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To cite this article: Marlyse F. Haward, Annie Janvier, John M. Lorenz & Baruch Fischhoff (2017) Counseling parents at risk of delivery of an extremely premature infant: Differing strategies, AJOB Empirical Bioethics, 8:4, 243-252, DOI: [10.1080/23294515.2017.1394399](https://doi.org/10.1080/23294515.2017.1394399)

To link to this article: <https://doi.org/10.1080/23294515.2017.1394399>



Accepted author version posted online: 19 Oct 2017.  
Published online: 10 Nov 2017.



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ARTICLE



## Counseling parents at risk of delivery of an extremely premature infant: Differing strategies

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### ABSTRACT

**Background:** It is not known how neonatologists address the affective and cognitive loads on parents deciding whether to resuscitate infants born extremely preterm. This study explores expert neonatologists' views on these decision-making processes and their own roles in counseling parents. **Methods:** Semistructured interviews asked internationally recognized experts to share their perspectives on perinatal consultations. Their responses were subjected to thematic analysis. **Results:** Eighteen of 22 invited experts participated. Approximately equal numbers reported employing a physician-driven approach, a parent-driven approach, and a combined approach during these consultations. Those who followed a physician-driven approach typically focused on conveying standard information about adverse outcomes. Those who followed a parent-driven approach typically focused on addressing parents' information requests, guiding their decision making, and providing affective support. Nearly all experts, in each group, endorsed addressing the child's quality of life, in terms of functionality, when discussing long-term outcomes. Although many believed that families adjusted to life with a disabled child, few discussed the topic during prenatal consultations. Most, in each group, reported trying to alleviate future "decisional regret" for parents whose premature infants subsequently became disabled. None spoke to parents about possible decisional regret after deciding to forgo resuscitation. **Conclusions:** Expert neonatologists are deeply concerned that parents understand the decision facing them. However, they differ on what information they offer and how they balance parents' need for cognitive and affective support. They expressed more concern about parents' decisional regret should their child survive resuscitation, but have severe disability, than about decisional regret after foregoing resuscitation.

Deciding whether to resuscitate infants born at the margin of viability forces physicians and parents to make difficult choices between active intervention and palliative care at birth (Cummings and Committee on Fetus and Newborn 2015; Raju et al. 2014; Rysavy et al. 2015). That choice raises challenging ethical questions, surrounded by deep uncertainty about predicting individual infants' chances of survival and long-term neurodevelopmental disabilities (Lorenz 2011; Younge et al. 2017). The professional community has responded with a commitment to engaging parents in ways that lead to decisions consistent with their values and medical realities (Cummings and Committee on Fetus and Newborn 2015). However, how this commitment is fulfilled has been quite variable, in terms of local norms and practices (Arzuaga and Meadow 2013; Rysavy et al. 2015).

One possible source of that variation is how physicians view parents whom they seek to help make these decisions. Policy statements often treat parents as rational decision makers, in hopes of ensuring that they receive the information needed for deliberative choices, such as probabilities of survival and developmental disabilities (Cummings and Committee on Fetus and

Newborn 2015; Griswold and Fanaroff 2010; Raju et al. 2014). However, based on research in end-of-life decisions (Barnato 2017), it is entirely plausible that parents do not uniformly follow rational decisional processes, but are influenced by judgmental biases and emotions that emerge under conditions of stress and uncertainty (Janvier et al. 2012; Renjilian et al. 2013; Zier et al. 2012). Those policy statements typically have little to say about how to address the time pressure, uncertainty, and emotional duress faced by parents of periviable infants (Cummings and Committee on Fetus and Newborn 2015; Raju et al. 2014) and by physicians themselves. As a result, balancing parents' cognitive and emotional needs and abilities is largely left to individual physicians.

This investigation explores how expert neonatologists approach these consultations and the challenge of addressing the cognitive and affective components of parents' decision-making processes regarding extremely premature infants. These interviews are the first phase of a mental models study, a methodology drawn from decision science (Bruine de Bruin and Bostrom 2013; Morgan et al. 2002), which begins by summarizing expert

beliefs regarding factors potentially affecting a class of decisions. Participants in these expert interviews are asked to reflect, in their own terms, on a class of decisions. The interview protocol begins by soliciting participants' own general thoughts, then proceeds to topics selected by the investigators based on the research literature. Participants are free and encouraged throughout to raise additional topics that occur to them. This approach seeks to balance the research goals of identifying aggregate patterns, by raising a core set of common topics for all participants, while preserving the nuances of individual perspectives. Thus, the interviews were designed to allow experts to express their views, in their own terms, about the topics relevant to parents' decisions about infants born extremely prematurely.

## Methods

### Participants

The three neonatologist investigators identified a target group of 22 neonatologists, including both academic experts and experienced community neonatologists in the United States and two Canadian provinces. The academic experts were selected on the basis of being recognized leaders in the field, as reflected in having (a) extensively published on perinatal decision making, (b) spoken at academic conferences on the topic, (c) led bioethics programs, or (d) served on national committees creating policy statements on decision making at the limits of viability. The community neonatologists were selected based on their reputation within the larger community and leadership roles within their institutions. Their published professional opinions played no role in the selection process.

Potential participants were invited individually by email in batches of two or three during 2014–2015, with a reminder sent if no response was obtained after 2 weeks. Each batch was sent after interviews of the previous batch were completed. Recruitment ended when a saturation point was reached, defined as no new topics emerging in three successive interviews. Participants were not compensated for their time. Consent was presumed by accepting the invitation. The study was accepted by the Einstein Institutional Review Board of the Albert Einstein College of Medicine and Montefiore Medical Center.

### Procedure

Semistructured interviews were conducted by one author (MH), either over the phone ( $n = 15$ ) or in person ( $n = 3$ ). The interviews began by asking participants how they approached these prenatal consultations, in general terms, then proceeding to questions about how they gave information to parents and addressed parents' cognitive and affective processes. Next, participants were asked questions that focused on four broad classes of outcomes. These outcomes were selected a priori by the investigators as central to these decisions, based on the research literature and their own clinical experience: short-term infant outcomes, short-term parent outcomes, long-term infant outcomes, and long-term parent outcomes. Finally, participants were asked to address any additional topics that they believed to be important.

The interviews sought a fluid conversational tone, allowing participants to direct the flow while providing opportunities, but not pressure, to address the focal topics. This design permitted the interviewer to elicit participants' beliefs and attitudes in their own terms, reflecting their interpretation of the science and professional experience. It also permitted (and indeed encouraged) participants to contribute information on topics outside the four focal ones. Interviews were recorded and transcribed. Recordings were destroyed after transcription.

### Analysis

We adopted a mixed method approach to analysis. We used descriptive statistics for quantitative estimates and qualitative analysis of emergent themes, followed by a structured coding of those themes. For the qualitative thematic analysis, the investigators independently developed themes and subthemes, based on their reading of a subset of transcripts (Creswell et al. 2003; Denzin et al. 2000; Hseih et al. 2005). Together, the investigators finalized the main themes and subthemes, defining each as clearly as possible (Hseih et al. 2005). All interviews were coded independently by two investigators (MH and JML). Differences in coding were resolved by consensus, with a goal of 80% inter-reviewer agreement for each interview. As participants were not randomly sampled from a known population, statistics refer to this sample alone and no inferential statistical tests were conducted.

## Results

Eighteen participants were recruited, representing all regions of the United States and one Canadian province. Sixteen practiced at Level IV academic centers and two at busy Level IIIB neonatal intensive care units. They represented 17 different centers. Five were mid-career neonatologists and the remainder senior neonatologists. As mentioned earlier, we reached saturation after 18 interviews, at which point no new issues had arisen in three successive interviews. Themes presented in the following reflect the four focal topics, as well as emergent themes.

### Nature of the decision and consultation

#### Consultation approaches

Three approaches to prenatal consultation emerged: physician-driven, parent-driven, and combined. Table 1 summarizes their frequency in this sample. Participants following a physician-driven approach typically focused on reviewing a standard set of concerns. In the words of one physician, those included

risks to both mother as well as the fetus that might increase risk of an adverse outcome ... range of outcomes in terms of both complications within the neonatal course, as well as longer term over time, both in terms of health and development.

Those who followed a parent-driven model described it in terms such as

I ask the families, what do you want to know about? And tell me what you want to hear and I'll do my best to try to give you the information...if [the data] is irrelevant to (their) way of thinking

**Table 1.** Nature of decision and consultation approach (number of neonatologists; percent of  $n = 18$ ).

Consultation approaches		Decision process themes	Uncertainty	17 (94)
	Physician-driven approach	6 (33)	• Discussed with parents	10 of 17
	Parent-driven approach	7 (39)	• Not discussed	7 of 17
	Mixed	5 (28)	Urgency	12 (67)
			Limitation of evidence	7 (39)
			Similar bereavement experiences	
			• Other acute loss/trauma	3 (17)
			• Miscarriage	2 (11)
			• None	13 (72)
Statistics utilized	Vague	9 (50)		
	Specific	7 (39)		
	Not mentioned	2 (11)		

about this, I'm not going to burden them with all this data that maybe meaningless to them.

Those following a combined approach mentioned elements of each.

### Decision process themes

Some participants commented on how perinatal decision making differed from rational decision making, offered observations about how parents balanced cognitive and affective needs, and described the implications for their own roles in helping parents.

Confronting the sort of imminent delivery or the imminent event, whether that's the birth or potential death, what a lot of parents will do is they just bargain, and they will bargain with whatever their belief system is, and if you just let this baby live, I will do whatever. And you just bargain. So that I think that you can have all of these very rational kinds of discussions, but in the sort of acute period, it's not really a rational discussion. It's not rational at all.

Some offered cautions based on their observation of that process, such as:

[We] sometimes forget the inherent optimism of parents. It's very difficult to compartmentalize it and isolate the focus that it is on the baby, but at the same time you have all of these other factors that are sort of circling around that I think are informing how families are thinking and what they are worrying about, whether they articulate it or not.

### Use of precise statistics varied

Participants were divided on whether to share precise statistics, with opposition often expressed in terms such as:

The single most important thing that you can do in a neonatal consult is not give people statistics.

Those who provided statistics reported using different methods (e.g., bar graphs, visual aids) and data sets (e.g., local, national statistics). None reported using formal decision aids. Some provided precise statistics only when parents requested. Some noted the risk of framing biases, with statements such as:

We have a huge responsibility how we present the data, we know it's going to influence the decision the parents make. We try to do it in a balanced way, but undoubtedly, our own bias is going to influence how we present it.

None offered opinions as to why they believed statistics should be shared.

### Concerns attributed to decision makers

#### Parental concerns

Table 2 summarizes coded responses to an open-ended survey question asking participants what they think parents fear most. The answers to this question are reflected in participants' concerns about their own roles, reported in the next section.

#### Neonatologist concerns

**Decisional regret.** Two-thirds of the participants mentioned worrying about setting parents up for regret by not properly informing them about what life might be like with a disabled child. Many felt responsible for addressing that topic explicitly. For example,

I don't want them coming back to me and saying you didn't tell me that this was what was going to happen to my child. Had I known, I would not have had everything done.

**Creating disability.** More than half of the participants referenced the guilt of "creating disability":

I think that what's on the physicians' minds greatly is the fear of being somehow responsible for creating a child with disability. The single most powerful motivating emotion in neonatology is guilt. I think we feel bad when we create a baby who is impaired.

None mentioned fear of litigation.

**Who decides and when.** Some participants said that an attempt at resuscitation was mandatory for all neonates, believing that decision making should wait until after birth:

**Table 2.** "What do parents fear most?" (participants could answer more than one).

FEARS	
Process-related	
Guilt about not giving a chance to life	6
Anticipated regret	5
Decision-making responsibility	3
Uncertainty	2
Making the wrong decision	2
Family interests	
Finances	1
Parental quality of life	1
Infant interests	
Death	5
Disability	4
Other	
They don't know	1

[We] attempt resuscitation of any baby that we think has a reasonable chance for a reasonable outcome ... the question of whether or not to resuscitate is rarely presented to the parents. Birth is probably the worst time to make a decision.

Others deferred to parents' decisions made prior to birth, regardless of their own professional preferences:

For instance, at twenty-four weeks, we don't recommend resuscitation for all the reasons that we've explained. But, we will fully support resuscitation if that's what they wish. And we do that at twenty-two, twenty-three, twenty-four, twenty-five, and twenty-six weeks. So, it's a very transparent process.

I usually engage in this process and desire parent participation virtually all the time.

Two participants mentioned the complexity of reconciling surrogate decision making and the best interest of the child, with one saying:

It would be interesting, if a family said to me, this is going to bankrupt our family ... and we don't want to resuscitate because of that.

Another offered this perspective:

So this gets to a fundamental question for me which I've spent forty years thinking about, [whether] ... all the academic [focus] towards this question, about whether to resuscitate in a delivery room where we don't know what the prognosis is, when nobody has seen or examined the patient, [whether it] isn't ... just a form of age discrimination? What distinguishes the way we make these decisions for extremely premature babies versus how we would make them for older children or adults—other than age?

Finally, some participants' experience led them to conclude that parents are uniformly satisfied with institutional policies that require resuscitating all patients regardless of parental preferences:

And what we find thus far ... none of our parents ever say this is cruel, this is torture, this is mean, I wish it would stop. But rather, they say, this is wonderful. You have to have faith. It'll be God's will. And the only time the parents feel guilty is not that they're putting their kid through this, but rather that they feel guilty that they need to be at the bedside enough, they can't be supportive in the quite the right way.

At the same time, other participants found that parents are uniformly satisfied with policies that permit parental discretion about resuscitation versus comfort care:

But we, in eighteen years and probably a couple thousand consultations, six hundred infants born between twenty-two zero and twenty-six six, one institution, multicultural, we've had only two complaints in eighteen years ... and one of them was because they felt like we were being "too aggressive."

None of the participants reported assessing to what extent parents wanted to be involved in the decision. Some said that parents typically had already decided on a course of action prior to meeting with them and attributed these choices to factors such as religion, cultural background, education, and whether the pregnancy was aided by reproductive technology.

## **Focal outcomes**

### **Short-term outcomes: neonate**

When considering decisions leading to resuscitation, two-thirds of participants reported routinely reviewing with parents the

short-term medical outcomes experienced by neonates during hospitalization. All but one commented on neonatal pain associated with complications; almost half mentioned procedures to monitor and treat pain; and almost half noted the repetitive everyday pain that infants would experience (e.g., from lancing the heel in order to draw blood):

Certainly these major complications, surgery of any kind, any of these procedures, there is certainly pain associated with those, but I think a day in the life of a preemie is a lot more painful, a regular day ... That is the major stress because it's repetitive, it's persistent. The average micro-preemie like this will experience something ... like about eight hundred painful procedures during their hospital stay.

One-third of participants reported describing the pain as manageable, while three were skeptical about controlling pain. Another third reported discussing pain with parents and five not.

We really don't know how to manage pain well at this point, irrespective of guidelines and everything else. People are still hesitant to use a lot of pain relief, especially for routine aspects of care. And we try to, and if we think that they're in pain ... we give them something for pain, and that we know that certain conditions are associated with pain. So, if you have necrotizing enterocolitis breathing or something, that we're cognizant of that fact, keep them comfortable.

Three participants distinguished between pain and suffering. In the words of one:

Suffering is an entirely subjective and existential sort of phenomenon and I'm painfully skeptical of any doctor or parent imputing what they perceive as suffering onto a neonate who doesn't relax consciously ... One thing we know is that they're not conscious; they don't have conscious experiences. And, I mean, I feel pretty strongly that that's well understood at twenty-four and twenty-five weeks and twenty-three weeks. Now, that doesn't also mean that they can't experience, sense something, but that's about as much as I feel like we know.

### **Short-term outcomes: family**

Almost half of participants discussed what it would be like to parent a baby in the NICU. I tell them that the journey that they're about to embark on is going to be like the scariest roller coaster ride that they've ever been on and that there are going to be emotionally very, very wild swings that are very hard to manage and understand and are outside of the realm of what anybody should be subjected to and that my best advice is just to recognize it for what it is, don't entirely abandon, but just realize that these things are out of your control.

Any baby born at this gestation is going to have a rocky road and some of them initially do very well. They have the classic honeymoon period and normally, after the first week of life, everything starts to fall apart for usually for infections reasons or hemorrhagic reasons. I think that's important just to keep the expectations very realistic and say that what's happening now may be very different in a few hours or a day or so from now.

We talk to them about the roller coaster ... [and they say] we were very happy that you talked to us about that ... because we were not expecting that it would have been so hard.

One addressed the period right after delivery:

My attempt to prepare them is to explain the process ... after your baby's born, there's going to seem like an intolerable amount of time where you're not seeing your baby and you're separated from

your baby ... it's going to seem like agony, but the reason that we're there is because we're doing all of these things ... And so, all of that, I think, is an attempt to emotionally prepare them for how hard it's going to be in just those moments after birth.

For decisions leading to comfort care, most participants reviewed the details of the dying process with parents only after the decision was made. They focused on aspects that they had observed to be most important, including the anticipation and management of gasping respirations.

With regard to parents who opted for comfort care, many said that parents undergo a period of intense grief as death occurs, which begins to dissipate after the baby dies and they enter mourning. Others cited the variability of individual parents' responses and the lack of predictability, sometimes noting the limited research evidence on parental bereavement after neonatal comfort care deaths. Many offered insights from their experiences:

You can't make it stress-free and you can't make it grief-free and I don't think we should try, but you can certainly at least make sure there's no friction in the team and between the team and the parents and be as supportive as we can.

In my own experience, parents are very apprehensive about watching or participating in their child's death. But after the fact, they express appreciation.

A few questioned whether there existed a well-defined standard for comfort care and highlighted the uncertainty surrounding the experience of dying for the neonate.

My question that you're probably hearing, is what do you call the standard of care, because it's not clear to me that there is a universal standard of care.

Myself as well as other neonatologists, will prescribe perhaps intermittent dosing of morphine whether it's IM, SUBQ IVs or oral. The absolute benefit for the child is essentially unknown ... the notion that the child must be in pain or because the child exhibits symptoms I must intervene and do something. I can't tell you that physiologically that's an absolute, but I think that's more a psychological and metaphysical phenomena.

### **Long-term outcomes: neonate**

In discussing long-term outcomes for infants who receive resuscitation, all but one participant considered functionality important. The majority addressed the topic directly with parents, sometimes acknowledging that it was hard to predict for individual infants, for example:

Personally, I'm very unsure how much weight we should give to those very long-term outcomes, because they are so difficult to predict. I don't think we should hide behind a prognostic uncertainty, but it's something which is so uncertain.

Participants varied in how they dealt with the relationship between long-term infant functionality and parent well-being:

[I] 100% agree with [discussing] functionality. It's a part of the conversation for me that probably is inextricable from the next topic, which is parent long-term outcomes, because I really try to see it in terms of, so what I mean is, you might have to have a house that's able to accommodate a wheelchair. And what I mean is, somebody may have to quit their job in order to take care of the child. And what I mean is the child may be deaf and you may have to learn sign language.

One of the most important predictors of a child having a good, long-term outcome is the family environment.

### **Long-term outcomes: family**

All but one participant addressed long-term outcomes for families. Some participants were skeptical about the data on long-term parent and family adjustment for those who choose resuscitation, with some citing intense encounters from their practice:

I would say that the literature has a problem here ... I think that it's very hard once you've made the decision to put your child through this, meaning resuscitate, multiple surgeries, ICU, and then come out and say I wish I hadn't done it. I think that those people don't participate in studies because that is a horrible, horrible psychological thing to have to deal with.

There's a lot of data about parents who did make the decision and ended up with a disabled child feeling that they did make the right decision and that they have, in spite of that disability and in spite of those problems have come to find a satisfactory life and have dealt with it and they feel satisfied with their life. Most parents will not say or do not feel that it's a major burden or that they would have done it any other way.

The difficulty with that literature is that doctors and nurses don't believe it. So, doctors and nurses continuously and continually express fear of these outcomes and guilt about these outcomes.

Do finances come into play at all? ... I was chatting with a family and the mom started crying. And she was like, we had to declare bankruptcy. She said, I've never told anybody that before. We had to declare personal bankruptcy in order to keep our house for our family.

Nonetheless, all but one participant felt that parents adapted, with two-thirds saying that parents had good quality of life. For example:

Well, I tell them what I know about the literature. I know that the first years are very difficult, and that afterwards, it's a little bit better. And the further they go, the easier it gets.

I think, my experience in dealing with parents in the short and long term, because I do follow-up, is that their adaptation is generally greater than we may have presumed and often may be greater than they individually may have presumed.

I think that a lot of families who look after disabled children actually find a great deal of fulfillment in looking after those children and find it a source of strength and certainly improves their sort of insight into what's important in life.

Some participants discussed the challenges and potential benefits of sharing their observations on resilience and adaptation with parents during the prenatal consultation. For example:

They might feel a little helpless while the baby's in the NICU or afterwards, they're going to have the biggest influence on their baby's life, however they end up in the end of the NICU stay. But, in terms of actually talking to the parents about what impacts that might have on their family, unless they were actually to ask me, I don't normally really bring that up.

I think it's actually a little bit too much of a blunt instrument to use in the context of imminent pre-term delivery to say, oh well, the child may have impairments, but you'll adapt to them better than you think. That's actually pretty cruel. But, in some sense, describing that many parents have demonstrated adaptation or many parents state that they value the life of their child regardless of functional impairment is a message that should be, in some way, shape or form, communicated during the perinatal counseling.

It destroys some families ... and then, there's other families that cope very well ... the value of pluralism ... We just accept that both happen. And we don't know at the time of counseling which that family would fit into.

In that initial conversation when we're trying to decide, often under time pressure, right, whether or not we should resuscitate there is some attention paid to how this is going to influence the family and how hard it's going to be for them. So, there might be a sentence in there essentially, this is going to be a long ordeal for you, as well. But we don't spend a long, long time talking about the parents' stresses when we're trying to figure out what to do for the child.

Regarding long-term outcomes for parents who opt for comfort care, many said that neonatologists are not in a good position to answer, given their lack of continuing relationships with those parents, and called for further research.

[Despite] a lot of data about parents who did make the decision [to resuscitate] ... the piece of data that is missing is the same question for the parents who made the other decision [comfort care]. Since they did decide not to resuscitate would they go back now, now fifteen years later, ten years later and they've now gone on with their life, in light of the fact that they might have had to deal with a disabled child for the last ten years, are they happy with the decision that they made to not resuscitate or does it haunt them that they didn't do that?

Participants who engaged in follow-up or had personal experience with prematurity felt that parents who opted for comfort care found a way to live with their decision.

[It] stays with you somewhere forever ... but major impacts on the family seem to be relatively uncommon. Feelings resurfaced if they have another baby even if it's at term ... then if they had ashes from the baby in a pendant that they continued to wear or a picture, it now comes outside of the shirt, rather than being tucked in and they talk about it very freely.

### **Cross-cutting theme: Pessimism and resilience**

Overall, participants emphasized preparing parents for morbidities rather than focusing on possible positive experiences, such as the joys of parenting, even when such experiences seem likely. Those who stated that short-term experiences were stressful for parents reported sharing this observation with parents. In contrast, all stated that parents adapted and coped with adverse neonatal outcomes; however, only some of the participants shared with parents their belief that families were resilient and adjusted to life with disabled children. Although fewer than one-third believed parenting a disabled child was parents' greatest fear, more than half reviewed the difficult aspects of that role (see [Table 2](#)).

### **Discussion**

There is a growing research and clinical literature on how to identify and present the information that parents need for making informed decisions about infants at the "limits of viability." Guidelines have been developed to standardize information based on medical evidence (Griswold and Fanaroff 2010). Research on decision aids has sought to improve communication of information that stakeholder groups have identified as important (Moore et al. 2017; Guillen et al. 2012). These efforts focus on facts deemed critical for rational decision making (Kim and Basir 2014). However, individuals' actual, and even desired, decision-making processes depend on their emotions, as well as their beliefs and cognitively represented preferences

(Slovic 2001). Our study is the first to examine how neonatology experts view these broader aspects of parents' responses to the decisions posed by infants born at the limits of survivability and how they accommodate those concerns in their consultations.

The expert neonatologists who participated in our interviews reported different approaches to addressing the cognitive and affective load on these parents. Roughly equal numbers pursued a physician-driven approach, typically focusing on outcome information; a parent-driven approach, seeking to discover individual parents' concerns and address them in a personalized fashion; or a combination of the two. Those who followed a parent-driven model often described having evolved in that direction, from a more physician-driven one, based on their own research, clinical experience, and reading of the medical literature. In the words of one, "I have evolved over time ... as I got in deeper in my own research ... to spend less time going over the quote, unquote facts and more time building a relationship with the family." Physician-driven consultations were oriented more toward cognitive processes, and patient-driven ones more toward affective processes (Croskerry 2013). Recent research has found diversity of opinions from parents regarding counseling at later gestational ages, with many preferring personalized and individualized information pertaining to the risks that they find most concerning (Gaucher et al. 2016). Our experts reported that their approaches reflected both what they had heard from parents and what they believed went unsaid, with the diversity of their personal and professional experiences perhaps accounting for some of the diversity in their approaches.

Physician- and patient-driven consultations might, in fact, support parents' needs in complementary ways. The former might provide the most relevant general information, expressed in terms of medical research and clinical experience; the latter might direct that flow in supporting parents' cognitive and affective needs. Each approach creates a physician-parent relationship that might work overall for some parents, by addressing the outcomes that matter most to them in ways that work for them. How well each approach addresses parent needs is an empirical question requiring additional research.

Even though our experts came from a narrow area of medicine, with many knowing or knowing of one another, they expressed surprisingly diverse views on many topics. They did not, for example, agree about whether parents should be offered the option of comfort care prior to delivery for infants born at the margins of viability. Some believed that information gained after birth critically refines the prognosis (Meadow and Lantos 2009), expressing concern about "age discrimination" or "prejudice against micropremies" (Janvier et al. 2008), whereas others "desir[ed] parent participation virtually all the time." Confidence in these positions was justified by anecdotal clinical experiences.

On some topics, the experts had strong, and differing, views on what the facts were and what information to prioritize. For example, the literature has emphasized the unique sensitivity of the developing nervous system to pain (Anand and Hickey 1987; Craig et al. 1993). Guidelines have therefore focused on monitoring and managing moderate to severe procedural pain (American Academy of Pediatrics [AAP] et al. 2006), which

research has found to be undertreated in neonatal intensive care (Carbajal et al. 2008; Simons et al. 2003). However, some participants believed that scientific evidence was limited regarding the effects of cumulative pain on the developing nervous system arising from brief, but daily, procedures or the effects of opioid analgesia on brain growth, neuronal maturation, and apoptosis (Attarian et al. 2014; Hofmeister et al. 2010; Gokulu et al. 2016; Kesavan 2015; Mancuso and Burns 2009; Taddio and Katz 2005; Whitfield and Grunau 2000). As a result, these experts disagreed about whether pain management could “keep the [infants] comfortable.” Those who were unsure often wondered whether to share that concern with parents. Some used the word suffering freely, whereas others distinguished pain and suffering. This heterogeneity may reflect both how experts navigate uncertainty in their decision making and how they integrate research evidence with their clinical experience.

Another striking contrast was that even though almost all the experts believed that family coping, resilience, and adaptation were important considerations, few addressed those topics directly with parents. Some thought that the evidence on parental experiences was too limited, especially for parents who chose comfort care, or that research reporting successful adaptation was biased by which families chose to participate in such studies and what they chose to say. Others quoted research, with high participation rates, that reported good quality of life, suggesting parental, child, or family resilience (Saigal et al. 2010). Our study was not designed to capture where participants stood on the long-standing ethical debate over the proper balance between patient and parent interests in these decisions (Blustein 1993; Hardwig 1990; Hardart and Troug 2003; Hardart 2000; Sayeed and Troug 2011; Walter and Ross 2014). However, the topic warrants further investigation, especially if parents struggle with the same concerns.

More than half of the experts expressed concern about parents’ distress over possibly having made the wrong decision, should their child survive with major disability. None of the experts, however, discussed parents’ potential regret about not having attempted resuscitation, despite having identified that outcome as a key parental fear. That preference might reflect a concern about “creating” disability’ (Janvier and Mercurio 2013), as well as physicians’ tendency to view life with disability more negatively than do disabled patients or their parents (Saigal et al. 1999; Saigal et al. 2010; Saigal et al. 2000; Schappin et al. 2013; Zwicker et al. 2008; Boss et al. 2017). The medical reality is that more than half of the infants born at these gestational ages survive without major neurodevelopmental disabilities (e.g., Lorenz 2011). Yet even neonatal providers who do not feel that they “create” disabled children feel responsible when appropriate treatments inadvertently cause injury or disrupt natural developmental processes. This feeling of responsibility may contribute to some neonatologists’ need to disclose all potential adverse outcomes, preparing parents for the “worst.”

Our study complements previous studies of neonatologists’ attitudes toward critically ill neonates (e.g., Gallagher et al. 2016), by considering how those attitudes are expressed in consultations with parents (Tucker-Edmonds et al. 2016). We find attention to informational needs similar to those identified in

studies developing decision aids (Guillen et al. 2012; Moore et al. 2017). However, we also find concern for the complexity of parents’ cognitive, social, and emotional processes, and the diversity of their responses, beyond the issues that decision aids address (Boss et al. 2008; Janvier et al. 2012; Voltz and Hertwig 2016; Walter and Ross 2014). How the experts translated these concerns into clinical practice appeared to reflect both their personal inclinations and their experiences in trying to serve their patients’ needs. The approaches here differ from those found in other domains, where physicians have typically been found to focus on medical issues, letting patients integrate those concerns with their worldviews, moral frames, and outcomes preferences (Britt et al. 2004; Payot et al. 2007; Walter and Ross 2014).

Formal decision aids have made progress in helping users to absorb and use information in ways consistent with informed consent and professional guidelines (Guillen et al. 2012; Kakki-laya et al. 2011; Muthusamy et al. 2012; Moore et al. 2017). Although our physicians were aware of such these advances, sometimes made at their own institutions, none reported using aids beyond visual depictions or graphs. Our results suggest the need to adapt such aids to clinical settings where physicians and patients grapple simultaneously with cognitive and affective load, and need enough flexibility to suit preferred consultation approaches (Gaucher and Payot 2011; Gaucher et al. 2016). Attending to the full range of parents’ needs could increase their confidence in their providers’ guidance and their own eventual decisions (Bohnhorst et al. 2015; Payot et al. 2007). Such confidence has been found to improve short- and long-term psychological outcomes (Bohnhorst et al. 2015; Caeymaex et al. 2013). Adapting consultation approaches to parents’ preferences would mean providing some with detailed information, while allowing others to focus on the big picture and digest information at their own pace (Gaucher 2016; Janvier et al. 2014; Staub et al. 2014; Walter and Ross 2014).

The scientific and clinical reputations of the participants whom we recruited are a strength of this study. They are recognized thought leaders in perinatal decision making; many are also active researchers. Our interview protocol was designed to allow them to describe their approaches in their own terms. Our analyses revealed diverse opinions on four focal topics, posed to all participants, as well as additional topics that they raised. We believe that these analyses capture how these experts view the scientific evidence (e.g., the bias in family adjustment research) and communicate it (e.g., not talking about family adjustment, despite believing it to be important). If so, then the study achieved the balance sought by the semistructured interview protocol: directing participants to common topics, while allowing unique views to emerge. These experts’ reports will guide future interviews of parents, comparing physicians’ beliefs with those of the parents they serve. Although we only had 18 participants, we reached saturation, in the sense of not hearing new perspectives in three subsequent interviews. Thus, we believe that we have captured much of the diversity in expert neonatologists’/thought leaders’ perspectives on perinatal counseling.

One limitation of the study is using an interview protocol that allows participants to direct the flow, within the general constraints of the investigators’ framework. This design is



intended to diminish any bias created by focusing on the four central topics (short- and long-term outcomes for parents and infants). However, it comes at the price of reducing standardization possible with a fully structured interview. By focusing on the four outcomes separately, we did not prompt participants for their beliefs regarding how to weight infant and parent outcomes when those conflict, nor did that issue arise spontaneously. Some participants addressed all four focal topics, while others did not, indicating the multifaceted nature of participants' perspectives and the dynamic character of these interviews. A future study, using the same semistructured interview strategy, could provide those, or other, concerns with similar detailed attention. It, too, could be followed by the kind of fully structured survey needed to assess the population prevalence of specific beliefs.

Our study relies on participants' self-reports, without observing their actual consultations. As with all self-reports, they are vulnerable to biases in how individuals think about and present themselves. They may also not capture how behavior is shaped by the interactions with parents and other health care professionals in the "consultation space," including nursing staff, obstetrical physicians, and family pediatricians. We hope that our planned interviews with parents will shed light on the accuracy of these accounts.

## Conclusions

Professional guidelines for neonatologists currently focus on what information to communicate, when consulting with parents about infants at the extremes of prematurity. Much less attention has been given to the nature of that consultation process, including parents' cognitive and affective limits and their relationship with their physicians. Our results reveal the current range of approaches to these consultations. That range might reflect an intermediate point in the profession's shift from physician-driven to parent-driven processes or an equilibrium point, where physicians can adopt the approach that they see as working best. Different approaches can be useful, if physicians are able to sense parents' needs and adapt to them, or if parents can find providers with suitable approaches. Although these approaches afford different roles to parents' emotions, all physicians in the study expressed deep concern about helping parents to avoid feelings of regret for having made the wrong decision. Most reported avoiding discussion of parents' long-term adaptation with a disabled child, despite viewing it as important and despite knowing the research evidence of successful coping and resilience. On other topics, such as how to discuss pain or whether to permit parental decisional discretion prior to birth, however, there was little consensus.

In several contexts, disagreement emerged in participants' trust in the medical evidence. For example, some saw great uncertainty in pain research, and some saw bias in studies of parental adjustment. As the interviews were not designed to examine these topics in depth, we believe that disagreement is a topic for future research—both to identify (or stimulate) studies that would address clinicians' concerns and to understand their implications for clinical practice (e.g., parents hearing conflicting messages).

The next stage in our project will involve interviewing parents in terms that allow comparing their views to those expressed by the physicians. We anticipate that parents, too, will have varying preferences for consultation approach and information sharing. By interpreting physician and parental perspectives in common terms, informed by basic research in judgment and decision making, we hope to contribute to better communication regarding these critical decisions.

## Acknowledgments

We acknowledge the experts who graciously offered their time and expertise for these interviews.

## Author contributions

Marlyse Haward, MD, Annie Janvier, PhD, MD, John M. Lorenz, MD, and Baruch Fischhoff, PhD, each made substantial contributions to each phase of this research and article development, including conception, design, data collection, and drafting and revising of this article.

## Funding

None.

## Conflicts of interest

None.

## Ethical approval

This study was approved by the institutional review board(s) at the Einstein Institutional Review Board of Albert Einstein College of Medicine and Montefiore Medical Center.

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