

REVIEW ARTICLES

SHARED DECISIONS IN NEONATAL INTENSIVE CARE – BIOETHICAL APPROACH

DECISÕES PARTILHADAS EM CUIDADOS INTENSIVOS NEONATAIS – ABORDAGEM BIOÉTICA

Carmen Carvalho¹, Ana Cristina Freitas¹, Liliana Pinho¹, Ana Novo¹

ABSTRACT

Technological and therapeutic advances in neonatal intensive care have led to a decrease in neonatal morbidity and mortality in recent decades. Along with technical and scientific expertise, it is important to provide a holistic and comprehensive approach to the care of the newborn and family. The purpose of this review is to describe and analyze strategies to improve decision-making within a shared process between health professionals and caregivers at neonatal intensive care setting.

The decision-making process is not linear or immutable over time and there is no consensus on the definition of ‘shared decision’. More unanimous is the role of communication as a therapeutic relationship pillar. Professional ethics, bioethics, and narrative medicine should be used as tools to address the vulnerabilities of families and professionals and as a way to consolidate and structure the human relational dimension intrinsic to medical practice.

Keywords: bioethics; decision-making; narrative medicine; neonatal intensive care; newborn

RESUMO

Os avanços tecnológicos e terapêuticos em cuidados intensivos neonatais levaram a uma diminuição da morbimortalidade neonatal nas últimas décadas. A par do conhecimento técnico e científico, é importante concentrar o cuidado do recém-nascido e sua família numa abordagem holística e abrangente. O objetivo desta revisão é descrever e analisar estratégias para melhorar a tomada de decisão através de um processo partilhado entre profissionais de saúde e cuidadores no contexto dos cuidados intensivos neonatais. O processo de tomada de decisão não é linear ou imutável no tempo e ainda não existe consenso na definição de ‘decisão partilhada’. Mais consensual é o papel da comunicação enquanto pilar da relação terapêutica. A ética profissional, bioética e medicina narrativa devem ser usadas como ferramentas para lidar com as vulnerabilidades de famílias e profissionais e como forma de consolidar e estruturar a dimensão relacional humana inerente à prática médica.

Palavras-chave: bioética; tomada de decisão; medicina narrativa; cuidados intensivos neonatais; recém-nascido

1. Neonatal Intensive Care Unit, Centro Materno-Infantil do Norte, Centro Hospitalar Universitário do Porto. 4099-001 Porto, Portugal. carmencarvalho.bioetica@gmail.com; anacrisfrei@gmail.com; liliana.pinho@gmail.com; anocas.novo@gmail.com

INTRODUCTION

Extraordinary progress has been achieved in neonatal intensive care in recent decades, mainly due to huge technological and therapeutic advances, with consequent neonatal morbidity and mortality reduction. All this progress requires adaptation, specific training, technical skills, permanent knowledge update, protocol adjustments, and use of clinical guidelines and standards of care based on international meta-analyses and evidence-based medicine. Along with all this technical and scientific progress, it is particularly relevant to integrate and focus the care on the newborn and the family. Efforts must be made towards a more holistic and comprehensive care, greater space humanization, and improved relationship and communication between professionals and families, addressing the various (bio)ethical questions involved.

Hospitalization of a newborn in a neonatal intensive care unit (NICU) constitutes a disruptive life event with great impact on family health.¹ During this period, parents need to assume new and unknown roles under adverse conditions, such as physical separation from their baby and constraints in contact opportunities, either due to the clinical severity of the baby's condition or to maternal illness. Moreover, parents fear for the present and future life of their child, while also experiencing feelings of guilt, hope, love, and happiness.²⁻⁴

In Neonatology, there is often uncertainty regarding prognosis, time urgency, and two instead of one patient (the critically ill infant and the mother).⁵ These circumstances raise ethical issues mainly related to withdrawing and withholding treatments during the neonatologist clinical practice. Not less relevant are health professionals' doubts, uncertainties, and emotions when exercising a highly demanding clinical activity, not only from a technical-scientific, but also emotional, relational, and psycho-social perspective.⁵⁻⁸

According to Rita Charon, skills conferred by narrative medicine, through reading, reflective writing, and decoding writing experiences, enable professionals to become more powerful readers, conscientious and attentive to their patients' narratives. These skills allow doctors to recognize suffering and to interpret and be sensitized by the story of those who suffer and people who care for them.^{9,10}

OBJECTIVES

The purpose of this article is to describe and analyze strategies for improving the process of shared decisions between doctors and parents in NICU.

DEVELOPMENT

Throughout the history of medicine, physicians have taken responsibility for their patient decisions. Over the last few decades, studies have shown that patients differ in their willingness to take

control of the decision and many prefer to delegate it to doctors. Decision-making in Neonatology should follow the same general principles applied to patients who cannot make decisions for themselves. Changes have occurred in Neonatology decision-making since the 1960s, when some decisions were scrutinized by government intervention and courts, as exemplified by the cases of Hopkins Baby, Baby Doe, or Baby K, among others.^{8,11,12}

Nowadays, neonatologists, nurses, and parents rely on moral cumulative past experiences. Decision-making is more transparent and shared among clinicians and parents, despite its potential difficulties, especially when cultural beliefs collide. Bioethical principles help to maintain moral insight and balance in difficult decisions.^{7,12} Respect for autonomy as a bioethical principle has provided the foundation for a different relationship between physicians and patients, moving from a paternalistic approach that denied patients the opportunity to take part in healthcare decisions to a dialogical one that allows for shared decision-making. This approach aligns with the concept of ethical deliberation by Diego Gracia.¹³ "A procedure that aims to reach wise and prudent decisions, obliging us to take others into account, respecting their different beliefs and values, and prompting them to give reasons for their own points of view".

Several ethical guidelines recognize the importance of parental involvement in decision-making. Still, many studies based on parents' and professionals' opinions show that it is far from being unanimous. Some professionals prefer to exclude parents from explicit participation to protect them from potential guilt feelings. Others believe parents should make the final decisions. On the other hand, some parents claim that they have to live with the consequences of decisions taken unilaterally by professionals. Most of the times, parents do not want to be excluded. Instead, due to the difficulties in decision-making, they often want to participate but not decide. Nevertheless, the type of parental involvement is influenced by their own cultural setting.¹⁴⁻¹⁶

A mother of twins suffering from twin anemia-polycythemia syndrome (TAPS) wrote: "After a routine ultrasound, when there was nothing to predict it, doctors told me that an urgent C-section had to be done. It was the worst nightmare of my life, I did not understand the reason for that decision, I did not have any pain, I did not feel bad and I did not have any signs of childbirth. I was told that one of the twins was in distress and at life risk (...) I did not know if M. would survive. The names of the exams were complicate and difficult to understand (...) sometimes doctors used a weird language. Other parents helped me understand what they were talking about."¹⁷

"I froze my heart and I promised that it would only restart beating when I would be able to take my baby home ... Every day I arrived at the hospital and my legs trembled. News rarely were cheerful, he had several complications due to extreme prematurity. Sometimes the silence of the doctors almost killed me. Nurses told me happy stories of little heroes and I got stronger." - narrative of a 25-week preterm mother.¹⁷

These narratives emphasize the importance of recognizing

the family's understanding level and the relevance of good communication.

The American Academy of Paediatrics (AAP) indicates three key factors of good communication: the quality and quantity of information provided; the interpersonal dimension (active listening and real interest in parent's feelings and concerns); and the bond between doctors and parents/children.¹⁸ In the neonatal area, communication is not linear (doctors and patients). Neonatologists care for the baby and a significant part of the communicative and relational work is directed at parents - this is known as the "neonatal triangle" (doctors, newborns, parents).¹⁹ Communication is therefore crucial to build a trusted relationship between parents and health professionals.²⁰ This is particularly relevant in the case of distressing news, since coping strategies can only be promoted if skillful communication takes place.²¹

The newborn's best interest has been central to decision-making. However, "best interest" definitions are ambiguous when it comes to seriously compromised newborns. In general, neonatologists are guided by bioethical principles: beneficence (do good), non-maleficence (do no harm), autonomy (respect for the right of own's decision or, in this context, respect for parental decision), and justice (treatment equity).^{7,22-24}

Each baby is unique, as each family is different and each course of life private, so there can be no absolute and rigid rules. However, to make good decisions, updated and correct data are required, as well as the ability to communicate it the best possible way. Some authors consider communication the most common "procedure" in medicine. Communication is the therapeutic relationship cornerstone, the basis of Ethics, and a physician's fiduciary obligation to patients and their families.²¹⁻²³

A 34-year-old vascular surgeon, mother of 30-week-preterm twins, wrote: "one Friday afternoon the doctors came and talked to me. I heard what they said and called my husband. I can't say what I felt at that moment. My little L. had multiple brain abscesses. My husband and I had no doubts that it would be preferable for her to die ... Well, I had some (...) for a moment I thought that if they could have been wrong ... I had a bit of hope (...) my brother, a psychiatrist, came to see the baby and the ultrasound. I was not able to do it. My doubts disappeared when my husband and my brother came to see me after seeing the cerebral ultrasound. I was afraid she would survive with cerebral palsy. We baptized my baby L. and I stayed with her all afternoon in my arms while the milk flowed through me. We all stayed together, me and my husband, the doctor, and the nurse (...) I was always calm, I was there for my baby, my little one. We went home after his death, it was already night. The shift was over, but no one left".¹⁷

Medical decisions regarding severely ill newborns affect caregivers in an intense and profound way. There are no simple answers to help guide doctors in the difficult decisions they must make, especially when family and medical staff disagree. Adopting the shared decision model will relieve parents from the full decision responsibility and

may encourage them to participate in the discussion.

There are several strategies to promote parental involvement: listening carefully (i.e., actively and intensely), using open-ended questions, sharing relevant information, giving parents time to think and reflect, and establishing a relationship of trust. The shared decision process involves at least two parties and bidirectional information. When the process is well conducted, it allows a balanced involvement of all parties, supporting both the family/baby and professionals.^{11,16}

Finding balance between the respect for parental autonomy and doctor's role and responsibility in the shared decision process requires insight, empathy, and enormous analytical and communication skills. This process has barriers and facilitators, which can be divided into knowledge, attitude, agreement, lack of expectations/hope, and behavior categories. Barriers include family characteristics, health system constrains (time, lack of medical care continuity, inadequate environmental conditions), inadequate relationships, linguistic barriers, lack of evidence to support the decision, biased attitudes, poor medical knowledge, and lack of applicability. The most common decision-making facilitators include caregivers' motivation, positive impact on the clinical process, and a correct patient prognosis definition.¹¹

This process generally implies tough decisions and should hence be done in a phased manner and led by the treating doctor, who has established a trusted relationship with the family.

Narrative medicine skills could help in shared decision-making by improving communication and understanding of parents' feelings, doubts, and uncertainties, empowering parents and also helping health professionals dealing with difficult situations and dilemmas.^{25,26}

Some practical aspects to consider include acknowledging the decision-making process, identifying key stakeholders, disclosing various therapeutic options in an unbiased way, recognizing the family's level of understanding and their expectations, identifying parties' priorities and preferences, and negotiating the "non-consensual issues" in a calm and sensitive way, scheduling follow-up or revisiting the decision until the end of the process.

Decision-making is a multifaceted process. Understanding risk information depends on relationships, trust, cognitive and affective balance, life experiences, subjective outcome interpretations, risk/uncertainty tolerance, and other personal factors. Doctors will need to learn new skills to help parents understand the choices they face, clarify their own values, and make good decisions.

CONCLUSIONS

The process of shared decision-making in Neonatology setting is not straightforward. The very own definition of 'shared decision' is not yet consensual. The deliberative process requires in-depth knowledge of bioethical issues, and therefore acquiring communication skills is vital. The vulnerability of those involved (newborns, parents/family,

and health professionals) demands commitment with professional ethics, bioethics, and narrative medicine, as a way of structuring and consolidating relational and human dimensions, inherent to a medical practice of excellence.

REFERENCES

- Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *J Clin Psychol Med Settings* 2010; 17:230–7. <https://doi.org/10.1007/s10880-010-9202-7>.
- Arzani A, Valizadeh L, Zamanzadeh V, Mohammadi E. Mothers' strategies in handling the prematurely born infant: a qualitative study. *Journal of Caring Sciences* 2015; 4:13–24. <https://doi.org/10.5681/jcs.2015.002>.
- Finlayson K, Dixon A, Smith C, Dykes F, Flacking R. Mothers' perceptions of family centred care in neonatal intensive care units. *Sex Reprod Healthc* 2014; 5:119–24. <https://doi.org/10.1016/j.srhc.2014.06.003>.
- Purdy I, Wadhvani R. Embracing bioethics in neonatal intensive care, part II: case histories in neonatal ethics. *Neonatal Netw* 2006; 25:43–53.
- Lantos J. Ethical problems in decision making in the neonatal ICU. *N Engl J Med* 2018; 379:1851–60. <https://doi.org/10.1056/NEJMra1801063>.
- Sauer P, Ethics Working Group of Confederation of European Specialists in Paediatrics (CESP). Ethical dilemmas in neonatology: recommendations of the ethics working group of the CESP (Confederation of European Specialists in Paediatrics). *Eur J Pediatr* 2001; 160:364–8.
- Bany-Mohammed F, Beals D. Neonatal Bioethics. In: Gomella T, editors. *Neonatology*. 7nd ed. New York: McGraw-Hill Education; 2013.
- Fanaroff J. Medical ethics in neonatal care. In: Martin R, Fanaroff A, Walsh M, editors. *Fanaroff and Martin's Neonatal-Perinatal Medicine: diseases of the fetus and infant*. 10nd ed. London: Elsevier Health Sciences; 2014.
- Charon R. *Narrative Medicine: Honoring the stories of illness*. Oxford: Oxford University Press; 2006.
- Charon R. The patient-physician relationship - A model for empathy, reflection, profession, and trust. *JAMA* 2001; 286:1897–902.
- Richard A, Levy S, Council on Children with Disabilities. Shared Decision-making and children with disabilities: pathways to consensus. *Pediatrics* 2017; 139:e20170956. <https://doi.org/10.1542/peds.2017-0956>.
- Meadow W, Lantos J. Ethics, data and policy in newborn intensive care. In: Gleason C, Devaskar S, editors. *Avery's diseases of the newborn*. 10nd ed. Philadelphia: Elsevier; 2018.
- Gracia D. Ethical case deliberation and decision making. *Medicine, Health Care, and Philosophy* 2003; 6:227–33. <https://doi.org/10.1023/A:1025969701538>.
- Hawley S, Morris A. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns* 2017; 100:18–24. <https://doi.org/10.1016/j.pec.2016.07.008>.
- Lee S, O'Brien K. Parents as primary caregivers in the neonatal intensive care unit. *CMAJ* 2014; 186:845–7. <https://doi.org/10.1503/cmaj.130818>.
- Weiss E, Barg F, Cook N, Black E, Joffe S. Parental decision-making preferences in neonatal intensive care. *J Pediatr* 2016; 179:36–41. <https://doi.org/10.1016/j.jpeds.2016.08.030>.
- Carvalho C, Vale A, Magalhães S. Communication and decision making in neonatal intensive care: why narrative medicine matters. In: Pope E, Brandão C, Rosário A, Costa A, editors. *Qualitative Research: practices and challenges*. Ludomedia; 2020. <https://doi.org/10.36367/ntqr.1.2020.104-121>.
- Levetown M. Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics* 2008; 121:e1441–60. <https://doi.org/10.1542/peds.2008-0565>.
- Zonza M. Narrative Based Medicine and Neonatology: an interpretative approach. *Journal of Pediatric and Neonatal Individualized Medicine* 2012; 1:49–52. <https://doi.org/10.7363/010114>.
- Wigert H, Dellenmark BM, Bry K. Parents' experiences of communication with neonatal intensive-care unit staff: An interview study. *BMC Pediatrics* 2014; 14:1–8. <https://doi.org/10.1186/s12887-014-0304-5>.
- Clarke-Pounder JP, Boss RD, Roter DL, Hutton N, Larson S, Donohue PK. Communication intervention in the neonatal intensive care unit: Can It backfire? *Journal of Palliative Medicine* 2015; 18:157–61. <https://doi.org/10.1089/jpm.2014.0037>.
- Daboval T, Shidler S. Ethical framework for shared decision making in NICU: Communicative ethics. *Ped Child Health* 2014; 19:302–4.
- Levetown M, American Academy of Pediatrics Committee on Bioethics. Communicating with children and families; from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008; 121:1441–1460. <https://doi.org/10.1542/peds.2008-0565>.
- Hester D. Interests and neonates: there is more to the story than we explicitly acknowledge. *Theoretical Medicine and Bioethics* 2007; 28:357–72.
- Kadivar M, Seyedfatemi N, Acbari N, Haghani H. The effect of narrative writing on maternal stress in neonatal intensive care settings. *J Maternal Fetal Neonatal Med* 2015; 28: 938–43. <https://doi.org/10.3109/14767058.2014.937699>.
- Donzelli G. Medical humanities and narrative medicine in perinatal care. *J Maternal Fetal Neonatal Med* 2015; 28: 1–2. <https://doi.org/10.3109/14767058.2014.900041>.

CORRESPONDENCE TO

Carmen Carvalho
Neonatal Intensive Care Unit
Centro Materno-Infantil do Norte
Centro Hospitalar Universitário do Porto
Largo da Maternidade de Júlio Dinis 45,
4050-651 Porto
Email: carmencarvalho.bioetica@gmail.com

Received for publication: 15.06.2020

Accepted in revised form: 19.01.2021