

A Response to Charland and Colleagues: Science Cannot Resolve the Problems of Capacity Assessment

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Commentary in Response to: "Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders" by Charland, Lemmens, & Wada

The passage into law of Québec's Act concerning end of life care and the federal government's Bill C-14 decriminalizing medical aid in dying took place on December 10, 2015 and June 17, 2016 respectively. The public discourse concerning medical aid in dying in Quebec situates it as a potentially appropriate healthcare option along the continuum of end of life care. This is understandable given that the legislation lies within the province's jurisdiction in healthcare. This stands in contrast to its framing in the rest of Canada where, in the absence of legislation in other provinces, it reflects the exercise of certain Charter rights in the face of a grievous and irremediable medical condition following the Supreme Court's judgment in *Carter v. Canada*. Nevertheless, in both cases, the question has been raised about extending the practice beyond its current boundaries to include those suffering from psychiatric conditions in the absence of another medical condition that placed the person either at the end of life (Québec) or rendered her death reasonably foreseeable (Canada). Including and excluding persons with psychiatric disorders has raised vigorous discussion from the public, professional, and academic communities. On the one hand, psychiatric conditions are not considered to involve less suffering than non-psychiatric conditions and like other conditions can prove refractory to extensive therapeutic efforts. Therefore, the possibility that medical aid in dying may be the only option left to relieve such suffering seems plausible. On the other hand, several psychiatric conditions give rise to suicidal thinking particularly when the condition is un- or partially responsive to treatment. How can one distinguish a request for medical aid in dying to

relieve the suffering caused by an illness, from a symptom of that very illness? In other words, how can one be sure that one is not unwittingly colluding with a person's pathology rather than respecting a person's well-considered judgment?

The answer to this question embedded in both laws is via the concept of decision-making capacity. The notion that a person must be capable to make his or her own healthcare decisions is reflected in provincial legislation across Canada following a series of court decisions in the 1980s. The definitions of capacity found in these laws vary by jurisdiction but tend to revolve around a person's abilities to understand and appreciate certain kinds of information such as the nature of his or her condition, and the risks and benefits of treatment and no treatment (Hospitals Act, Nova Scotia; Health Care Consent Act, Ontario). Understanding is defined in its literal sense of cognitively grasping the information presented whereas appreciation is taken to mean one's ability to apply that information to oneself in order to come to a decision (*Starson v. Swayze*). This legal concept is applied in practice by clinicians.

According to both Loi 2 and C-14, a person requesting medical aid in dying must be capable of making the decision to receive such an intervention. Both laws enshrine the autonomy of persons with respect to the timing of their deaths given certain facts about their medical circumstances. Thus, from the point of view of the legislators, establishing decision-making capacity before providing medical aid in dying serves as a legal safeguard enabling healthcare providers to ensure that a person's request for medical aid in dying is truly autonomous.

It is at this point that Charland and colleagues enter the discussion, raising the question of whether patients with psychiatric conditions

have the capacity to make a decision to receive medical aid in dying. Their argument – although not explicitly stated as such – proceeds in the following manner:

1. To be considered eligible to receive medical aid in dying, a person must have capacity (legally defined) to make this decision.
2. The legal definition of capacity is inadequate because it is limited to cognitive abilities and therefore does not provide an empirically accurate reflection of human decision-making (which involves other characteristics such as mood, emotion, etc.).
3. Several mental illnesses are characterized by disturbances to one's moods or emotions, therefore a person with mental illness may be not capable using a more encompassing definition of capacity.

Therefore, we should not extend medical aid in dying to persons with mental illness.

Most of the paper focuses on the second element of the argument, that is, that the legal definition of capacity does not adequately reflect human decision-making. With this point, we agree. One need only reflect on the manner in which people make life-changing decisions with profound consequences, such as the decision to have children, to note the multitude of non-cognitive factors at play. Because of its exclusive focus on cognition, Charland and colleagues worry that the current definition of capacity will lead to medical aid in dying being permitted for people for whom it ought not to be, that is, people we might think would be incapable were we to use an expanded definition of capacity.

What is their solution to this problem given that the current legal definition is implicit in both laws concerning medical aid in dying? First, the authors call for a more robust concept of capacity that takes into account the complexity of human decision-making while also recognizing that the manner in which individuals make decisions will vary by individual, by decision, and over time. They believe that such a concept could then be subject to scientific evaluation to ensure that it is a valid measure of capacity. In the interim they note that, “a more independent assessment of the reasonableness (emotional and otherwise) of a request for MAID involving an assessment of vulnerability, seems more appropriate” (Charland et al., p. 6). By “a more independent assessment” they may be hinting at a judicial process similar to the type required between February 2016 (when decriminalization of medical aid in dying took effect in Canada outside Québec) and June 2016 when C-14 entered into law. However, they do not elaborate on what this assessment would entail, who would conduct it, or what would make it more independent, and so it is not possible to assess the merits and flaws of this proposal. Therefore, in the rest of this paper, we will focus on their call for a more robust concept of capacity and the assumptions that lie behind it.

In the subsection entitled, “Philosophical Challenges”, the authors state that “Initially, clinical research on decision-making capacity undertaken on persons diagnosed with mental disorders, showed that some individuals who might have been deemed incapable of making their own treatment decisions, or consent to participate

in research, on account of their mental disorder, were in fact capable to do so.” What do the authors mean when they write that these individuals were “in fact” capable? The studies they cite in support of this point are empirical investigations of the MacArthur Competency Assessment Tool (MacCAT)¹. The MacCAT is to help clinicians evaluate capacity based on an assessment of four specific cognitive abilities including: understanding, appreciation, rational manipulation (reasoning)², and expression of choice (Grisso et al. 1995, p. 128). Another way of putting the authors’ point here is to say that some individuals who might have been deemed incapable [by some former standard, test, belief, or clinical judgment] were deemed capable based on their results on the MacCAT. In the next paragraph they write, “More recently there has been a concern that some individuals suffering from mental disorders, notably severe anorexia, who are shown to be capable to make their own treatment decisions using established instruments, may not in fact be capable to do so, clinically speaking³.” By established instruments, the authors are again referring to the MacCAT. What do they mean when they write incapable “clinically speaking”? In the papers they cite to support this point, incapacity means the lack or compromise of abilities beyond those captured by the MacCAT. What underlies both of these statements is the idea that when it comes to capacity, there is a fact of the matter. A person has capacity to make a certain decision or not and this is true regardless of what any one rating scale or test of capacity indicates.

The authors’ assumptions become clearer when they refer to the normative and descriptive nature of capacity. The authors write, “There is the descriptive question whether someone has the decision-making capacity to consent to a particular treatment, or not, and the normative question whether someone ought to be considered capable to do so, or not.” We contend that whether someone has capacity or not is not a descriptive question. Instead capacity is a fully normative concept that reflects a legal judgment about the kinds of abilities a person must have in order to be permitted to make certain kinds of decisions for herself. An expanded, more empirically accurate concept of decision-making capacity such as the one called for by the authors does not alter this normative nature. In other words, there is no fact of the matter. The descriptive component of capacity assessment is limited to the extent to which a person’s abilities – cognitive or otherwise – match those that have already been judged to be necessary. A method/tool/instrument of assessing whether or not a person has these abilities, no matter how well-researched, does not change the fact that some persons (e.g. judges, legislators) have decided that it is necessary for people to have these abilities in order to be considered capable. They could have decided some other types of abilities are necessary, or they could have decided that no specific abilities are necessary as is the case with most of life’s decisions (we do not assess people’s capacity to select an occupation, make major purchases, or choose a spouse). Thus, an individual does not have capacity; a clinician determines if a person meets the legal test for capacity either by interviewing the patient and comparing his answers to the definition (as in a usual clinical evaluation), or by questioning the person according to a scale designed to reflect the legal definition (like the MacCAT).

To return to Charland et al.’s concern, deeming someone to be capable or incapable is a judgment based on the kinds of abilities that the legal system has declared necessary for certain types of decisions. An expanded concept of capacity will simply reflect

another version of what we judge to be necessary abilities in making certain decisions. In an article addressing the normativity of capacity and its assessment, Banner (2012) argues that capacity assessment is intrinsically normative, “The distinction between descriptive and ethically normative components of capacity is thus misleading: it assumes that the only normative considerations relevant to capacity are ethical norms that impact on assessment after the fact of making a descriptive judgement about a person’s capacity. However, the descriptive assessment about whether or not a person is using or weighing information is underpinned by a non-ethical normative judgment about the appropriateness of that decision-making process” (p. 1040).

The authors evoke future scientific (empirical) research and greater objectivity as a way forward for the refinement of the concept of capacity and its evaluation. Their claim masks the fact that future empirical research of capacity can only determine the extent to which a legal definition matches the way that people do make difficult decisions. No amount empirical research can tell us how people ought to make such decisions; that is a threshold we set as a society. Furthermore, empirical research on methods to evaluate capacity can only reveal the extent to which a given method – whether a clinical interview or an instrument – captures what we have already decided we want it to capture. Recognizing this makes it more transparent that capacity is a normative (legal) concept and situates it as a procedure required within a specific context rather than as a feature of a person. Continued reflection is the only way to determine what the appropriate definition of capacity should be in a context for requests for medical aid in dying and clinical experience with difficult cases will expose areas where a given definition is difficult to apply.

The authors ask the question whether mistakes are possible in doing capacity assessments. Indeed, their article can be read as expressing the fear that the wrong definition and assessment method of capacity will cost vulnerable people their lives. As we have argued, the word “mistake” is misplaced as there is no fact of the matter. But to their deeper point of whether there may be situations in which we later regret that we provided medical aid in dying to a person because s/he might have been incapable on an expanded definition, the answer is yes. This is a problem inherent to permitting medical aid in dying. Excluding patients with psychiatric disorders changes neither the uncertainty nor the normativity involved in defining and assessing capacity. It does restrict the population of people who can access this practice although it is not clear from what the authors have presented that all people with psychiatric disorders ought to be judged incapable of deciding whether to receive medical aid in dying. In the end, science can never ensure that there will be no regrets. The only way to achieve such a result is to forbid medical aid in dying. But this is no longer an option.

Footnotes

1. Charland and colleagues emphasize the capacity criteria used by the MacArthur Competency Assessment Tool (MacCAT) and the research that has been done on this instrument. Yet, it is worth noting that the MacCAT is not used routinely in clinical practice.

2. Reasoning ability does not figure in legal criteria for capacity in any province in Canada.
3. Although, earlier in the paper, they also express doubt about the validity of clinical evaluation stating that “...the current standard of care in the area is still the individual clinical judgment of the attending physician, which is highly subjective and can often be highly variable, especially in difficult cases.” (Charland et al p4).

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Acknowledgements: none

Competing Interests: none

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Date of Publication: November 18 2016