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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

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Katharine Birkness[a], Abraham Rudnick[b,c]

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Mots-clés
éthique, (ir)remédiabilité, aide médicale à mourir, AMM, maladie mentale, principisme

Abstract
Medical assistance in dying (MAiD) is scheduled to be legalized in Canada as of March 2024 for individuals with mental disorder/illness as their sole underlying medical condition (MAiD MD-SUMC). As guidelines are being developed for the safe and consistent provision of MAiD MD-SUMC, sufficient consideration must be given to the interpretation of ambiguous terminology in current legislation, and to ensuring sound use of acceptable ethics principles in these interpretations.

Keywords
ethics, (ir)remediability, medical assistance in dying, MAiD, mental illness, principlism

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INTRODUCTION

The choice as a medical practitioner to provide medical assistance in dying (MAiD) requires extraordinarily careful deliberation given the significance and finality of the intended outcome, i.e., the relief of intolerable suffering in life by means of the provision of care to facilitate death. There are thus criteria encoded in law that must be met for MAiD to be conducted. These legal criteria are related, but not identical, to ethical considerations such as those encoded in the Canadian Medical Association's Code of Ethics. This document endorses autonomy (respect for self-determination of persons with health challenges), beneficence (maximizing positive outcomes such as well-being of persons with health challenges), non-maleficence (minimizing negative outcomes such as harm to persons with health challenges), and justice (particularly as fairness, such as equity) (1,2). Ethics deliberation is needed in this context, as is careful analysis of legal requirements and precedent.

The legal requirements for MAiD in Canada as of May 2021 are as follows. The patient must be eighteen years or older, have (related) decision-making capacity, be eligible for publicly funded health care, make a voluntary request (for MAiD) free of external pressure, and provide informed consent (3). Once these criteria are met, the eligible individual must meet a final criterion: they must have a grievous and irremediable medical condition. This is defined as meeting all of three conditions: 1) having a serious illness, disease, or disability; 2) being in an advanced state of irreversible decline; and 3) experiencing intolerable physical or psychological suffering from this illness, disease, disability, or state of decline that cannot be alleviated under conditions the person considers acceptable (3). The decision of whether to administer MAiD as a medical practitioner is difficult as terminology like "irreversible decline", "intolerable suffering", and "acceptable conditions" must be interpreted in the unique context and circumstances of specific patients. In relation to MAiD, it is in conditions of legal uncertainty when ethical considerations come to the forefront of the decision-making process.

Uncertainty in MAiD eligibility in Canada is expected to involve new legal and ethical horizons as MAiD is extended to patients with mental disorder/illness (4) as their sole underlying medical condition (SUMC) for requesting MAiD (MAiD MD-SUMC). Introduced in March 2021, Bill C7 granted MAiD eligibility to those whose death was not reasonably foreseeable but excluded mental illness from this category until March 2023. Its introduction was then further delayed until March 2024 (5). The extension of MAiD eligibility to those with non-terminal illnesses was based on the principle of justice, i.e., that there were insufficient differences between those with non-terminal illnesses to justify their exclusion from MAiD eligibility. Through the comparison of these two groups, the courts found that they were, however, different enough to justify different MAiD eligibility tracks. Similarly, it was found that mental illness was sufficiently analogous to non-terminal physical illness to also eventually include this group in MAiD eligibility (6). At this moment, the question of whether non-terminal physical illness and mental illness are sufficiently different to justify a different set of criteria for mental illness, and what those criteria might consider, has not been answered. Numerous papers have explored theoretical similarities and differences in ethical and criteria application for MAiD between these groups (7,8). This study aims to further explore this question in a new way, that takes the comparison of these two groups beyond the theoretical to the practical, by analyzing a hypothetical example of a patient with a physical non-terminal

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illness. The ethical challenges that arise in the course of the example's analysis are extrapolated to assess whether they also apply to mental illness, and in what ways (if any) they would be inapplicable to MAiD MD-SUMC. The goal is to highlight pertinent moral considerations and related ethical challenges, and to identify issues to be considered by those involved in the development of guidelines for MAiD MD-SUMC.

The example is based on an amalgamation of clinical patient encounters primarily based on experience of the first author as a recent medical student, designed to highlight relevant ethical considerations, with key personal details changed to maintain patient confidentiality. Guidelines from the Netherlands, Belgium, and Luxembourg are also addressed when appropriate for any precedent set by these countries, where MAiD for non-terminal illnesses including mental illness has been legal since the 2000's. This paper finds that key considerations for the developers of MAiD MD-SUMC guidelines will be in defining severe mental illness, how to interpret irremediability for mental illness, and whether alternatives to MAiD to relieve suffering must not only be considered but trialled by requestors.

Such an analysis is timely in Canada, especially as MAiD MD-SUMC guidelines are expected to considerably affect Canadians suffering from mental illness. Also, Canadian guidelines related to MAiD MD-SUMC eligibility have the potential to influence how MAiD guidelines are developed worldwide as this procedure may become more widely accepted and used globally.

EXAMPLE

Brian is a 73-year-old Canadian citizen. He was diagnosed with type-2 diabetes mellitus 20 years ago. After multiple attempts at taking diabetes medications consistently, he chose not to take any medications to control his blood sugar levels because he found the daily burden of medication management too great. He was found to have capacity to decide about care for his diabetes, and he was willing to accept the known risks of having uncontrolled diabetes. Lately, he has developed diabetic sequelae including chronic kidney disease, peripheral artery disease, and neuropathy. He has developed numerous chronic non-healing ulcers on his lower legs, with infections requiring IV antibiotics in-hospital. Recently, an infected ulcer became gangrenous. Brian underwent a below-knee amputation of his left leg to prevent progression to life-threatening sepsis. Brian has since developed a severe fear of further complications from his diabetes. He developed insomnia and finds his daytime thinking preoccupied by this fear. Brian now requests MAiD. He was assessed and it was found that he has acceptable decision-making capacity related to MAiD. Alternatives were proposed, including starting medications to treat diabetes and prevent, as much as possible, its further progression; but Brian has declined these alternatives due to the continued belief that the burden of managing diabetes medications is too high for him and the belief that the utility of starting blood sugar medications would now be relatively low.

DISCUSSION

Brian clearly meets the legal criteria for MAiD decision making in Canada. He is of age, has related capacity, is eligible for publicly-funded health care, and has made a voluntary request for MAiD. He has autonomously made the decision not to take diabetic medications, based on receiving full information and reasoned deliberation. The question remains whether he meets the legal criterion of having a grievous and irremediable disease, as well as whether it is ethically sound to provide MAiD in this situation.

Brian's request for MAiD was made based on his main underlying medical condition of type-2 diabetes. While there is no agreed-upon standard for determining when a non-terminal illness becomes 'serious', or 'advanced', in Brian's case, it is arguably the sequelae of Brian's diabetes which cause it to be considered both serious and advanced. These include microvascular changes such as those resulting in peripheral artery disease and neuropathy that have led to poor wound healing and chronically infected ulcers, and consequently the loss of one leg, causing significant disruptions to his day-to-day functioning and multiple hospitalizations. Given these significant sequalae, and that much of this physiological change is not reversible, Brian's diabetes can be considered serious and in "an advanced state of irreversible decline". Thus, he meets the first and second conditions which characterize a "grievous and irremediable medical condition."

Is it possible to extend this reasoning to mental illness, and view the notions of serious, advanced, and irreversible, in a similar way to physical non-terminal illness? According to this reasoning, his disease severity was largely determined based on the pathophysiological changes the illness had wrought, which is not something that is usually testable in relation to mental illness. We are currently unable to access pathophysiological brain changes of mental illness to a sufficient degree to assess severity of mental illness, but perhaps this may one day become possible. Another way the severity of Brian's illness was assessed was based on functional limitations and hospitalizations. These are criteria that can be applied to determining the severity of mental illness, and it is a common way by which the severity of mental illness is assessed. Despite many attempts to create a standard definition of serious mental illness (SMI), or severe and persistent mental illness (SPMI), there is currently no related theoretical or operational consensus definition in psychiatry and psychology, the two main professions currently responsible for diagnostics of mental disorders. However, there are factors relevant to mental illness severity that can be considered, including diagnosis, whereupon schizophrenia spectrum disorder and major mood disorder are more likely to be considered serious than other mental disorders (recognizing that some people with these other mental disorders may have a particularly severe form). Other relevant factors include the degree of disability or functional impairment caused by the illness in various realms like activities of daily living, social, and occupational roles, duration of the illness, and the need for long-term treatment (9,10). Severity may be assessed in this way, but how can it be determined whether the person is in an "advanced state of irreversible decline"? Given that the pathophysiological trajectories of various mental illnesses are not as well-understood as those of physical illnesses, and that the recovery of functioning of individuals with mental illness is varied, one way would be

to determine if the decline is in fact reversible with available treatments. Indeed, many operationalized definitions of SPMI include minimum durations of treatment that must be attempted before the illness can be viewed as persistent (10). However, requiring much if not all treatment before the provision of MAiD is ethically fraught; this issue is further discussed below.

The third condition that Brian must legally meet to be eligible for MAiD in Canada is that he have intolerable physical or psychological suffering from the disease or state of decline that cannot be alleviated under conditions that the patient considers acceptable. Psychological suffering can be difficult to conceptually grasp, let alone systemically assess. In Luxembourg's MAiD guidelines, intolerable suffering is considered largely subjective, "and depends on their personality, there [sic] pain perception threshold, their conceptions and their values" (11). While many guidelines agree that suffering is subjective, according to Dutch guidelines the suffering must also "be palpable and understandable to the physician" (12). This implies that in the Netherlands, a patient who reports intolerable suffering may be denied MAiD if that suffering cannot be understood by the physician receiving the request. This clarification is important in Canada, where assessors may be meeting the patient for the first time. This also creates a potential for bias against vulnerable patients in the Canadian context, where the absence of long-term patient knowledge may instead be replaced by prior perceptions of patient groups. For example, for a patient with low socioeconomic status requesting MAiD, their suffering may be less understandable to a more privileged Canadian physician if a long-term relationship or knowledge of circumstances or community is not present. Not requiring this understanding of suffering by the physician may increase patient autonomy as well as ameliorating concerns about social justice. However, requiring some amount of physician understanding of patient suffering allows physicians to better understand reasonable alternatives to alleviate suffering, in line with the principle of beneficence; this also aligns with epistemic justice, aiming to reduce if not eliminate unnecessary knowledge-related power disparities such as the medical knowledge differential of physicians, particularly psychiatrists in this context, over patients (13). One solution would be to create recommendations in upcoming Canadian guidelines for considerations to better understand intolerable suffering such as circumstance, community conditions, values, length of time, personal biases, or patient vulnerabilities that may lead to bias.

In Canada, it is not required in MAiD eligibility criteria that patients necessarily try alternatives to relieve their suffering, to determine whether suffering can be alleviated under acceptable circumstances (3). Returning to the case of Brian, it may be that he is overestimating the burden of having to manage daily diabetic medications. If this is so, Brian would have less to fear if he did start diabetic medications since better blood sugar control can prevent the development and progression of complications. However, it is also possible that denying MAiD to Brian because alternatives exist that, according to many others, are deemed acceptable, will prolong his suffering. It could cause further harm by denying his autonomy, risking iatrogenic harm from such medications, and increasing the amount of time he lives in fear. In Canadian law, for patients whose death is not reasonably foreseeable, to be eligible for MAiD, "you and your practitioners must have discussed reasonable and available means to relieve your suffering, and all agree that you have seriously considered those means" (4). If Brian receives all pertinent information and is able to reason in relation to it, to his condition, and to weigh the options, it is likely that this will be sufficient to say that he has given serious consideration to his options. The potential harm in this case is that there could be termination of Brian's life when there may have been methods to alleviate his suffering while alive. In this case, a question is whether there is a situation in which one has seriously considered alternatives, but despite there being an effective alternative to relieve suffering, it is acceptable that the patient still decides to choose MAiD instead? The difficulty in answering this question with certainty lies in part in the variance in weighing of consequences that different people will demonstrate in answering this question, given their differing values, life experiences and other key personal factors.

This reasoning can be extended to a person suffering from a serious mental illness such as persistent depressive disorder. Suppose that this person is requesting MAiD but has never been treated with relevant evidence-based interventions – such as psychotropic medication (e.g., antidepressant medications), psychotherapy (e.g., cognitive behavioural therapy), or neuromodulation (e.g., transcranial magnetic stimulation) – because they have decided that these alternatives are unacceptable or intolerable. Much would depend on the individual's reasoning to determine whether they have given serious consideration to the alternatives. Suppose this person has weighed the alternatives and perceives living as a worse harm than premature death. Is there a situation in which MAiD should be provided when the patient has not tried alternatives for treatment? Interestingly, in the Dutch Regional Euthanasia Review Committee's 2018 Euthanasia Code, it explicitly states that in circumstances of mental illness, "if the patient refuses a reasonable alternative, he cannot be said to be suffering with no prospect of improvement" (12). The Canadian law is sufficiently ambiguous that it could be argued that Canadian guidelines on MAiD MD-SUMC should include a proviso similar to that of the Netherlands, in which there must be a sufficient trial of standard treatments for mental illness prior to the provision of MAiD MD-SUMC to better determine irremediability. Additional provisos recommended for consideration in MD-SUMC guidelines based on this analysis include developing a standardized definition of severe/persistent mental illness and seeking consensus on whether medical practitioners must understand a patient's suffering and what considerations should factor into this understanding.

CONCLUSION

In this paper, morally ambiguous terminology in legal criteria for MAiD in Canada were interpreted based in part on a principlist approach. Guidance for the interpretation of these terms was sought through a selective review of relevant grey and white literature from Canada, the Netherlands, Belgium and Luxembourg. These interpretations were applied to a hypothetical example of a patient with a physical non-terminal illness requesting MAiD and extrapolated to assess their applicability to mental illness. Ongoing issues in applying these terms to mental illness include deciding on a consensus definition for severe mental illness/severe and persistent mental illness, defining irremediability for mental illness, and ascertaining whether trial(s) of standard evidence-based interventions will be required for MAiD eligibility where mental disorder/illness is the sole

underlying medical condition. These are issues that are expected to be addressed in the forthcoming guidelines, but it may be that there are no uniform answers to these questions. If so, the development of an ad hoc or standing ethics committee to discuss challenging MAiD MD-SUMC requests and provide guidance to health care practitioners could be a solution to support ethically sound MAiD MD-SUMC services (currently it is not required for such a forum to be involved in advance of any MAiD provision in Canada). Other issues remain to be addressed in relation to MAiD MD-SUMC, such as MAiD for substance use disorder, the distinction from suicidality, the lack of sufficient accessibility to some evidence-based treatments for mental illness (e.g., psychotherapy, which is not readily available in Canada, unlike other jurisdictions such as the UK that has publicly funded psychotherapy for those in need), and social determinants of mental health (e.g., some people with mental illness who lack affordable housing and adequate income may request MAiD MD-SUMC due to such disruptive social determinants). The question of whether to pause MAiD indefinitely for an individual while these social determinants are addressed is challenging as it may be discriminatory to withhold a public service on the grounds of an individual being irrectifiably socially disadvantaged. Certainly, rectification of social determinants should first be attempted (in the limited ways in which physicians are able to do so), but if this is not feasible within a timely manner, MAiD then should be considered. These issues will ultimately have to be addressed by authorities such as provincial governments, in order to guide providers in their approach to MAiD referrals and assessments, as well as in their approach to seeking alternatives; and this should be done with input from scholars and other experts, as well as people with lived experience of mental illness, to ensure that the provision of MAiD MD-SUMC is ethically sound.

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