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Improving diagnosis and neonate-centered care

Abstract

The 2024 World Patient Safety Day theme "*Improving diagnosis for patient safety*" raises the discussion about diagnosis improvement in healthcare. Considering the neonates' vulnerabilities, the consequences of diagnostic errors in neonatology, and the right to safe and quality care, this article discusses the need to improve diagnosis in neonatal care and how neonate-centered care can impact the proper diagnosis. Diagnostic errors are preventable and increase healthcare costs. For precise diagnosis, strict collaboration between health professionals, patients, and families is needed. Only by recognizing neonates as patients can we situate them in the center of care, engage with them, and perceive their clinical conditions, for accurate diagnosis.

Keywords: Diagnosis, neonatal care, patient safety, pediatric patients

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Introduction

"*Listen to your patient, he is telling you the diagnosis*". This famous quote from Sir William Osler, a physician who worked at the University of Pennsylvania, reinforces the art of listening during the clinical encounter and its importance in the diagnosis process. The announcement of the 2024 World Patient Safety Day theme "*Improving diagnosis for patient safety*" highlighted the relevance of a correct diagnosis for patient safety all over the world, and this is an objective of The Global Safety Action Plan 2021-2030.[1] It has been reported that diagnostic errors are under-recognized and under-reported, as there is a certain difficulty in measuring them, and can account for around 16% of preventable harm across the health systems.[2–4] Also, these errors are a result of cognitive and systemic factors, and not caused by "bad persons", requiring multifaceted interventions that include improvement in patient history and clinical examination, access to diagnostic tests, access to technology-based solutions, and the maturity to measure and learn from diagnostic errors. The Committee on Diagnostic Error in Health Care recognized the need to engage patients and families in healthcare and teamwork, to achieve a more appropriate diagnosis and better outcomes.[5–7] Diagnostic errors account for medical claims, suffering, poor prognosis, and elevated costs in healthcare, and it is estimated that it is likely that most people will experience at least one diagnostic error in their lifetime. Improving the diagnosis process is a moral, professional and public health imperative.[5] Most of the literature about diagnostic errors in neonatology refers to critical neonates, reporting a 6.2% frequency, and the most frequent associated factor was missing maternal history. In this scenario, maternal history plays an essential role in neonatal diagnosis, as maternal and neonatal diagnoses are interconnected.[8] It is well recognized that considering research in safety and quality of care, few studies are devoted to diagnostic errors.[9] The diagnostic process is complex, iterative, and dynamic, involving patients, families, and teams of health professionals. According to the Committee on Diagnostic Error in Health Care, errors in this process occur when there is a failure to establish an accurate and timely diagnosis or to communicate it to the patient.[3] The diagnosis must be communicated to the family in the neonatal scenario, but the decisions impact both the neonate and the family.

Neonates deserve quality and coordinated care, in a period of life when many preventable deaths occur worldwide.[9–12] As a unique patient, with body immaturity, fragility, and complete dependence on an adult, added to the cognitive immaturity that impairs verbal communication, the resulting patient has added vulnerability, which needs to be considered. Although studies have pointed out this vulnerability linked to prematurity and low birth weight, it is important to emphasize that the neonate is vulnerable at different levels, and this modulation depends on gestational age.[13] The current neonatal care model must consider these particularities to provide more efficient and empathetic care. There is a need to reframe neonatal care from an empathic perspective, putting the neonate in the center of care.[14] Neonates need to be protected, and they need a health surrogate to make decisions about their care considering their best interests. In 2024, the American Academy of Pediatrics published a document reinforcing that neonates have the same rights as every other individual.[15] Quality and safe care is a patient's right and the neonate deserve it, so we should improve it.[16] The dynamic and complex diagnosis process involves the patient, family, and health professionals in a co-constructed process.[5] There are particularities in the neonatal scenario. Most of all, the neonate cannot speak and verbally express his/her feelings so there is a demand to connect with him/her and interpret what is happening. Regarding all these particularities, improving diagnosis and reducing diagnostic errors is a worldwide challenge, especially in neonatology. Considering this scenario, this theoretical article aimed to discuss neonates' role as patients and the importance of patient-centered care in neonatology for a proper diagnosis. We adopt The Global Safety Action Plan 2021-2030,[1] the Convention on the Rights of the Child (CRC),[17] and Improving Diagnosis in Healthcare,[5] a document elaborated by the Committee on Diagnostic Error in Health Care, and literature regarding this issue. This article is structured into three parts: Why we need to improve diagnosis in neonatal care, Child-centered care, and Improving diagnosis through neonate-centered care.

Why we need to improve diagnosis in neonatal care

Diagnostic errors are missed opportunities and are understudied, especially in neonatology. Maybe this occurs because of the difficulty of measuring them. There is a combination of silence surrounding these errors, with repercussions for patients, families, health professionals, institutions, and the entire society. The frequency and impact of these errors are still unknown. Neonates are susceptible to diagnostic errors, and these have worse consequences when the neonate is critically ill.[18] The observation of safety incidents in a neonatal intensive care unit pointed out that diagnostic errors were the second most frequent, and represented a 10% frequency being mostly preventable events.[19] Delayed or incorrect diagnosis has been reported as the leading cause of the complaints involving neonatal care, with financial implications, harm to babies, and distress to parents. Factors implicated in clinician errors that resulted in complaints were lack of clinical and communication training, inadequate supervision of junior clinicians, lack of work culture and hierarchy, not listening to families' concerns, and system failure.[20] These results reinforce the need to strengthen health professionals' soft skills. The Global Safety Action Plan 2021-2030 highlights the burden of death and disability worldwide because of unsafe healthcare, especially in middle and low-income countries, estimating a social cost of patient harm around US$ 1 trillion to 2 trillion a year. Misdiagnosis is included in these estimates. Also, the document claims for patients' and families' engagement as partners of care.[1] But how do we engage neonates in their care? And do we engage their families the way they should be? Achieving safe care requires that patients be informed, involved, and treated as full partners in their care, and this can be achieved only if the neonate is positioned in the center of care with the family participating and communicating actively in the care process.

In 2005, the National Patient Safety Agency in the United Kingdom highlighted the risks of misplaced nasogastric tubes in neonates and the difficulties in diagnosing whether the tube is in the correct location. Most of all, they pointed out, after the death of a child, that the case was the "*tip of the iceberg*", as subsequently, other deaths were discovered. The root cause analysis identified many factors involved in these incidents and the importance that medical staff supports nursing staff when they raise concerns about this issue was emphasized.[21] This report brings the discussion about the need for strict collaboration between health professionals to ensure patient safety and the underreporting of those incidents. Diagnosis should be made in a co-constructing manner involving all the healthcare team, patients, and families. These results are aligned with some of the principles of team-based healthcare, suggested by the Committee on Diagnostic Error in Health Care, which recommends shared goals, clear roles, mutual trust, effective communication, measurable processes, and outcomes.[5] Unfortunately, teamwork in the diagnosis process in neonatology has been poorly studied. Recent technological advances have been acquired to improve healthcare. In neonatology, algorithms have been developed, through artificial intelligence, to detect clinical conditions in a fast way, and with accuracy. This occurred with neonatal jaundice, for example, with the development of point-of-care analysis.[22] The difficult recognition and diagnosis of this condition, especially borderline cases, was overcome by those technologies. Nonetheless, those technologies are operated by health professionals, requiring that they have cognitive and affective concerns with patients, and these attributes are operated on a clinical basis. Summarizing, there must be a balance between technological advances and clinical relationships, to improve diagnosis. Herchline et al. reported a case of misdiagnosis that occurred in an infant and illustrated the aspects involved, such as system and clinician loss of opportunities, increased costs, harm, and stress experienced by the family, highlighting that some of the consequences from misdiagnosis cannot be easily measured, but are concerning.[23]

Healthcare must be effective, safe, patient-centered, timely, equitable, integrated, and efficient. According to the Convention on the Rights of the Child (CRC), article 24th, States Parties recognize the child's right to enjoy the highest attainable standard of health and facilities for treating illness and rehabilitation of health. This encompasses accurate diagnosis.[18] This way, improving diagnosis in neonatology reifies children's rights, to all neonates. Diagnosis is an essential part of care, although less studied as a safety concern. The CRC came into force in 1990, and it is the first-ever global set of legally binding rights to apply to all children and ensures that children are individuals with their own distinct set of rights, reflecting a shift from a conceptualization of children as 'objects of concern' to a perception of children as human beings with agency and capacity.[17] However, the change in the child's legal status did not have an impact on the way health care was conceived, especially in Brazil, due to misunderstandings about the meaning of parental authority and the paternalism of health professionals, who kept the child in the position of an object of care, maintaining pediatric care centered on the disease.[24,25]

Child-centered care

Patient-centered care is a component of quality care, but family-centered care (FCC) is the prevailing model practiced in Pediatrics, including Neonatology. In FCC, the family's values and priorities are central in care planning, the family is the unit of care and it involves healthcare providers working in partnership with families. Therefore, the focus remains on adults, both parents and health professionals, rather than the child.[26] In response to the perceived shortcomings of the FCC, a new model has been proposed –Child-Centered Care (CCC). The concept of CCC in health care is relatively new and, as Carter et al. have identified, not yet clearly defined. Nevertheless, its proponents advocate for a more prominent role of the child in healthcare decision-making, recognizing that the child's needs and interests may differ from those of their caregivers. The concept of child-centered care puts children in a central position in healthcare, being the center of thinking and practices. Child-centered approaches recognize that children experience illness and disability differently than adults and that their healthcare needs are different from those of adults. In this concept, there is the premise that children's best interests should be paramount consideration.[26] Under the best interests' principle, the interests of the child may diverge from those of their parents, and thus, the child's interests should be afforded priority. In the event of a conflict between the interests of the child and the interests of the family, health professionals should conduct their practice based on what best serves the child. This entails focusing on the children's quality of life, considering suffering and pain, and opting for what is most beneficial to them, once the pros and cons have been weighed up. Indeed, in neonatal care, when the family, and more specifically the parents, are the primary focus of care, there is a risk of neglecting the neonate's most important needs. Child-centered care in healthcare is framed by the CRC and the recognition of the rights of pediatric patients, particularly those that empower them to assume the role of active participants in their care. The fulfillment of these rights is inextricably linked to the very provision of the CCC.

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In this way, CCC represents the practical implementation of the CRC in the context of healthcare.[25] Finally, it bears noting that CCC does not deny the benefits of the family's presence and participation in the care of children, particularly neonates. Indeed, CCC recognizes the importance of the family in caring for and promoting the child's development and well-being. Nevertheless, this acknowledgment does not imply that the family should assume a primary role in neonatal care. Instead, the neonate should be the primary focus, and it is the responsibility of health professionals to provide care that considers the neonate's needs and interests first and foremost. Lastly, but not less important, safe and quality care is a patient right, and improving diagnosis is crucial to qualify clinical care. The right to safe care derives from the right to health, and we should emphasize that safety is an essential component of quality [27] and neonates hold these rights when they are patients.

Improving diagnosis through neonate-centered care

Neonatal care is complex and so is diagnosis. The neonate's and mother's health are strongly interconnected. You examine the patient and communicate with the mother as if the semiology was fragmented. This way, interconnections should occur between health professionals, the mother, and the neonate (Figure 1). Also, the neonatal team should work in collaboration with the maternal care team, and improve communication. This reinforces the need to improve other means of communication, especially non-verbal neonates and families. Only by acknowledging neonates as the center of care, and connecting with them, we can establish proper communication, and offer better care, while supporting the family. This neonate-centered strategy recognizes the neonate's particular suffering as the patient and is founded on CCC and Pediatric Patient's Human Rights as already pointed out, but unfortunately, has been poorly explored in literature. On the other hand, FCC has been the rule for neonatal care, as a way to reduce the emotional trauma associated with neonatal disease, empower families in their role as caregivers, and as a consequence, improve neonatal care.[28]

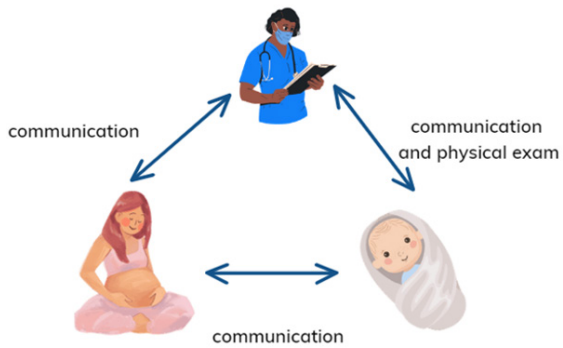

Figure 1 The diagnosis process in neonatal care (this figure was made by the authors).

Coyne has been arguing for a conceptual move from FCC to CCC for many years, recognizing the asymmetric relationship between children and adults, and the need to promote children's rights and strengthen their perspectives. This mode of care values children as active agents, respecting their interests.[29] Considering neonates' immaturity, limited competence, paucity of clinical signs in many clinical conditions, and impairment in verbal communication, we recognize that putting them at the center of care is challenging, but it has to be done. Only by recognizing the neonate as the patient, can we situate him/her in the center of care. A model of care that does not value the neonate as the patient tends to not include him/her in this process and we should reflect on this. Communication barriers among the challenges to effective patient and family engagement in the diagnosis process include dismissing families' complaints, fragmented care, and failure to review and follow up on diagnostic results. [5] Maybe a reflection on a specific clinical situation contributes to the understanding of how neonate-centered care can improve diagnosis and quality of care. Ilhan et al. discussed pain management in neonates in such an emblematic article. Pain is a symptom frequently associated with many clinical conditions and to manage pain, we need to perceive it. Neonate-centered care has come to change this perception and refocus clinical care. The authors claim for a change in the way health professionals perceive neonates, and we want to reinforce this. There is a need to take their perspective, and this can only be accomplished by clinical empathy. Also, the article emphasizes that although access to pain management is a basic human right, many neonates are cared for without pain management. Furthermore, considering neonates' inherent vulnerability, their existence relies on a caregiver, and this is an essential conceptual point. Understanding neonatal care with these concepts, it is reasonable to conclude that neonates require a relationship to be built between them and their caregivers.[30,31] Health professionals need to be actively engaged with neonates and this way, they can perceive their clinical conditions properly, construct accurate diagnoses, and make proper clinical decisions.

Final considerations

Diagnostic errors are preventable and increase healthcare costs. There is a need for strict collaboration between health professionals, patients, and families for a proper diagnosis. Healthcare technological advances over time should be balanced with better clinical relationships. It is essential to reinforce that safety is a component of quality care, both are patient's rights and neonates deserve it. Nonetheless, only by recognizing neonates as patients can we situate them in the center of care, engage with them, and perceive their clinical conditions, for accurate diagnosis.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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