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POINT OF VIEW

The importance of resignifying pediatric care beyond clinical protocols

The importance of resignifying pediatric care beyond clinical protocols

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Abstract

Although infant mortality rates have been improving, pediatric care needs to evolve to consider children and adolescents as patients, active and central participants in their care. Illness and hospitalization leave indelible marks on people's lives at all ages. In this scenario, we need to look at things more gently, respecting children's rights, and this approach should be implemented by pediatricians, caregivers, educators, researchers, and health managers.

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Childhood is a crucial period in people's lives. We know that birth brings a unique, individual experience, and that afterward, the child's interactions with the environment and the adults who participate in their care leave their mark on their development (psychological, somatic, and cerebral), with long-term effects. These interactions are essential for the exercise of subjectivity, intersubjectivity, and individual psychic development. Childhood is, therefore, a place of constant revisiting and a space of opportunity for the individual to construct their being and their existence¹. Illness and the need for hospitalization during this period should consider these particularities.

Social interactions that occur from birth are fundamental to human development. Intrauterine life and the first two years of life are considered a window of opportunity, during which the brain's structural and functional architecture is intensely developed, making it a period of high vulnerability. Fine-tuning and reorganization of neural networks continues throughout the following years².

The impact of early social interactions on future development has been the subject of research. A recent systematic review of 55 studies suggested that several aspects of relationships between children and their caregivers are associated with or predictive of a variety of neurological responses in children and adolescents. Further longitudinal studies are needed to explore this topic and provide greater evidence of causality. For example, the sensitivity and bonding between mother and child appear to be related to the volume of structures in the limbic system and cerebellum; the brain reacts and adapts to environmental stimuli, giving rise to what we call an individual neurophenotype³.

Furthermore, it is known that children possess an interpretative power over the world around them from an early age, interacting actively with everything and everyone around them, constructing their intersubjectivity in a unique way with others⁴. The separation that occurs between parents and their babies in pediatric units, especially neonatal units, for example, deprives them of a unique relationship capable of recovering and reconstructing a sensory memory initially shaped in the womb, and providing them with security and comfort. Thus, the sensory deprivation, silence, and solitude of incubators must be replaced by appropriate cuddling, speech, and touch⁵. The way we view these children and the environment to which they are exposed in hospitals and outpatient clinics must change, recognizing them as others, as subjects with rights, and offering more humane care.

Pediatric care is an art. It encompasses the promotion of the health and well-being of children and adolescents, who are the foundation of society. Although efforts still need to be made to practice pediatrics based on scientific evidence, combined with professional experience, the uniqueness of each patient must be recognized and respected⁶. Thus, child health must be understood broadly, deeply, and holistically, integrating their biological, social, psychological, and spiritual

needs, within a humanistic vision of care⁷. This agenda is urgent.

It is true that the quality of childcare has evolved significantly in recent decades, but challenges remain. Infant mortality, which refers to deaths of children under one year of age, has been decreasing worldwide, but child deaths remain unacceptably high, especially in the neonatal period. We know that children have unequal chances of survival based on their socioeconomic conditions and where they live. Although progress on these indicators is possible, many low-income and lower-middle-income countries will not achieve the Sustainable Development Goals (SDGs), according to the 2023 report from the United Nations Children's Fund (UNICEF)⁸. Another challenge, beyond the quantitative reduction of mortality, is improving the quality of life of these children. Yet another challenge concerns the pediatric care model, which is increasingly distant from the needs of children and adolescents, both for acute and chronic conditions⁹.

Historically, children have been considered and treated as objects of care, with a paternalistic and reductionist view of their capabilities, across all age groups. This includes various aspects of their lives, including their position as patients. Movements originating from different fields of knowledge, notably human rights and social sciences, have contributed significantly to changing this scenario, which is urgently needed¹⁰. Children, as active and central participants in their care process, contribute to its quality and safety. There are different ways for this participation that can and should be implemented in daily pediatric care¹¹. Although children want to be included in their own care, there is a huge gap between the right to be heard and their actual involvement. Furthermore, studies assessing this are scarce. A recent study analyzed pediatric consultations in Germany for children and adolescents aged 4 to 18. Although the number of words spoken in the recorded conversations was the same between the children and their parents, the number of words spoken by the children was half that of their parents, and both were much lower than those spoken by the attending pediatricians (11%, 23%, and 66%, respectively). When the child's participation in decision-making processes was taken into account, this participation was even lower¹². We need to improve our listening, both quantitatively and qualitatively.

For this reality to change, a change in roles in pediatric care is necessary, with children occupying their rightful place, enshrined in the Convention on the Rights of the Child since 1989¹³ and to which they are entitled: that of patient. The one who suffers, and who undergoes various diagnostic and therapeutic procedures, and whose experience is unique and non-transferable. A change in the relationships established in this delicate process of caring for and being cared for, which implies a shift in the care model, focusing on the child and considering the family context, and not the other way around. A true Patient Revolution, as portrayed by Professor Victor Montori, in favor of gentle and genuine care, not

“accidental,” with the empowerment of the pediatric patient and the establishment of co-creation processes in healthcare¹⁴. This change is not detached from the role that children have played in the family and society, and should include residency programs, which are the foundation of pediatric specialist training. It is up to us, pediatricians, caregivers, educators, researchers, and managers, to drive this change, which is urgent for all ages, removing it from discourse and promoting care beyond clinical protocols, making a difference in the lives of children, their families, and society.

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