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Response to the Question asked by Health and Social Care Committee of Parliament of United Kingdom: "What can be learned from the evidence in countries where assisted dying/assisted suicide is legal?"

MAID in Canada– promise, success and failure

Motto: Medical Assistance in Dying or MAID is the most profound change in medical practice in modern times. (Canadian Medical Association, 2020).

Personal statement: The writer is co-editor (with D. Shannon) of book "Medical Assistance in Dying in Canada (MAID): Critical Multidisciplinary Perspectives" to be released by Springer, an international academic publisher. This book will be the first known comprehensive analysis of the MAID program with contributions from more than 30 experts. The information and understanding I have obtained while working on this book are highly relevant to the task of your committee.

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MAID'S PROMISE:

When, in response to the direction of the Supreme Court, the Canadian Parliament in 2016 enacted Bill C-14 to amend the Criminal Code and to create an exemption for "medical assistance in dying" (MAID) when provided by a medical practitioner or nurse practitioner, the preamble to the law promised that the law strikes the most appropriate balance between

a) Autonomy of persons who seek medical assistance in dying because they have an "enduring and intolerable suffering" due to "a grievous and irremediable medical condition" on one hand

and

b) The interest of vulnerable persons in need of protection and those of society, on the other.

To achieve that balance, the law limited access to MAID to "competent adults whose deaths are reasonably foreseeable" and who are not under external pressure, and it established certain listed safeguards that medical practitioners or nurse practitioners must respect. The court established new offences and punishments related to this law aimed at practitioners who fail to comply with the law.

Was the promise of a balanced law and a balanced program delivered to Canadians in 2016 fulfilled? An emphatic No!

MAID's ADMINISTRATIVE SUCCESS

1. Rapid creation of country-wide MAID delivery system

The Supreme Court of Canada legalized MAID by invoking the Charter of Rights and Freedoms, and so MAID (which encompasses voluntary euthanasia and assisted suicide) was indirectly established as a quasi-right of Canadians. It became the responsibility of the federal and provincial/territorial ministries of health to assure that people could exercise this right. Although MAID's provision, in law, is an arrangement between physicians or nurse practitioners and their patients, the health ministries could not readily or directly summon or force these practitioners to perform; first of all, the nurse practitioner as a professional group was not established in all provinces; secondly, physicians are mostly independent contractors; thirdly, the law states that no one can be compelled to administer MAID. The provincial governments addressed this challenge of MAID provision by imposing the task on hospitals, health sciences centres or regional health authorities which are all governed and funded by federal and provincial governments. These health organizations in turn recruited (at times aggressively) physicians, or nurse practitioners as well as support staff, often creating multidisciplinary teams. In this way, MAID started to be delivered in many places within days or weeks of legalization.

2. Rapid annual growth of MAID interventions

Since the legalization of MAID (2016) up to the end of 2021, more than 30,000 Canadians died by MAID, over 10,000 of those were in 2021 alone, the most recent year for which statistical data are available. In 2021, the total number of MAID provisions increased by 32.4% (2021 over 2020), and similar increases took place the preceding years. As numbers continue to increase steadily every year, it "may be seen by some as a "triumph of patients advocacy" and represent an "incredible success" (Frolic, 2022).

3. High numbers of MAID deliveries achieved by small fraction of providers

The total number of unique MAID practitioners has been slowly increasing year by year. in 2021 of the 1,577 providers, 94% were physicians. This translates into 1.5% of the total number of available (95,000) physicians, which appears to be sufficient and satisfies the demand. The implementation of the MAID program necessitated the new position of a MAID Care Coordinator. In many places, the institution's support staff deals with the paperwork, prepares the patient, get drugs ready and starts the intravenous line; the physician's or nurse practitioner's role is to inject the drugs and wait until the patient can be pronounced dead, which takes only minutes. The assessment for eligibility likely takes more time, but many of those are increasingly done remotely or online.

MAID's CASUALTIES

By having mobilized the entire public health care system to universally perform euthanasia and assisted suicide to those who apply and are broadly eligible, the Ministries of Health have **1)** caused serious harm to the inherent moral structure and mission of Canada's public health care system, and to the ethos of its once trusted health care professionals; as well as **2)** the weakening or possible destruction of citizen's initiated social and medical support services and institutions that provide care to identifiable, marginalized groups. But the whole responsibility of this damage cannot be totally attributed to the bureaucratic fervor of wanting to succeed at lightening speed and at all costs. Some, if not most of that responsibility must be shared with **3)** the courts' MAID law that presented access to MAID as a fundamental human right (the first in the world), plus a lack of safeguards, and language that is generalized and too inclusive which gives way to a broad interpretation of eligibility; as well as **4)** the many levels of government which have failed to construct a robust, transparent, and timely accountable system that would be open to public scrutiny and evaluation.

1) Health care system and its professionals

(i) Canada's Public Health Care system is strained

Once the aspiring model for countries who wished to emulate it, the Canadian health care system is being torn asunder by MAID's intrusion. Collegial ties between professionals are being severed. Also severed are the bonds of trust between patients, who are opposed to MAID and the health care providers. The ethos of the profession is severely challenged and professionals, who do not want to be involved with MAID are weary.

The presence of MAID teams, groups, clinics and offices created by health corporations to deliver MAID has changed the culture of health organizations and it encourages an increasing number of consumers to be streamed to them. The Institution's MAID practice as well as its MAID Continuing Education programs aimed at health care staff and physicians has begun to normalise the practice, so much so that not all patients under their care are encouraged to regain their health. Some patients, particularly the elderly, feeble, frail or those with long-term disabilities, whose quality of life is perceived to be low are now seen first and foremost as MAID candidates. Increasingly, patients, families and staff are reporting that some patients are being offered MAID, rather than treatment and care. MAID is emerging as a super-drug; as a solution for a growing number of health problems.

(ii) Health care workers are pressured to abandon their conscientious objection to MAID

Legislators and regulators of medical practice have affirmed in principle the importance of upholding the freedom of conscience of physicians. In practice, however, varying policies have been implemented nationwide, with some regulators compelling physicians to refer patients to available providers who would be willing to administer medical assistance in dying (MAID). Policy makers do not wish to understand how conscience operates in the context of medical practice vis-à-vis the goals of medicine and supporting virtues, and that professional obligations, not just religious faith, can necessitate conscientious objections. When physicians who do not want to provide MAID are required to make an "effective referral" by their College, it must be understood that the act in question is not a morally neutral act. Reasonable disagreement can exist regarding the consistency of MAID with the goals of medicine, but further education and discussions are needed (Czajkowski, Murphy, Goliger 2023).

(iii) The high number of MAID deliveries represents a failure of Canadian society

From a narrow, managerial perspective, the rapid growth of the MAID program can be seen as an "incredible success," but from a humanistic and medical perspective, these statistics are evidence that Canada's health care system has failed to provide care and support to over 30,000 people, so that they, in spite of diseases, disability or aging, would have been able to live a comfortable and meaningful life to the end of their natural lifespan.

2) Weakening and possible destruction of citizen's initiated social/medical support services

(i) MAID program interferes with or even negates suicide prevention programs

The introduction of Medical Assistance in Dying (MAID) legislation in 2016 has affected suicide prevention in significant ways. The philosophy of suicide prevention is that every suicide is a tragedy and governments were convinced to fund these programs for decades. People considering suicide and people considering MAID may both express a wish to die. These two groups, however should be considered distinct entities. Suicide is a possible, yet preventable outcome of mental anguish, burdensomeness, and psychological pain in the context of a painful life. Recovery from suicidal ideation is possible – it is not irremediable. On other hand, MAID is not "preventable", persons who wish to get it and who are eligible will receive it and will die. A person with suicidal ideation who presents to a psychiatrist can be counselled and, if consenting, will start a treatment. If the same person presents to a MAID coordinator or provider, and is MAID eligible, the person's life will end.

If Bill C-7 (proposes eligibility to people whose sole underlying medical condition is mental illness) is implemented, it will expand eligibility criteria to a very high number of citizens. The impact on suicide prevention will be severe because distinctions between suicide and MAID will disappear. Vulnerable individuals may decide on MAID without fully exploring recovery options. Those in suicide prevention believe a shift in values must occur to mitigate the impacts of this legislation. This means, ultimately, a belief that 'mental health care is health care' and those suffering mental illness must have open and easy access to care (Olson, Grunau, Walker 2023).

(ii) Palliative care appears to be a casualty of MAID.

Palliative care differs fundamentally from MAID in its philosophy, intention and approach. While access to MAID has been guaranteed as a right, access to palliative care and other supports for living, including home and disability services, have not. MAID services continue to expand, whereas palliative care access is even more difficult to obtain than pre-MAID because in some areas, MAID expansion has come at the cost of reduced access to palliative care resources. Very few Canadians have access to specialist palliative care, and this can negatively impact patients' outcomes. Without access to high-quality palliative care, some patients may feel that MAID is their only option because their suffering has been inadequately addressed or because they perceive that their families or social supports would carry an excessive burden. This lack of access to palliative care should be considered a failure of the health care system and a medical error. Palliative care must remain distinct from MAID to ensure clarity and to avoid the potential for people to refuse palliative care services because they fear it might hasten death (Herx & Kaya 2023).

3) Generalized, vague, broadly inclusive terminology in the Court's MAID law

(i) Vague definitions of eligibility and gradual elimination of safeguards.

The law's terminology is not medical terminology and physicians are instructed to use their "professional judgement" when assessing people for eligibility for MAID. If a person is refused eligibility by one physician, that person can go shopping for one that will consider them eligible. The safeguard of a minimum 10-day waiting period after one's assessment and before one could receive MAID has been eliminated, so, technically, a person can now put in an application in the morning and receive MAID before the end of the day.

(ii) Probability that patients with solely mental disorder will be receiving MAID.

The practice of Euthanasia and Assisted Suicide" (MAID), evolved within a span of six years from being initially restricted to individuals, whose natural death was reasonably foreseeable, to accepting for MAID those who may have a normal lifespan but live with a chronic illness or a disability, that they claim causes them suffering and decline of their condition. It is further projected (by 2023) to include eligibility for non-dying individuals suffering solely from a mental disorder. However, responding to a strong opposition to this measure, Canadian Government indicated in December of 2022 the intention of delaying expansion of MAID to include mental disorders, without specifying a timeline.

The extension of the practice of MAID for Mental Disorders as a Sole Underlying Medical Condition (MD-SUMD) has generated extensive debate in professional bodies advocating for and against the inclusion of mental disorders in the provision of MAID with the majority of practitioners objecting the extension (Tang, Gaind, Lau 2023).

(iii) MAID disrupts family relations

Due to Canada's law on confidentiality and privacy, and the current understanding of extreme autonomy, a patient, even if very sick, when considered "capable" to decide can apply for MAID and receive it without the spouse or family being aware of the development. This creates social discontent. One MAID provider joked that the main risks in her work are angry families. A spouse, who went to court to stop MAID for her husband of 30 years, whom she knew was not capable to decide about his health care, was told by the judge that she had 'no standing' in his court.

(iv) The MAID program has no identifiable governance.

The MAID program is based on the federal law, and laws later adopted by the Canadian provinces and territories. No particular governmental officer(s), department(s), or committees can be identified that can be said to govern the MAID programs in the provinces and territories. The federal government's Ministry of Health is the recipient of legally required reports from MAID providers and assessor, but it uses these reports only to provide annual statistics, and does not examine the received data for adherence to the Criminal Code. Adherence to the Criminal Code resides with the provincial governments, yet, except for Quebec, and some activity in Ontario and British Columbia, it is unknown if the other provincial and territorial authorities are doing any oversight.

(v) Monitoring and public reporting on MAID system is only marginal.

The MAID Law of 2016 articulated that to minimize risks and harms, the program will require a careful design and proper administration, with a monitored system of eligibility criteria and procedural safeguards. Federal regulations further elaborated on this aspect of the program, mandating a collection

of data from MAID providers, assessors and pharmacists, and the publishing of reports based on this data. Yet, those legal and regulatory efforts have yet to produce evidence that the program operates as intended. We have no publicly accessible evidence that the eligibility criteria and safeguards prescribed by law were respected and that the Criminal Code has not been transgressed. It is absolutely essential that all provincial or territorial governments and their agencies responsible for oversight of MAID activities start collecting and analyzing data from their territories, take appropriate actions and share their findings with the public, or where necessary, with law enforcement agencies. This is not happening and no plans have been released that would indicate that the situation will be corrected. It also would be desirable for the federal government to undertake annual on-site reviews of a certain number of randomly selected MAID cases. Finally, health care institutions need to take responsibility for quality control and quality assurance of their MAID programs and keep their communities informed. Monitoring of MAID calls for effective collaboration of federal, provincial, territorial and local authorities which has not yet been achieved.

4) Governments' grave failure to construct a robust, transparent, and accountable system

(i) To a high degree MAID became an intervention for psychological and social problems.

More and more frequently, the media presents stories of patients who have applied for MAID, not because of unbearable suffering due to an illness or a life-threatening disability, but because of unacceptable housing, not enough money to buy food or medicine, lack of home care, lack of access to specialised treatment, and so on. In these instances, a non threatening illness can become a convenient reason to get MAID approved. These cases are ignored by governmental bodies and do not seem to be investigated. MAID providers are aware of those situations and one provider publicly expressed her view to what amounted to this: that individuals have the autonomy to decide for MAID if they deemed their personal or social circumstances to be too difficult. A too difficult life could be experienced by people in these categories: the poor, the disabled, the displaced, the isolated, the depressed, the dispossessed, the marginalized, the old, the sick, the unfortunate, and so on. This proves that there is a profound misunderstanding between the MAID's law's intention and its interpretation. Existential, social, psychological, material and economic problems, which are often mixed with illness, were never meant to be, nor should they ever be acceptable criteria for qualifying for MAID. For a government to allow for the resolution of these issues by the availability of MAID is of course much easier, faster, more expedient and economical than to attempt to lighten the citizen's burdens of social deprivation, and existential angst, by other means using positive action. This is supported in part by the Governmental Annual Report of 2022, which indicates that the nature of suffering of those who received MAID is often in the social sphere: loss of dignity 54%; excessive burden to family, friends or caregivers 36%; isolation and loneliness 17%. These are all remediable problems, but neither the reports from the Ministry of Heath, nor peer reviewed publications indicate that when these social issues are detected some corrective actions need to be taken so that the person may possibly withdrawn the MAID request.

(ii) The MAID system is lacking quality control.

There appears to be no quality control process built into the MAID delivery program. The data that some institutions are providing as an indication of 'quality', actually deals with the satisfaction of staff and families with the MAID program. But there are not publications to indicate that institutions are carrying out the basic review of MAID cases documentation (for example, to verify that the assessment is signed by two physicians = assessors who are independent, as the law requires), or verified that it is the diagnosis of an incurable disease that leads to MAID, even if we know that the rate of error in diagnosis

is in the range of 10-20%. As of January 2023, no formal methodology for MAID quality control has been published.

CONCLUSION

Has this program been successful in meeting its objectives and the promise made to Canadians? The answer is no. There is clear evidence that this promise has been broken in multiple ways, and is being broken every day as the delivery of MAID across the country continues. In spite of the managerial success of the program, its impact in medical, social and human terms has been negative. Not only has it failed to meet the minimal objectives of justice and safety, but it has become a way to compensate for lack of resources, and reduce healthcare costs. MAID threatens the ethos of the medical profession, and for people who are non-MAID adherents, their trust in the medical profession is quickly waning.

What can be learned from the evidence in countries where assisted dying/assisted suicide is legal? If this committee is looking for models that could be followed in United Kingdom, Canada's model is the one to definitely avoid. To support this assertion, I have briefly reviewed the success and the casualties of the MAID program as they are manifest in January of 2023. I will be glad to provide further details and respond to questions.

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