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Capacity for Preference – Respecting Patients with Compromised Decision-Making

By *Jason Adam Wasserman and Mark Christopher Navin, The Hastings Center Report, 2018*[1]

Short summary:

This paper proposes an approach to capacity for preference that builds on 'supported', 'assisted' or 'guided' decision-making models. Patients who lack decision-making capacity can have capacity for preference; i.e., wishes or desires about their own health care irrespective of their capacity for making decisions. The authors argue that capacity for preference should be taken into consideration in decisions about the patient's health care.

Introduction

The authors frame their argument around a case featuring a forty-one-year-old male patient, paralyzed from the waist down and with a brain injury after a car accident. The patient has consistently refused wound care of four ulcers on his legs that are the result of poor hygiene. He also denies that he is paralyzed. As it has been determined that the patient doesn't have decision-making capacity for treatment decisions, the guardian has provided permission to treat the patient against his wishes. The health care team has identified three options for treatment: a six-week course of intravenous antibiotic; amputation below the knee; or comfort care. As members of the hospital's ethics consultation team, the authors were called in to assist the health care team in the ethical deliberation of the three options. During this process the authors found that the surrogate decision-maker couldn't provide insight into the patient's wishes, values and beliefs; and that the patient had not been consulted about his preferences. The authors recommend asking for the patient's preference among the possible treatment options that the healthcare team and the guardian have identified, and to consider this preference in decision making about the patient's care.

Key arguments:

Empirical prerequisites:

Research studies shows that patients without decision-making capacity often can express preferences or opinions about their health care that are relevant for medical decision making. Additionally, the process of incorporating pediatric assent is widely recognized in making treatment decisions for children who don't have decision-making capacity.

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[1] Wasserman, J.A. and Navin, M.C. (2018). Capacity for Preference – Respecting Patients with Compromised Decision-Making, *The Hastings Center Rep*ort Vol. 48 (3): 31-39.

Preferences matter morally

The standard view in a case where a patient lacks decision-making capacity is that the patient's current preferences matter morally only insofar as they are seen to promote the patient's best interests or if they provide a surrogate decision-maker with a clue about what the patient wants. In opposition to the standard view, the authors argue patient preference also matters morally when the patient lacks capacity for decision-making. Capacity for preference is based on best interest, respect for persons, and the principle of liberty. Considering a person's desires, drives and commitments when making decisions on their behalf is a way to ensure that treatment is in the best interest of the patient, and it shows respect for the patient as a person. Moreover, any treatment that has the potential to violate the patient's right to freedom from bodily coercion would require justification.

Addressing practical problems

In the case described, it was difficult to determine which treatment option was in the patient's best interest, partly because the surrogate couldn't make a substituted judgement and partly because the expert consultants favored different treatment options. Moreover, the patient's beliefs were affected by delusion: the patient denied being paralyzed. However, the third option would result in death from a preventable disease, which diverged significantly from best interest from a medical perspective. *If* the patient had been able to express consistent preference for either antibiotic or amputation over a sustained period, the capacity for preference would have revealed a decisive argument for one treatment over the other. As a result, a patient's capacity for preference could mean that health care teams sometimes find themselves in a situation where they are following a treatment option that is suboptimal with regards to best interest from a medical perspective.

Complicating the hierarchy of decision-making criteria

Clinical ethics promotes a deliberation process for decision-making based on a hierarchy of successive criteria: patient autonomy, surrogate decision-making and the patient's best interest. Autonomous preferences are morally more significant than non-autonomous preferences. However, a patient's autonomous decision-making is often constrained to the medically appropriate options that the health care team have identified based on best-interest considerations. Patients with capacity have the right to make autonomous choices that don't necessarily promote their best interest from a medical point of view. The authors argue that patients with capacity for preferences should also be permitted to choose options that deviate to some degree from their best interest, but within a smaller scope.

Conclusion

When making decisions about care for patients without capacity it is important to pay attention to the patient's preferences, in addition to the inputs from a surrogate decision-maker. To the extent possible, the patient's own preferences should guide the decision-making process. The moral reasons for doing so are founded in liberty and respect for persons.