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Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders

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ABSTRACT

This essay is concerned with proposals to amend the Canadian criminal law to allow medical assistance in dying (MAID) to persons with a diagnosis of mental disorder. A key element in this process is that the person requesting MAID be deemed to have the 'mental capacity' or 'mental competence' to consent to that option. In this context, mental capacity and mental competence refer to 'decision-making capacity', which is a distinct area of clinical study and research in the theory of informed consent. The purpose of this discussion is to bring several controversial but insufficiently acknowledged issues associated with decision-making capacity to the forefront of the proposed extension of MAID to persons diagnosed with mental disorders. Open-ended access to MAID by persons who suffer from mental health conditions already exists in Belgium and the Netherlands, where the issues raised here are equally relevant.

Keywords: Decision-Making Capacity; Mental Capacity; Medical Assistance in Dying; Physician-Assisted Suicide; Autonomy; Palliative Care; Euthanasia, Criminal law; Mental Competence.

'the euthanasia doctor found in the pronunciation of the word 'huppakee' sufficient evidence for a clear and present desire to die'

Victor Lamme, "The Practice of Euthanasia Has Landed on A Slippery Slope. Huppakee Gone"
De Volkskrant (16 January 2016) translation:
https://trudolemmens.wordpress.com/2016/02/
Accessed March 23, 2016 10:*55 am*

Canadian Context

On June 10, 2014, the province of Quebec enacted Bill 52, its Act Respecting End-of-Life Care, which includes provisions permitting medical assistance in dying (MAID), situated in the general context of providing appropriate end-of-life care, including palliative care (Parliament of Quebec, 2013). Quebec thereby preempted the Canadian Supreme Court February 2015 *Carter v Canada*, which declared that the absolute prohibition in the Federal Criminal Code of MAID infringed the section 7 right to life, liberty and security of the person of the Charter of Fundamental Rights and Freedoms, without proper justification. The Supreme Court suspended its declaration of invalidity and gave the government first a year to implement a new 'strict regulatory regime' (Supreme

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Court of Canada, 2015), then in another ruling a prolongation of this suspension with another four months (Supreme Court of Canada, 2016). In the second judgment, it ruled that Quebec's Act Respecting End-of-Life Care, which only allows MAID in conscribed circumstances at the end of life, could be used to allow individuals to obtain MAID in the province awaiting final federal legislation. The second ruling also introduced an exemption clause for Canadians who wish to seek MAID outside Quebec and protection from criminal prosecution for physicians who provide it, through prior authorization by a Superior Court (Smith, 2016; Supreme Court of Canada, 2016).

Since then the ethical and legal landscape of end-of-life care in Canada has changed forever, even though it remains to be seen whether the short-term changes will be as sweeping as some have pushed for, or more restrained. To date, at least ten persons have requested and been granted MAID under the new Quebec law (Radio Canada, February 16, 2016). People from Alberta (Canadian Press, March 2, 2016), Ontario (CTV News, March 17 2016), and Manitoba (CBC News, March 15, 2016) have also already availed themselves of the Supreme Court exemption, through a request to the Superior Court, and received MAID. All of these patients were at the end of life and none of them was identified as suffering solely from a mental health condition.

Most recently, the federal government submitted Bill C-14 to the Federal Parliament (House of Commons of Canada, 2016), which must be adopted by the House of Commons and the Senate before the Supreme Court's deadline of June 6, 2016, expires. With the Bill, the government proposes to allow MAID — as the Bill terms it — for an adult competent person who suffers from a "grievous and irremediable medical condition," which is in line with the language of the parameters used in the *Carter* case. In order to prevent so-called suicide tourism, the Bill specifies that only people who are covered by provincial health insurance or will be so at the end of the mandatory wait-period, can have access. The Bill also appropriately provides a further definition of what constitutes 'grievous and irremediable', terms that the Supreme Court did not define, as it explicitly left it up to Parliament to develop the details of a regulatory regime that sufficiently protects those who are vulnerable (Lemmens, 2016a; Pothier, 2016a). People suffer grievously and irremediably, the Bill specifies, if (a) they have a serious or incurable illness, disease, or disability; (b) they are in an advanced state of irreversible decline in capability; (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining (Article 241.2(2)) (House of Commons of Canada, 2016).

Bill C-14 has been criticized from very different angles but clearly more so by those who felt that the legislation is too restrictive. Those who have been arguing for a more prudent approach to MAID have expressed overall agreement with the definition of 'grievous and irremediable', even if the vagueness of the 'reasonably foreseeable' natural death has been pointed out, but some of them have criticized the absence of a prior review system that would provide an arms-length assessment of MAID requests (Chochinov, 2016; Lemmens, 2016b). Editorials in the Globe and Mail (April 15, 2016), the Toronto Star (April 21, 2016) and the Montreal Gazette (April 14, 2016) lauded the government's 'cautious approach'.

Those who have been championing a more open-ended access regime have been critical of the detailed definition, since it largely limits access to MAID to end-of-life situations—however broadly defined— and does not appear to cover most situations of MAID requests on the basis of suffering from mental health disorders (Downie, 2016; Guichon, 2016; MacCharles, 2016; Picard, 2016). Indeed, it will be very exceptional that a psychiatric disorder will with some degree of certainty result in the reasonably foreseeable natural death of a person. They have also criticized the limitation of MAID to adults, without any access for mature minors. These critics, primarily health law and bioethics scholars (Downie, 2016; Guichon, 2016) and public commentators (Picard, 2016), have claimed that these criteria are not in line with the *Carter* decision, even if constitutional and other health law and bioethics scholars (including one of us, namely TL) argue that a more restrained approach as reflected in the Bill would be in line with the decision (Baker, Sharpe, & Lauks, 2016; Fremont, 2016; Lemmens, 2016a; Pothier, 2016a). In very strongly worded reactions, some parliamentary members have already announced that they will push for significant changes to Bill C-14, with some Senators even suggesting that they may prevent the Bill from being adopted before the deadline (Coyne, 2016). This would create a legal vacuum that would open the door to MAID without even the most minimal safeguards (Pothier, 2016b).

Among the most hotly contested issues in the parliamentary debate will certainly be whether the new legislation should include MAID on the basis of mental disorders and MAID access for mature minors. In fact, a Manitoba man suffering from depression indicated that he wanted to obtain MAID and is awaiting further federal legislation. Under the Quebec law, mature minors cannot request MAID, nor can people request access to MAID for purely psychological suffering. They are also not explicitly given access under the federal Bill—at least not for MAID on the basis of mental health conditions alone—, but a Joint Parliamentary Committee Report (House of Commons Special Joint Committee on Physician-Assisted Dying, 2016), as well as a Provincial-Territorial Expert Advisory Group (2015) preceding it have recommended to include in the new legislation the option to obtain MAID on the basis of mental disorder. We leave aside the case of mature minors for now in order to focus more exclusively on persons diagnosed with mental disorders, though often the issues we consider pertain to both.

If as a result of pressures to alter Bill C-14 the federal government would opt to adjust the Bill and go beyond Quebec's Act Respecting End-of-Life Care, in accordance with the recommendations of the Joint Parliamentary Committee (House of Commons Special Joint Committee on Physician-Assisted Dying, 2016) and the Provincial-Territorial Expert Advisory Group (2015), then persons diagnosed with mental disorders would be eligible to request and be granted MAID based on the suffering associated with those disorders. More precisely, they would be allowed to request and consent to the procedure, but only if they are deemed mentally capable to do so. But what exactly does it mean to say that someone has the mental capacity to consent to MAID? And how does that play out in the context of MAID? This is the problem that will concern us here. We focus primarily on how mental capacity to consent can be affected by mental illness, but our discussion is also relevant

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more generally for the MAID debate. Indeed, people who request MAID in the context of a catastrophic life-threatening illness or an accident that leaves them paraplegic, for example, may also have diminished capacity to consent based on the emotional turmoil and contextual factors that impact on their decision-making. Our discussion reveals, more generally, the kinds of challenges we are likely to face when we rely on assessments of 'mental capacity' in the context of requests for access to MAID.

Central Question

In technical medical and legal terms, 'mental capacity' in this context concerns the decision-making capacity of persons to consent to MAID. Decision-making capacity is also sometimes referred to as 'mental competence'. Different jurisdictions use variable terms in their health care consent laws and laws dealing with mental health issues (Charland, 2008b). This variable terminology creates a confusing situation for those accessing health care services and even health care providers. A further complication is that 'mental competence' is also often reserved for questions of criminal responsibility, which is not the same as decision-making capacity to consent to treatment. Yet, as just noted above, the term 'competence' is also often used to refer to decision-making capacity to consent to treatment, making it sometimes unclear what is really meant. Public education is essential in order to prevent and minimize confusion in this terminological and conceptual morass, which is nobody's fault, but simply reflects the evolution of the relevant law across different jurisdictions.

There is a single issue that absolutely must be discussed when one considers the role of 'mental capacity' in consent to MAID. The issue in question is present in all cases of consent to MAID. But it is especially acute in cases that involve persons diagnosed with mental disorders. It can be summarized in one question that is rarely explored in sufficient detail but is very practical indeed:

When, and under what circumstances, does a person seeking MAID have the mental capacity to decide to choose and consent to such a medical intervention? The question is absolutely fundamental since the decision-making capacity of an individual to consent to or refuse treatment is a pillar of our medical and legal system.

With some exceptions (Canadian Association for Community Living, 2016; Canadian Psychiatric Association, 2016; Claes et al., 2015; External Panel on Options for a Legislative Response to Carter v. Canada, 2015; Kim, De Vries, & Peteet, 2016; Lemmens, 2016a; Picard, 2015; Wente, 2014), medical specialists, professional organizations, law-makers, two of the committees set up in the wake of *Carter* (House of Commons Special Joint Committee on Physician-Assisted Dying, 2016; Provincial-Territorial Expert Advisory Group 2015), and academics, have in general failed to adequately point out the practical and ethical challenges embedded in this question. In particular, even the exceptions mentioned above do not discuss the detailed state of science in this area and its remaining limitations – which is the focus of the present discussion – even though they raise concerns about the problems of relying on capacity and informed consent to determine access to MAID. One could argue that the general public and law-makers have thus not been adequately educated and prepared for proper discussions on the challenges we will face, particularly when we rely on the concept of 'mental capacity' for more drastic life-ending interventions. Perhaps this is because the technical literature and current institutional practices that surround the assessment and determination of decision-making capacity, specifically, are so complex and specialized. Whatever the case may be, and while this obviously already raises questions about current end-of-life medical practices, the assessment of capacity as a tool for accessing life-ending interventions raises the stakes for all of us. Discussion is in order.

The point then is that it is impossible to properly assess the implications of this sweeping legal extension of the 'right to obtain MAID' to persons diagnosed with mental disorders, or indeed mature minors, without some basic knowledge of what decision-making capacity is and the state of knowledge and research in the area. We must know how decision-making capacity is assessed and how exactly it figures in consent.

All of this is true no matter which side of this debate one ultimately chooses to support. Knowledge of current policies and practices is another equally important area to consider, but falls outside the bounds of this essay, which focuses primarily on theory and current knowledge and research only. New institutional practices and paperwork and appeal processes will form an important part of the hurdles and challenges any new legislation of this sort must face. Changing job descriptions and training are part of this. Decision-making capacity is therefore a theoretical concept with enormous practical ramifications that range from institutional procedures, to forms and questionnaires, training, administration, and record keeping, and so on. Yet the concept and its practical implications are hardly mentioned in discussions of MAID, which tend to be very general and ideological and conveniently overlook practical details. This, however, is a practical question with a parlaying theoretical sting, as problems here could quite simply vitiate core assumptions in debates surrounding MAID to date: notably, that 'mental capacity' can be reliably and fairly assessed.

More specifically, there are two reasons why decision-making capacity is important to debate on end-of-life care. First and most obvious, people need to be properly informed about these matters in order to fully participate in consultations and make up their minds about the end-of-life care options they desire. Second and less obvious, is the fact that the determination of decision-making capacity is actually a matter of considerable controversy among many researchers and clinicians.

It is true that there has been much scientific and clinical progress in this domain since the first psychometric test for 'mental competence' was developed in 1975: the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975). But there is still much disagreement about how to ensure determinations of capacity are conducted in a scientific manner, with reliable and objectively verifiable procedures, even with the new tests we have (Berghmans & Widdershoven, 2003; Breden & Vollmann, 2004; Charland, 2006, 2008b; Howe, 2009; Owen et al., 2013; Tan, Stewart, Fitzpatrick, & Hope, 2006; Zapf & Roesch, 2005). Canadians must be aware of these controversies as they attempt to inform themselves about the nature and implications of this newly proposed legislation and seek optimal end-of-life care for themselves and their loved ones. Since only psychiatrists and concerned legal experts are usually aware of the difficulties, health care providers in general also need to be educated on the matter.

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One point in particular needs to be stressed at this time, which it would be dangerous to overlook.

It is doubtful that our current knowledge and practices governing the determination of decision-making capacity will be able to bear the weight of the new federal legislation. Despite scientific advances like the above, 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. In addition, most health professionals receive little or no training in this area. As things stand, then, difficult cases and challenges could multiply quickly and we need to realize this when contemplating new legislation, and be prepared for this if the legislation extends to some more controversial areas. A brief review of current health care legislation and procedures surrounding decision-making capacity to consent to treatment should illustrate why this is so and why caution is in order.

Philosophically this is a case where one cannot divorce the means from the ends, since the means may ultimately interfere with our ability to attend the desired ends. Without a workable theory and method for the assessment of decision-making capacity, the right to MAID will be open to arbitrary abuses and challenges. Let us see why.

Decision-Making Capacity

According to contemporary law and ethics, decision-making capacity is one of the core elements of the doctrine of informed consent (Lemmens, 2015). Each province and territory has its own health law but the essentials remain the same across jurisdictions. The 1996 Ontario Health Care Consent Act is a good example of consent legislation with standard provisions related to decisional 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; and (d) not be obtained through misrepresentation or fraud (Hiltz & Szigeti, 2004; Ontario Government, 1996).

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' (Hiltz & Szigeti, 2004; Ontario Government, 1996). Similar provisions can be found in other provinces and legal jurisdictions in Canada.

While consent to medical treatment can arguably be seen as being of a very different nature than consent to MAID, the same basic conditions are very likely to apply. An 'opinion' of the mental capacity of the person seeking MAID is required of the practioner in both cases. Like medical treatment, MAID requires a determination of the mental capacity of a person to consent to the intervention in question. More exactly, it requires an 'opinion' on their decision-making capacity to make that particular decision, at that particular time, in those particular circumstances.

Unlike determinations of cognitive status and mental ability made with the Mini-Mental Exam which provide a global measure of mental capacity, the law now requires determinations of capacity to be decision specific (Hiltz & Szigeti, 2004; Ontario Government, 1996); that is, relative to a particular decision, for a particular person, at a particular time, facing a particular treatment decision. The law also insists that determinations of decision-making issue in a binary – yes or no – threshold formulation.

But how exactly is decision-making capacity determined? Is it simply a matter of subjective clinical judgment, an 'opinion' of a particular practioner, on a particular case, on a particular occasion? Are mistakes possible and how do we adjudicate cases where professional opinions differ? These are not new questions and in some provinces and jurisdictions there are regulations and procedures to deal with challenges that occur when mistakes are made or opinions differ (Consent and Capacity Board (Ontario), n.d.). However, problems that arise in such cases are likely to be exacerbated with the proposed extension of MAID, which will doubtlessly create new problems of its own. A major reason is that the outcome can be an irreversible life-ending practice. In fact, there already exist concrete, documented, controversies of the kinds of challenges that would likely arise if the federal government were to proceed with the proposed extension of the Quebec law on MAID and extend it to cover persons diagnosed with mental disorders. The challenges fall in four different areas: methodological, theoretical, ethical, and philosophical. Overlap is possible and in both practice and theory a challenge may pose problems in all domains.

Methodological Challenges

Probably the best and most popular measure of decision-making capacity to date is the MacArthur Treatment Competence Assessment Tool developed by psychiatrist Paul Appelbaum and psychologist Tom Grisso. Their account of capacity is published in a small and very popular book entitled, *Assessing Competence to Consent to Treatment: A Guide for Physicians and other Health Professionals* (Grisso & Appelbaum, 1998). The version of the MacArthur assessment tool they present in that book was explicitly developed in order to reflect and comply with widely accepted developments in the relevant law on consent, which in this respect is quite similar across North American jurisdictions.

The assessment instrument Appelbaum and Grisso outline has been extensively tested and validated and is currently the gold standard for the assessment of decision-making capacity in the medical clinical and research literature. Unlike the Mini-Mental State Examination, the semi-structured MacArthur interview questionnaire does not assess 'global competence'. Instead, it ties competence to individual particular decisions made at a particular time in a particular context. This is important since capacity can change over time and not all decisions require the same degree of capacity. High risks decisions require more scrutiny, time, and detail than low risk decisions. This can be problematic and practically cumbersome and confusing when dealing with challenges or problems surrounding capacity that stretch over long periods of time where circumstances change. Not to be forgotten is the fact that the MacArthur instrument itself is also rather

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cumbersome compared to the Mini-mental Examination and takes considerably longer to administer: approximately 20-30, compared to 10-15 minutes. It also requires substantially more training.

Theoretical Challenges

Because it is designed to reflect and comply with existing health law on consent, the MacArthur Instrument is clearly legally biased. Like the law, it focuses on the cognitive abilities that underlie decision-making and reasoning. This is normally thought to be a virtue – even a requirement – of such a test. However, an instrument designed to capture the full scope of human practical decision-making could reasonably be expected to go beyond the MacArthur test in certain ways.

Emotion is a case in point and even the authors of the MacArthur test seem prepared to concede this (Appelbaum, 1998, 2006, 2007). The question is: 'Can an instrument modeled on the cognitive bias of the law do justice to the facts of everyday practical clinical decision-making in the context of decisions to consent to treatment or MAID?' Such decisions are likely to be greatly influenced by emotions as well as underlying values of the individual making them (Charland, 1998a, 2001). Emotion arguably plays an even more dominant role in the context of end-of-life decision-making. Can, and should, the MacArthur test adequately capture these facts of decision-making?

According to the MacArthur theoretical model, treatment decisions are comprised of four cognitive abilities:

(a) understanding the facts that are involved in the decision at hand; (b) appreciating that those facts and the decision itself pertain to oneself; and (c) rationally weighing consequences of those facts and that decision as they relate to oneself. There is also a forth component which is not so obviously cognitive in nature but is obviously practically essential: (d) being able to express a choice. As it is explained by its authors, the Macarthur model is clearly cognitive in orientation. And of course cognitive reasoning and abilities are essential to sound decision-making.

But now consider this. Treatment decisions are often made on the basis of hope. Hope, for example, can be present or absent, reasonable or unreasonable, appropriate or inappropriate (Charland, 1998a, 1998b). It is not entirely irrational but is susceptible to rational scrutiny. As philosophers say, emotions often function as reasons for actions, and such reasons can be judged good or bad, rational or irrational. The point is that they are never non-rational or a-rational: that is, not susceptible to rational assessment and scrutiny. Emotions such as hope, anger, joy, sadness, fear and many others, are all open to such an analysis. They also often play a major role in health care decisions to consent to or refuse treatment, and consent or refusal of MAID.

In sum, it is hard to deny that the presence or absence of emotion both can, and often does, influence and motivate decision-making in very different but quite specific ways. Yet at present there is no consensus or theoretical vision on how to incorporate such facts into the MacArthur model. Who decides whether hope is appropriate or not and how do we determine this? It all looks very subjective and personal. Discussion of such matters is just beginning and the way forward is certainly not clear, although there seems to be agreement on all sides that the issue is worth exploring (Breden & Vollmann, 2004). This perhaps is an appropriate point to emphasize that, despite the great success and practical value of the Macarthur Test, theoretical and clinical research on decision-making capacity is nonetheless in a very early stage.

To emotions we must add feelings and moods, which are other components of the affective life. Like emotions, they also influence cognition and motivate decision-making. All of these components of the affective life are deeply subjective and personal. Even though they can be objectively studied to some extent, whether they are reasonable or unreasonable, appropriate or inappropriate, is a normative question that defies easy resolution in objective terms.

Not to be forgotten are passions. These are affective syndromes that direct and organize emotions and feelings in accordance with a fixed idea (Charland, Hope, Stewart, & Tan, 2013; Charland, 2010, 2013). In contrast to feelings and emotions, which are affective states of relatively short duration, passions can extend for weeks and months and even years. Passions are essential to the human pursuit of meaning in life but they can also veer into psychopathology and come to morbidly dominate the affective life.

William James famously cites the passion of willingness – 'willingness to be' – and a passion of acquiescence as central affective components of the recovery process from serious physical and mental illnesses (James, 1902). Théodule Ribot, another pioneer of modern scientific psychology who was well-known to James, took the passions equally seriously and considered them necessary components of any adequate theory of the affective life (Ribot, 1907).

Since passions are so fundamental to questions of the meaning of life, they would seem to be important to any assessment of decisions to consent to end life, like MAID. After all, passions are largely what motivate us to pursue some ends rather than others. Yet at present there exists no way to incorporate such considerations in our cognitive tests to assess decision-making capacity.

Values are also central to decision-making since they are essential to weighing risks and benefits (Buchanan & Brock, 1998; Charland, 2001). But again, who decides which values are the right ones and how? Decisions to seek MAID are obviously deeply tied to personal and sometimes societal and cultural values. But this too looks highly subjective and personal. At times, values can also be warped by disease and illness. Anorexia nervosa is a case in point, as is addiction (Charland et al., 2013; Charland, 2001; Tan et al., 2006).

A person suffering from chronic treatment resistant depression might as a result acquire pathological values and simply cease to care for themselves and their future (Rudnick, 2002). They might also as a result abandon the passions that have brought meaning to their life and fall subject to new morbid passions associated with guilt and dejection. Importantly, values vary with cultural assumptions and mores, which makes their assessment difficult in multi-cultural societies.

So, apparently both the affective components of decision-making and our values are inextricably involved in practical decision-making. They influence, motivate, and direct our preferences

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and express what is meaningful to us and why. As such, they are fundamental and one would think ineliminable from medical treatment decision-making, especially decisions to request and consent to MAID.

Yet on its own, cognition simply consists in understanding, appreciation, and rational manipulation of facts, which of course is also fundamental. However, it does not move us to choose to decide anything in particular or even anything at all. In other words, without values, emotions, moods, feelings, and passions, our cognitions are basically pointless and powerless. Therefore, a model of decision-making that relies exclusively on cognitive abilities seems very incomplete as a model for practical decision-making capacity in treatment contexts of the sort that is required here.

On the other hand, are we going to let persons with obviously pathological values, emotions, feelings, and passions, decide for themselves if they can pass simple tests for cognitive reasoning like the MacArthur test? What about borderline cases? There is at present no scientific model or theory of decision-making capacity that can provide answers to such questions. That does not mean that everything goes, since 3rd party agreement and consensus provides some means of practically securing objectivity of some sort (Charland, 2001). But then experts must say so and the public must be informed accordingly. This is a case where it is not only wrong but also impossible to hide behind the purported scientific objective status of 'rating scales' and 'structured interviews' and the public deserves to know this.

The impact of emotions such as hope, frustration, anger, on decisions related to health care makes it all-the-more problematic to integrate directly in a new statute, without further specification, the Supreme Court's all-too-brief explicit confirmation in *Carter* of the right to refuse treatment and opt for MAID. In the declaratory part of the judgment, the Court clarifies that its reference to the 'irremediable' nature of a health condition as a requirement for access to MAID "does not require the patient to undertake treatments that are not acceptable to the individual." (para. 127) (Supreme Court of Canada, 2015) The right to refuse treatment is a widely accepted principle, of course, in health law and bioethics.

In our view, there is in and of itself currently insufficient attention given to how emotions such as a lack of hope in the outcome of continued treatment could impact on decision-making capacity and influence a patient's decision to refuse further treatment. Lack of hope may impact on treatment refusal and become much more problematic when directly connected with the option to ask for MAID in a system without other restrictions on access. When patients refuse treatment in standard medical care situations, the decision is most often not immediately final, and further communication with the patient can result in a reversal of the treatment refusal. But by connecting the right to refuse treatment with an option to obtain MAID, a mere temporary loss of hope could lead to the performance of a drastic life-ending action, even if the reason for refusing would by most standards be considered 'unreasonable' and even if with adequate and sustained support, hope could be restored overtime. An emotionally exhausted patient who is nevertheless deemed competent could thus refuse effective treatment for an easily treatable condition, and at the same time, choose to have her life ended by a medical professional. This example makes it clear why a more independent assessment of the reasonableness (emotional and otherwise) of a request for MAID, involving an assessment of vulnerability, seems more appropriate. It also makes it clear that obligatory wait-periods (adjusted in situations of urgency) reflect an appropriate cautious approach.

A further important component is that clearly more so than in other areas of medical practice, MAID also involves the integrity and emotional judgment of others, in particular health care providers.

Ethical Challenges

People clearly have very strong ethical opinions about the appropriateness of MAID in general or further making it available to persons diagnosed with mental disorders. At times strong passion, feelings, and emotions dominate the debate, likely also because it is a debate that affects so many individually and as family members of people affected by mental disorders.

Medical and legal professionals, academics, bioethicists, representatives of religious groups, and members of advocacy organizations also have strong personal opinions or feelings. People seeking help and information regarding MAID must be protected from undue influence and ideological manipulation. In such a case, persons seeking or using health care services have the right to balanced advice or at least a declaration of people's ethical attitude towards the issues and their potential conflicts with regards to providing appropriate care, information, or referral in this context. This is emphasized in the recently developed Vulnerable Person Standard (n.d.), which states that 'in all discussions related to physician-assisted death with the patient, neutral, independent and professional interpretation services, including ASL/LSQ [American Sign Language/la langue des signes Québécoise], must be provided as required' (Safeguards, para.9) .

An ethical conflict of interest can exist when a medical professional or other important individuals involved in the provision of information on MAID inadvertently or willfully withholds, or fails to declare, the fact that they have strong personal ethical opinions on the case at hand that may impact on what information they can or will convey about that case, their recommendations, and the options that are available. Bioethicists in particular are famous for asking other health care professionals to declare their conflicts of interest when those conflicts may affect the information they provide or the decisions patients ultimately make. They seem to forget that they may themselves have ethical conflicts of interest of this sort which need to be openly shared and declared (Charland, 2008a). Ironically, there is no provision for ethical conflicts of interest in ethical codes for bioethicists. This must change if we want to trust bioethicists to provide advice and leadership in this context.

Every health care or other professional who is involved with the delivery of MAID must declare their own personal ethical or religious opinion and record of practice on MAID, when these may influence the recommendations they make or the information they provide. Clinicians, counselors, bioethicists and legal professionals who are often involved in the adjudication of challenges and difficult cases should be especially transparent on this matter.

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Philosophical Challenges

Health care law and ethical theory in Canada are dominated by the philosophical ideal of the autonomous self-determining individual, who at the same time is portrayed as an ideal cognitive rational agent. This ideal derives from the work of the German philosopher Immanuel Kant who is also widely cited as the author of the philosophical doctrine of respect for persons. According to this view, we should always treat persons as ends in themselves, and never merely as a means.

We in the West live in an age of autonomy. In considering MAID, it is important to be aware that this is not the only way to approach health care decision-making. Collectivist societies differ on this approach and members of such cultures in a multi-cultural society like Canada may feel uncomfortable with such an approach and espouse different fundamental values. Within our own society, feminist scholars have done much to promote and defend the ideal of relational approaches to decision-making in health care contexts (Sherwin, 1992). But within the relational approaches to decision-making, autonomy is still a key concept, and some seemingly defend it at all costs (Gans & Gunn, 2013). It is also interesting to note that some of those who have argued strongly for a more contextual and relational approach in other areas of bioethics and health law (Downie & Llewellyn, 2011) appear to promote in the context of MAID a narrow individual right and seemingly atomistic autonomy-based approach (Downie, 2004). Despite the more relational approaches to health care decision-making, a narrower concept of autonomy has a firm foothold in Canada and that is unlikely to change in the short term. Its wide appeal is also reflected in and reinforced by law because it is easier for courts and legislators to work with a 'one-dimensional' concept of autonomy (Lemmens, 2015).

In this kind of ideological climate, the celebration, promotion, and protection of individual autonomy is pivotal – a kind of bottom-line assumed by everyone and a collective passion shared by many, which is reflected in society and its institutions. With regards to research and findings that relate to decision-making capacity, this raises the question whether assessments of capacity made in such a cultural and institutional environment, and the instruments used to assess it, are sufficiently free from a bias that favors autonomy, so that they can be trusted.

In point of fact, decision-making capacity is a rather mercurial theoretical concept, in that it has both descriptive and normative elements, which can often vacillate back and forth ambiguously (Charland, 2001). 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. Furthermore, psychometric instruments developed to measure capacity, must invariably build on some accepted assumptions or established pre-theoretical intuitions regarding what exactly those instruments are designed to capture theoretically – that is, paradigm cases of capacity and incapacity (Charland, 2006). Often, the law functions as the basis – a minimum ethic, if you will – for such paradigm cases, although ironically, it is also where challenges to such paradigm cases arise, and are sometimes overturned, and new, different, paradigm cases, are suggested (Charland, 2008b). The predominantly cognitive orientation of the law, therefore, exerts a strong cognitive bias on the manner in which decision-making capacity research and its instruments are formulated and deployed (Appelbaum, 1998).

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 (Appelbaum & Grisso, 1995; Grisso, Appelbaum, Mulvey, & Fletcher, 1995; Grisso & Appelbaum, 1995). Further research on capacity has shown that individuals diagnosed with mental disorders like depression (Hindmarch, Hotopf, & Owen, 2013), schizophrenia (Kaup, Dunn, Saks, Jeste, & Palmer, 2011), and addiction (Moran-Sanchez, Luna, Sanchez-Munoz, Aguilera-Alcaraz, & Perez-Carceles, 2016) are not necessarily, for that reason, incapable of consenting to treatment, or to participate in research. These findings support the cause of autonomy and were no doubt carried out with the best of intentions and care to avoid biases or any other confounding variables.

Nonetheless there is still reason to worry whether there might be biases imported from the general context of research and the culture and institutions in which it takes place. 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 speaking (Charland et al., 2013; Charland, 2015; Tan et al., 2006). These findings suggest that despite the fact that the instruments we use to assess decision-making capacity are widely accepted and satisfy normal canons of scientific rigor, they can issue in false positives; that is, cases where individuals are deemed to be capable to consent to or refuse treatment, but should not be.

This brings us back to the pre-theoretical paradigm cases alluded to above, which are largely cognitive in their orientation, and inherited from the law. In this particular anorexia study, the individuals in question satisfy standard measures of understanding, which are mostly cognitive, but fail on appreciation measures, for reasons that have to do with pathological values that arise from their disease, and the general affective orientation it imposes on their lives. Appreciation, indeed, appears to be central and difficult to ascertain in the assessment of decision-making capacity and the generation of determinations of incapacity (Grisso & Appelbaum, 2006; Owen et al., 2013; Vollmann, 2006). One way to explain this is to suggest that appreciation is more closely tied to affectivity and values than to understanding and that, as things stand, current instruments fail to capture the contribution of affectivity to capacity sufficiently well.

This very brief and highly selective sketch of the history of decision-making capacity research, and some of its clinical findings, is admittedly oversimplified and requires much elaboration and appraisal. Nonetheless, it should be sufficient to show that this is a scientific domain in its infancy, subject to powerful cultural and other societal and institutional pressures, which may result in biases of many sorts, at many levels, including, notably, a cultural bias in favor of autonomy. There is a need to balance autonomy as a fundamental right against its consequences.

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Interface with Palliative Care

Quebec Bill 52 (Parliament of Quebec, 2013) references palliative sedation and MAID back to back as part of end-of-life care. To date, however, the palliative care community has not necessarily been favorable toward MAID (Barutta & Vollmann, 2015; Gallagher, 2016). For example, a qualitative study investigating the impact of legalizing MAID in Belgium and Netherlands revealed that palliative care providers perceived palliative sedation (which lowers the patient's consciousness in order to alleviate otherwise untreatable and unbearable symptoms) as a preferable alternative to MAID (Seymour, Janssens, & Broeckaert, 2007).

Professional bodies in palliative care domains largely do not consider MAID within their scope of practice while they do endorse palliative sedation as a treatment (American Academy of Hospice and Palliative Medicine, 2014; Canadian Hospice Palliative Care Association, 2010; International Association for Hospice & Palliative Care, 2016; Royal Dutch Medical Association, 2009; Verkerk, van Wijlick, Legemaate, & de Graeff, 2007) despite the controversies over its potential life shortening effect (Claessens, Menten, Schotsmans, & Broeckaert, 2008; Janssens, van Delden, & Widdershoven, 2012; Seymour et al., 2007). Position statements by these professional bodies maintain that palliative sedation and MAID are different, the former aiming at symptom relief whereas the latter aiming at bringing death (American Academy of Hospice and Palliative Medicine, 2014; Canadian Hospice Palliative Care Association, 2010; International Association for Hospice & Palliative Care, 2016; Royal Dutch Medical Association, 2009; Verkerk et al., 2007). The attitudes of health care professionals in palliative care illustrate their aversion to hastening death, even in situations where death is imminent.

The patient's decision-making capacity has been an issue in providing palliative sedation (Royal Dutch Medical Association, 2009) as a variety of external and internal factors including physical and mental conditions may influence decision-making capacity (Etchells, Sharpe, Dykemna, Meslin, & Singer, 1996; Roberts, 2002). As stated in Quebec Bill 52 (Parliament of Quebec, 2013) and in a guideline by the Royal Dutch Medical Association (2009), palliative sedation may be administered by consent of a substitute decision maker (SDM) when the patient is deemed incapable. Additionally, the Dutch guideline (Royal Dutch Medical Association, 2009) recommends clinicians discuss palliative sedation at an earlier stage when patients are likely to be capable (if the patient agrees to such discussion occurring).

Regarding MAID for terminally ill patients, some legislations require the patient to provide consent and do not allow SDM consent (Northern Territory of Australia, 1995; Oregon Government, 1997; Parliament of Quebec, 2013). Considering psychiatric disorders that may impair the patient's judgment, the Oregon Death with Dignity Act (Oregon Government, 1997) requires an evaluation by a psychiatrist or psychologist when such disorders are suspected. The Rights of the Terminally Ill Act (Northern Territory of Australia, 1995) requires a psychiatrist's evaluation for all cases to rule out treatable depression. These stipulations provide a safeguard based on a recognition that psychiatric disorders may compromise the patient's decision-making capacity, are associated with suicide, and are often treatable (Ganzini, 2000).

However, determination of decision-making capacity of terminally ill patients may be challenging due to little evidence-based knowledge about the influence of psychiatric disorders among other conditions on their decision-making capacity as well as the lack of standards for assessment (Sullivan, Ganzini, & Youngner, 1998). Without a robust standard to examine decision-making capacity, a psychiatrist may be making a judgment based on whether the patient's wish to die is reasonable or not, rather than the process of reaching the decision to request MAID (Sullivan et al., 1998). A questionnaire completed by 290 forensic psychiatrists in the United States uncovered that 78% preferred a stringent standard for capacity assessment; importantly, those who perceived MAID as unethical showed a higher rate in choosing the stringent standard compared with those who perceived MAID as ethical in all or some cases (Ganzini, Leong, Fenn, Arturo Silva, & Weinstock, 2000). These results imply that the particular psychiatrist's view on MAID may influence the determination of the patient's decision-making capacity.

A brief overview of the issues revolving around informed decision-making for MAID (and palliative sedation) may indicate that a patient with psychiatric disorders severe enough to be eligible for requesting MAID likely requires capacity assessment which is complex and without an agreed on standard. Further, in contrast to the palliative care context, the vagueness of criteria regarding the exhaustion of treatment resources (Fekadu et al., 2012; Vergunst et al., 2013) and the possibility of shortening a person's life in some cases by a number of years add serious concerns.

Evidence from Belgium and the Netherlands

The evidence from Belgium and the Netherlands demonstrates, in our view, why it is problematic to rely on capacity assessment by individual physicians in the context of MAID, particularly when access-criteria are open-ended and physicians have significant discretionary powers to decide who should have access to MAID. MAID is in those countries increasingly performed outside of the paradigm, largely end-of-life cases that were initially invoked to support claims for legalization. Case-reports reveal that it is increasingly being performed on people whose decision-making capacity may be affected by various factors that render them vulnerable and may undermine meaningful autonomy.

For example, a growing number of people who expressed concern about becoming dependent on others and who are worried about loneliness and decline of quality of life, emotions which may impact on capacity, are being euthanized (Hamilton, 2015; Lippens, 2015). Theo A. Boer, a former member of one of the Dutch regional review committees, who as recently as 2011 defended Dutch euthanasia practices, now raises concerns about the growing number of people who request euthanasia because they are lonely and isolated, including elderly couples who express the desire to die together out of concern about the future (Boer, 2015, 2016; Humo, June 17, 2014; Verbakel, 2009). Fear for future dementia also appears to push many people to request euthanasia (Lemmens, 2016a). But concerns about capacity assessment are even more prominent in the context of euthanasia for mental health conditions, which is significantly increasing in Belgium and the Netherlands. In Belgium, euthanasia for neuropsychiatric disorders has increased

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from 1.2% of cases in 2004/05 to 3.7 % (of 67 cases) in 2013/14. There are also other indications that the number of people with mental illness expressing an interest in MAID is significantly increasing in Belgium (Lemmens, 2016a).

Two studies published in the medical literature give us more information about the practice of euthanasia involving mental health patients in Belgium and the Netherlands. Both studies raise concerns about whether capacity assessment functions as a sufficient safeguard. A 2015 study in BMJ Open discusses euthanasia requests of 100 Belgian patients who were assessed in the clinic of one consulting psychiatrist between 2007 and 2011 (Thienpont et al., 2015). The authors state that "[a]ll patients were legally competent under the Law. Each patient's capacity for discernment was evaluated during the process . . . according to explicit criteria described in the Belgian Legal Doctrine." The legal criteria in Belgium are along the same lines of what we discussed above. But considering the wide variety of disorders patients suffered from, including mood, personality, post-traumatic stress, anxiety, eating disorders, schizophrenia, addiction, autism (Asperger syndrome), and complicated grief, most with co-morbidities, it is remarkable that capacity is simply asserted in the publication without any discussion or even acknowledgment of the complexity of determining decisional capacity in this population of patients (Thienpont & Verhofstadt, 2016). The authors also suggest that "[i]n all patients, the suffering was chronic, constant and unbearable, without prospect of improvement due to treatment resistance" (p.5) (Thienpont et al., 2015). Yet, the outcome of the study (37 patients euthanized out of 48 approved; 38 withdrawals of requests out of 100 applied; 11 postponing of euthanasia after request granted; and 5 independent suicides) raises serious doubts about the original determination of being 'treatment resistant,' the absence of possible recovery, and the capacity of all people.

In a letter to the editor, a group of Belgian psychiatrists, psychologists, and ethicists question various components of the study, including the capacity assessment in this highly vulnerable population, the high rate of approval of the requests and the all-too-easy determination of treatment resistance. The authors of this letter also point out how the study shows that one psychiatrist appears primarily responsible for most of the euthanasia cases of mental health patients in Belgium (Claes et al., 2015). This last issue is a serious warning sign for any other jurisdiction that contemplates providing access to MAID on the basis of vague criteria and with capacity assessment by individual physicians as a primary safeguard for access to MAID: a handful of physicians could change the practice of MAID and provide access in areas where most other physicians would not want to venture. Vague criteria make it then also very hard to provide further professional or legal control and sanction of those individual practices.

Another study, by Scott Kim and colleagues, focused on individual case summaries of persons who received MAID for psychiatric disorders in the Netherlands (Kim et al., 2016). The study reveals that, as in Belgium, euthanasia is performed on people with a variety of psychiatric conditions: severe depression, psychosis, cognitive problems, autism, grief, and other disorders. The authors report that more than 50 % of the cases involved people who were lonely and isolated. The study also shows that there is frequent disagreement among the physicians involved about the question whether the regulatory criteria for MAID are met and that the reporting system does not explain how these disagreements are solved. The justification for providing access to MAID is limited in the reports. With regards to capacity assessment, the reports provide little information about why patients were deemed to have capacity. The authors also found that there was often disagreement about the patient's capacity to consent to MAID, and that in a significant number of cases, no independent psychiatrist reviewed the clinical assessment and capacity assessment.

At a time when Canada and other jurisdictions are contemplating legalizing MAID, it is worth pointing out that opposition against some components of the euthanasia practice is growing in Belgium and the Netherlands. For example, a group of 65 Belgian psychologists, psychiatrists, other health care professionals and ethicists published an open letter and op-eds, asking that psychiatric conditions be removed from the Euthanasia Law as a basis for MAID, even though other scholars responded by expressing their support of current practice (Bazan, Van de Vijver, & Lemmens, 2015a, 2015b; Bazan, 2015a, 2015b; Braeckman, Ravelingien, & Boudry, 2015). They did so after family members of a 38-year old woman went public with a complaint about the manner in which their daughter and sister had been euthanized, in troubling circumstances in the presence of her upset family. Tine Nys had suffered from mental health issues in her younger years, and she had been treated at that time. She had, however, been doing fine for more than 15 years until the break-up of a romantic relation. She was seen by a psychiatrist, and requested access to euthanasia shortly after entering into the treatment relation. Two months later, her psychiatrist diagnosed her with autism and ruled that she fulfilled the criteria of the law. The psychiatrist also deemed her to be competent, although she appeared to have been very distressed.

Recently, in the Netherlands, there was public outrage, reflected in several editorials (Lamme, 2016), after the broadcasting of a television documentary that followed doctors working for a specialized end-of-life clinic, which offers life-ending services when family physicians refuse to be involved. It showed the final days of three different people, including Hannie Goudriaen, a woman diagnosed with dementia who seemed incapable of adequately communicating, but who otherwise appeared to have a decent quality of life. In the documentary, she is seen attending a skating competition, driving her car, and having a drink in a bar. Yet her husband insists she wants to die, and the doctor finds in her meaningless expression "Huppakee weg" ('Huppakee gone,'), about the only thing she appears to say, a legitimate confirmation of her prior advanced directive, signed 5 years earlier. In the documentary, Ms. Goudrien appears distressed, confused about what is happening, and suddenly utters 'this is horrible' before she dies, after the doctor injects her with a lethal dosage. Another case involved a 100-year old woman whose primary problem appeared to be that she was lonely and isolated. Dutch commentators expressed outrage at the practices reflected in the documentary and suggested that there was a need to tighten the practice of euthanasia in the Netherlands (Lamme, 2016; Rutenfrans, 2016).

In the coming weeks, the Canadian Parliament will debate the extent to which people will have access to MAID in Canada. Under the current provisions of the Bill, persons diagnosed with mental disorders will not be able to request MAID purely on the basis of their disorder, but pressure to extend the legislation appears

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significant. Even if MAID on the basis of mental disorder is not included in the current legislation, there will likely be proposals to include it at a later stage. The considerations and worries outlined above will be relevant for any future discussion about the wisdom of providing access to MAID on the basis of psychiatric disorders, including in any further litigation that may ensue and in which arguments will be made about the reasonableness of excluding certain categories of illness from the legislation. In and of itself, our arguments are also relevant for any discussion of relying on the assessment of decision-making capacity as the main safeguard for determining whether someone should have access to MAID.

Conclusion

The methodological, theoretical, ethical, and philosophical controversies outlined above throw doubt on the manner in which decision-making capacity determinations are made. After all, this is a very young science, and standards and assessment procedures for the determinations of capacity may change as the science evolves. Certainly there is cause for concern in the fact that the current gold standard in decision-making capacity unilaterally treats people as cognizers when they are also emoters. The law may very well arbitrarily choose to look at decision-making exclusively through the lens of cognition. However, any empirically adequate clinical model of human decision-making must also include feelings and emotions. Especially in a context like the present one, namely, decision-making capacity to consent to MAID.

Under these conditions, it is very doubtful that our current means for assessing decision-making capacity can bear the weight of the proposed extension of the right to die to persons who request MAID because of their mental health condition, which is being discussed in the context of the new federal legislation due June 6, 2016. We have been able to largely ignore and overlook the challenges outlined above to date, because controversies associated with capacity have been relatively few and far between, have in relation to MAID occurred in other jurisdictions and been publicized in other languages, and usually fail to capture the interest of the public at large. That situation is likely to change as the large influx of cases caused by the proposed new legislation expose the ethical and philosophical biases of our research on decision-making capacity and its theoretical and methodological limitations. Nascent science, inadequate regulations, economic pressures and incentives, and an overly zealous commitment to autonomy and individualism at all costs, make us worry whether autonomy may actually be turning on its own and is poised to devour its most vulnerable subjects (Charland, 2004).

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