

Friday, April 29, 2016

Re: Decision-Making Capacity and Medical Assistance Dying

Dear Mr. MacPherson,

I am writing to bring the topic of Decision-Making Capacity to your attention and would be happy to appear before your committee to discuss the matters I will share in this memo.

If you may pardon the expression, Decision-Making Capacity is the proverbial 'elephant in the room' in all the current debates on Medical Aid in Dying surrounding Bill C-14, no matter which side of the debate one wishes to support.

Decision-Making Capacity (sometimes also referred to as 'mental capacity' or 'mental competence') is a central concept in health care law and ethics. It is one of the pillars of the doctrine of informed consent.

Decision-Making Capacity, in this sense, and in this context, is not the same as criminal responsibility and mental capacity or competence to stand trial, which is an entirely different matter. Legal usage and terminology is variable in these domains and confusion is often unavoidable. Clarification is therefore imperative. So is public education.

Decision-Making Capacity in the present context refers to the psychological ability to consent to or refuse medical treatment.

The 1996 Ontario Health Care Consent Act is a good example of consent legislation with standard provisions relating to decision-making capacity.

The Act stipulates that in order to be deemed valid, consent must: (a) relate to the treatment; (b) be informed; (c) be given voluntarily; (d) not be obtained through misrepresentation or fraud.

The Act also stipulates that 'a health care practioner who proposes a treatment for a person shall not administer the treatment' unless the practitioner is: (a) 'of the opinion that the person is capable with respect to the treatment, and the person has given consent', or (b) 'of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf'.

The key word here is: 'capable'.

There is an emerging scientific area of research and clinical study concerned with decision-making capacity, though it is very much in its infancy. Previously, the assessment of a patient's mental capacity to consent to, or refuse, treatment was solely a matter of subjective judgment made by the attending physician reported in yes-or-no form. In general this is still the standard of care, though the point is seldom emphasized as much as it should, probably since the standard so inarticulate and subjective.

However, with the advent of the Mini-Mental State Examination in the 1970s and, more recently, the development of the MacArthur Treatment Competence Assessment Tool (MacCAT-T) in the mid-1990s, clinicians and the courts have been increasingly turning to more standardized and reliable modes of assessment of the mental capacity of patients to consent to or refuse treatment. I have published extensively on the MacArthur Competence Assessment Tool (MacCAT-T) and my views on this topic have been cited in the New England Journal of Medicine, the British Journal of Psychiatry, and Archives of General Psychiatry, among others. The central problem with the MacCAT-T, I argue, is that because it is modeled on the cognitive assumptions of the law, it fails to adequately reflect and incorporate emotions and values in health care decision-making, most notably, consent.

Despite the fact that the MacCAT-T is by all accounts the current gold standard in the area of decision-making capacity assessment — a reputation it justly deserves — it still falls seriously short of what a satisfactory assessment tool in this domain truly requires. I have even gone so far as to argue that the MacCAT-T is empirically invalid as a psychometric instrument, since it fails to properly capture, and theoretically account for, the kinds of decision it is supposed to explain. No wonder! We are not simply cognizers, as the law would have it, but also emoters, which medical law seems determined to downplay or ignore. The alleged objectivity of cognition always seems to win out over the alleged subjective character of values and emotions when law and science turn their attention to these domains.

In sum, the science of decision-making capacity has seen great and very promising leaps forward recently. Yet it is still very young and riddled with fundamental theoretical and practical problems. This leads me to believe that our current scientific measures of decision-making capacity and the institutions and practices that support them, simply cannot bear the weight that will be put on them if we extend access to medical assistance in dying to persons diagnosed with mental disorders and mature minors.

I suggest that we need to proceed with extreme caution as we enter debates surrounding who ought to be eligible for medical assistance in dying, and when. We can certainly not ignore the central importance of capacity in discussions of these topics, as we have to date.

I would be happy to elaborate on this matters if you should deem it helpful.

Sincerely,

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