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A Pilot Study of Neonatologists' Decision-Making Roles in Delivery Room Resuscitation Counseling for Periviable Births

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Abstract

Background—Relatively little is known about neonatologists' roles in helping families navigate the difficult decision to attempt or withhold resuscitation for a neonate delivering at the threshold of viability. Therefore, we aimed to describe the “decision-making role” of neonatologists in simulated periviable counseling sessions.

Methods—We conducted a qualitative content analysis of audio-recorded simulation encounters and post-encounter debriefing interviews collected as part of a single-center simulation study of neonatologists' resuscitation counseling practices in the face of ruptured membranes at 23 weeks gestation. We trained standardized patients to request a recommendation if the physician presented multiple treatment options. We coded each encounter for communication behaviors, applying an adapted, previously developed coding scheme to classify physicians into four decision-making roles (informative, facilitative, collaborative, or directive). We also coded post-simulation debriefing interviews for responses to the open-ended prompt: “During this encounter, what did you feel was your role in the management decision-making process?”

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CONFLICTS OF INTEREST: Amber Barnato previously served as Vice President and Trustee for the Society for Medical Decision Making and received reimbursement for travel to two board meetings.

ETHICAL APPROVAL: This study was approved by the institutional review board at Indiana University.

Results—Fifteen neonatologists (33% of the division) participated in the study; audio-recorded debriefing interviews were available for 13. We observed 9 (60%) take an informative role, providing medical information only; 2 (13%) take a facilitative role, additionally eliciting the patient’s values; 3 (20%) take a collaborative role, additionally engaging the patient in deliberation and providing a recommendation; and 1 (7%) take a directive role, making a treatment decision independent of the patient. Almost all (10/13, 77%) of the neonatologists described their intended role as informative.

Conclusions—Neonatologists did not routinely elicit preferences, engage in deliberation, or provide treatment recommendations—even in response to requests for recommendations. These findings suggest there may be a gap between policy recommendations calling for shared decision making and actual clinical practice.

Keywords

periviability; neonatal intensive care; mechanical ventilation; perinatal palliative care; patient-doctor communication; shared decision making

INTRODUCTION

Parents and neonatologists making decisions about resuscitation for infants born at 23 weeks, considered the edge of viability, face the unfortunate choice between comfort measures only versus attempted resuscitation and prolonged life supporting treatment with uncertain risks and benefits. Parents make these value-laden, time-pressured decisions under emotional duress. These are decisions that most persons have never faced, or even contemplated, and so, they may rely heavily upon physicians to help them make sense of their diagnosis, prognosis, and options for care.

The Institute of Medicine (IOM) has declared that patient-centered care is a critical component of safe, effective, high-quality healthcare (2001), and the American Academy of Pediatrics (AAP) has endorsed a shared decision-making (SDM) approach to periviable counseling (Batton 2009). An SDM model incorporates the physician’s experience and expertise with the patient’s values and preferences in a deliberative exchange that results in joint decision making. SDM stands in contrast to informed decision making, whereby physicians present treatment choices and information about these alternatives but do not participate in deliberation; or paternalistic decision making, whereby the physician makes the decision for, and independent of, the patient (Charles, Gafni, and Whelan 1997).

Despite the AAP recommendation, there is ongoing controversy about physicians’ ethical obligations and appropriate role in resuscitation decision making for periviable neonates. Some commentators argue for an informed decision-making model in which the resuscitation decision is solely the parents’, as they are ultimately responsible for the care of the child and the most appropriate “surrogate” decision makers to determine the child’s best interests. Others argue for a more paternalistic approach because they consider it untenable to place the burden of responsibility for such high-stakes decisions on parents in the setting of substantial duress and potential time constraints (Boss, Henderson, and Wilfond 2015;

Halpern 2003; Janvier, Bauer, and Lantos 2007; Janvier, Lorenz, and Lantos 2012; Kon 2006; Lantos and Meadow 2009; Ross 2003; Ruddick 2003; Truog 1999; Truog 2003).

Though several studies have explored neonatologists' practices and perspectives regarding periviable counseling (Grobman et al. 2010; Kaempf et al. 2006; Kaempf et al. 2009; Mehrotra et al. 2013; Singh et al. 2007; Weiss et al. 2007), relatively little is known about the decision-making roles neonatologists take in helping families navigate resuscitation decisions for neonates delivering at the threshold of viability. While authors have explored factors that influence end-of-life (EOL) decision making in intensive care settings (Barnato et al. 2011; Bastek et al. 2005; Fishman et al. 2009; Janvier et al. 2008; Lavin et al. 2006; Mitchell 2011; Partridge et al. 2001; Peerzada, Richardson, and Burns 2004; Singh et al. 2007; Wennberg et al. 2004), no studies have directly assessed the role that neonatologists take in making periviable resuscitation decisions.

The purpose of the current study was to explore the decision-making roles that neonatologists take when counseling a patient presenting to the hospital with ruptured membranes at 23 weeks gestation. We adapted a coding framework developed by White and colleagues (2010) and informed by Charles and colleagues' conceptual framework for SDM (Charles, Gafni, and Whelan 1997) to characterize physician decision making roles in EOL decision-making for incapacitated adults in the intensive care unit (ICU).

White and colleagues (2010) classified critical care physicians' approaches to decision making about withholding or withdrawing life-sustaining treatment during family meetings into 4 different categories of decision-making roles:

1. A collaborative role in which the physicians share in deliberations with the family and provide a recommendation (51%);
2. a facilitative role in which the physician guided the family by clarifying values and applying those values to the decision, but refrained from providing a recommendation (37%);
3. an informative role, in which the physician solely discussed the patient's prognosis and treatment options but failed to elicit values, engage in deliberation, or provide recommendations (11%); and
4. a directive role, in which physicians assumed all responsibility for the decision (1%).

Their findings suggest that the majority of adult ICU physicians demonstrated collaborative and facilitative approaches to care, consistent with an SDM model. In light of the AAP's recommendations for SDM, we thought it useful to apply this methodology in the antenatal context in order to examine neonatologists' roles in decision making when counseling patients with threatened periviable delivery.

METHODS

Study Procedures

This is a qualitative content analysis of transcripts from encounters between standardized patients (SPs) and neonatologist physician-subjects recorded for a previously published simulation-based study of periviable counseling (Tucker Edmonds et al. 2014). 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.

We randomly assigned physician subjects to counsel two standardized patients and video-recorded the encounters. One encounter was simulated by a black SP; the other by a white SP. The two SPs presented with different complaints, but comparable histories and diagnoses of preterm premature rupture of membranes (PPROM). Each encounter ran until a physician completed their counseling or 30 minutes elapsed. After the two SP encounters, the physician participants completed a self-administered survey. Finally, they completed a debriefing interview.

Informed consent was obtained prior to participation, but physician participants were not informed of the primary aim of the study until the end of their debriefing interview. Each physician received \$100 for participation. The Indiana University Institutional Review Board (IRB) reviewed and approved the study.

Simulation

Because periviable deliveries occur infrequently, typically without warning, and often under stressful circumstances, a simulation-based study design was selected as a less expensive, time-consuming, and ethically challenging opportunity to observe periviable doctor-patient interactions. Previous studies have found simulation to effectively result in high levels of verisimilitude and fidelity to clinical experiences of periviable counseling (Boss et al. 2012).

The case depicted a 31-year-old woman presenting with PPRM at 23 weeks gestational age. A multi-disciplinary team of physicians, including specialists from neonatology, maternal-fetal medicine, and palliative care, contributed to case development. We trained SPs to play the patient/mother role based on detailed symptom and psychosocial profiles. Consistent with previous simulation work (Barnato et al. 2011), the actresses received more than 10 hours of training to ensure standardization. This included training on rules of engagement and protocolized prompting strategies. For example, we trained SPs to request a treatment recommendation (“*Doctor, what would you do?*”) if the physician presented more than one treatment option in the course of counseling. If only one option or no option was presented, the patient did not present the prompt, but rather, listened in silence or accepted the physician’s recommendation. The clinical components of the simulation were further developed and refined in a series of pre-tests with three physician volunteers.

Study Population

We recruited faculty and fellows from the Division of Neonatology at a large, urban academic medical center through in-person presentations at faculty meetings; e-mails to Division distribution lists; and calls or visits to physicians' offices.

In qualitative studies, thematic saturation is customarily reached with 10–15 participants in relatively homogeneous populations (Guest, Bunce, and Johnson 2006). Because we utilized a mixed qualitative and quantitative methodology in the parent study, our target for recruitment was 16 neonatologists to allow for balanced treatment groups after randomization. We excluded neonatologists who participated in case development or pilot testing. Study participation took 2 hours and included completion of two simulation encounters; completion of a self-administered demographics survey; and a debriefing interview.

Codebook Adaptation

We adapted a codebook that we previously developed to assess physician decision-making roles in adult intensive care unit family meetings (White et al. 2010). The original coding scheme outlined 4 domains: *Providing Medical Information* (subcodes: medical condition, prognosis, treatment options); *Eliciting Patient's Values* (subcodes: previously expressed treatment preferences, general values and life goals, trade-offs between length and quality of life, states worse than death, unacceptable therapies); *Engaging the Surrogate in Deliberations* (subcodes: highlighting preference sensitive nature of the decision, explaining principles of surrogate decision making, summarizing patient's values, highlighting key considerations, bridging statements); and *Providing a Recommendation*. The original codebook also provided an algorithm to categorize groups—based on the absence or presence of specific domains—into the 4 aforementioned physician “decision-making roles”: collaborative, facilitative, informative or directive.

We adapted this original codebook to the context of our study—perivable counseling encounters. We then applied the codebook to five encounters and, in an iterative manner, three authors (BTE, FM, AB), along with a neonatologist who served in an advisory capacity, revised and refined the adapted coding scheme. The final coding scheme maintained the four domains evaluated with the original codebook: providing medical information, eliciting patient values, engaging patients in deliberation, and providing a recommendation (prompted or unprompted).

Within these 4 domains, we defined 16 individual behaviors for coding (Table 1). As presented in Table 1, each of the four domains was characterized by distinct behaviors, with no overlap in classifications. We applied this final codebook to the transcript from the physicians' first counseling session in a content analysis, coding for specific physician behaviors.

Debriefing Interviews

Immediately after completing the SP encounters, physicians completed a 20-minute, semi-structured debriefing interview. The purpose of the interview was to: (1) discuss the

verisimilitude of the simulation and (2) provide “think aloud” commentary after reviewing segments of their video-recorded SP counseling encounters. In the course of the interview, we asked each neonatologist, “During this encounter, what did you feel was your role, as the physician, in the management decision-making process?” Two of the debriefing interviews were not available for analyses due to recording malfunction (audio not captured), leaving 13 for analysis and comment.

Data Analyses

We video-recorded each SP encounter; then transcribed the audio verbatim. Two investigators (JP and EM) first independently coded a random sample of transcripts to ensure agreement; then independently applied the final coding scheme to each encounter. We resolved coding discrepancies between reviewers by consensus.

We then used the previously developed algorithm to categorize the physicians into one of the four decision-making roles. We also analyzed the debriefing interview to identify neonatologists’ intended decision-making roles. We dichotomized responses into intentions to play a shared decision-making role (based on discussions of partnership or joint decision making) versus intentions to play an informative decision-making role (based on discussions of solely providing information or data for the patient/family to make the decision). We used descriptive statistics (counts, proportions, and measures of central tendency) to summarize the study population and their observed and intended physician decision-making roles. NVivo 10 software was used to facilitate qualitative analysis.

RESULTS

Fifteen of 45 eligible (33%) neonatologists participated in the study (1 shy of our recruitment target). Table 2 describes our study population, and Table 1 displays the coding frequencies for each communication behavior coded within each domain, along with sample quotations. Here we summarize those findings.

Communication Behaviors

Providing Medical Information—All 15 (100%) of the neonatologists provided medical information to the mothers. Most often, this included a discussion about prognosis for survival. Though all neonatologists discussed prognosis if the baby were to survive, only 7 (47%) explicitly discussed prognosis without resuscitation:

If you don't want your baby to face possible suffering, it is very reasonable to say we will keep her comfortable and with you, and we won't support her, and she will then die. (N-11)

Fourteen (93%) explicitly discussed treatment options with the mother and made mention of long-term prognosis or quality of life considerations:

In the babies this small what we really worry about is those major problems like blindness, deafness, cerebral palsy, thinking problems and really their ability to sort of interact with their environment and be part of it and have a good quality of life. (N-15)

These discussions varied in depth and length. Eight (53%) neonatologists went on to explain that long-term prognosis was uncertain: “We can get an idea of how kids are doing and then we can sort of project but even then we’re not very good.” (N-15)

Eliciting Patient Values—Only a third of the neonatologists elicited the mother’s values during the course of counseling. Four (27%) of the neonatologists inquired about values or treatment goals:

Do you feel like there's a certain quality of life that you want your child to have to sort of be considered what I would just frankly say is worth living. Like there's a minimal quality of life that you feel like a child needs to have? (N-5)

Only one (7%) asked about the mother’s treatment preference: “Have you thought anything about if you want chest compressions on a baby this little?” (N-12)

Engaging Patients in Deliberation—Almost all of the study participants (93%) engaged mothers in deliberation. Most commonly, they did so by highlighting the preference sensitive nature of the decision to pursue comfort measures versus resuscitative therapies:

You know, every person makes that decision, and there is no right or wrong, okay, because it's very much dependent on how you are feeling about having a baby that may have may be born prematurely, the support, what your beliefs are. (N-14)

Some (33%) also highlighted key considerations that the mother might contemplate in making her decision:

Some parents feel that maybe they don't want us to do everything when they are born because it would, it could involve a lot of long procedures that can be painful that may not change the outcome in the end and they don't want to put their child through that. (N-7)

Roughly a quarter (27%) of the neonatologists utilized bridging statements to link patients’ values with a management plan or course of action: “It is possible that you might need a cesarean section if you want to do everything possible to help your baby” (N-11).

None of the neonatologists provided summary statements or assessments of the mothers’ values or preferences. This is in keeping with the fact that most neonatologists did not explicitly elicit the mother’s values or preferences. In fact, bridging statements were typically utilized in reference to hypothetical families’ values rather than the mother’s actual, elicited values.

Providing a Recommendation—Overall, 6 (40%) neonatologists provided a recommendation to the mother, sometimes implicitly by describing the default practice: “So generally at 23 weeks in the delivery room if the baby is breathing or has a heart rate, what we do initially is help the baby breathe” (N-13). Each of these recommendations was made without first attempting to elicit the mother’s values. Therefore, the neonatologists’ recommendations were neither congruent nor incongruent with the mother’s values because her values were never stated.

Physicians' Decision-Making Roles

Table 3 summarizes the “decision-making roles” identified among our study participants. The majority of neonatologists (n=9, 60%) took an informative role in counseling the mothers whereby they provided medical information but did not elicit the mother’s values, engage her in deliberations, or make a recommendation:

My job really is just to help you make kind of the informed decision and just to give you all the data that you need. All the information that you need. (N-12)

Two neonatologists (13%) took on a facilitative role by providing medical information, eliciting the mother’s values, and engaging in deliberations, but refraining from making a recommendation. Twenty percent (n=3) of the providers were collaborative in their approach to counseling. Like the facilitative role, these neonatologists provided medical information, elicited parental values, engaged mothers in deliberations, but also went on to make a recommendation with or without prompting.

Finally, one of the neonatologists (7%) was directive in their approach. This study participant provided medical information, then proceeded to make a treatment decision independent of the mother—simply informing her of what the plan of care would be.

Debriefing Interviews

Ten (77%) described their intended role as solely informative, rather than shared: “I think that my job is really to provide the information they need to make an informed decision” (N-1). Three neonatologists expressed that they saw themselves as partners, facilitating joint or shared decision making throughout the course of counseling: “...not to inform them solely, but to start a relationship”(N-10). Of interest, two of these three were observed to take an informative role rather than a shared facilitative or collaborative role.

DISCUSSION

We set out to examine the “decision-making role” that neonatologists take when counseling standardized patient mothers presenting to an inpatient setting with ruptured membranes at 23 weeks gestation. We found that the majority of neonatologists were informative in their decision-making role—providing information without eliciting values, engaging in deliberation, or making recommendations to mothers. These observed roles were consistent with their self-described, preferred role in counseling and decision making. Specifically, most of the neonatologists see their role as that of an informant rather than a partner.

Although ours is the first study to apply this decision-making roles framework to the context of neonatal resuscitation decision-making, our findings are consistent with many of the patterns observed in end-of-life counseling and surrogate decision making. Previous studies of discussions with surrogates and family members regarding resuscitation decisions for older adults found that values elicitation and deliberation with patients were frequently absent from the discussions. Counseling encounters focused more heavily on medical information and life-sustaining interventions and procedures rather than attending to the patients’ larger life goals (Anderson et al. 2011; Barnato et al. 2007; Barnato et al. 2009; Deep, Griffith, and Wilson 2008; Heyland et al. 2015; Uy et al. 2013).

The importance and appropriateness of making a recommendation in value-laden decision-making has been a topic of debate, with some authors having championed value-neutrality and non-directiveness (Pochard et al. 2003), while others have made the claim that providing patients with a professional recommendation is an important part of shared decision making (Charles, Gafni, and Whelan 1997) and the informed choice process (Baylis and Downie 2001).

The literature suggests that patients usually desire physician guidance in treatment decision-making. For example, a systematic review of 115 studies of patients' preferred roles in decision making, found that almost two-thirds of patients preferred sharing decisions with physicians (Chewning et al. 2012). Patients also desire, and often times request, physician advice in value-laden decision-making.

Observational work among families in ICU family meetings found that roughly 30–40% of patients or family members will request a recommendation from their physician regarding whether to limit life support (White et al. 2010). Moreover, one study found that 40% of ICU surrogate decision makers wanted to share control over discontinuing life support equally with physicians, while 5% wanted the physicians to make the decision (Johnson et al. 2011).

Similarly, in the perivable context, interviews among families facing perivable resuscitation decisions have found that while the majority want information and desire to be active participants in decision making, most also expressed that they needed a recommendation from the physicians (Kavanaugh et al. 2005). This suggests that shared decision making is the preferred strategy for most, but not all, patients, and reminds us of the importance of assessing a patient's decision-making preference to provide more patient-centered care.

Limitations

Our study has important limitations that must be considered in interpreting our findings. As a small, single-center pilot study, our findings can neither be considered reliable prevalence estimates in our center nor generalizable to neonatologists in other hospital settings and regions. Moreover, as a convenience sample of volunteers, our study participants may be more skilled communicators or have greater interest in the study topic, and therefore, may not be representative of other neonatologists. Indeed, qualitative methods are not intended to generate generalizable findings, but rather to develop theory and generate hypotheses.

A number of study participants were neonatology fellows, with less experience than attending neonatologists. While fellows may lack experience, they are typically the first-line of communication for neonatology consult services in academic centers, and so we felt it important to capture this population. Moreover, we did not note substantive qualitative differences between the content of fellows and their attendings, who teach/model behavior for them.

It is also possible that Hawthorne effects might bias our results: under observation, providers are likely to behave as they think they “should” behave—which may not accurately reflect their actual behavior in real patient encounters. Some studies have suggested that doctors are

generally quite directive (Barnato et al. 2011; Singh et al. 2007; White et al. 2010; Uy et al. 2013). Therefore, the absence of directive counseling in this study might reflect study participants' expectations that the observers would want them to be more non-directive in their counseling.

Finally, the physician "decision-making role" framework was developed and validated in a different clinical context. Though it has been adapted to other end-of-life contexts, it remains an open question as to whether it is an appropriate framework to apply when end-of-life decisions are being made at the very beginning of life.

CONCLUSIONS

The IOM has declared that patient-centered care is a critical component of safe, effective, high-quality healthcare (2001). In doing so, they suggest that shared decision making, which would correspond with a more collaborative or facilitative physician decision-making role, is the model paradigm for most preference-sensitive medical treatment decisions. Moreover, the AAP has designated shared decision making as the optimal model of deliberation when resuscitation decisions are being considered at the limits of viability (Batton 2009).

We offer preliminary evidence that there may be a gap between policy recommendations calling for shared decision making and actual clinical practice. Instead, neonatologists approach periviable counseling interactions with the primary goal of providing information; though some will address parents' preferences and values as considerations, many may be reluctant to provide them with recommendations and engage in more collaborative decision-making. Though this likely results from a high regard for parental autonomy and a desire to avoid unduly influencing parents' decisions, the fact that parents facing this decision have voiced the need for guidance beyond information and options from their providers (Grobman et al. 2010; Kavanaugh et al. 2005; Moro et al. 2011) may require that physicians reexamine what "partnership" should look like in their efforts to optimize periviable care.

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REFERENCES

- Anderson WG, Chase R, Pantilat SZ, Tulskey JA, Auerbach AD. Code status discussions between attending hospitalist physicians and medical patients at hospital admission. *Journal of General Internal Medicine*. 2011; 26(4):359–366. [PubMed: 21104036]
- Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *Journal of General Internal Medicine*. 2009; 24(6):695–701.
- Barnato AE, Chang CC, Saynina O, Garber AM. Influence of race on inpatient treatment intensity at the end of life. *Journal of General Internal Medicine*. 2007; 22(3):338–345.
- Barnato AE, Mohan D, Downs J, Bryce CL, Angus DC, Arnold RM. A randomized trial of the effect of patient race on physicians' intensive care unit and life-sustaining treatment decisions for an

- acutely unstable elder with end-stage cancer. *Critical Care Medicine*. 2011; 39(7):1663–1669. [PubMed: 21460710]
- Bastek TK, Richardson DK, Zupancic JA, Burns JP. Prenatal consultation practices at the border of viability: a regional survey. *Pediatrics*. 2005; 116(2):407–413. [PubMed: 16061596]
- Batton DG. Clinical report--Antenatal counseling regarding resuscitation at an extremely low gestational age. *Pediatrics*. 2009; 124(1):422–427. [PubMed: 19564329]
- Baylis F, Downie J. Professional recommendations: disclosing facts and values. *Journal of Medical Ethics*. 2001; 27(1):20–24. [PubMed: 11233372]
- Boss RD, Donohue PK, Roter DL, Larson SM, Arnold RM. "This is a decision you have to make": using simulation to study prenatal counseling. *Simulation in Healthcare*. 2012; 7(4):207–212. [PubMed: 22569285]
- Boss RD, Henderson CM, Wilfond BS. Decisions regarding resuscitation of extremely premature infants: should social context matter? *JAMA Pediatrics*. 2015; 169(6):521–522. [PubMed: 25915579]
- Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science & Medicine*. 1997; 44(5):681–692. [PubMed: 9032835]
- Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. *Patient Counseling and Health Education*. 2012; 86(1):9–18.
- Deep KS, Griffith CH, Wilson JF. Communication and decision making about life-sustaining treatment: examining the experiences of resident physicians and seriously-ill hospitalized patients. *Journal of General Internal Medicine*. 2008; 23(11):1877–1882. [PubMed: 18800206]
- Fishman J, O'Dwyer P, Lu HL, Henderson HR, Asch DA, Casarett DJ. Race, treatment preferences, and hospice enrollment: eligibility criteria may exclude patients with the greatest needs for care. *Cancer*. 2009; 115(3):689–697. [PubMed: 19107761]
- Grobman WA, Kavanaugh K, Moro T, DeRegnier RA, Savage T. Providing advice to parents for women at acutely high risk of periviable delivery. *Obstetrics & Gynecology*. 2010; 115(5):904–909. [PubMed: 20410761]
- Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? *Field Methods*. 2006; 18(1):59–82.
- Halpern J. Responding to the need behind the question "Doctor, if this were your child, what would you do?". *Journal of Clinical Ethics*. 2003; 14(1–2):71–78. [PubMed: 14628810]
- Heyland DK, Dodek P, Mehta S, et al. Admission of the very elderly to the intensive care unit: Family members' perspectives on clinical decision-making from a multicenter cohort study. *Palliative Medicine*. 2015; 29(4):324–335. [PubMed: 25645668]
- Institute of Medicine (IOM). *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academies Press; 2001.
- Janvier A, Bauer KL, Lantos JD. Are newborns morally different from older children? *Theoretical Medicine and Bioethics*. 2007; 28(5):413–425. [PubMed: 17985104]
- Janvier A, Barrington K, Deschenes M, Couture E, Nadeau S, Lantos J. Relationship between site of training and residents' attitudes about neonatal resuscitation. *Archives of Pediatric and Adolescent Medicine*. 2008; 162(6):532–537.
- Janvier A, Lorenz JM, Lantos JD. Antenatal counselling for parents facing an extremely preterm birth: limitations of the medical evidence. *Acta Paediatrica*. 2012; 101(8):800–804. [PubMed: 22497312]
- Johnson S, Wolke D, Hennessy E, Marlow N. Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment. *Developmental Neuropsychology*. 2011; 36(1):74–95. [PubMed: 21253992]
- Kaempf JW, Tomlinson M, Arduza C, et al. Medical staff guidelines for periviability pregnancy counseling and medical treatment of extremely premature infants. *Pediatrics*. 2006; 117(1):22–29. [PubMed: 16396856]
- Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. *Pediatrics*. 2009; 123(6):1509–1515. [PubMed: 19482761]

- Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decisions for extremely premature infants: report of a pilot study. *Journal of Pediatric Nursing*. 2005; 20(5):347–359. [PubMed: 16182094]
- Kon AA. Answering the question: "Doctor, if this were your child, what would you do?". *Pediatrics*. 2006; 118(1):393–397. [PubMed: 16818588]
- Lantos JD, Meadow W. Variation in the treatment of infants born at the borderline of viability. *Pediatrics*. 2009; 123(6):1588–1590. [PubMed: 19482770]
- Lavin PJ Jr, Kantak A, Ohlinger J, et al. Attitudes of obstetric and pediatric health care providers toward resuscitation of infants who are born at the margins of viability. *Pediatrics*. 2006; 118(Suppl 2):S169–S176. [PubMed: 17079620]
- Mehrotra A, Lagatta J, Simpson P, Kim UO, Nugent M, Basir MA. Variations among US hospitals in counseling practices regarding prematurely born infants. *Journal of Perinatology*. 2013; 33(7):509–513. [PubMed: 23348867]
- Mitchell JJ Jr. The findings of the Dartmouth Atlas Project: a challenge to clinical and ethical excellence in end-of-life care. *Journal of Clinical Ethics*. 2011; 22(3):267–276. [PubMed: 22167990]
- Moro TT, Kavanaugh K, Savage TA, Reyes MR, Kimura RE, Bhat R. Parent decision making for life support for extremely premature infants: from the prenatal through end-of-life period. *Journal of Perinatal and Neonatal Nursing*. 2011; 25(1):52–60. [PubMed: 21311270]
- Partridge JC, Freeman H, Weiss E, Martinez AM, Kilpatrick S. Delivery room resuscitation decisions for extremely low birthweight infants in California. *Journal of Perinatology*. 2001; 21(1):27–33. [PubMed: 11268864]
- Peerzada JM, Richardson DK, Burns JP. Delivery room decision-making at the threshold of viability. *Journal of Pediatrics*. 2004; 145(4):492–498. [PubMed: 15480373]
- Pochard F, Grassin M, Kentish-Barnes N, Azoulay E. Patient autonomy and the end of life. *Critical Care Medicine*. 2003; 31(2):662–663. [PubMed: 12576994]
- Ross LF. Why "doctor, if this were your child, what would you do?" deserves an answer. *Journal of Clinical Ethics*. 2003; 14(1–2):59–62. [PubMed: 12953354]
- Ruddick W. Answering parents' questions. *Journal of Clinical Ethics*. 2003; 14(1–2):68–70. [PubMed: 14628809]
- Singh J, Fanaroff J, Andrews B, et al. Resuscitation in the "gray zone" of viability: determining physician preferences and predicting infant outcomes. *Pediatrics*. 2007; 120(3):519–526. [PubMed: 17766524]
- Truog RD. "Doctor, if this were your child, what would you do"? *Pediatrics*. 1999; 103(1):153–154. [PubMed: 9917452]
- Truog R. Revisiting "Doctor, if this were your child, what would you do?". *Journal of Clinical Ethics*. 2003; 14(1–2):63–67. [PubMed: 14628808]
- Tucker Edmonds B, McKenzie F, Fadel WF, et al. Using simulation to assess the influence of race and insurer on shared decision making in periviable counseling. *Simulations in Healthcare*. 2014; 9(6):353–359.
- Uy J, White DB, Mohan D, Arnold RM, Barnato AE. Physicians' decision-making roles for an acutely unstable critically and terminally ill patient. *Critical Care Medicine*. 2013; 41(6):1511–1517. [PubMed: 23552510]
- Weiss AR, Binns HJ, Collins JW Jr, deRegnier RA. Decision-making in the delivery room: a survey of neonatologists. *Journal of Perinatology*. 2007; 27(12):754–760. [PubMed: 17762845]
- Wennberg JE, Fisher ES, Stukel TA, Skinner JS, Sharp SM, Bronner KK. Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *British Medical Journal*. 2004; 328(7440):607. [PubMed: 15016692]
- White DB, Malvar G, Karr J, Lo B, Curtis JR. Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework. *Critical Care Medicine*. 2010; 38(3):743–750. [PubMed: 20029347]

Table 1

Coding Frequencies for Communication Domains and Behaviors with Sample Quotes

Domains	Domain Rate N (%)	Communication Behaviors	Behavior Rate N (%)	Coding Examples
Providing Medical Information	15 (100)	Explains patient's medical condition	15 (100)	"Her lungs are still developing and you know, even if she comes out into the world, and does try to breathe, usually lungs are just too tiny and too underdeveloped to function well."
		Explicitly discusses treatment options	14 (93)	"Whether we should put your baby on life support or, which is aggressive medical care, but because of the risks of the disabilities and dying no matter what we do, some family have asked us just to hold it, knowing that he or she would die in your arms over the next perhaps minutes or hours."
		Implicitly discusses treatment options	9 (60)	"...if we stabilize her over here and bring her over to [location], she would be put on a ventilator and there are several types of ventilators."
		Discusses prognosis with resuscitation	15 (100)	"...about fifty percent of the time, babies born right now will survive, and that includes, you know, will survive the delivery room; go to the NICU; and then survive to go home with you."
		Explicitly discusses prognosis without resuscitation	7 (47)	"... if you don't want your baby to face possible suffering, it is very reasonable to say we will keep her comfortable and with you, and we won't support her, and she will then die."
		Implicitly discusses prognosis without resuscitation	9 (60)	"...if the baby delivers that we just try to keep her comfortable and let her spend time with you as a family..."
		Discusses prognosis for overall survival	15 (100)	"...at this point survival is probably less than 50%, kind of depending on how much she weighs."
		Discusses long term prognosis for physical or cognitive function or QOL	14 (93)	"...in the babies this small what we really worry about is those major problems like blindness, deafness, cerebral palsy, thinking problems and really their ability to sort of interact with their environment and be part of it and have a good quality of life."
		Discusses the longer term uncertainties	8 (53)	"We can get an idea of how kids are doing and then we can sort of project but even then we're not very good."
Elicits Patient's Values	5 (33)	Inquires about values or general treatment goals	4 (27)	"Do you feel like there's a certain quality of life that you want your child to have to sort of be considered what I would just frankly say is worth living. Like there's a minimal quality of life that you feel like a child needs to have?"
		Inquires about specific treatment preferences	1 (7)	"Have you thought about anything if you want chest compressions on a baby this little?"
		Asks permission to start a treatment	0 (0)	
Engages Patient in Deliberations	14 (93)	Any statement that indicates a decision is dependent on values or preferences and not solely based on medical facts	14 (93)	"You know, every person makes that decision, and there is no right or wrong, okay, because it's very much dependent on how you are feeling about having a baby that may have may be born prematurely, the support, what your beliefs are."
		Bridging statements and hypothetical	4 (27)	"It is possible that you might need a Cesarean section if you want to do everything possible to

Domains	Domain Rate N (%)	Communication Behaviors	Behavior Rate N (%)	Coding Examples
		recommendations that link patient values with specific treatment decisions		help your baby.” “...you can get steroids and that improves the chances of survival... so that's something that if, if we would want to do everything we can for your daughter, I think those would be, those would be very important to give her the best chance we can.”
		Highlights a key consideration to guide decision-making	9 (60)	“Because everybody wants a smart kindergartener who is running and athletic. Everybody does. I don't know anybody that doesn't. How much of that child...that dream are you willing to forego so that you can have a child that survives?”
		Summarizes patient's preferences or values	0 (0)	
Providing a Recommendation	6 (40)	Recommending or providing an opinion for the best course of treatment that does not align with the patient's values.	0 (0)	
		Recommending or providing an opinion for the best course of treatment that aligns with the patient's values.	0 (0)	
		Recommendation about best treatment without eliciting patient values	6 (40)	“...so generally at 23 weeks in the delivery room if the baby is breathing or has a heart rate, what we do initially is help the baby breathe.”

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Table 2

Study Population (N=15)

	N	Percent
Age	45 (mean)	30–69 (range)
Years Since Residency	14 (mean)	1.5–40 (range)
Level of Practice		
Attending	9	60
Fellow	6	40
Race		
White	12	80
Black	1	7
Asian	2	13
Sex		
Male	5	33
Female	10	67
Marital Status		
Single	0	0
Married or Partnered	13	87
Divorced or Separated	2	13
Parent		
Yes	12	80
No	3	20
Religion		
Protestant	6	40
Catholic	3	20
Muslim	2	13
Other	3	20
None	1	7
Prior Malpractice Lawsuit		
Yes	5	33
No	10	67

Table 3

Decision-making Roles

	Informative	Facilitative	Collaborative	Directive
Coding Domains	1 only	1+2	1+2+3+4	5
1 - Providing medical information	X	X	X	
2 - Eliciting patient values		X	X	
3 - Engaging patient in deliberation			X	
4 - Providing a recommendation			X	
5 - Decision and plan made by MD				X
Number (%) of Neonatologists/Role	9 (60%)	2 (13%)	3 (20%)	1 (7%)

X=required domain

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