

Shared decision-making: why, for whom, and how?

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Almost 2,400 years ago, Hippocrates advised that “*physicians as the ones who command and decide*” and that “*patients must place themselves fully in physicians’ hands and obey commands*” ¹ (p. 670). This type of view, characteristic of medical paternalism, in which the duty of beneficence and non-maleficence sustains this type of passive posture of patients, has prevailed in medicine in the last 24 centuries. However, rather than making hasty judgments, it is interesting to observe the context, that is, basically all other forms of social relationship that were so common in such period. By examining law, politics, relationships between spouses, or between parents and children, we will see the same pattern ². And if we look into even older times, into the social relations in the human societies of hunters and gatherers, or even if we look into biology, into the social relations between primates or between canids, we will ultimately see the same pattern ³. The individual with the highest social ranking commands, while the others obey. Coalitions among individuals with greater power ensure the maintenance of the model, where the will of the most powerful prevails.

According to Norberto Bobbio ⁴, one of the minds behind the *Universal Declaration of Human Rights*, this model begins to collapse in the Modern Age, initially with the Religious Wars. At the time, the sovereign-subject model begins to be replaced by the State-citizen model, where the right to self-determination becomes, slowly and gradually, guaranteed to citizens, who before, as subjects, did not even have the right to choose which faith to profess. Nevertheless, according to the Italian jurist: “*Human rights however fundamental are historical rights and therefore arise from specific conditions characterized by the embattled defense of new freedoms against old powers. They are established gradually, not all at the same time, and not forever*” ⁴ (p. 5). This gradual and heterogeneous change faces greater resistance in some parts of the social fabric. That is what we perceive in health and, especially, in medicine. And, thus, it was only in the 1970s that these new freedoms reached patients. It was the revolution of autonomy in the relationship between physician and patient. However, beyond that, it was the beginning of the erosion of the sovereign-subject model in medicine, in which not only patients, but also family members, nurses, legislators, among others, obeyed the orders of the sovereigns in the field of medicine. And, as in other fields of knowledge, this change was not at once, nor was it free from turbulence and problems.

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Basically, and especially in Western democracies, the role of patient autonomy in the physician-patient relationship was very often guaranteed after conflicts where the judicial and legislative branches, which previously simply supported the opinion of physicians ⁵, began to ensure that individual freedoms already achieved in other fields also had value for individuals in the condition of patients. And then, in a shift that combines defensive medicine with situations increasingly more complex from an ethical point of view, in increasingly busy times, physicians began to offer options for patients to choose as consumers. This consumerist autonomy, or as brilliantly argued by Hossne et al. ⁶, this solitary autonomy, became the most common model. And the pendulum went from one extreme, where beneficence was valued and autonomy was not recognized, to the opposite extreme, where autonomy is valued and the duty of beneficence is abdicated. And phrases such as “it’s their choice, I don’t care” have become common in the discourse of health care professionals. The tragic aspect is that caring is precisely one of the foundations of the concept of health care. In other words, in the name of respecting choice, they gave up on providing minimally humanized health care.

However, it is worth remembering that this is a 50-year movement, in a history of at least 2,400 years. It would be excessive optimism to imagine that it would change perfectly and conclusively in such a short time. And, thus, relationships kept changing. It has been only in the last 20 years in developed countries, and in the last few years here in Brazil, that it has been increasingly understood that this solitary autonomy also does not lead to good decisions, precisely because it deprives patients of physicians’ advice and knowledge exactly in the most vital and delicate moments of existence ⁷. What we witness – timely – is the growth of the shared decision-making model.

To this end, it is necessary to understand that shared decision-making is neither paternalistic nor consumerist decision-making, but rather a middle ground between the two, where professionals provide their technical opinions on diseases, but firstly seek to understand the values of life of patients, so as to respect patients as persons as ends in themselves and also respect a good evidence-based professional practice. To understand that a patient’s right to refuse an intervention is supported by autonomy, but the right to demand a treatment hurts the professional’s autonomy, which is also an end in itself. To understand that more than common sense, shared decision-making is a method, in which communication skills and competencies are the necessary tools. To understand that technology makes bioethics more complex, and thus requires enhanced training of professionals in this field, so they can act in increasingly challenging dilemmas. And, above all, to understand that they cannot give up neither the respect for autonomy, nor the duty of beneficence. After all, as has already been said, the opposite of love is not hate, but indifference. Caring for the suffering of others and acting to alleviate it is the basis of contemporary palliative care ⁸, an area that has driven and continues to drive the growth of shared decision-making, by showing that we need techniques to treat diseases and also techniques to care for suffering. Thus, shared decision-making proves the ideal decision-making model ⁷, covering not only the physician-patient relationship, but also interprofessional relationships ⁹.

This issue of CSP provides precisely a collection of new articles on this subject. Starting with a necessary and relevant joint position of the Brazilian National Academy of Palliative Care (ANCP) and the Brazilian Society of Geriatrics and Gerontology (SBGG) on shared decision-making in palliative care ¹⁰. Followed by an important article pointing out the importance of palliative care for Public Health and its importance in primary health

care ¹¹. As the authors show, the irregular advance of access to palliative care in Brazil reflects the lack of a public health policy organizing and structuring this field of knowledge in the country. And, next, an article based on the perspective of emergency services as an important space for palliative care ¹². Reflecting on an extremely common case, in which unfortunately the lack of knowledge about palliative care leads to increased suffering of patients, family members, and health professionals, in addition to decreased efficiency of the health system itself, also compromising the access of other patients to it, these authors point out how knowledge about palliative care (or lack thereof) impacts everyone. Much of the knowledge about shared decision-making was created through the approach to palliative care. Today, decades later, we observe that shared decision-making does not need to be restricted to situations of serious illness. This knowledge goes beyond the scope of palliative care, covering much larger areas. Shared decision-making is the basis for an ethical relationship between individuals who have the right to self-determination, not in a way that each party does not care about the other, but rather as individuals who seek the same common goal: the patient at the center, and professionals who care and seek, through dialogue, to provide quality and safe health care, respecting human values and evidence-based practice. This is the State-citizen relationship finally reaching the bedside.

Additional information

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1. Will JF. A brief historical and theoretical perspective on patient autonomy and medical decision making: Part I: the beneficence model. *Chest* 2011; 139:669-73.
2. Platão. República. 2nd Ed. São Paulo: Escala; 2007.
3. Wrangham R. The goodness paradox: the strange relationship between virtue and violence in human evolution. New York: Pantheon Books; 2019.
4. Bobio N. A era dos direitos. Rio de Janeiro: Elsevier; 2004.
5. Rothman D. Strangers at the bedside: a history of how law and bioethics transformed medical decision making. New York: Basic Books; 1991.
6. Hossne W, Pessini L, Siqueira JE, Barchifontaine CP. Bioética aos 40 anos: reflexões a partir de um tempo de incertezas. *Bioethikos* 2010; 4:130-43.
7. Barry MJ, Edgman-Levitan S. Shared decision making: pinnacle of patient-centered care. *N Engl J Med* 2012; 366:780-1.
8. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* 2015; 373:747-55.
9. Michalsen A, Long AC, DeKeyser Ganz F, White DB, Jensen HI, Metaxa V, et al. Interprofessional shared decision-making in the ICU: a systematic review and recommendations from an expert panel. *Crit Care Med* 2019; 47:1258-66.
10. Vidal EIO, Kovacs MJ, Silva JJ, Silva LM, Sacardo DP, Bersani ALF, et al. Position of ANCP and SBGG on shared decision-making in palliative care. *Cad Saúde Pública* 2022; 38:e00130022.
11. Rodrigues LF, Silva JFM. Palliative care: pathway in primary health care in Brazil. *Cad Saúde Pública* 2022; 38:e00130222.
12. Ribeiro DL, Carvalho Filho MA. Palliative care in emergency care: invoking Kairos and rethinking health care systems. *Cad Saúde Pública* 2022; 38:e00127922.

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