

Shared decision making as a strategy for vulnerability in health

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Abstract

The premise that every human being is vulnerable by nature stems from the notion of vulnerability as susceptibility to harm, as well as the interrelations and intrinsic interdependence of human beings with their socio-environmental context. It is up to society to establish institutions capable of promoting both the protection and autonomy, under equal conditions. Besides the professional duty to inform patients of the benefits and harms from possible interventions, including the consequences of denying any intervention, patient-centered care integrates a collaborative approach that considers shared decision-making essential. This theoretical review analyzes the concept of vulnerability and its relations with respect for and promotion of patient rights, proposing and justifying shared decision-making as a good strategy for mitigating increased vulnerabilities.

Keywords: Health vulnerability. Bioethics. Human rights. Patient rights. Decision making, shared.

Resumo

Tomada de decisão compartilhada enquanto estratégia para vulnerabilidade em saúde

A premissa de que todo ser humano é vulnerável por natureza advém da noção de vulnerabilidade enquanto suscetibilidade ao dano, assim como da inter-relação e interdependência intrínseca do ser humano com seu contexto socioambiental, cabendo à sociedade estabelecer instituições capazes de promover tanto a proteção quanto a autonomia das pessoas, em equidade de condições. Para além do dever profissional de informar benefícios e malefícios das intervenções possíveis, incluindo as consequências de negar qualquer intervenção, o cuidado centrado no paciente integra uma abordagem colaborativa que considera fundamental a tomada de decisão compartilhada. A partir de uma revisão teórica, neste artigo analisa-se o conceito de vulnerabilidade e sua relação com o respeito e a promoção dos direitos humanos dos pacientes, propondo e justificando a tomada de decisão compartilhada no que se refere a uma boa estratégia de mitigação de vulnerabilidades acrescidas.

Palavras-chave: Vulnerabilidade em saúde. Bioética. Direitos humanos. Direitos do paciente. Tomada de decisão compartilhada.

Resumen

La toma de decisiones compartida como estrategia para la vulnerabilidad sanitaria

La premisa de que todo ser humano es vulnerable por naturaleza parte de la noción de vulnerabilidad como susceptibilidad al daño, así como de la interrelación e interdependencia intrínseca del ser humano con su contexto socioambiental, y a la sociedad le corresponde establecer instituciones capaces de promover tanto la protección como la autonomía de las personas en igualdad de condiciones. Además del deber profesional de informar de los beneficios y perjuicios de las posibles intervenciones, incluyendo las consecuencias de negar cualquier intervención, la atención centrada en el paciente integra un enfoque colaborativo que considera fundamental la toma de decisiones compartida. A partir de una revisión teórica, este artículo analiza el concepto de vulnerabilidad y su relación con el respeto y la promoción de los derechos humanos de los pacientes, proponiendo y justificando la toma de decisiones compartida como una buena estrategia para mitigar el aumento de las vulnerabilidades.

Palabras clave: Vulnerabilidad en salud. Bioética. Derechos humanos. Derechos del paciente. Toma de decisiones conjunta.

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Vulnerability concept

The heterogeneity of the concept of vulnerability is a challenge for the field of public health, as it depends on a precise and scientific definition to identify and act according to the measures necessary for its mitigation. However, varied perspectives come to light when it is understood that this concept results from a sum of interactive processes that permeate individual, cultural, and institutional contexts.

Closely linked to the concepts of risk and protection, bioethics initially addressed vulnerability through questions about research ethics. Present in the *Declaration of Helsinki* (1964)¹ and the *Belmont Report* (1978)², it was cited given the need for special protection, at the individual and population level, admitting from that moment on the existence of groups socioeconomically more subject to risks and injustices than others.

Following the human immunodeficiency virus (HIV) epidemic between the 1980s and 1990s, there was a need to conduct clinical trials on a larger scale, highlighting the urgency of integrating measures to defend human rights in search of greater justice and social equity. Thus, the concept of vulnerability was understood as a gradation resulting from personal and contextual processes, demarcated by limitations of access to means of protection³.

Still, in the second half of the 20th century, social movements claimed and postulated various civil rights for women and patients, contesting medical paternalism favoring self-determination and the right to one's own body⁴. The premise that every human being is vulnerable due to nature comes from the conception of vulnerability as susceptibility to damage and the interrelationship and intrinsic interdependence of human beings with their socio-environmental context. Therefore, it is up to society to establish institutions capable of promoting both the protection and autonomy of people under equal conditions.

By admitting that vulnerability can be understood as a universal human characteristic, it is understood that it permeates and influences the scope of collective health. This leads to the

proposition of a conceptualization of health that differs from that promulgated by the World Health Organization (WHO), which relates it to the complete state of well-being.

The occurrence of disease-cure processes throughout human life explains human vulnerability and capacity to strengthen and reestablish itself from it, which allows it to be understood as a characteristic movement of a healthy human life, such as the fluctuation of interdependence throughout the different stages and moments of life⁵.

Judith Butler, as stated by Herring⁵, relates the concept of vulnerability with that of resistance, seeking to make natural our constant exposure to danger—especially corporeal—opposing the humanist and Enlightenment matrix, which saw rationality as a sufficient tool to make the human susceptibility an exception, not the rule. Thus, the author inclines us to conceive of human vulnerability not as fallibility or smallness but as a power to be achieved through the good use of the power that such a condition imposes, temporarily, based on an interrelationship⁶.

Souza, Ribeiro, and Facury⁷ point out that this perspective, which understands vulnerability as an element to be accepted and valued in the culture of care, is also discussed by Emmanuel Levinas, based on the reminder that man is a social being, capable of understanding and acting according to the vulnerability of the other, based on the recognition of their similarity. Reception, sensitivity, and solidarity become tools for reconstructing subjectivity through otherness, floating between positions of vulnerability and ethical responsibility.

Shared decision making

Shared decision-making (SDM) is considered a gold standard⁸ in the relationship between physician and patient since it is based on the ability to make mutually beneficial decisions. According to the literature⁸, adherence to SDM has been slow. However, it is advantageous, resulting in reduced conflicts and increased satisfaction in decision-making.

In addition to the professional duty to inform possible benefits and harms of the

interventions, including the consequences of denying any intervention, patient-centered care integrates the patient in a collaborative approach that considers shared decision-making essential. In this model, the patient's values and preferences are considered when choosing treatment and outcome, not limiting their role to signing an informed consent form.

The Montgomery case⁸—in which a baby had complications arising from natural birth not mentioned as a risk based on the mother's medical specificities—showed that the physician's duty of care must derive from the patient's values and preferences. Therefore, the evaluation of treatment options needs to be carried out from the perspective of what is essential and relevant according to the patient's context and values, not that of the physician, whose role is to clarify the clinical implications and risks of each option, regardless of their personal opinion.

In this specific case taken to court, shared decision-making went from regulatory guidance to a legal requirement, understood as an obligation to adhere to best practices, considered the basis for validating informed consent⁸.

The consent form can only be considered valid if it represents the formalization of discussions and clarifications provided previously, using language appropriate to the patient's ability to understand. Therefore, consent acquired with a routinely requested signature with a quantity of incomprehensible technical information from a layman's point of view or when clinical clarifications are neglected is not considered valid⁸.

Sharing the decision also directly reflects on accountability for the outcome: the initial dialectical practice prevents questioning, problematization, and even processes that will subsequently be significant, and is mutually beneficial. In this context, patient feels valued and respected in their individuality, based on their own values, contexts, and preferences, and the physician is relieved of absolute responsibility for the treatment and results obtained.

Sharing decisions and results does not mean submitting clinical care entirely to the patient's will, disregarding medical

evaluation, but rethinking clinical options together, checking among the viable and possible ones, which would be the best and most appropriate in that situation, based on the most critical values for the patient. Considering the patient's preferences and wishes does not nullify the medical possibility of refusing futile or clinically inappropriate treatment. The physician's paternalistic role is not replaced or superimposed by patient autonomy; there is, on the contrary, the incorporation of the patient's values into the process of choosing and deciding on the best treatment.

Final considerations

The relevance of analyzing the concept of vulnerability in the health area and patient care is undeniable and can be understood as a risk determinant³. The terminologies and the language and its nuances directly imply the understanding, analysis, and consequently, in the approaches used by health professionals, potentially influencing the decision-making capacity to resolve cases.

Supporting this premise, according to Clark and Preto⁹, Piggott explores the semantic differences that can characterize the understanding of vulnerability as an internal or external problem to the subject. On the other hand, Rendtorff is cautious when discussing the possibly negative attribute of the term, indicating that every human being is vulnerable. However, this does not exempt us from dealing with the issue. On the contrary, it imposes an ethical duty to seek justice and promote autonomy for health equity⁹.

We argue that the protection claimed and promoted by human rights must also be applied in the health area to guarantee autonomy and dignity to everyone indiscriminately, regardless of internal or external factors. The undeniable importance of social support and protection networks is evidenced by the erroneous but common perception that vulnerability is doomed to a limitation of rights⁴. Thus, we justify that the delimitation of concepts necessary for bioethical questions, such as vulnerability, and using the human rights framework are valuable and necessary instruments to guarantee the protection of vulnerable individuals within the scope of healthcare¹⁰.

Ward and collaborators⁸ encourage implementing patient-centered care based on shared decision making. The authors conclude that both the bases used in the trial and the decision in the Montgomery case itself help in medical training by indicating that

a dialogue addressing clinically significant issues leads to a shared decision, making it possible not only to consider but to prioritize, values and patient preferences, solidly structuring the validity of consent.

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