

Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics

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“I did not want my baby to suffer, nor to run the risk of having cerebral palsy”. Clinicians working in neonatology have all heard about parents who say that they would not have considered aggressive resuscitation if someone had explained to them the ‘truth’ about the risks to their premature infant’s long-term outcome. These parents may well be saying that they were not satisfied with their participation in the determination of their infant’s ‘best interest’.

The newborn’s best interest has always been central to decision making, but there is no single, unequivocal definition of the ‘best interest’ of a seriously compromised newborn. Traditionally, in justifying ethically challenging decisions, neonatologists often quote the Principles of Bioethics, which are commonly promoted in medical literature and medical education but often limited to four main principles (1). These four principles include: beneficence, or concern for well-being; nonmaleficence, or “do no harm”; autonomy, or respect for the right to make one’s own decisions and, in the context of neonatology, the respect for parental decision-making authority; and justice as fairness, or equals ought to be treated equitably (2). The majority of neonatologists believe that the determination of the best interest of the infant is guided by beneficence and nonmaleficence, which is based on medical data regarding probabilities of survival and morbidities (3).

Beyond the purview of such evidence-based rationale is the often-overlooked fact that parents and neonatologists each have their own personal experience, value system and interpretation of the medical data that shape their own moral judgments regarding what is in the best interest of the infant (4). They also do not have equal positions of power in this context. As demonstrated by Anspach (5), parents faced with “the knowledgeable physician’s” strong opinion regarding the medical best interest of their newborn may not share their thoughts and worries, but rather feel helpless, unheard, fearful and unsupported. Such parental reactions could, in turn, cause the medical team to misinterpret the apparently reserved or distant parents as not wishing to participate (5,6). As often happens in seemingly conflictual situations, rather than true dialogue, assumptions are made about the intent of the other party rather than exploring each party’s interpretation of the facts and the resulting fears, desires and feelings that are elicited (7). The lack of meaningful dialogue may result in a loss of the parents’ opportunity to participate in these important decisions.

Seeking a voice for parents and families, and ethically justifiable decisions for infants, Helen Harrison wrote a seminal article about family-centred care in neonatology (8). Since its publication in 1993, neonatal intensive care units across North America have gradually introduced clinical practices in accordance with

family-centred care principles, and shared decision making is now being promoted by North American professional societies (9,10). Nevertheless, paternalistic behaviour remained strongly anchored within the neonatologist community, as Bergeron (6) found in her 2008 study of the current Canadian Paediatric Society (CPS) position statement, ‘Treatment decisions regarding infants, children and adolescents’, and of research on decision making in the neonatal intensive care unit. She concluded that the ‘shared’ component of decision making as well as consent from parents are sought only when the medical team considers that there is sufficient uncertainty in the outcomes of infants based on medical facts. When medical data support a certain treatment plan, from intensive to palliative care, the circumstances, justification and details of the plan, as contained in ‘gestational age-based neonatal guidelines’, are put into action by the neonatologist, purportedly in the best interest of the newborn (6).

Although clinical practices are evolving toward shared decision making, Haward (3) found in 2011 that a significant proportion of neonatologists still believe they provide the ‘best’ answers in the quest for the best interest of sick infants, not recognizing the fact that the interpretation of research data predicting prognosis may vary even among themselves. The recommendation, albeit weak, of the latest CPS position statement concerning extremely preterm birth (9) (that “active treatment is appropriate except when there are significant additional risk factors” for most infants of 25 weeks’ gestational age) could still adversely influence the neonatologist’s attitudes and communication with parents. Our own recent qualitative study observed a resident presenting only the full-care option to parents of a baby at risk of being born at 26 weeks’ gestational age. The resident believed that, according to the guidelines and the instruction of his supervisors regarding the infant’s best interest, parents had no other options than to agree to resuscitation (11). Neonatologists feeling bound to offer only therapies with curative intent, especially concerning infants of older gestational age, may share information with parents in such a way as to frame the message in positive terms regarding survival so that parents will be guided to choose resuscitation as being in the infant’s best interest, as the results of the Haward et al (12) study suggest. Such communication styles, restricting parents’ opportunity to participate in decision making, are in contradiction to shared decision making and family-centred care. The traditional Principles of Bioethics and the latest CPS position statement do not describe how to ethically communicate to assure that parents have the opportunity to participate to their satisfaction in the important decisions regarding the best interest of their infant.

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Accepted for publication March 15, 2014

TABLE 1
Factors and strategies to promote parents' participation

Factors	Strategies
Alternating 'expert' role (accept that everyone is morally equivalent)	Listen to parents and avoid interruption Ask 'open-ended' questions to parents: "What do you need to help you to understand the situation?" or "What is your understanding of the situation?" or "What did you discuss with the medical team previously?"
Sharing 'weighted' information	Disclose the limits, risks and benefits of treatment options Describe the limits of statistical information when looking at the outcome for premature infants
Offering options	Discuss treatment options including options that may not be recommended from a medical perspective: "Would you like to discuss options that I may not have mentioned?" or "Have you thought about another approach that you would like to discuss with me?" Offer treatment options based on the infant's expected or possible clinical progression: "In the case that your child does not respond to resuscitation manoeuvres, would you like to discuss limitations of care?"
Provide time to think	Mention that there is no need for an immediate answer or, if in an urgent situation, offer a few minutes for the parents to discuss alone Offer a follow-up visit
Trustful relationship	Make eye contact and engage in active listening Validate parents' emotions, reactions and thoughts: "I realize that it is hard for you to discuss this issue" or "What you think is very important to your baby's care?" Validate the decisions that were made in the past and build on them if needed: "What you have previously decided with the medical team is very appropriate, ..." Ask parents how they would like to be supported: "Is there anything that I can do to help you?"

Adapted from reference 11

The manner in which the 'best interest' of the very premature newborn is determined needs to keep time with the evolving importance of shared decision making and family-centred care (8,9,13). This evolution requires that the very concept of 'best interest', as well as the modalities to clinically determine it, be transformed to transcend the traditional basis in the Principles of Bioethics and the definition of ethical dilemmas as "conflicts between principles". Clinicians may also need to reflect on their own values regarding the legitimacy of parent participation as well as their way of communicating ethically with the parents for these important decisions.

In light of the evolution of clinical norms favouring shared decision making, communicative ethics, proposed by Jürgen Habermas, could be particularly useful and pertinent in describing the modalities to reach ethically justified shared decisions (14-16). According to communicative ethics, the treatment decision made by shared decision making cannot be separated from the communicational process used to reach it. Communicative ethics proposes rules to ensure the unfettered, open and honest participation of each actor in the decision-making process to reach a consensus. The rules include: to recognize and promote all actors' participation in the discussion; to recognize the differences among actors; and importantly, to accept that everyone is morally equivalent to one another. For example, in clinical practice, these rules are followed when a neonatologist says: "I am here to help you to better understand prematurity. My role is to explain the different types of care, and work with you so we can decide together on a care plan in the event that your baby is born in the next few days. I would like to help you to participate in the discussions by asking you how I can help you better understand the situation." Using such words as 'participate' and 'together' helps the parents to understand that their input is sought. Other practical strategies that promote parent participation in the decision-making process are described in Table 1 (11,14). All successive physicians involved in the patient's care could also use these strategies to assure the continuity of care and the development of the physician-patient relationship.

Because the decision comes from the group through ethically structured communication, no one opinion takes priority in

reaching a mutual understanding of the situation and agreement on a course of action. Even in nonideal situations in which agreement appears to be intractable because of participants' opposing positions on the definition of 'best interest' of the infant, a process of open discussion is proposed (14,17). By reviewing and understanding one another's perspective, concerns, roles and duties, an agreement acceptable to all may be achieved – perhaps midway between participants' various positions.

Such 'ethical communication' leading to the building of consensus regarding the best interest of the infant in neonatal intensive care is consistent with shared decision making and family-centred care. Communicative ethics offers concrete lines of action for neonatologists to evolve from a paternalistic "doctor knows best" stance applying his own interpretation of the bio-ethical principles of beneficence and nonmaleficence, to that of a facilitator of open and honest communication between all parties, thereby assuring parents the opportunity to participate to their satisfaction in these decisions. The result is an ethically justifiable definition of the best interest of the newborn.

ACKNOWLEDGEMENTS: The authors are grateful to Samantha Somers and Margaret Sears for their review and editorial assistance.

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