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## Letter to the Editor

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## Medical Assistance in Dying (MAiD) in Canada: Why Coelho and colleagues are incorrect to suggest the MAiD framework is in significant distress

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Available online in July of 2023, Ramona Coelho and colleagues present their findings of what they suggest was a comprehensive review of the state of Medical Assistance in Dying (MAiD) in Canada. The authors claim that these findings suggest countless issues with the existing MAiD framework, including that it lacks appropriate safeguards, fails to collect necessary data, and does not have an ability to sufficiently oversee the process and related details to protect Canadians against premature death (Coelho et al. 2023). With the respect owed to these authors, their findings rely on incomplete information, inadequate assumptions, or both. In this short reply, I present a portion of the original authors' concerns, and suggest several additional considerations to more robustly inform a position on whether Canada's current MAiD regime is indeed suffering.

The concerns are numerous, and include the following:

1) That data are acquired from MAiD providers via self-reporting.

Unfortunately, the authors suggest no other manner by which to collect data. Interestingly, within a self-regulating profession, into which physicians fall, self-reporting is a regular mechanism for review. Perhaps what the article suggests is that MAiD assessors and providers (physicians and nurse practitioners) should have additional oversight in this area, and other areas of their work.

2) That there is no mechanism for objectively, prospectively, or retroactively identifying or uncovering any errors or abuses of the process.

Despite what the authors describe, this is not true. The Office of the Chief Coroner, as they later acknowledge (at pg. 2 "Furthermore, cases of noncompliance with MAiD law and policy have been documented by different oversight bodies such as the Chief Coroner of Ontario"), has an obligation to retroactively review MAiD cases that are submitted via a MAiD Death Report form. This form verifies that the eligibility criteria for MAiD were met, asks questions about whether additional health-care provider consultations were requested, and whether palliative care or disability support services were needed, among other things. In addition to the Coroner's notification, since the approval process for MAiD involves multiple providers (at least 2, with the option to also obtain other expert opinions at any time), there are additional checks and balances in place during the process. These are mechanisms for objectively reviewing the process for errors and abuses. Whether the authors are satisfied with these processes is a separate issue, and it should therefore not be claimed by the authors that no such mechanisms exist.

3) That MAiD providers are unlikely to declare any error or deviation from legal frameworks.

There has been no evidence presented to suggest that error or deviation from the key criteria is happening. If anything, having stringent, legislated criteria during the MAiD process are likely to encourage assessors and providers to be hyperaware of their obligations. If the claim is that there are issues with trustworthiness of the professionals in question, then the concern should not be brought through one of many legal processes in place in Canada, but to the professional colleges or associations from which the physicians and nurse practitioners are members. Given the qualifications of some of the paper's authors, this should be evident.

4) That Health Canada's Annual Report falsely claims high numbers for access to palliative care.

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1102 Joshua T. Landry

Without access to Health Canada's raw data, the concern cannot be supported as unequivocally true. The Health Canada Report referenced claims that 80.7% of patients received palliative care, and that it was available to 88% of patients. The single report that the authors compare this to, in order to draw their conclusions, comes from The Ottawa Hospital (TOH) (Munro et al. 2020). The report from TOH suggests that 59.5% of patients received palliative care in any setting before a MAiD request. After a MAiD request is received, the process at TOH is that the Most Responsible Provider is expected to offer a palliative care consultation to the patient. This is part of the practice of this particular program, and not an issue with any MAiD regulatory framework. In theory, then, 100% of patients that come through this particular program should have access to a palliative care consultation. Of course, not all patients will choose to accept palliative care even if it is offered. Patients have a right to refuse any and all services that they do not feel will be beneficial to them, including palliative care. Even if the Health Canada report states that 80.7% had received palliative care, and TOH reports 59.5% of patients receiving the same, this is not to say that palliative care consultations were not offered nor available. In addition, it is worth emphasizing that the TOH paper reported on patients who received palliative care before the MAiD request, and there is a distinction to be made about who may have received it after the request, and because of the referral.

5) That a patient once deemed suicidal had access to MAiD, and that families are not well informed of their loved one's MAiD request.

On the former: A patient's initial diagnosis may have been limited, or inconclusive. Even if correct, the suicidality may not have persisted. A patient's decision-making capacity can fluctuate over time and is dependent on the decision at hand. Even if there were concerns for the decision-making abilities of a patient at one time, this does not guarantee those concerns will continue. The concern that a patient once contemplated suicide, and presumably – as inferred by the authors - was incapable of making MAiD treatment decisions, does nothing to say that the patient had not become capable at a later time, as would be required by the current MAiD framework. On the latter concern regarding the provision of information: The family of a patient would have no right to interfere with a patient, capable of making their own medical decisions and carrying out their autonomous wishes. In addition, the patient also has a right to privacy, and existing legislation would prevent the family from being informed without the patient's consent of their health condition or proposed plan. This privacy concern is not about the MAiD process.

6) That many believe there is a positive right to access MAiD – although there is no reference provided to understand who these "many" are.

A positive right to MAiD is separate from the availability of other services which could ameliorate suffering. Still, there is no absolute positive right to access a MAiD procedure. If there was, this would create a corresponding obligation on (presumably) physicians and nurse practitioners to provide MAiD to anyone who requests it. The argument that has been presented speaks more to the perception of a positive right to access an assessment for MAiD, which is more likely to be supported by the authors' later points. That being said, there has been no argument presented against this point to persuade readers that patients should not have access to

legal, medical assessments, which may be appropriate in order to alleviate their suffering in ways that the patient finds appropriate and in line with their values.

7) That MAiD is being guaranteed when there exist gaps in public funding for other resources, such as pharmacare, and mental health counseling.

Despite this and the preceding concern, patients are not being guaranteed MAiD. As noted above, there is no absolute positive legal right to obtain a MAiD procedure, and in some cases even the MAiD assessments can be difficult to come by (Manduca-Barone et al. 2022). Simply because MAiD is an available service – and perhaps more accessible in some areas than the others that have been pointed out – the current MAiD framework ought not to be the target. Instead, questions should be raised about the lack of availability of mental health-care, pharmacare, and other services. The conversation should not be construed as an "us versus them," but rather one that should focus on ensuring all necessary services are available and accessible in Canada: mental health care, dental care, pharmaceutical funding, and MAiD.

8) That because social determinants of health exist, patients should not have access to MAiD.

The type of arguments the authors attempt to utilize here are common, but should not succeed in persuading the reader that the existing MAiD framework is the problem. Udo Schuklenk does well to describe the failure of such argumenta ad passions, or appeals to emotions (Schuklenk 2022). In the cases described by the authors, social determinants of health appear to have undoubtedly contributed to the suffering of patients and led to subsequent MAiD requests. Based on the regulatory responsibilities in Canada, health care falls to the Provinces to address, while the MAiD framework is under Federal oversight. The fact that the Federal government has developed a more liberal MAiD framework than the authors believe is appropriate is pointing fingers in the wrong direction, as it is the responsibility of provinces to ensure the social and health resources available to citizens are sufficient. In addition, as Schuklenk points out elsewhere (Schuklenk 2022), a more important ethical question to ask is how the patient who presented with chemical sensitivities would have been better off for not being able to choose MAiD as an option, given her circumstance? While it may be appropriate to criticize the provincial government "for not providing adequate housing for people like the woman in this case, [....] it does not follow that therefore she should not be able to access MAiD" (Schuklenk 2022).

9) That MAiD is simply a cost-savings initiative.

The fact that cost savings are a potential consequence of allowing MAiD would seem to be objectively true since health care would not be continued, at any expense, for patients who have chosen MAiD. This must be differentiated from the inappropriate and morally repugnant suggestion implied by the authors that the cost savings are the reasons that MAiD has been pursued, or access has been expanded in Canada.

10) That MAiD is being offered to patients without them bringing it up first.

The authors raise suspicions because MAiD has been offered to specific patient populations, which includes veterans and a Paralympian. Whether the patients in question were veterans or Paralympians, in itself, is irrelevant to an argument against Canada's MAiD framework. A veteran or Paralympian would have as much of a right to access MAiD as anyone else, as long as they met the legislated eligibility criteria. The information presented says nothing of whether these people might have been eligible, and to not allow them access if so would result in a significant violation of their rights under the Canadian Charter. Regarding the practice that MAiD should not be offered to patients who have not raised the idea themselves, a compelling argument, or any argument for that matter, has not been offered as to why this ought not to be the case. Under the right circumstance, MAiD should be offered among standard options from which patients may choose. In fact, it would be irresponsible to only offer MAiD as a last resort, as implied here, since it could unnecessarily prolong the suffering of those who may wish to make an informed decision and choose it as an end-of-life option. A paper these authors reference from the Canadian Association of MAiD Assessors and Providers (CAMAP), which apparently does not alleviate their concerns, describes the reasons why MAiD should be offered by care providers. These reasons include that it: is important for ensuring the patient is able to consider all available options in the informed consent process, and manage effective advance-care planning while so doing (Canadian Association of MAiD Assessors and Providers (CAMAP) 2019).

11) That because bias exists in health care, MAiD should not be offered, or access should be more restricted.

The fact that certain populations of patients more commonly face provider biases is a significant problem. Unfortunately, the authors do not point to any specific failures of the existing MAiD processes as being responsible for, or even exacerbating the problem of provider bias. While the issue of bias is in need of careful consideration and addressing, it is an issue that should be dealt with in our health-care system on the whole. Not doing so, and centering the problem on one single part of a person's health-care journey (e.g. an Emergency Room visit, the MAiD process, visits to pain-specialists, etc.) will not address the issue in any meaningful way.

12) That it is inappropriate for patients to be permitted to subjectively define their own suffering for the purpose of MAiD.

The authors' concern that suffering is subjectively defined lacks any recognition that to define it objectively would be near impossible, and potentially inappropriate. Suffering is a subjective experience of the patient, which is best defined by the patient themselves. There are legal mechanisms that exist to make decisions on behalf of incapable or incompetent patients, and these aim to add some objectivity to the nature of harm and benefit to be incurred in a particular circumstance. This rationale, however, cannot be used in cases of MAiD since the eligibility criteria depend on the patient's own perception of their suffering, which a capable patient has to

express themselves. What the authors are suggesting is that it would be ethically permissible to take away the right of patients to define and express their own suffering. In place of this, the authors may offer a characteristically paternalistic approach which would see health-care providers reverting to the old adage of "doctor knows best" to inform their patients whether they are suffering enough, or worse, suffering at all.

13) That even though patients have undergone an informed consent process, and determined that certain treatments are not appropriate in relieving their suffering in ways that are acceptable to them, they should not be eligible for MAiD because they have not tried the other treatments.

The authors' position on this issue is troubling. The concern that no standard treatments must have been tried is inextricably linked to the concern above which sees defining suffering subjectively as problematic. If the patient was forced to accept any particular treatment before accessing MAiD, the concept of informed consent would risk being undermined. A patient need not try any particular treatment to determine whether, as the MAiD legislation requires, those treatments would relieve suffering under conditions the patient considers acceptable. The treatments may have a role in relieving suffering, of course, but the important consideration is that the patient does not consider the conditions under which they must accept the treatment, acceptable. This regularly occurs in other areas of medicine, too - foregoing chemotherapy for cancer, for example – where death may also occur as a result. If the authors suggest removing the right of MAiD patients to refuse potential treatments for their underlying conditions, it would appear that they cannot maintain or support the right of patients in non-MAiD scenarios to refuse further life-sustaining or -prolonging measures.

Based on the above concerns, I suggest Coelho and colleagues reconsider their position on the state of affairs of MAiD in Canada.

**Competing interests.** The author of this manuscript has no competing interests to declare.

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