

Presentation

Promoting healthcare decision making and the inherent dignity of patients

Promover la toma de decisiones en materia de salud y la dignidad inherente de los pacientes

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Abstract

Catholic moral teaching affirms that the consent of patients is necessary to authorize healthcare interventions affecting them but does not specify conditions for obtaining consent or assessing decision-making capacity. This article reviews papers in this issue that authors have developed from presentations they made during a recent International Association of Catholic Bioethics (IACB) colloquium held in Quebec City, Canada. These papers contribute to advancing ethical thinking on decision-making capacity and consent. In various ways, they call for respecting the dignity of all

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patients by promoting their participating as much as possible in making healthcare decisions. These papers consider decision making to be relational and to encompass a range of capabilities. They examine the role of family members and other decision-making supporters in promoting the capabilities of patients whose mental health condition or disability renders them unable often to meet typical clinical and legal standards for decision-making capacity.

Keywords: decision making, consent, vulnerable populations, supported decision making, relational autonomy, patient participation.

The papers in this issue of *Medica y Ética* all relate to respecting the inherent dignity of patients by promoting their participating as much as possible in making decisions regarding their health care. These papers were developed from presentations at the Ninth International Association of Catholic Bioethics (IACB) Colloquium held in Quebec City, Canada, from June 16-21, 2019. The International Association of Catholic Bioethics (IACB) is a community of bioethicists and providers of health and spiritual care founded in 2005.¹ Forty-eight participants from different countries took part in this colloquium, which was on the theme of promoting capabilities of persons who need support to make healthcare decisions.

To focus discussions, participants in the colloquium considered four groups of patients: those with intellectual and developmental disabilities (e.g., down syndrome, autism spectrum disorder), progressive neuro-cognitive impairments (e.g., Alzheimer's disease, dementia due to Parkinson's disease), compromised mental health (e.g., depression, schizophrenia) or addiction (e.g., to alcohol, substances). Such patients are often at the periphery of decision making regarding their own health care. The colloquium's participants also discussed the important role of family members and other care-

givers in supporting patients to make healthcare decisions. The main conclusions of the colloquium are presented in this issue in the consensus statement, «Promoting capabilities to make healthcare decisions», together with some recommendations for implementing these conclusions.²

There is a long tradition of reflection in Catholic bioethics regarding respect for patient agency, autonomy, and consent. Jos Welie's paper³ reviews main insights in this tradition. He also discusses the moral status of advance care directives, withdrawing life-sustaining treatments once they have been initiated, and involuntary treatments. These are all issues on which a range of views exists among Catholic bioethicists. Central to Jos Welie's review is the position, consistently held in Catholic teaching on health care, that, without consent, the healthcare provider is not authorized to initiate treatment. The consent gives healthcare providers a right they did not have before, that is, to move from benevolence (wanting the good of the patient) to beneficence (doing the good of the patient). From this, Welie elaborates that actively engaging patients in all stages of decision making regarding their health care is an ethical duty for healthcare providers grounded in respecting their patients' inherent dignity. He argues, moreover, that it is possible to promote patient agency within an objective ethical framework.

This issue of *Medica y Ética* includes a tribute by Paulina Taboada to the late Elio Cardinal Sgreccia. Sgreccia's important work in promoting personalist bioethics emphasizes the basic ethical principle of honouring the personhood and inherent dignity of all patients.⁴ According to Sgreccia: «The patient's involvement in managing his own illness and the personalization (where possible) of treatment plans and health care protocols are... all objectives that should be pursued according to an ethics that looks to the dignity of the person, promotes the humanization of medicine, and strives to replace the paternalistic model with the model of beneficence based on trust».⁵

Do these ethical considerations regarding patients' participating in making decisions regarding their care apply also to patients who might need support from others to do so? The paper by Julian Hughes surveys a range of ethical issues commonly encountered in caring for persons with dementia and other progressive neuro-cognitive impairments.⁶ He highlights three important points that apply to all such patients, but these points could equally be related to other patients: 1) ethical issues in health care entail making decisions; 2) assessing decision-making capacity of patients is never value-neutral, and 3) the most basic ethical principle in caring for patients is honouring their personhood and inherent dignity. Like Elio Sgreccia and Jos Welie, Hughes proposes that respecting patients' dignity entails finding ways to include and involve patients as much as possible in making decisions regarding their care. In other words, this ethical duty of healthcare providers holds for patients who are deemed capable of making healthcare decisions on their own as well as those who require support from others to do so.

Sander Welie's paper⁷ describes the unique role that patient advocates play in the Dutch mental health care system. In the Netherlands, supported decision making in mental health care does not involve primarily family members and other persons close to the patient but government-employed officials referred to as patient advocates. Such advocates are mandated to provide legal guidance to patients regarding their rights in mental health care. Sander Welie points out that such advocates are not impartial. In imparting legal advice, they are expected to regard promoting the patient's best interests as paramount. This raises ethical issues, however, when a patient aims at goals that are shaped by a mental health condition that affects the patient's thinking or mood, such that what the patient wants is either not reflective of the realities of her or his situation or even possibly harmful to the patient or to others. The patient advocate, who might not know the patient very well, might not be in a position to interpret the patient's authentic values, which could be different from the patient's momentary and

transient wishes. Moreover, the patient advocate is bound to provide counsel to the patient, taking as a given that the patient's expressed wishes should always be pursued as far as the law permits. Sander Welie concludes that this role of patient advocates is ethically problematic and distressing when, for example, the advocate is confronted with a patient request or a law with which she or he disagrees with on moral grounds, such as the Dutch law on euthanasia for some advocates.

Christian Elia, in his paper, also discusses euthanasia.⁸ Since 2016, assisted suicide and euthanasia have been legally permitted in Canada. Elia coins the term «suicide relativism» to refer to the view that the moral character of suicide, i.e., a person's intentional ending of his or her life, can vary depending on the reasons used to justify it. Typically advocates of assisted suicide justify this practice ethically as «rational» suicide and distinguish it from other instances of suicide, which they agree society has a duty to prevent. Elia argues that suicide relativism can influence the decision making of patients who request assistance in terminating their lives. Such patients might also seek spiritual care at the end of life. This places healthcare providers and spiritual and pastoral care providers in the ethically problematic and distressing position of having to act against their conscience, if they are compelled by law or guided by unclear pastoral directives to cooperate with the decisions of such patients.

The IACB colloquium considered the important role of family and other caregivers in promoting the decision-making capabilities of patients. Kay Wilhelm, who has many years of clinical experience working with patients with compromised mental health or addictions in Australia, reflects on her experience with families who support such patients in making their healthcare decisions.⁹ She concludes that, while some issues for family caregivers who are supporting capabilities of their loved ones to make healthcare decisions will vary depending on the type of health condition in-

volved, some principles apply across all groups of patients. For example, all caregivers need recognition and support for the roles they undertake. They need access to evidence-based, coherent and trustworthy information about available options, how best to fulfil their roles as decision-making supporters, and how to look after their own health and well-being in order to look after the person for whom they are caring.

Marie-Jo Thiel's paper presents an important ethical perspective on healthcare decision making from a non-Anglo-American context.¹⁰ Elaborating on the insights of Paul Ricoeur, Thiel, like Sullivan, Heng, and Bach, understands patient agency and autonomy as *relational*, but for a different, complementary reason. She writes: «To consent is to 'intuitively grasp, in a sensitive way', not only the stakes of a clinical situation *with* myself (i.e., my opinions and my beliefs) but also *with* others in order to accept a proposal for medical treatment that is not disruptive to my existence-with the doctor who informs, family members and other caregivers, because they too are part of my existence». This insight underlies her analysis of difficult ethical decisions regarding withdrawing life-sustaining treatments for patients who are unconscious but who either have no advance directives or whose directives are unclear. Although French law, in contrast with laws in Anglo-American countries, designates healthcare providers, and not family members or other substitute decision makers for the patient, as the final decision makers in such situations, Thiel argues that health care at the end of life should be family-centred. Family members of patients will inevitably be affected by decisions to withdraw life-sustaining treatments. She urges optimizing communication between healthcare providers and families of patients, responding to their concerns regarding the care of their loved one, and addressing their needs arising from the prospect of losing a loved one. Thiel proposes that death is a unique, definitive moment, and often the experience of relatives with the patient conditions both the decision-making

process regarding their loved one's end-of-life care and the extent of trauma related to their own mourning process.

The papers in this issue of *Medica y Ética* present thought-provoking and practical contributions to bioethical thinking regarding healthcare decision making. They are substantial in both breadth and depth of reflection. They highlight the importance not only of involving patients as much as possible in making decisions regarding their care, but also of offering them accommodations and help from decision-making supporters that they might need for any aspect of the decision-making process. The papers highlight also the fundamental role of family caregivers and other decision-making supporters, who themselves will need good communication, care, and support from healthcare providers for that role. Partnership among patients, their family members, other supporters, and healthcare providers best promotes decision-making capabilities of patients and their agency and autonomy. Agency and autonomy are inherently relational.

These papers leave us with many bioethical questions to explore. They also issue a practical challenge to all to strengthen healthcare partnerships as described above and to find ways of fostering friendships and other close relationships with those who are socially isolated and lack trusted and close persons in their lives who can support them in making healthcare decisions when they need such support.

Bibliographic notes

¹ For information regarding the IACB, see: <http://iacb.ca>.

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