including explanations regarding outcomes of prematurity.[12,16,17]

Results

Overall, 229 participants completed the survey (73% response rate) (**Figure 1**; available at www.jpeds.com). Participants' demographic characteristics are presented in **Table I**. The majority of consultations took place in the obstetrics ward (74%) or in the delivery room (24%). Several participants reported they were not informed that they would meet with a neonatal provider (19%). Staff neonatologists performed most of the consultations (78%). Nurse practitioners (2%) or residents/fellows (4%) rarely provided antenatal counseling alone, and 6% of women reported receiving the information from more than one provider; however, 10% of women were unsure of the role of the provider they met during the antenatal consultation. In 65% of cases, 1 health care provider was present for the consultation; 2 people were present in 24% of consultations and, rarely, 3 or more (8%) were present. Women whose spouses/partners were present wanted this significantly more than women whose spouses/partners were absent during the consultation (median 5 vs 3 on 5-point Likert scale, $P < .001$). Most consultations (68%) lasted 20-30 minutes; 6% lasted 10-20 minutes, and 26% more than 30 minutes. Consultations that lasted longer than 20 minutes were associated

Table I. Participants' demographic characteristics

Demographic characteristics	n (%)
Median age, y (min, max)	29 (18, 42)
Median GA, wk (min, max)	30 (26, 34)
Ethnic origin (n = 199)	
White	167 (84%)
African-American	16 (8%)
Other	16 (8%)
Language (n = 228)	
French	195 (86%)
English	20 (9%)
Other	13 (6%)
Education (n = 228)	
Primary	8 (4%)
High school	72 (32%)
College or university	148 (65%)
Current occupation (n = 219)	
Works in health care	56 (26%)
Stay-at-home mother	24 (11%)
Works in education	27 (12%)
Student	10 (5%)
Other, employed	99 (45%)
Religion (n = 208)	
Atheist/none	18 (0%)
Christian	181 (87%)
Other	9 (4%)
Religion/spirituality important (n = 220)	71 (32%)
Married or common-law partner (n = 227)	215 (95%)
Previously pregnant (n = 226)	125 (55%)
Previous premature baby (n = 228)	41 (18%)
Previous baby hospitalized at birth (n = 228)	30 (13%)