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### Communication Study

# "Doctor, what would you do?": Physicians' responses to patient inquiries about periviable delivery



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#### ABSTRACT

*Objective*: To qualitatively assess obstetricians' and neonatologists' responses to standardized patients (SPs) asking "What would you do?" during periviable counseling encounters.

Methods: An exploratory single-center simulation study. SPs, portraying a pregnant woman presenting with ruptured membranes at 23 weeks, were instructed to ask, "What would you do?" if presented options regarding delivery management or resuscitation. Responses were independently reviewed and classified.

Results: We identified five response patterns: 'Disclose' (9/28), 'Don't Know' (11/28), 'Deflect' (23/28), 'Decline' (2/28), and 'Ignore' (2/28). Most physicians utilized more than one response pattern (22/28). Physicians 'deflected' the question by: restating or offering additional medical information; answering with a question; evoking a hypothetical patient; or redirecting the SP to other sources of support. When compared with neonatologists, obstetricians (40% vs. 15%) made personal or professional disclosures more often. Though both specialties readily acknowledged the importance of values in making a decision, only one physician attempted to elicit the patient's values.

Conclusion: "What would you do?" represented a missed opportunity for values elicitation. Interventions are needed to facilitate values elicitation and shared decision-making in periviable care. *Practice implications*: If physicians fail to address patients' values and goals, they lack the information needed to develop patient-centered plans of care.

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#### 1. Introduction

Periviable neonates bear the greatest burden of perinatal morbidity and mortality. Roughly half survive and, among survivors, up to two-thirds suffer moderate to severe neurodevelopmental disabilities [1]. Despite advances in neonatal intensive care, long-term neurodevelopmental outcomes for these infants have not improved in recent years [2]. Periviable births are emotionally and financially costly for families and the healthcare system [3–5]. Because these infants are unable to survive without ventilatory support, periviability presents parents and physicians

with the unique challenge of having to make 'end-of-life decisions' at the very beginning of life. These are high-stakes, highly stressful decisions that patients have likely never faced nor contemplated. Patients rely heavily upon physicians to help them make sense of their diagnosis, prognosis, and options for care. Overcome by emotion and overwhelmed with medical information, it is not uncommon for patients to ask their physician, "Doctor, what would you do?"

A number of commentaries and editorials have offered physicians ethical frameworks to understand this question and professional techniques to navigate their responses [6–12]. Periviable counseling encounters call for shared decision-making [13,14] and "What would you do" represents a pivotal question in these encounters. Few research studies have explored physicians' response patterns to this question [15], and none have included both obstetricians' and neonatologists' responses when the question is posed at the limits of viability. Given the multispecialty

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nature of periviable care, it is important to understand the role each specialty plays in counseling patients. The purpose of this study was to qualitatively assess and compare obstetricians' and neonatologists' responses to standardized patients (SPs) asking: "What would you do?" while discussing delivery management and resuscitation at 23 weeks gestation.

#### 2. Methods

#### 2.1. Study design

With approval from the Indiana University Institutional Review Board, we conducted an exploratory single-center simulation pilot study. The data were drawn from a larger parent-study designed to determine the effect of patient race and insurance status on the quality and content of periviable counseling. The case depicted a 31 year-old woman presenting with preterm premature rupture of membranes (PPROM) at 23 weeks gestational age. A multidisciplinary team of physicians, including specialists from neonatology, maternal fetal medicine, and palliative care, contributed to case development. The clinical components of the simulation were further developed and refined in a series of pre-tests with three physician volunteers. We trained SPs to play the patient role based on detailed symptom and psychosocial profiles. Consistent with previous simulation work [16], the actresses received more than 10 h of training to ensure standardization. We instructed SPs to ask the provider, "What would you do?" if the provider presented more than one treatment option during the course of the counseling encounter. We video-recorded and later transcribed each counseling session.

#### 2.2. Study population

We recruited facutly and fellows from the Indiana University School of Medicine Department of Obstetrics and Gynecology (OB/ GYN) divisions of General Obstetrics and Gynecology and Maternal Fetal Medicine and from the division of Neonatology at Riley Hospital for Children through in-person presentations at faculty meetings; e-mails to departmental distribution lists; and calls or visits to physicians' offices. OB/GYNs practicing gynecology - only as generalists or subspecialists were excluded from eligibility; likewise, obstetricians and neonatologists who participated in case development or pilot testing were excluded. In qualitative studies, thematic saturation is customarily reached with 10-15 participants in relatively homogeneous populations [17]. Therefore, our target for recruitment was 16 OB/GYNs and 16 neonatologists among 37 eligible OB/GYNs and 45 eligible neonatologists. Study participation took 2 h and included completion of simulation encounters; completion of a self-administered demographics survey; and a debriefing interview. Study participants received \$100 compensation.

#### 2.3. Data analyses

We analyzed the video recordings and transcripts using a modified grounded theory approach [18]. After viewing the video-recorded responses, we created an initial codebook that was derived inductively from physician responses to the question, "What would you do?". We then reviewed the transcripts and amended the codebook to reflect additional observations. Two trained reviewers (BTE, JP) independently coded all transcripts to ensure reliability of the coding scheme. We resolved coding discrepancies between reviewers by consensus. We used NVivo 10 to code all data and to facilitate qualitative analysis.

Codes for physician responses fell into five major categories: Disclose, Don't know, Deflect, Decline and Ignore. The 'Disclose' code applied to any direct response to the question that included a personal or professional opinion, preference, or recommendation. 'Don't know' applied if the provider responded by stating, 'I don't know' or voicing uncertainty (e.g. 'I'm not sure' or 'It's difficult to say') in their response. 'Deflect' applied to any response (other than a refusal) that failed to provide a direct answer to the SP's question. 'Decline' applied to refusals to answer the question. 'Ignore' applied to absence of a direct response, refusal, or even acknowledgment of the question. Additionally, the code, 'Values,' was applied if the provider told the SP that the decision needed to be based on the personal values, preferences or faith of a given individual or family. Codes were not mutually exclusive, meaning that more than one code could be applied to a physician's response. Though we had initially expected respondents to fall into a simple 'did- vs did not-disclose' binary, in the process of coding we discovered that physicians' responses were often circular and indirect. Consider the following example:

#### Physician X

You know, that is a great question. I will tell you in our training they just kind of told us that we shouldn't answer that, that it's not fair to the family, but you know... the honest answer is, I don't know ... I used to think that oh I would know and you know what happened? I got pregnant. I got to 23 to 24 weeks and I was terrified. I had no problems. I was very fortunate but, you know, it's different being a mom and so I can't begin to put myself into your shoes. I appreciate you asking the question. I'm not trying to avoid it. I just think really there's no right or wrong answer ... I can tell you I hope, you know what I know about... the struggles those babies go through and ultimately what their life can be like when they survive ... I hope I would at least consider providing comfort if I could ... [15-N]

In this physician's response, 'Don't know,' 'Values,' then 'Disclose,' codes were applied to the three underlined statements, respectively. Ultimately, we found that more than one code applied in 22 responses. Therefore, we decided to capture as many codes as applied.

#### 3. Results

Sixteen obstetricians (43%) and 15 neonatologists (33%) participated in the study. We describe participant characteristics in Table 1. All but three encounters (28/31) included the SP's "What would you do?" prompt. In one of the three encounters, the SP failed to utilize the prompt despite being presented with more than one management option; in the other two, the physicians (one neonatologist and one OB) did not provide the patient with options.

Here, we describe each category of physician response, and its subcategories, in further detail, and in Table 2, we present coding frequencies for each. Because categories were not mutually exclusive, we also present physicians' responses stratified by whether or not they made a disclosure (Table 3) for ease of interpretation.

#### 3.1. Disclose, deflect or decline

Overall, physicians did not readily disclose personal perspectives to patients in response to the prompt. However, obstetricians made disclosures more often than neonatologists. Six of 15 (40%) obstetricians provided a personal preference, opinion, or recommendation; while only 2 (15%) of the neonatologists did (Table 3). To illustrate, when faced with the question, one obstetrician explained:

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