

Ethics in shared decision making

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The ethical aspects of decision making in pediatrics have evolved substantially over the last decades. And so have the models of the relationship between health care providers, patients, and their families. Traditional approaches, which show the antagonism between paternalistic positions and more contractual models, are based on an individualistic and abstract conception of autonomy. While, in paternalistic relationships, providers override the decision-making capacity of patients and families in pursuit of an alleged principle of beneficence, in contractualism, they only provide information and refrain from any other intervention, for the purpose of not interfering in the outcome of decisions.¹ With the incorporation of concepts of relational autonomy, a hierarchy is established in the relationship interactions, the focus is on the process rather than on the outcome, and health care providers acquire a new role, becoming enablers in the search for the families' values, preferences, and goals.²

Shared decision making is defined as “a process of communication in which clinicians and patients work together to make optimal health care decisions that align with what matters most to patients.”¹ Health care providers in this new role help patients and families to

understand decisions based on their own values, through the development and implementation of communication and listening skills, sensitivity to the patient's needs, and awareness of one's own biases.³

The book *The Ethics of Shared Decision Making*,³ recently published by John Lantos, offers a compilation of different perspectives that help health care providers understand the shared decision-making process. I recommend reading this book not only because of its in-depth analysis of these processes, with chapters dealing with the history of decision making and the philosophical foundations and particular characteristics of these decisions in the pediatric population, but also because it includes guidelines and analysis strategies that allow their implementation. In this regard, it is worth noting the sections that deal with the identification of biases and heuristics that could hinder autonomous decisions and others that provide practical frameworks that systematize shared decision-making processes for their implementation, as one of the ways of providing effective person-centered care, one of the dimensions of quality of care.

Person-centered care is defined by five core concepts: the provision of care from a bio-psycho-social perspective, the concept of the patient as

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a person, the sharing of power and responsibility between providers (professionals) and users of the health care system (reconceptualization of the “patient”), the therapeutic alliance, and the value of the provider as a person.⁴ The organizations working to improve the quality of care and safety in health care processes recognize the importance of establishing trust and open communication with patients and their families to protect their cultural, psychosocial, and spiritual values. To promote these rights, these institutions begin by involving patients and families in decision making, teaching staff to understand and respect beliefs and values, and providing considerate and respectful care that promotes and protects the dignity and self-esteem of families.⁵

Despite the recognition of their importance to the quality of care offered to patients and families, there are still many barriers to the implementation of shared decision-making processes. Conceptual barriers have been described in the bibliography, such as the persistence of paternalistic positions that perpetuate the debate between the promotion of respect for autonomy and the alleged best interest of the patient, the mistaken belief that families do not wish to participate in decision making, and the lack of practical guidelines based on proven evidence.³

However, among the difficulties described, a key element in shared decision-making processes is not prioritized. That is, the relationship between the parties. One of the most important challenges in implementing person-centered care is to establish a humanized dialog and generate a connection that, from a compassionate point of view, recognizes the subjectivity experienced by each family when going through the different circumstances associated with health care. A space must be created that allows the interpretation of what is relevant to each party, providers and families, within the framework of a personalized health care.⁶ To achieve this goal, a different preparation is required, which must be urgently prioritized at the level of training, organizations, and care.

In relation to the above, it is worth noting the experience of an educational initiative in health carried out in Brazil.⁷ Paideia learning is

organized as a matrix support methodology that brings together the various professionals in the network, establishing more horizontal, dialogic, and democratic relationships. In turn, it stimulates the expanded clinic which, similar to person-centered care, brings the subject closer to the clinic, and includes organic/biological, social, and subjective care, and “expects the patient to be actively involved in the development of their therapeutic project and that their social context and subjective aspects be always considered in the care process.” It is a Latin American experience worth highlighting, since, in addition to the incorporation of these perspectives, it aspires to advance health education beyond the mere introduction of theoretical contents, helps students to escape from their condition of subordination and conformism, and favors a critical and thoughtful positioning.

In our academic institutions and health care organizations, it may be difficult to find a space for teaching or modeling the ethics of caring for others. However, it is a path that we must necessarily take in order to get out of the normalizing and exemplary role of the current undefined medicalization and provide a truly reformed care, closer to the needs of patients and families and capable of reversing the insensitivity and the frequent abuse of power. ■

REFERENCES

1. Sullivan A, Cummings C. Historical perspectives: Shared Decision Making in the NICU. *Neoreviews*. 2020; 21(4):e217-25.
2. Lantos J. Ethical Problems in Decision Making in the Neonatal ICU. *N Engl J Med*. 2018; 379(19):1851-60.
3. Lantos J. *The Ethics of Shared Decision Making*. New York: Oxford University Press; 2021.
4. Russell G. Have we forgotten the moral justification for patient-centred care? *BMJ Qual Saf*. 2022; 31:172-4.
5. Joint Commission International. Atención centrada en el paciente. In *Estándares de acreditación de la Joint Commission International para Hospitales*. 7° ed. Illinois: Joint Commission Resources; 2020. Pages 59-78.
6. Gaucher N, Payot A. Focusing on relationships, not information, respects autonomy during antenatal consultations. *Acta Paediatrica*. 2017; 106(1):14-20.
7. Viana MMO, Terra LSV. Formación Paideia en atención primaria: análisis de la democracia institucional y las relaciones de poder en las prácticas laborales en salud. *Salud Colect*. 2021; 17:e3298.