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Title: Patient-reported outcomes and medical decision making: Ethical implications of response shifts and dispositions

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Objectives

Medical decisions increasingly involve patient-reported outcomes (PROs): outcomes that cannot be measured clinically but only patients can tell, such as pain, fatigue and overall quality of life. It is known that self-reports may be subject to ‘response shifts’: changes in the meaning of patients’ self-evaluations. Furthermore, patients’ dispositions (e.g. optimism/pessimism, denial/catastrophizing) may also affect self-evaluations. These influences may lead to differences in self-reports between patients with the same health state. The possible consequences for individual patient care and health care policy have never been ethically analyzed.

Discussing these consequences contributes to the conference theme ‘acknowledging different perspectives on what is right and justified’.

Methods

We analyzed how response shifts and dispositions may influence medical decisions, and analyzed the possible consequences from the perspectives of beneficence, non-maleficence and autonomy, and two theories of just distribution: utilitarianism and fair equality of opportunity.

Results

At the patient level, we discuss the possible consequences for treatment decisions when response shifts and dispositions influence 1) published PRO results that inform shared decision-making; 2) patients’ (informal) self-evaluations; and 3) patients’ treatments preferences.

At the health policy level, we discuss possible consequences for 1) devising treatment guidelines; and 2) deciding which treatments are included in the basic health care package.

Whether these consequences are problematic, depends on the concepts of health and the ethical theories that are used. For example, using broad or preference-based conceptions of health (e.g. well-being) or a utilitarian approach, it does not matter whether changes in patients’ self-reports result from adaptation or from actual changes in health defined as biological functioning. Conversely, from the perspective of health as biological functioning, under- or overtreatment are possible consequences due to over- or underestimation of health or treatment effects.

Conclusion

PROs are of paramount importance in health care. However, if used without awareness of the influence of response shifts and dispositions of patients, from an ethical perspective it may lead to suboptimal decisions and hamper a just distribution of health care resources.

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Key words: Patient-reported outcomes; response shift; dispositions; shared decision making; health care policy.