

EDITORIAL

Embracing Narrative Medicine in Neonatal Intensive Care Settings

A medicina narrativa em contexto de cuidados intensivos neonatais

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In recent decades, extraordinary advancements in neonatal intensive care have significantly reduced morbidity and mortality rates in neonates, ushering in a new era of enhanced care quality.⁽¹⁾ However, these technological and therapeutic progresses bring increased ethical complexities to decision-making, highlighting the critical need for parental involvement in these processes.⁽²⁾

As diagnostic capabilities improve and therapeutic options for rare and complex diseases expand, the ethical landscape of neonatal care becomes increasingly intricate. Healthcare professionals often face challenging decisions requiring a delicate balance between the benefits and risks of various interventions. In this context, active participation of parents in decision-making is essential.^(3,4) Parents offer a unique perspective, informed by their deep understanding of their child's needs and their own values and preferences, ensuring that decisions are made in the best interests of the child and family, aligning medical interventions with familial values.

In response to these ethical and relational challenges, narrative medicine has emerged as a crucial approach. Originating in the 1990s, narrative medicine emphasizes the importance of listening to and understanding patients' stories to enhance the quality of care. 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.⁽⁵⁻⁷⁾

Narrative medicine promotes changes in attitudes, behaviors, and culture, which are essential for effective communication. It is an interdisciplinary field focused on enhancing communication between healthcare providers and patients, demanding self-reflection skills beyond more communicative abilities.^(8,9)

In neonatal care, where patients cannot communicate their needs directly, the narratives of parents and healthcare professionals are

especially important. Despite the recognized importance of narrative medicine, its specific application in neonatal intensive care has not been extensively studied. However, understanding and utilizing these narratives can profoundly impact communication and decision-making processes.^(3,10)

The hospitalization of a newborn in a neonatal intensive care unit (NICU) constitutes a disruptive life event with a significant impact on family health. Parents of neonates in NICUs experience a wide range of emotions, from hope and joy to fear and despair.^(10,11) Their narratives offer invaluable insights into how their experiences influence interactions with healthcare providers and decision-making processes. These stories highlight the profound sense of responsibility parents feel for their child's well-being, shaping their preferences for certain treatments or interventions.

Parental narratives also reveal the emotional and psychological toll of having a critically ill neonate, emphasizing the need for clear, compassionate communication from healthcare providers. Understanding these narratives enables healthcare professionals to provide more empathetic and effective support, facilitating better decision-making and enhancing the overall care experience.

Healthcare professionals in NICUs also encounter significant emotional and ethical challenges. Their narratives often explore complex ethical dilemmas, such as balancing the potential benefits and risks of interventions or making decisions about end-of-life care. These stories highlight the moral distress that providers may experience when faced with difficult decisions that have profound implications for their patients and families.^(10,12) Moreover, healthcare professionals' narratives underscore the importance of teamwork and communication in neonatal care. Effective collaboration among medical staff is crucial for providing high-quality care and making informed decisions.

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The importance of practice-based evidence and narratives in informing clinical practice cannot be overstated. By systematically collecting and analyzing narratives, healthcare providers can gain valuable insights into the experiences and needs of parents and healthcare professionals. This knowledge can inform the development of policies and practices that promote ethical and person-centered care.⁽¹³⁾

To fully realize the potential of narrative medicine in neonatal intensive care, investing in training and education for healthcare professionals is imperative. Comprehensive programs in bioethics, medical ethics, and narrative medicine can provide the foundational knowledge and skills required to integrate narrative practices into everyday clinical work.^(2,14) These programs should emphasize the development of active listening skills, empathy, and the ability to engage meaningfully with the stories of patients and their families.

Healthcare institutions can benefit from creating spaces and opportunities for healthcare professionals to share their own narratives. Regular debriefing sessions, narrative workshops, and support groups can provide valuable forums for healthcare providers to reflect on their experiences, discuss ethical dilemmas, and seek peer support. These initiatives can help reduce moral distress, improve job satisfaction, and foster a culture of ethical reflection and compassion within NICUs.^(10,13)

In the digital age, technology offers innovative ways to capture and share narratives in neonatal intensive care. Digital storytelling platforms, video diaries, and online support communities can provide parents with new avenues to express their experiences and connect with others who share similar journeys. These digital tools can also serve as valuable resources for healthcare professionals, offering insights into the lived experiences of families and enhancing empathy and understanding.⁽¹⁵⁾

Electronic health records (EHRs) can be designed to include narrative components, allowing healthcare providers to document and access patient and family stories alongside clinical data.⁽¹⁶⁾ This integration of narrative and medical information can support more personalized and compassionate care, ensuring that the unique context of each family is considered in clinical decision-making.

The integration of narrative medicine into neonatal intensive care holds great promise for enhancing communication, decision-making, and ethical practice. Continued research and training in this area are essential to fully realize the potential of narrative medicine in improving the care of neonates and supporting their families and caregivers. As we advance technologically and therapeutically in neonatal intensive care, it is crucial to also enhance our communication and ethical decision-making skills. Embracing narrative medicine helps ensure that the voices of parents and healthcare professionals are heard, leading to better outcomes for neonates and holistic support for families.

By fostering a deeper understanding of the narratives within neonatal care, we can create a more compassionate, empathetic, and ethically grounded healthcare environment that truly meets the

needs of patients and their families.

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