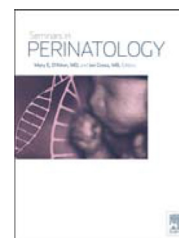


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Personalized communication with parents of children born at less than 25 weeks: Moving from doctor-driven to parent-personalized discussions

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ABSTRACT

Communication with parents is an essential component of neonatal care. For extremely preterm infants born at less than 25 weeks, this process is complicated by the substantial risk of mortality or major morbidity. For some babies with specific prognostic factors, the majority die. Although many of these deaths occur after admission to the intensive care unit, position statements have focused on communication during the prenatal consultation. This review takes a more comprehensive approach and covers personalized and parent-centered communication in the clinical setting during three distinct yet inter-related phases: the antenatal consultation, the neonatal intensive care hospitalization, and the dying process (when this happens). We advocate that a 'one-size-fits-all' communication model focused on standardizing information does not lead to partnerships. It is possible to standardize personalized approaches that recognize and adapt to parental heterogeneity. This can help clinicians and parents build effective partnerships of trust and affective support to engage in personalized decision-making. These practices begin with self-reflection on the part of the clinician and continue with practical frameworks and stepwise approaches supporting personalization and parent-centered communication.

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Abbreviations: GA, Gestational age; NICU, Neonatal Intensive Care Unit

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hope
bonding
guilt
parenthood

You are consulted to see Ms. Featherstone and her husband. She is a 31-year-old G1 P0 who presents in chorioamnionitis, with active preterm labor at 22 weeks and 4 days estimated gestational age (GA) (dates based on assisted reproduction). The estimated weight of the male fetus is 510 g. Delivery is anticipated before the baby receives a full course of antenatal steroids.

You are planning to update Ms. Gladwell, a 19-year-old single mother, who delivered her second child, a 620 g baby girl at 23 weeks and 5 days of GA. Her daughter, Amelie, suddenly developed a severe pulmonary hemorrhage overnight. The head ultrasound has extensive bilateral grade 4 intraventricular hemorrhages. She is on 100% oxygen and has been anuric for the past 24 h.

When parents share their experiences of delivering extremely preterm infants, who are at a high risk of death, many invoke themes of fear, distress and guilt as illustrated by the following quotes:

*"She looked down there and she's like, you're six centimeters, and her face... [...] and then all of a sudden... that's when it started, everybody come in, people scanning me, people checking me, people talking to me, telling me right, this is what's happening [...] you're delivering tonight, you're delivering now"*¹

*"I was probably a deer in a headlight at that moment. Like I do not really remember a lot of what we talked about"*²

*"It's selfish to say we are going to let her live for us. But it's also selfish to say that we are going to let her go to protect others"*³

*"They (the doctors) came to tell us that she was going to die, at the same time, it was our choice - but what choice? As if you can talk about a choice. It was surrealistic for me"*³

Conversations and decisions taken with parents during these critical moments are among the most complex in pediatrics and often, parents relate, the worse moments of their lives.⁴ Babies born under these circumstances are at significant risk of death and potential for severe disability, albeit many can survive with no, mild or moderate disabilities.⁵⁻

¹¹ Fortunately, many 'one size fits all' policy statements about caring for these infants using uncertain estimates of gestational age have improved by incorporating additional clinical factors shown to impact outcomes.¹²⁻¹⁴ Yet, despite variations in infant outcomes and parental preferences for information and decision-making, recommendations aimed to personalize communication with parents have not taken place. In addition, communication guidelines have focused primarily on antenatal consultations,¹²⁻¹⁴ rarely considering discussions that occur in the neonatal intensive care unit (NICU), at discharge, or during/after death. Given that many babies born at less than 25 weeks die in the NICU, and those who survive generally sustain at least one major complication,¹⁵⁻¹⁷ essential conversations and decisions taken with parents often happen after birth.

Personalized, parent-centered, and family-centered communications can be defined as an approach which titrates clinicians' interactions with the parents' reality, supporting them in ways they need it, at the time when they need it. It emphasizes partnerships to individualize counseling focused on relational goals of trust and value awareness. This contrasts with approaches where all parents receive standardized information at the same time. Personalized communications aim to empower parents by aligning knowledge, insights and emotional support with parental values and decision-making preferences.¹⁸⁻²¹ Personalized communication recognizes parents as "rational, emotional, creative and interdependent" who are part of complex social networks rather than isolated decision-makers.^{22,23} Physician determined sets of facts are de-emphasized in favor of information addressing parent concerns and variability in decision-making,²⁴⁻²⁶ shifting consultation goals away from outcomes towards process.²¹ Process-oriented goals understand that extreme prematurity is a novel experience, granting parents discretion as they explore uncertainty and values to set expectations.

In this review we will focus on personalized and family-centered communication during three distinct yet inter-related phases in the life trajectory for the extremely premature infant born at less than 25 weeks: the antenatal consultation, the neonatal intensive care hospitalization, and the dying process when this happens. Throughout each of these phases, personalization and parental support is paramount. We supplement many of the concepts with practical suggestions and present frameworks to facilitate application and reflection in clinical settings in Table 1,^{19,227} and 3²⁸ with suggested templates for consultation in Figs. 1 and 2.²⁰ This article is part of an issue on babies born at less than 25 weeks GA but these concepts could apply to parents of other fragile babies^{29,30} and parents of babies born in later gestations.¹⁸

Part 1: Antenatal consultation

Current recommendations for the antenatal consultation focus on equalizing knowledge imbalances by providing parents with physician-derived sets of information to facilitate rational, data-driven choices.¹⁴ These information sets span short and long-term morbidities, survival and mortality statistics determined by physicians, with little input from parents.³¹ Although recommendations¹⁴ suggest exploring values, they fall short in acknowledging the 'process' of relationship building. Relationship building is critical for establishing trust and facilitating value awareness.^{2,21,23} These 'relational outcomes' in turn might foster desired informational outcomes through greater understanding and parental insights. Therefore, the antenatal consultation should

Table 1 – SOBPIE¹⁹ Framework for the Prenatal Consultation.

Reflection and preparing to meet parents	
Situational Awareness Is there a choice?	Infants like Leo can be offered resuscitation or comfort care depending on institutions. In some institutions, parents do not have a choice and are told that “all babies of such gestation die”. What is the policy at my institution? How am I able to convey this to parents? If parents have a choice, I need to be cognizant that Mrs. Featherstone may have underlying value systems that preclude choices.
Opinions and Biases What are my thoughts on these options? What are my biases about outcomes?	What are my views about babies born that early? I need to be aware of my biases and provide a balanced consultation. If my hospital does not allow intervention, can I help parents who want to give their child a chance? I know that Mrs. Featherstone needed assistance to conceive. I should be mindful that although she desperately wanted to become pregnant, she may or may not want to resuscitate her baby under these conditions.
Beginning Basic Politeness Proximity Respect	I will be doing a joint consultation with the Obstetrician who she already knows. We turn off our pagers, enter the room and sit down face to face. “Good evening Mrs. Featherstone. I am Dr. Apgar the doctor who takes care of babies born premature. I realize this must be a very difficult time for you so we will take it one step at a time. Your Obstetrician, Dr. Hurley is here to help as well. Is this a good time? Would you want somebody else to be here or for us to call that person?”
Personalizing and Supporting the Partnership Parental Perspectives Information Desires Emotional Support	“Tell me about your pregnancy thus far.” “Do you know of babies that were born premature?” (serves to understand previous experiences, engages the parent to tell their story). “Have you chosen a name for your baby?” (use the name throughout the consultation) (make connections). “How can I help you and Leo today?” “What are you most afraid of for Leo?” (Allow silence) (Acknowledge emotions, clarify values, re-engage). “Many parents in your situation will feel overwhelmed, angry or sad. These are normal feelings. We will take things one step at a time and focus on issues that are important to you. Does this sound reasonable?” “I also wish that Leo is not born preterm. Are there other things that you hope for?” “I hear that you value giving Leo a chance at survival but are concerned about his ability to be independent later in life.” (Explore decision-making and information preferences). (Some... other... strategies). “Some parents prefer to hear the big picture, others want to know numbers and statistics. What would work best for you?” “Some parents want doctors to give them all the information and make these decisions on their own, other parents want to take these decisions with doctors. Other parents want doctors to give them recommendations. What kind of parent are you?” (Janvier et al. 2014). (Permit silence). (Provide information that aligns with their preferences: decision aids, recommendations etc).
Follow-up (if needed) Repeat SOBPIE	Repeat consultations with same considerations and approach.
Adapted from: Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. <i>Semin Perinatol</i> . 2014;38(1):38-46.	

include ‘relational outcomes’ (trust and value awareness) through affective support and personalizing partnerships in decision-making.^{2,20,21,23}

Building trust

Neonatologists meet the Featherstones under complicated circumstances: parental experiences and personal beliefs are unknown, family support networks are physically absent, and time is limited. They try to be cognizant of implicit biases leading to erroneous assumptions about families,^{19,21,27} while remaining humble and open to parental beliefs and culture to build rapport and trust.³²⁻³⁵

Likewise, parents cannot choose which neonatologist counsels them. They may harbor misperceptions or mistrust of medical professionals based on previous interactions with health care systems.²⁵ First impressions from this encounter can shape their future interactions with the medical team.³⁶ Their perspectives may or may not be influenced by their religion, culture, and ethnicity, or even, as in this case, how the baby was conceived.^{32-35,37-40}

Therefore, establishing rapport and trust early in the clinician-parent relationship develops therapeutic alliances facilitating care and decision-making, empowering parents both during and after the antenatal consultation.^{18,30,41-44} Indeed, positive relationships correlate with satisfaction of care after

Table 2 – ouR-HOPE Framework for Communication Reflections²⁷.**Preparing for the partnership****Reflections**

How do my experiences shape my prognostic interpretations or inform my counseling approaches?

Humility

Can I adjust my communication style to meet the needs of this family?

Can I accept the prognostic uncertainty in my predictions?

Open Mindedness

Am I open to appreciating differing perspectives on outcomes?

Am I open to understanding how different factors impact outcomes?

Personalizing and Supporting the Partnership**Partnerships**

How do I make parents feel like partners in this consultation?

How can I empower them?

How do I adopt a consultation approach that meets their needs?

Engagement

How am I committed to best practices, ethically and clinically?

How can I decrease feelings of abandonment as we move through this trajectory?

The last baby I sent home with a grade 4 IVH is now 6 years old. Her parents bring her to speech therapy, occupational therapy twice weekly. She is a happy child and well cared for. I should be cognizant that I may consider Ms. Gladwell not capable of this sort of care because of her age and my assumptions about her socioeconomic status.

I recognize that my predictions are inherently uncertain. I need to remember to be upfront about what we know about cerebral palsy, about neurological predictions in the face of neural plasticity and the impact families can have on outcomes.

I realize that Ms. Gladwell and her family are somewhat hesitant of Western medicine and have expressed concerns about “too many tests”. They may not be wrong in some instances.

I did not realize, in Ms. Gladwell’s culture, there is a lot of mothers whose children are raised by the maternal grandmother. Her mother seems to be very involved in her life as is her Grandmother. I should remain open to other child rearing arrangements and always include the grandmother in these discussions, as is Ms Gladwell wish. I have to continue explaining to the rest of the team the inappropriateness of the comment: “it is not the grandmother who will raise the child”.

I will ask Ms. Gladwell open ended questions. I know from previous conversations that she has a strong faith and supportive church community.

“Good morning Ms. Gladwell, can you tell me about Amelie today” “what do you understand of how Amelie is doing?”

(Allow silence).

“What is your most pressing concern?”

(Seek silence, reflect back emotions, re-engage).

“I am hearing that it is important to you to involve your mother and grandmother in our conversations and that information about what we can do to maximize Amelie’s potential is important to you. Let us talk about that and what you can do to help.”

“Thank you for pointing this out. You know Amelie so well.”

Whatever the path the discussions will take, and whichever decision is made, I will commit to give my best to accompany the family in what is important to them (even if I feel it’s not the choice I would have made or expected, even if I may be treated harshly).

“The good choice is the one you feel is the best for Amelie and for you”. “We will be here with you and give Amelie the best possible care, whatever way she decides to take.”

Adapted from: Racine E, Bell E, Farlow B, et al. The ‘ouR-HOPE’ approach for ethics and communication about neonatal neurological injury. Dev Med Child Neurol. 2017 Feb;59(2):125-135.

birth, while negative experiences can have long lasting effects beyond discharge or death.^{1,4,43,45}

In practice, building trust within the constructs of any relationship is a ‘two-way street’. However, steps taken by clinicians during the consultation, such as adopting a posture of openness: using positive body language, listening to parents and personalizing connections (Table 2) sets the tone for the partnership.^{19,27,30,44,46} Specific behaviors, such as asking if they have chosen a name for their baby and using that name in conversation, helps the Featherstones feel cared for and their infant valued.^{30,44} Frameworks and reflections, such as SOBPIE¹⁹ or ouR-HOPE²⁷ organizes these behaviors and acts as guides or checklists for clinicians (Tables 1 and 2). For example, ensuring the environment is conducive to dialogue includes behaviors grouped as Basic politeness (the B in SOBPIE)¹⁹: introductions, common courtesy, empathy, and good bedside manner (Table 1).¹⁹ Keeping these frameworks in mind helps, as even empathetic physicians can forget to sit while speaking to families or overlook opportunities to personalize consultations when pressed for time.

Affective support

The Featherstones may experience conflicting and volatile emotions, mixtures of apprehension, love, guilt, and grief which can overwhelm their ability to absorb information.^{47,48} Many parents are in the process of grieving the loss of their pregnancy or “parenthood project” when consultations occur.⁴¹ Initiating dialogues about outcomes without first providing affective support can lead to disengagement⁴¹ making it difficult for parents to connect the information received with the infant they are carrying and make decisions.^{41,49} This disconnect could jeopardize informational goals. Even when informational needs are met the emotional shock of premature birth and heightened anxiety impacts parents.^{50,51}

In practice, permitting periods of silence helps address the Featherstones’ emotional vulnerability to build rapport and empower them to participate in the process of decision making to the extent they desire.^{41,42,44,52} Silence enables time for parents to express emotions (Tables 1 and 2).^{19,27,53} Embracing, tolerating and then breaking these silences provide opportunities to reflect on the Featherstones’ emotions and

Table 3 – Step Wise Framework for End-of-Life Counseling, Delivery Room Example²⁸.

Before
<p>Name of Infant: Leo.</p> <p><i>"My name is Beth Wilson, I am the neonatologist, a doctor who takes care of children and infants. I will be here in the delivery room helping to take care of Leo."</i></p> <p><i>"I may not have time to speak with you, but we will be there for him and for you."</i></p> <p><i>"Leo is not doing well, we are preparing for the worse but hope for the best."</i></p>
During
<p><i>"Dad, you can come close to the bed if you like."</i></p> <p><i>"You can take Leo's hand."</i></p> <p><i>"You can update mom if you like."</i></p> <p><i>"Mom, we are taking care of Leo."</i></p> <p>Prepare for the death in a step wise fashion:</p> <p><i>"Leo is not doing well despite a tube to help him breathe and medication to help his heart."</i></p> <p>Dad and Mom, we are trying a medication, but it is not going well. We will try one last dose if it does not work we will stop the resuscitation and place Leo in your arms.</p> <p>Mom and Dad, Leo is dead. We tried everything we could to save him. I'm sorry.</p> <p>Stop the resuscitation without asking the parents. Clearly state that Leo is dead.</p>
After
<p>Address guilt: <i>"Mom and Dad there is nothing you could have done to prevent this."</i></p> <p>Sit Down.</p> <p>Provide proximity.</p> <p>Allow opportunity to ask questions.</p> <p>Know what happens to Leo after death.</p> <p>Offer spiritual support.</p> <p>Offer future support.</p>
<p>Adapted from: Lizotte M, Barrington KJ, Sultan S, et al. Techniques to Communicate Better With Parents During End-of-Life Scenarios in Neonatology. Pediatrics. 2020;145(2):e20191925</p>

body language. In fact, naming parents' emotions helps re-engage them in dialogue, while acknowledging that clinicians care for what they feel. For example, clinicians can tell Mrs Featherstone *"when something happens to our baby, as a parent, we often think of all the things we could have done, like you are doing now. There is nothing you could have done to prevent what is happening to your pregnancy"* or *"You did an amazing job carrying the pregnancy as far as you did. That helped your baby tremendously"*.⁴⁷ Or, if she is angry, saying, *"You sound angry and sad at the same time. Many parents in your situation report the same feelings. It is so unfair what is happening to your family."* can help (Table 1).

Values and hopes

The Featherstones' values can guide how they want to make decisions, their informational needs, and finally their choices. Threatened preterm birth and life-and-death decisions in the NICU do not 'routinely arise' in daily life, so parents do not have the advantage of previous experiences with a 'go-to' set of predetermined values.⁵⁴ Rather, they may need to infer their values from similar situations in other domains, and in

some cases, loosely or inappropriately apply heuristics.⁵⁴ For example, the Featherstones may make care decisions for their infant based on a neighbor's "premature infant" who was born at 32 weeks.⁵⁵ Without knowing one's values, people are susceptible to contextual and communication effects such as framing.^{25,56,57} For other parents, overarching values and belief systems dictate choice such that regardless of how an intervention is proposed, parents feel an obligation to proceed because of their religion or worldview. Keeping an open mind with parents who call upon faith or 'letting God decide' strengthens partnerships.^{4,27,54}

Hopes can both reflect parents' values and be used to foster connections. The Featherstones may express hope that their baby will not be born preterm. Acknowledging and sharing their hope assures parents that clinicians are on their side.^{58,59} Multiple domains of hope can co-exist, appear contradictory, and evolve as new knowledge is learned.⁶⁰⁻⁶² Hope, however, does not prevent honesty: a *"reconciliation of hope and honesty requires skillful management of multiple co-existing hopes, played out over time, always guided by a therapeutic intent"*.⁶²

In practice, clinicians can explore new hopes without diminishing fundamental wishes by saying, 'We also wish Leo will not be born today, but later. What other hopes do you have for Leo?'.⁵⁸ Parents may respond, *"I hope Leo does not suffer"*, or *"he has no disability"* or *"Leo is okay"*. Checking in regularly,⁶¹ personalizes and validates evolving hopes⁶² while strengthening trust and partnerships.⁶¹ Mrs. Featherstone may express hopes unrelated to Leo such as *"I want to be a mom and I am so scared I may never have a child"*, *"I hope my relationship with my husband survives this"* or *"I hope I can be strong enough. I just had a depression, I do not think I have the strength."*

Expressions such as 'doing everything'⁶³ or 'doing nothing' should be avoided or reframed into what is possible and consistent with parental values and hopes. 'Doing everything' still requires choices.⁶³ Likewise, there is no such thing as 'doing nothing'. Palliative care is not nothing. Clinicians may have a different sense of what 'everything' (the gamut of medical interventions) or 'nothing' (comprehensive comfort care with one-on-one dedicated nursing) means than parents.⁶³ Re-defining 'everything' or 'nothing' along value defined goals can help parents understand the limitations of care possible for their infant. For example, *"We will do everything that we think will help Leo and the goals you have for him"*.

Frameworks standardize this process. An important step in exploring parental values is determining whether a choice will be offered to parents, portrayed in SOBPIE as 'Situation' (Table 1).¹⁹ In some institutions, choices are not available for parents. Wide practice variations exist at 23 weeks;⁹ in many units in France⁶⁴ babies are not offered interventions while elsewhere interventions are routinely offered.^{5-8,11} Next, the Opinion¹⁹ of the clinician requires reflection on implicit and institutional biases that can inadvertently frame discussions with parents. Self-reflection and humility, portrayed as R -H in our HOPE,²⁷ to understand those who may think, and act differently can help improve systems of care. 'Parental perspectives' (Table 1)¹⁹ can illustrate values through questions such as *"How can I help you?"*, *"What are you most concerned about?"*. Answers might be, *"I am scared my wife will seize, she is sick. In a way, if Leo comes out soon, my wife will no*

Prenatal Consultation Checklist		Mother's name: _____	
____/____/____		ID: _____	
Reason for consultation: _____		OB name: _____	
<input type="checkbox"/> Communication with OB team: _____		Joint consultation with OB: <input type="checkbox"/> yes <input type="checkbox"/> no	
Parent told about consultation: <input type="checkbox"/> yes <input type="checkbox"/> no		Significant person present: _____	
Allow enough time / Limit interruptions (phone/pager) / Ensure privacy (# people) / Sit down			
Establish trust with parents <input type="checkbox"/> Neonatologist introduction / role <input type="checkbox"/> NICU team introduction <input type="checkbox"/> Ask about the baby "Do you have a name?" _____ "Tell me about your baby" _____ "Does he/she have siblings?" _____ <input type="checkbox"/> Ask and Listen to parents' main concerns - "What is your greatest fear?" - "What is most important to you as a family?" - "Is anything worrying you at home or work?" - "What do you expect from this consultation?" - "What can I do for you?"		Address personalized parental concerns & questions <input type="checkbox"/> Ask parents if they prefer statistical data, general terms, or both <input type="checkbox"/> Discuss potential complications of prematurity relevant to them <input type="checkbox"/> Explain their role as parents of a premature baby - Parental roles: touching, talking, family attachment - Baby appearance and behavior - Parent as caregiver: feeding/breastfeeding, clothing - Parental involvement in future decisions <input type="checkbox"/> Explain how the NICU works - NICU visit offered <input type="checkbox"/> yes <input type="checkbox"/> no date: ____/____/____ - Allied HCP visit offered <input type="checkbox"/> yes <input type="checkbox"/> no	
Comments: _____			
NICU team members (Name, role): _____			
Follow-up <input type="checkbox"/> NICU visit done (Date: ____/____/____) <input type="checkbox"/> Allied HCPs consulted (Role & date): _____		<input type="checkbox"/> Follow-up visit (ideally) by same neonatologist - Date: ____/____/____, GA: _____ <input type="checkbox"/> Written documents given Further comments: _____	

Fig. 1 – Prenatal Consultation Checklist²⁰ from Haward MF, et al. Clin Perinatol. 2017;44(2):435.

longer be at risk." or "I hope Leo will have a good quality of life." or "What will happen to my couple, my other children and my family?"

If the Featherstones have difficulty speaking about their concerns, consultants can provide balanced prompts. For example, clinicians can explore prognostic uncertainty by helping parents interpret predictions while reminding them that for their child outcomes are either 'all or none'. Clinicians can admit the limitations of their prognostic abilities.⁶⁵ Clinicians can also provide 'balanced' views of disability and explore how families may or may not cope by reminding parents that disabled children often report better than expected quality of life and family functioning.^{66,67} They can empower parents with the knowledge that their efforts in the first few years of life can modify outcomes.⁶⁷

Decision-making support

Babies born at less than 25 weeks have high mortality rates, influenced by where they are born.⁹ The extent to which parents want to be involved in and approach decisions that result in death vary.^{30,68} For those who want to make decisions, some use rational choice models^{24,25} which resemble informed consent and base choices on data, facts, and

outcomes worth. Some follow heuristic decision-making approaches, where intuition and inferences such as feelings or 'instincts' drive decisions.^{24,25,69,70} Still others, oscillate between rational choice and heuristic decision-making models.⁴ Yet, in all models, while emotions may not always drive decisions, they play a substantial role; acknowledging their presence authenticates the dilemma and the parent's struggle.

Identifying which model Mrs. Featherstone prefers can help optimize information for her deliberation style while ensuring she has acquired sufficient information, such that future perspectives or information learned later, will not invalidate her choices or create regret with the process.⁷¹ This, however is complicated and requires flexibility from both the parent and the physician balancing cognitive insights, emotional intuition and value awareness.⁵⁴

In clinical practice, using the "some parents... other parents" approach can help uncover preferences with statements such as "Some parents do not want to be the ones to make life-and-death decisions for their baby... Some want to decide with the medical team, and others want to be the ones to make the decision. How would you feel most comfortable approaching these decisions?" or "Some parents know in their gut what decision feels best, some want to use data to make decisions, and some do a little bit of both. Which approach seems best for you?" To understand how much

Date: __/__/__ OB Name: _____ Reason for consultation: Prematurity Other _____	Mother's Name: _____ DOB: __/__/__ Room nr.: _____ Hosp. ID: _____	
BABY GA: _____ (U/S _____ LMP _____) Singleton Twin _____ EFW: _____ (__/__/__) Gender: _____ β-methasone __/__/__ __/__/__ __/__/__ _____ _____ _____ _____ _____	MOTHER Age: _____ G _____ P _____ A _____ Blood Gr: _____ Serol.: _____ Habits: _____ _____ Medications: _____ PMH: _____ _____ OBST. H: _____ _____ _____	

CURRENT PREGNANCY T1 _____ T1 U/S(__/__/__) _____ T2 _____ T2 U/S(__/__/__) _____ T3 _____ T3 U/S(__/__/__) _____
--

DISCUSSION	Mother OB present: _____ Baby's name: _____	Father _____	Other significant: _____ NICU Team: _____
Parents' main concerns: _____ Family situation: _____			
Information discussed relative to parents' needs:		Complications of prematurity How NICU works	Parental roles
_____ _____ _____ _____ _____			
<input type="checkbox"/> NICU visit offered		Written documentation provided : <input type="checkbox"/> yes <input type="checkbox"/> no	

Follow-up <input type="checkbox"/> NICU visit done (Date: __/__/__) <input type="checkbox"/> Allied HCPs consulted (Role & date): _____ <input type="checkbox"/> Follow-up visit by neonatologist: _____ Date: __/__/__, GA: _____	Neonatologist Name: _____ Signature: _____ Date: __/__/__
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 Fig. 2 – Template Prenatal Consultation²⁰ from Haward MF, et al. Clin Perinatol. 2017;44(2):440.

information to provide, clinicians can say “Some parents want to know all the numbers, statistics and percentages while some want the big picture. What kind of parent are you?”¹⁹ Consultants can provide decision aids for parents who need data in this form or to solidify knowledge if Mrs. Featherstone prefers to make decisions independently. Conversely, they can provide recommendations if she does not want to assume responsibility. Decision aids alone, however, while improving knowledge, do not diminish decisional conflict or assist in decision-making,⁷² and should be used only as a supplement within the constructs of a clinician-parent partnership. Proposing decision aids in a personalized fashion will benefit parents who may wish to us them.

Part 2. Communication during the neonatal hospitalization

Parent-centered communications during neonatal hospitalizations follows similar concepts. This section will add how continuity of care and ‘good parenting beliefs’ can help manage uncertainty, hope, and realism. We will consider the case of Ms. Gladwell.

Parenthood support and helping parents cope in the NICU

Helping Ms. Gladwell cope in the NICU can be encouraged through communication that supports good parent beliefs.⁴⁷ Good parent beliefs are a series of personally defined beliefs that guide strategies for decision-making and coping reported by parents of critically ill or dying children.⁷²⁻⁷⁶ There are many dimensions of ‘good parenting beliefs’, expressed as “being informed”, “decreasing the pain of my child”, or “making sure my child feels loved”; these are personal and likely evolve over time.⁷²⁻⁷⁶ Actions taken by clinicians to support these beliefs can facilitate adjustment and / or encourage participation in care decisions.⁷⁴

Parents in the NICU may face additional challenges.⁴⁷ Ms. Gladwell’s journey is complicated by the fact that she may not feel like a “real parent”, the way she was for her first child. Rather than engaging in typical parenting behaviors to comfort her child, she must try to feel like a parent in the surreal setting of an intensive care unit with a critically ill baby she cannot hold or feed who is attached to large machines. She must then accept that she is not a ‘bad parent’ in order to feel like a ‘good parent’ and develop a personal collection of good parenting beliefs.⁴⁷ Feelings of guilt, augmented by unintentional external judgments or an internal sense of inadequacy or culpability, can inhibit, or derail this transformation.⁴⁷

In practice, clinicians can support parents’ transformations using ‘some parents...other parents’ strategies, and permitting flexible care models.⁴⁷ Statements such as “Some parents love the positive feelings that they get from doing kangaroo care. Others feel stressed and do not enjoy it for a while. We want to find ways for you to help your child that are comfortable for you.” gives Ms. Gladwell permission to choose her own path. Reminding her how she has helped her infant such as “Thank you for pointing this out. You know Amelie so well.” empowers her to trust her parental instincts and engage more confidently in parenting behaviors.⁴⁷

Continuity and personalization during family-centered care

Families are all different. The Featherstones are married and pregnant with their first child, while Ms. Gladwell lives with her mother and 18-month old daughter. Ms. Gladwell may consider her mother her support person and give her parental visiting NICU privileges. Clinicians should be aware of this information.

When there is continuity in how care is delivered to Amelie, Ms. Gladwell may feel less anxious about adapting to new provider expectations or feel pressure to prove herself a ‘caring parent’ each time shifts change. Continuity creates shared knowledge encompassing values, hopes and goals from which complex medical information is understood.⁷⁷ The same clinician is not always necessary for continuity, as continuity can be fostered by clear documentation of parental preferences for bedside care and decision-making in the chart or during signoffs. For example, if parents attend rounds, it is helpful to know whether they want to present their infant before asking them to do so. Documenting how and when parents want to be notified when conditions change avoids unnecessary stress from unwanted calls (or from calls that did not happen). Taking note of maternal conditions that interfere with expected care behaviors, such as recommendations to forgo nighttime breastmilk pumping due to risks of severe depression, or personal values, such as religiosity, can prevent unintentional harms from ‘innocent’ clinician suggestions.

In practice, managing environmental stress helps diminish parental vulnerability. For example, delivering difficult news privately away from large crowds of people on rounds in academic centers is preferred by parents.⁴ Clinicians who attend to affective needs while inviting reflection on experiences and concerns with open ended questions^{78,79} prepares parents to receive complicated information. Tailoring information for the ‘big picture’ or details^{19,27} and balancing medical with psychosocial information⁷⁸⁻⁸² respects preferences and provides context. Replacing statements such as “Amelie is stable” with “this is what we expect”, “this is what we hope”, or “this is what we fear” when presenting next steps promotes healthy optimism while being honest and realistic.

Preferences may change and therefore should be verified by asking

“You previously told Dr. Apgar that you did not feel comfortable presenting Amelie at rounds. Many parents feel the way you do but some change their minds after a while in the unit. I just wanted to make sure you still felt this way to make sure it is OK if I do not ask you to present her every morning.”

Physicians who try to overcome uncertainty by diving deeper with medical information or statistics rather than accepting uncertainty for what it is, lose opportunities to engage Ms. Gladwell.⁸³

When Amelie deteriorates, the medical team knows Ms. Gladwell’s support person is her mother. Other mothers or parents have different sources of support, such as a priest, family member or doctor. Many also benefit from support by NICU clinicians such as social workers, psychologists, or spiritual advisors.

Part 3. Dealing with death: the importance of a stepwise approach

Generally, for babies born at less than 25 weeks, neonatal death occurs relatively early when the infant does not respond to interventions, often within the first 3 days of life for the most immature babies.⁸⁴ Other babies die when respiratory support is removed after death is judged inevitable, or for quality of life concerns.¹⁵ For parents like Ms. Gladwell, when death is not immediate, time permits knowledge to be acquired and values to be clarified influencing how choices are interpreted.⁸⁵ Conversely, parents like Mrs. Featherstone, may not have opportunities to meet with neonatal staff prior to delivery and reflect on the situation. During these highly emotional conversations, a stepwise framework can be invaluable to transition goals of care for the infant (Table 3).²⁸

Stepwise preparation following the baby's life trajectory

Consistent with Ms. Gladwell's stated preferences, she was immediately notified by phone of Amelie's clinical deterioration and comes to the hospital for a meeting with the medical team. Ms. Gladwell has asked her mother to come and support her. The meeting begins by letting them know that what they are about to hear will be difficult. Dr. Apgar states in practical terms that they hope Amelie will start producing urine and stabilize her saturations, reiterating for Ms. Gladwell her primary wish that her infant survives. They say they fear however that Amelie's heart may start to slow as she gets tired and communicates that Amelie will likely die and risk serious disability if she survives. After a period of silence and affective support, Dr. Apgar explores new hopes with Ms. Gladwell and her mother. Ms. Gladwell states she is uncomfortable deciding on the date of Amelie's death and that "God will decide when Amelie leaves the earth."

Ideally, in non-emergent end of life scenarios, principles of palliative care and relationships begin early in the trajectory of critical illness before acute deterioration. Topics such as pain, long-term values and goals can be discussed throughout the hospitalization as hopes evolve with changes in clinical conditions.⁶¹ Recommendations, when asked, can be provided in a structured and cautious manner, such as after a clinical interdisciplinary meeting. Offering choices neutrally can leave parents feeling abandoned whereas recommendations presented too strongly can lead to disengagement.^{86,87}

In clinical practice, delivering bad news can be separated into three time points: preparation, next steps, and support and affirmation of the decision. Preparation begins with 'warning shots' – such as "what you are going to hear is difficult" – followed by silence to allow Ms. Gladwell time to prepare to receive information.⁵⁸ "I wish" statements acknowledge emotions or fundamental desires while individualizing information with the infant's clinical status.⁵⁸ Seeking new hopes, even as life recedes, maintains the process of 'hoping'.⁵⁹ After allowing Ms. Gladwell time to digest the news, phrases such as "Given what you are up against, what are you hopeful for?"⁵⁹ can re-engage her in the discussion.

Next steps frame guidance on what can be done, rather than what is likely not to work. Phrases such as "we have done

everything that we think could help to keep Amelie alive" can relieve tension and scaffold the decision. Reminding Ms. Gladwell of her strengths as a parent both in life and in death provides affective support such as "You have been there in Amelie's life. Amelie is dying and we will continue to be there for both of you. When babies like Amelie die, we know that many parents want to hold their baby in their arms during that process. Amelie can still feel your touch, smell and hear you." Speaking directly without ambiguity about how, when and where death will occur, the role the clinicians will play, and addressing religious ceremonies is generally constructive. Ms. Gladwell should feel comfortable asking questions about what happens to her infant's body or expressing her values such as "God decides". Transparency can be fostered by speaking about the practicalities of death with honest compassion whenever parents ask rather than "we will cross the bridge when we come to it". Many parents need guidance during those difficult moments. For example, parents may want to hear about how to help grieving siblings or ways to preserve memories.

Affirmation of the decision once made, without any hesitation from all staff, helps start the grieving process.^{4,88} Although few parents want to choose the date and time of their infant's death, respecting the role they want to play in decisions surrounding death is vitally important and can avoid complicated grief.⁸⁶ Even if a "new" clinician is present at the time of death, clear communication provides knowledge about parental values, 'good parenthood beliefs', preferences, and coping styles. Strong clinician relationships are correlated with positive perceptions of care, increased participation in end-of-life discussions, and better coping after death.^{80,81,89}

In the case of Mrs. Featherstone, her labor progressed precipitously, and the neonatal providers were unable to consult with her prior to delivery. The Featherstone's have asked to give Leo a chance if there is a chance he can live, but interventions in the delivery room do not succeed.

Parents whose infants die during resuscitative efforts in the delivery room may not have had opportunities to meet and develop relationships with neonatal clinicians in advance. While good communication under these circumstances is condensed, it can still be separated into three time points: before (preparation), during (next steps), and after resuscitation (support and affirmation) (Table 3).²⁸ These steps foster good communication when a baby dies during resuscitation²⁸ or becomes acutely unstable in the NICU.

Before resuscitation, simple yet important measures such as maintaining eye contact, introducing oneself and using the infant's name can set the stage for meaningful connections. Statements such as 'we prepare for the worst but hope for the best' or 'we may not be able to speak to you while we are helping Leo, but we will speak to you as soon as we can' convey urgency and intensity of the moments to come for the Featherstones. Optimally, during an emergent resuscitation, a person dedicated to communicating with the Featherstones is available. However, when this is not possible, parents can still feel well cared for²⁸ if the clinician remains calm and presents the situation in a stepwise manner when infants do not respond to resuscitation.

For example, a clinician starts with, "Leo is not doing well but we hope he will improve", then "we are trying medication for the

heart but if it does not work he will die and we will bring him to you and your wife", and finally "Leo is dead". Preparing the Featherstones for death in this manner highlights the importance of communicating what clinicians fear and hope for. They can see that the intervention did not result in the desired effects. Parents should not be asked for their consent to discontinue unsuccessful resuscitations.²⁸ Bereaved parents have recommended that clinicians avoid metaphors such as "He is with the Angels", "He is in a better place", "He is with God", "He has passed"²⁸, and encouraged clinicians to speak slowly, avoid medical jargon, and permit silence.⁷⁸

Communication does not end after death, but rather continues to support parents. Many parents express the desire to learn more information about their child's death, obtain emotional support, and/or provide feedback.⁹⁰ For some it is when they become pregnant again. Meetings held remote from acute crisis with the primary treating physicians and/or the clinician who was present at the time of death can reassure parents by validating decisions and confirming clinical events.⁹¹ While neonatal teams are not experts in providing thorough bereavement counseling, checking in with families is perceived as caring.⁹⁰ Parents heal better when they know that their child had meaning and/or transformed clinicians and will be remembered by those who had the privilege to know them.^{4,45}

Conclusion

Parents and families will live with these experiences for the rest of their lives. How they remember the communication process and care their infants received depends on their perceptions of the relationships built with clinicians and their ability to 'justify' what happened within the context of their values. Behaviors that make them feel disrespected or their infant not valued can leave lasting impressions, whereas trusting partnerships solidifies their roles as parents. Personalized communication is more than information. It is a titrated process which gives as much attention to medical statistics and outcomes as to the process by which those outcomes are presented and ultimately supported. It emphasizes partnerships built on trust and value awareness. In the care of babies with a high risk of death or disability, these processes are essential. Parents do not approach these decisions from one perspective, instead perspectives are intertwined within a complicated network of emotions, relationships and previous experiences that shape their ability to process, decide and cope with the outcomes. Distilling communications to 'one size fits all', transfers of information or decision aids disregards the multi-dimensional nature of decision-making, emotions, values, outcomes, and hope. Hope that parents find ways to live with outcomes, knowing they are or were good parents, can help them heal and rewrite their story in ways that makes sense to them.

Declaration of Competing Interest

None of the authors have financial or personal conflicts of interests.

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