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Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology

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ABSTRACT

The nature and content of the conversations between the healthcare team and the parents concerning withholding or withdrawing of life-sustaining interventions for neonates vary greatly. These depend upon the status of the infant; for some neonates, death may be imminent, while other infants may be relatively stable, yet with a potential risk for surviving with severe disability. Healthcare providers also need to communicate with prospective parents before the birth of premature infants or neonates with uncertain outcomes. Many authors recommend that parents of fragile neonates receive detailed information about the potential outcomes of their children and the choices they have provided in an unbiased and empathetic manner. However, the exact manner this is to be achieved in clinical practice remains unclear.

Parents and healthcare providers may have different values regarding the provision of life-sustaining interventions. However, parents base their decisions on many factors, not just probabilities. The role of emotions, regret, hope, quality of life, resilience, and relationships is rarely discussed. End-of-life discussions with parents should be individualized and personalized. This article suggests ways to personalize these conversations. The mnemonic “SOBPIE” may help providers have fruitful discussions:

(1) What is the **Situation**? Is the baby imminently dying? Should withholding or withdrawing life-sustaining interventions be considered? (2) **Opinions and options**: personal biases of healthcare professionals and alternatives for patients. (3) **Basic** human interactions. (4) **Parents**: their story, their concerns, their needs, and their goals. (5) **Information**: meeting parental informational needs and providing balanced information. (6) **Emotions**: relational aspects of decision making which include the following: emotions, social supports, coping with uncertainty, adaptation, and resilience.

In this paper, we consider some aspects of this complex process.

Abbreviations: BPD, bronchopulmonary dysplasia; PMA, post-menstrual age; CPR, cardiopulmonary resuscitation; ELGAN, extremely low-gestational-age infants; GA, gestational age; NEC, necrotizing enterocolitis; NICU, neonatal intensive care unit

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1. Introduction

In this article, we suggest ways to personalize conversations concerning withholding or withdrawing life-sustaining interventions for infants born at periviable gestations and other neonates with life threatening conditions. We recommend that the mnemonic "SOBPIE" may help the healthcare providers to have fruitful discussions with families with compassion and respect, and help the families to arrive at satisfying decisions.

The elements of the mnemonic SOBPIE are as follows. The first element is the *situation*, or whether or not the infant is terminally ill with little chance for survival; the second is the *opinions and options*, which are the personal biases of the healthcare provider and potential options they can offer the parents; the third is the *basic* human interactions; the fourth is a consideration for the *parents'* personal stories, concerns, needs, and goals; the fifth element, *information*, is the process of meeting the parents' need for information, as well as providing a balanced set of information; and the sixth element pertains to *emotions*, which specifically concerns that one should be sensitive to the emotional and relational aspects of decision making, parents' social support, their ability to cope with uncertainty, their adaptation to the inevitable, and their resilience. These can be considered with the following examples.

> *Jessie*: Mrs Garnier is 23 weeks' pregnant. The Garniers already have a name for their unborn child. They wish to call her Jessie. Mrs Garnier has severe preeclampsia and will probably deliver in the next few days.
>
> *Coralie*: Coralie was born at 24 weeks' gestational age. She is now 6 weeks old. She had a relatively uneventful course until she developed sepsis 3 days ago. Since then, she has deteriorated rapidly and is now in terminal shock: she has not passed urine for the past 2 days and her blood pressure is unmeasurable, despite maximal therapy. It has become clear that Coralie will not survive.
>
> *Adrian*: Adrian was born at 30 weeks of gestational age, and was stable until he developed necrotising enterocolitis (NEC) and sepsis at 3 weeks of age. At surgery, a large segment of the intestine was resected, and later he required another surgery to relieve intestinal strictures. He has had 2 sepsis episodes. He is now 38 weeks' postmenstrual age, and has short-gut syndrome, in addition to and severe bronchopulmonary dysplasia (BPD). Today he developed another perforation of his intestine today that requires an urgent surgical intervention. But, he is physiologically unstable, and would be a high anesthetic and surgical risk for dying; furthermore, even if he survives, he is likely to be left with significant long-term disabilities. Many healthcare providers would consider that another surgery may harm Adrian more than it may benefit him.

2. Parents are different: A need for personalized care

These 3 stories are not rare in modern neonatal intensive care units (NICUs). Parents are unprepared for these situations and each react differently in these difficult moments. Some parents want a lot of scientific information; others do not find it helpful.[1] Parents interpret and evaluate information in the context of their own experience and of their baby's condition. Parents decide with their brains, assimilating data and information, but also with their hearts, handling their emotions and feelings. A rigid "checkbox menu" of all the possible information to uniformly transmit to parents is suggested by some authors[2,3]; but this approach ignores individual differences, which should be avoided. We will explore how to personalize and individualize communication with families. Each step of the acronym **SOBPIE** is described in Figure 1.

3. Communications with parents of neonates with potentially life threatening conditions: the SOBPIE acronym

3.1. *What is the Situation, and how should communication about life-sustaining intervention take place with the family?*

Survival after intensive care and life-sustaining intervention can be either with or without disability; if death occurs it may be early or after several weeks in the NICU. In some cases such as the example of Coralie, a baby quickly deteriorates and parents have to rapidly be informed that their baby is dying. In other cases, when babies deteriorate gradually, death may not be imminent. Whenever there is a critical situation in a neonatal patient, healthcare providers should ask themselves whether there should be discussions about the extent of life-sustaining interventions or if communication with parents should occur about the meaning of this serious deterioration. Sometimes, these conversations occur too late in the hospital course of the dying infant.[4] In cases such as that of Adrian, the healthcare personnel may encounter emotional difficulties to speak about life and death, and hence may decide to send the patient for a third surgery or treat a third sepsis. Healthcare professionals must have the moral courage to speak about death in these situations.

3.2. *Opinions and options: What are the alternatives? What are my biases?*

In industrialized countries, the majority of neonatal deaths now occur in neonatal intensive care units (NICUs), and the majority of these deaths follow a decision to withhold or withdraw life-supporting interventions.[5,6] The opinions, attitudes, and biases of caregivers influence the way patients die and contribute to variations of practice and health outcomes for critically ill neonates.[6,7] Consider, for example, the cases described. In some units, Jessie would always be admitted to the NICU and in others, rarely or never.[7–9] In some units, Adrian's parents would be informed about the surgery and either be encouraged to accept or refuse it, while in other units parents may only be informed that Adrian was dying, or that he would undergo an emergency surgical

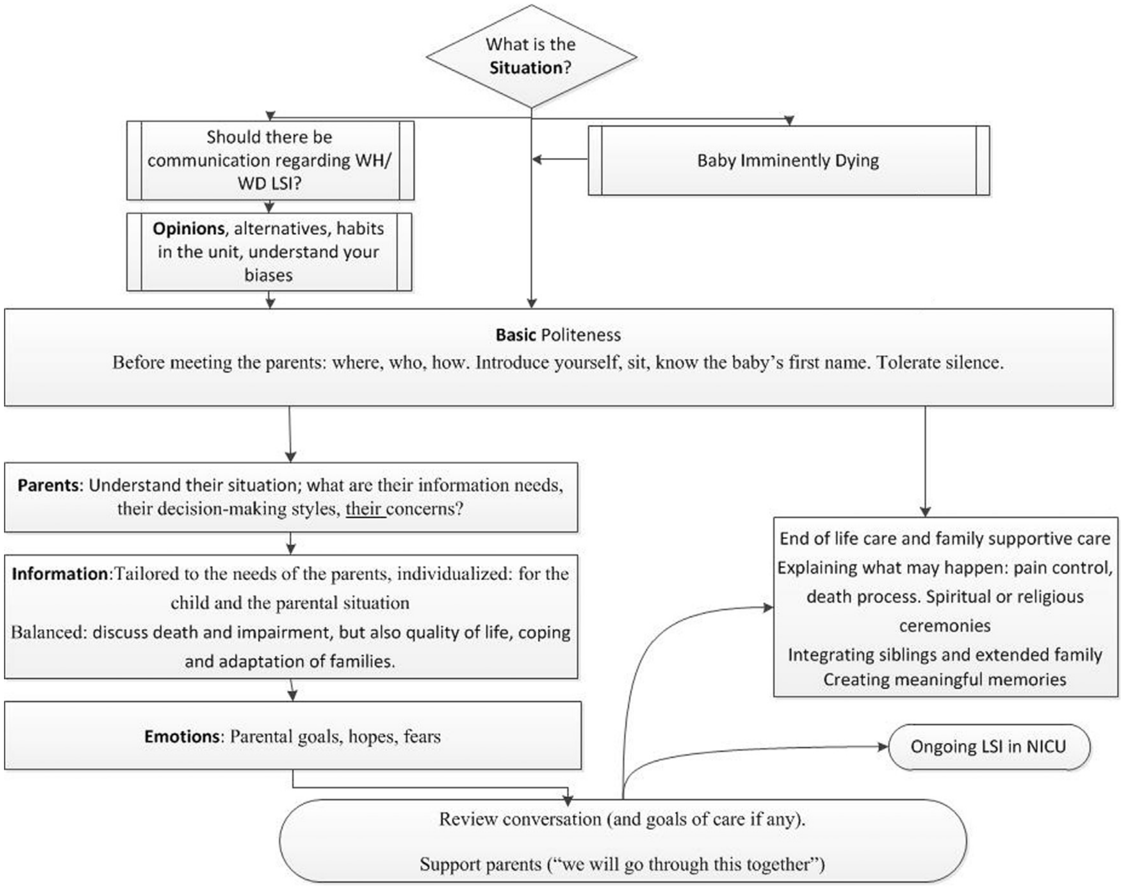


Fig. 1 – Communication with parents of neonates with potentially life threatening conditions (SOBPIE mnemonic). Abbreviations: CPR, cardiopulmonary resuscitation; LSI, life-sustaining interventions; QOL, quality of life; WD, withdraw; WH, withhold.

procedure. In contrast, Coralie is imminently dying. There are no "life-or-death decisions" to make, but the choices still exist regarding *how* she will die. Coralie can die on the respirator, after having had cardiopulmonary resuscitation, or in her parents' arms, after all the tubes, monitor leads, and tapes are removed.[5,6] We have demonstrated that the outcome for the cases described varies across different NICUs: babies die differently in different NICUs.[5–7] In some NICUs, the healthcare professionals may approach these cases in a relatively uniform manner, developing "habits" or patterns of thought in which they approach particular situations, creating an ethical microcosm.[5,6] Parents make decisions based in part on the information with which the healthcare professionals provide them, and on the manner in which they are informed. Their decisions affect institutional statistics, which in turn, affect the information provided to other parents in the future. It is therefore imperative that providers acknowledge their personal and institutional biases.

A useful method to classify and compare death and dying in the delivery room with NICU utilizes strict definitions of physiology and life-sustaining interventions (Table 1).[5,6] Uniform classification of death provides the ability to be transparent about the values guiding these decisions.

3.3. *Basic human interactions*

There is little empirical evidence on how to improve communications with parents regarding withholding and withdrawing life-sustaining interventions in the NICU. Most healthcare professionals believe that they interact with parents in an empathetic manner, but sometimes, this is not obvious to the families. Often, it is not *what* the doctor says, but *how* it is said.[10] This simple list of suggestions can ensure good, basic human interactions.

- The nurse taking care of the baby should be aware that a difficult conversation will occur with the parents and should be invited to be present for the conversation. This may also apply to other significant healthcare professionals.
- Limit the number of healthcare professionals during difficult conversations or while attending complicated deliveries.
- Make sure you do not get interrupted: ask a colleague to cover your routine duties, avoid bringing your pager and other electronic devices during the counseling session.
- Language matters: a baby is not a "23-weeker" or "a difficult case of NEC." If the parents have given the baby a name, please refer to the infant by his/her name.
- Choose a convenient place suitable for parents while conducting difficult conversations.

Table 1 – Categorizations of death. (adapted from Verhagen et al.[5])

	WH/WD LSI	Stable physiology with LSI
WH NICU admission	Yes	NA
With CPR	No	No
On the respirator without CPR	Yes WH CPR; not LSI	No
WH/WD because death imminent	Yes	No
WH/WD because of QOL	Yes	Yes

Abbreviations: CPR, cardiopulmonary resuscitation; LSI, life-sustaining interventions; QOL, quality of life; WD, withdraw; WH, withhold.

- If the parents want another significant support person to be present, wait for that person to arrive, if time permits.
- Introduce yourself to the parents.
- Explain your role in the team caring for their baby, and why you are there.
- Sit down during difficult conversations.
- Tolerate silence.

Although the above list may appear obvious and patronizing to many healthcare providers, a decent atmosphere for such basic human interactions ought not to be forgotten.[11] Parents are particularly and naturally sensitive about the discussions related to withholding or withdrawing life-sustaining interventions for their child. Many parents of preterm infants feel guilty and question what they could have done to protect their baby or to prevent these harms from occurring. Acknowledging that they are good parents, and that there is nothing they could have done to prevent prematurity or its various complications can be very valuable to them.

3.4. *Parents: What is their story, their concerns, and their needs?*

Parents have different perspectives and informational needs. Healthcare professionals have to be sensitive to the needs of each set of parents. They should consider the needs of the parents rather than that of their own preconceived notion about what is important and how the information has to be provided. The following outline can help personalize communication:

For antenatal consultations

"Do you have a name?"

- Jessie's parents may have different answers to this question:
    - "All first daughters are called Jessica in our family. But we are unsure about the name because we were told she's going to die."
    - "We knew her name was Jessie, as soon as we saw the positive pregnancy test."
    - "This is a stupid question and it is not relevant."
    - "Should we give her a name if she dies?"

Many parents have a name before birth and appreciate this gesture. When it is the case, they are making a decision for Jessie, not for "a 23-week 2/7 fetus."

For all parents

- "Tell me about Jessie/Adrian/Coralie," "What do you understand about the situation?"

The parents' answers to such questions will help to individualize the ongoing communication. Answers to such a question may be very different from one parent to another. Listening to the answers often helps healthcare professionals to examine how much parents understand about the medical situation and their value system:

- "We do not have a choice, we want to give Jessie a chance."
- "You want to convince us to resuscitate Jessie; we don't want to listen to you."
- "Do you think Adrian is tired?"
- "Adrian won't die; he is a fighter."
- "We hope the super antibiotics will work for Coralie."

"What concerns you the most?", "What are your hopes for your child?", and "What are your goals for your child?"

- Answers to these questions will vary and may surprise us:
    - "I am scared my wife will seize, she is sick. In a way, if Jessie comes out soon, my wife will no longer be at risk."
    - "I do not want Adrian to die, not after all he went through."
    - "I do not want to have any regrets, to feel I have abandoned my child. I want to be able to live with myself."
    - "I am concerned about the pain Jessie may have."
    - "I hope Jessie will have a good quality of life."
    - "What will happen to my couple, my other children, my family?"

Sometimes, one parent's biggest concern may be that "she will be handicapped" while the other will answer that "she will die." These answers may help couples understand each other's perspectives.

- "Is there something you think you cannot deal with?" or "What are your fears?"
  Some parents cannot imagine being the parents of a dead child; others cannot imagine how they would feel to be the parents of a disabled child. Some women cannot imagine being abandoned by their partner after an unplanned pregnancy. These serious concerns need to be addressed.
- "What do you want to know? How can we help you?"
- "Some parents want to know all the numbers and statistics while others want the big picture, what kind of parent are 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?"

The last 4 questions help to assess parental decision-making style and their information needs, which allow personalizing the remainder of the discussion.

One of the most valued principles in North American ethics is autonomy. The parents of Jessie, Coralie, and Adrian may not feel autonomous. They may not want to decide alone for their child. Many ethicists writing from a feminist viewpoint have pointed out that the autonomy principle is flawed.[12] Parents and mothers have relationships, other children, spouses, and communities. Important decisions affect these relationships, and are thus rarely taken in a purely individualistic, autonomous fashion.

Shared decision making for difficult decisions is a valuable alternative to patient autonomy,[13,14] but again there is no one model of shared decision making, it is a continuum,[13] where the parents are on that continuum needs to be addressed. If Adrian's parents ask the physicians to decide whether to take him to surgery, we think they should have the moral courage to give the parents an opinion. In this case, we would recommend a multidisciplinary meeting with healthcare professionals involved in his care. The meeting may not come to a consensus, but rather a moral compromise. For example, Adrian's parents may be told that the majority of healthcare professionals advised against the surgery, and a few did not, but that they all agreed that if there was a significant portion of the remaining intestine that would need to be removed, they would advise to close without further resection.

3.5. *Information: Giving parents personalized and balanced information*

The American Academy of Pediatrics recommends that, "When considering non-initiation of resuscitation for an infant, established ethical principles require that the parents be fully informed about their infant's prognosis and care options."[15,16] The neonatologist should also try to confirm that parents understand the information provided before they make a decision. Does every possible risk, and all the data regarding the long-term outcomes need to be discussed? Recent research in this domain focuses mainly on how to transfer information to parents in order for them to have access to all the information on which to base their decision. Research should also be oriented toward examining how to personalize information rather than how to develop uniform "neutral" tools.

We need to investigate how best to describe proportional outcomes, which is the majority of the information that we try to transmit. Communicating information about proportional outcomes has been extensively investigated,[17] for example, many individuals do not understand percentages. Tools to inform patients of the risks of different treatment alternatives, developed mainly for adults with cancer, may improve the understanding of patients,[18] but how the information is presented affects the choices they make. Patients will often choose a procedure when the risk of death is described as being 24 out of 100 over an otherwise identical procedure with a risk described as being 120 out of 1000,[19] because 120 is a larger number. It is likely that this phenomenon would also apply to the choices of parents for withholding and withdrawing life-sustaining interventions. Presenting a list of complications of an intervention starting with the rarest and ending with the most common is more likely to lead to a choice against having the intervention than presenting the same list in a reverse order. Presenting the worst outcome at the beginning of a list, compared to placing it at the end[20] also affects the choices that parents make. The manner in which the information is framed influences decision making.[21] One study depicted a hypothetical vignette of a threatened delivery of an extremely preterm infant with prognostic outcome information framed as either survival free of disability (positive frame) or risk of dying and disability (negative frame) with exactly the same proportions of outcomes.[21] In the positive frame, more respondents chose interventions.

The "ethos" of the hospital may also influence decision making. In some hospitals, healthcare professionals may be more positive about interventions for babies like Jessie. A positive attitude may translate in framing differences during important conversations between physicians and parents. It may also extend to day-to-day care, such as the body language of nurses and other healthcare providers who take care of women on bed rest. Despite these limitations, informing parents is important and communications about withholding and withdrawing life-sustaining interventions are essential. The responses to the questions above will help healthcare professionals know how to personalize the information given to parents.

A current research focus in neonatology concerns decision aids (diagrams, pictograms, written information, pictures, etc.).[3,22] In some decision aids, a picture of a wheelchair is used to represent disability, when in reality only a small minority of surviving disabled preterm infants need a wheelchair, or state that babies die when "nothing is done."[22] Discussing doing "nothing" is misleading and might be negatively perceived by parents. The provision of good palliative care is not "nothing."[23] We have to stay humble and keep in mind that, despite our attempts to be neutral, we will be biased. Healthcare professionals should know these important concepts. In fact, many parents may want us to be biased and provide a recommendation, to personalize the information.

3.6. *Emotions: Addressing relational aspects of decision making*

3.6.1. *Emotions and decision making*

Recognition of the parents' love for their baby and expressing to them the importance of their love in their baby's life can be very valuable for parents to hear (for example telling parents: "The most important thing in Adrian's life is that he has parents who love him"). When parents' decisions do not appear to be in their baby's best interest, we tend to worry that they are making an emotional decision rather than a rational one. Knowledge and intelligence do not counter powerful emotions. In fact, most big decisions in life are not purely rational: which partner to choose, whether to have children, where to live, etc.[24] Parents not only make decisions with their heads, but also with their hearts: love, guilt, regret, and tolerance of uncertainty will affect their decision. Should emotions be seen as an undesirable interference with the rational processes that ought to guide decisions? Or, are emotions the highest manifestation of human response to an overwhelmingly stressful situation? When faced with the difficult task of judging probabilities and making decisions, people use a number of strategies, called heuristics. Decision making is powerfully influenced by the heuristics that parents use,[25] rather than by rationally balancing all the possible risks (Table 2).[26–29] The traditional approach of informed consent may be irrational in its emphasis on rationality.[30] Considerable research gaps exist in how to recognize and deal with emotions (Table 3).

3.6.2. *Coping of families, adaptation, and resilience*

When parents of ex-preterm infants were asked how communications in the delivery room could be improved,[3] they spoke about many issues: factors affecting processing ability, how to be a parent in the NICU, communication of information to make decisions, framing of information, trust, factors affecting coping ability and perceptions, and uncertainty of outcomes. Another study showed that parents' decisions were not affected by physicians' predictions regarding the infant's possibility of survival or disability.[31]

When engaging in discussions about withholding or withdrawal of life-sustaining interventions, physicians often limit the discussion to 3 possibilities: survival without disability, survival with disability, or death. However, for parents, the outcomes are more complex. Parents often assess their ability to cope with these situations as individuals, couples, and families. Any decision will have lifelong consequences. Parents often ask "Will she have a good life?", "Will he be happy?", and "Will our family be happy?" Describing the proportions of infants who die or are impaired does not answer these important questions. Parents often want the meaning behind the numbers. For Jessie, guidelines state that we should give an exhaustive list of all adverse outcomes preterm infants may have, but not a list of what they *can* do, nor evidence related to their quality of life and that of their families.[32] We do not speak about how parents are resilient, adapt, and may undergo a positive transformation in the process both as individuals and as a couple or family. The NICU (or disability) transforms families, and not always for the worse.[11,33–35]

Parents are more positive about survival with disability than are healthcare professionals. Parents are also generally more tolerant of disabilities than are healthcare professionals,[36] they are more likely to think that death is worse than very severe disability.[37] Parents of ex-preterm infants routinely judge the quality of life of their children higher than do healthcare professionals.[38–40]

Many healthcare providers believe that when preterm infants survive with disability, this causes harm to couples, to individual parents, to siblings, and to careers.[11] However, empirical data do not support these opinions. Investigations on how individuals anticipate, adapt, and cope with significant neurological or physical disability are numerous.[39,41,42] After an important health problem causing permanent limitations, patients generally have a substantial decrease in quality of life, which returns to baseline in about 24 months. Not all patients return to their baseline "hedonistic state," but most do. Factors that influence resilience and coping are as follows: (1) if the condition is amenable to change; (2) intrinsic factors—the outlook on life, the impression of control over the situation, and the level of education; (3) social support (social or religious community, relationships, and couple/partner) and socioeconomic status; and (4) society—healthcare system, education system, and work environment[43] (Fig. 2). Studies of the impact of preterm infants or disabled infants on families[44,45] have come to similar conclusions. There is a substantial increase in depression, anxiety, and financial stresses after the birth of a preterm infant[46]; these generally decrease over time. On the other hand, there is greater cohesion in the family (bonding of siblings), less conflict than in typical families, and no

Table 2 – Common cognitive features (Heuristics) that influence decision making.

Cognitive bias	How this may influence communications between healthcare providers and parents of critically ill neonates
Anchoring effect: tendency to rely on the first piece of information received (the anchor). This piece of information is used to make subsequent judgements	Speaking about risks before benefits may influence parents
Focusing effect: placing too much importance on one aspect of the situation which falsifies the prediction of a future outcome. People often predict happiness on conventional measures of achievement (income) rather than on everyday routine	Speaking about all possible disabilities Jessie may have for a lengthy period; and not speaking about Jessie's likely abilities and how to promote resilience, may influence parents
Availability effect: estimation of the probability of an event is associated with vivid memories of similar events happening (which strongly influences the estimation)	Adrian's parents may remember the 3 last times healthcare providers told them their son was probably going to die and he did not. They may then overestimate the probability of recovery
Effective forecasting: how outcomes are framed as "good" and "bad" and how regret and future moods are anticipated as a consequence of a decision. Individuals often inaccurately predict future health states. Individuals are resilient and stronger than they predict	Parents may not be able to imagine living with a disabled child, or going through the death of their child
Loss aversion: the tendency to strongly prefer avoiding losses to acquiring gains (losing $100 causes more loss of satisfaction than the satisfaction gained from winning 100$)	How healthcare providers frame information as losses or gains will influence parents: "giving Adrian the best and most comfortable life he can have," "Avoiding death and losing Adrian"

Table 3 – The importance of emotions for decision making.

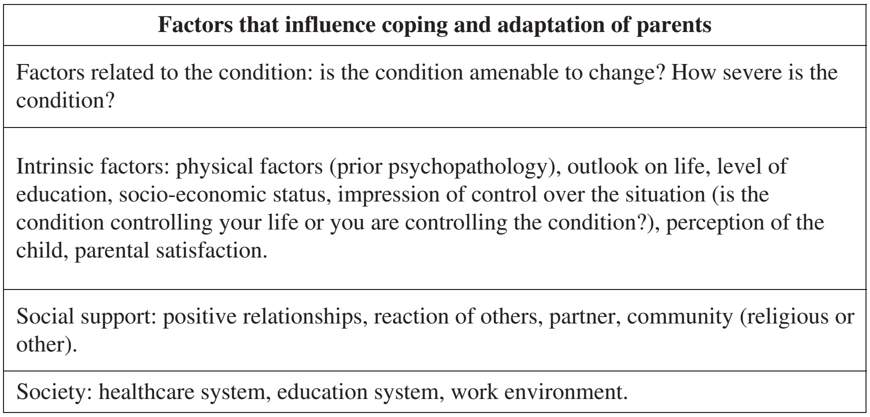
Emotions in decision making	Examples from the cases presented (Coralie, Adrian, and Jessie)
Knowledge: know that emotions and "non-rational" aspects of decision making are important for healthcare providers and parents	
Acknowledge: recognizing emotions when they occur	– For individual providers: Being able to pause and think "I feel angry about not asking for an X-ray earlier," "I feel so sad about this family," and "I feel stressed because I will communicate with this angry father." – For teams of healthcare providers: interdisciplinary "team" feedback before and/or after a difficult conversation will help team building and avoid that every HCP may feel isolated with his/her own emotions. – Parents: being able to recognize emotions in parents: "I can see you are very upset," "This seems to make you angry."
Manage emotions and construct something meaningful	– Sometimes, parents need to "digest" the information as they are overwhelmed by what we tell them. "I am sorry to bring bad news again. I can see how very upset this makes you feel, how much you love Adrian. Do you want us to come back later and leave you with your family?" – When parents cry, hold their heads, stare in space, seem in shock, sometimes, the best thing to do is wait. Tolerate silence, "be" there. When parents are very emotional and talk after a period of silence, often values, fears, and critical information are "released." – Acknowledge both parents. Sometimes, one parent speaks a lot while the other is silent. "We have been talking about Adrian for a while. You have been silent, is there something you may want to add?"

increase in divorce. The most important factor predicting good family functioning and resilience was social support.[44] The list of disabilities preterm infants face should be accompanied by balanced information about how families cope.

4. Words are important

We have recently investigated what words parents of children with life-limiting conditions found hurtful or offensive.[11] Parents said that the following terms should be avoided: "doing everything," "nothing we can do," "no hope," "lethal," "incompatible with life," "futile," "vegetable," "this child will cause harm to (you, your kids, your job, your finances, and your couple)," "you can have another one," and "we do not take these kids in our NICU." Parents particularly disliked healthcare professionals who did not call their child by name but by the condition or adverse events they have; those who labeled their child and did not personalize their care.[11] Some words ("24 weeker" and "Short gut") label children and carry a negative connotation.[47]

Parents adjust their hopes.[48] When parents decide to have a child, they hope for a healthy pregnancy and a strong child. The parents of babies like Coralie, Jessie, and Adrian will generally change their hopes when their baby is sick. They hope their child will not have disabilities. They may hope their child simply survives, or that they can at least take their



Factors that influence coping and adaptation of parents
Factors related to the condition: is the condition amenable to change? How severe is the condition?
Intrinsic factors: physical factors (prior psychopathology), outlook on life, level of education, socio-economic status, impression of control over the situation (is the condition controlling your life or you are controlling the condition?), perception of the child, parental satisfaction.
Social support: positive relationships, reaction of others, partner, community (religious or other).
Society: healthcare system, education system, work environment.

Fig. 2 – Factors that influence coping and adaptation of parents.

child home. For Coralie's parents, there is still hope that they can be there for her; that they can live without regret and remorse; and that they can heal after the death of their child.

5. When the child is imminently dying

When a child is dying and cannot be cured, there is still "something we can do." We can guarantee Coralie's parents we will do everything in our power so that Coralie dies without pain. We will support them to plan the death of their child. When babies like Coralie reach the end of their lives, it is important to not give unrealistic hopes to parents, such as that the third super antibiotic may work. This wastes precious moments Coralie's parents may want to share engaging in moments that will no longer be available later.

Exploring parents' needs at the end of life is important. Spiritual or religious ceremonies that are meaningful to parents are valuable. Some parents do not want their child to die in the palliative care room. Parents of one child who died in our unit wanted her to die outside (despite the cold), for her soul to rise. Social support and family members should be offered to parents. Parents may be afraid to integrate siblings when their baby is dying, but we can generally help them be a family for a little while. A family picture can be very valuable when the siblings grow up. Integrating siblings can create valuable memories for parents.

Healthcare providers have experienced many deaths. They have developed routines: the "special room," the quiet moves, the memory box to fill with pieces of hair and footprints, the ritual with the final physical exam certifying the baby's death. When a decision to withdraw life-sustaining interventions is made, healthcare providers have a critical role and opportunity to help families heal. Parents do not have experience in this matter; they usually do not get a second chance to improve their skills. The decisions parents make for their baby and every detail of the events surrounding their child's death will likely become a permanent memory. As families struggle to heal and move on with their lives, they may question the decision they made. When we truly individualize and personalize our approach, we will contribute to the long-term well-being of the family. It is our obligation and privilege to serve our patients and families in this way.

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