REFLECTION

Capacity to Consent to MAID

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As a geriatric psychiatrist who has been involved in assessing capacity for patients wanting to access medical assistance in dying (MAID) over the past year I would like to share some observations about my experience. The capacity assessments I have performed over the past year with regards to MAID have been of two types: the first during the period February - June 2016 when Ontario Court guidelines in the absence of federal legislation required that a psychiatrist assess the patients' capacity; and the second after federal legislation when medical colleagues asked for a more comprehensive capacity assessment in the setting of patients with mental health diagnoses, either co-morbid with a terminal illness or as a primary reason for requesting MAID. This paper will focus on capacity assessment for MAID. My comments will focus on the Ontario context, but the principles explored are generalizable.

In Ontario, medical treatment decision making is governed by the Health Care and Consent Act (HCCA) (1). The HCCA explicitly defines capacity to make a specific decision as the patient having the ability to both understand and appreciate the treatment decision being proposed. These are the two parts of the capacity test. The patient must *understand*, for example if a given treatment is proposed for diabetes, that diabetes is an illness with a range of treatment options with benefits and side effects; and *appreciate* that the decision at hand actually applies to him or her. The clinician proposing the treatment is legally bound to assess the capacity of the patient who is being offered a specific treatment. If the patient is found to be capable then the patient simply proceeds to make the decision; if the patient is found incapable then the clinician must inform the patient of this finding and if the patient does not agree he or she may appear before the Ontario Consent and Capacity Board (CCB) to challenge the clinician's finding, and the burden of proof lies with the clinician to demonstrate why the patient was found incapable. If the patient does not challenge the finding of incapacity or if the finding is upheld by the CCB, then a substitute decision maker, as per the prioritized listing in the Health Care Consent Act will make the decision on behalf

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of the incapable patient in accordance with the patient's previously expressed wishes (2).

It must be acknowledged that the entire legal and medical history of informed consent and capacity does not take into account a health care decision such as medical assistance in dying. The history of informed consent is specific and emerged from research ethics, patient rights movements particularly in mental health, patient safety movements, and the growth of bioethics (3). The purpose of informed consent and legal tests of capacity are to protect the patient's autonomy to make a specific health care decision at a particular moment in time. We are currently finding our way with trying to understand how to assess capacity with medical assistance in dying. Examples like the Rasouli case have demonstrated how the classic conception of capacity doesn't fully accord with complex end-of-life care decision-making when the issue for family and treating health care teams is less about the specifics of every treatment decision, but more about the overall direction of care (ie. palliative approaches versus active acute medical care)(4). The decision to access MAID is profoundly and qualitatively different from other health care decision making in that it is an existential question. MAID is also practically a specific decision - the patient's death will be planned to occur at a particular time and place, in a particular manner, and with meaningful others present or not.

When I as a geriatric psychiatrist am asked to assist clinical teams in determining if a patient is capable to make a decision to access MAID I am particularly interested in how this decision fits in with the pattern of decisions that this patient has made over the course of his or her life. I am trying to understand what MAID means to the patient requesting it, and how it fits in with her or his own life story. I am trying to understand the person through their own eyes. I review the medical record, interview the patient, and with permission of the patient will also try and speak to significant others in the patient's life (spouse, child, or other person the patient identifies as a resource). In my experience, determining capacity can take some time for MAID, and actually means determining three aspects of capacity. In order to be capable to access MAID the patient must understand MAID, appreciate how MAID applies to his/her particular circumstance, and make the decision *in a manner which is consistent with his/her own life's experience and values*. In addition, as I have worked with patients and families seeking and completing MAID it has been uniformly apparent that the patient derives substantive value from talking openly and explicitly about his/her life. The patient, as mortality is being contemplated, has a deep human need to be understood. We know in geriatric psychiatry that telling another about one's entire life course is vitally important (5,6). Adding in the consistency criterion allows the clinician assessing capacity to actively understand how MAID is experienced in the context of the patient's life.

I would like to propose that we learn from the MAID experience and change the law around

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consent and capacity in Ontario to move from a two pronged test evaluating *understanding* and *appreciating,* to a three pronged test adding in an evaluation of internal *consistency.* The addition of the *consistency criterion* will explicitly establish that the decision making around MAID, and other direction of care decision making, is in accordance with the patient's own life experience and values. The addition of a *consistency criterion* also explicitly requires the health care practitioner to engage in a detailed manner with the patient to understand his or her experience. Evaluating *consistency* formally compels the health practitioner to understand how the MAID decision fits with the patient's beliefs, values, and previous decisions.

MAID decision making introduces a new class of health care decision making into Canadian society. If we are to continue to provide compassionate patient focused care our standards to assess decision making must evolve as well. Explicitly introducing a consistency criterion into the Ontario legal definition of capacity is a start to make our medico-legal understanding of capacity more robust. As the MAID landscape evolves in Canada the clear assessment of a patient's capacity will become even more essential.

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Acknowledgements: none

Competing Interests: none

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Date of Publication: May 25, 2017

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