

Medical Assistance in Dying: Challenges of Monitoring the Canadian Program

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Volume 3, Number 3, 2020

URI: <https://id.erudit.org/iderudit/1073799ar>

DOI: <https://doi.org/10.7202/1073799ar>

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Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

[Explore this journal](#)

Cite this article

Kotalik, J. (2020). Medical Assistance in Dying: Challenges of Monitoring the Canadian Program. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 3 (3), 202–209. <https://doi.org/10.7202/1073799ar>

Article abstract

The Canadian medical assistance in dying (MAID) program, based on an ambitious piece of legislation and detailed regulations, has failed to provide Canadians with sufficient publicly accessible evidence to show that it is operating as mandated by the requirements of the law, regulations, and expectations of all stakeholders. The federal law that was adopted in 2016 defined the eligibility criteria and put in place a number of safeguards that had to be satisfied before providing assisted dying to a person in order not to transgress the Criminal Law. The responsibility of monitoring for the purpose of investigating compliance with the eligibility criteria and procedural safeguards was assigned by the Federal Ministry of Health (responsible for all monitoring) to the provincial and territorial governments. Some of the governments have released statistical data concerning the program, but none have yet issued a comprehensive report on adherence to the eligibility criteria and its safeguards as required by the law and regulations. This paper explains the process, explores the possible reasons for this shortfall, and offers some suggestions for actions that could rectify this aspect of the MAID program. Accountability and transparency are integral to the delivery of MAID and the publications of the mandated federal as well as provincial/territorial monitoring reports are one important approach to achieving confidence and trust in the program.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Medical Assistance in Dying: Challenges of Monitoring the Canadian Program

Jaro Kotalik^{a,b}

Résumé

Le programme canadien d'aide médicale à mourir (AMM), qui repose sur une législation ambitieuse et des règlements détaillés, n'a pas réussi à fournir aux Canadiens suffisamment de preuves accessibles au public pour montrer qu'il fonctionne comme le prévoit les exigences de la loi, les règlements et les attentes de toutes les parties prenantes. La loi fédérale qui a été adoptée en 2016 a défini les critères d'éligibilité et mis en place un certain nombre de garanties qui devaient être satisfaites avant de fournir une aide à mourir à une personne afin de ne pas transgresser le droit pénal. La responsabilité du contrôle du respect des critères d'éligibilité et des garanties procédurales a été confiée par le ministère fédéral de la santé (responsable de l'ensemble du contrôle) aux gouvernements provinciaux et territoriaux. Certains gouvernements ont publié des données statistiques concernant le programme, mais aucun n'a encore publié un rapport complet sur le respect des critères d'éligibilité et des garanties, comme l'exigent la loi et les règlements. Cet article explique le processus, explore les raisons possibles de cette lacune et propose quelques suggestions d'actions qui pourraient rectifier cet aspect du programme d'AMM. La responsabilité et la transparence font partie intégrante de la mise en œuvre du programme d'AMM et les publications des rapports de suivi fédéraux et provinciaux/territoriaux obligatoires constituent une approche importante pour obtenir la confiance dans le programme.

Mots-clés

aide médicale à mourir, euthanasie, suicide assisté, surveillance

Abstract

The Canadian medical assistance in dying (MAID) program, based on an ambitious piece of legislation and detailed regulations, has failed to provide Canadians with sufficient publicly accessible evidence to show that it is operating as mandated by the requirements of the law, regulations, and expectations of all stakeholders. The federal law that was adopted in 2016 defined the eligibility criteria and put in place a number of safeguards that had to be satisfied before providing assisted dying to a person in order not to transgress the Criminal Law. The responsibility of monitoring for the purpose of investigating compliance with the eligibility criteria and procedural safeguards was assigned by the Federal Ministry of Health (responsible for all monitoring) to the provincial and territorial governments. Some of the governments have released statistical data concerning the program, but none have yet issued a comprehensive report on adherence to the eligibility criteria and its safeguards as required by the law and regulations. This paper explains the process, explores the possible reasons for this shortfall, and offers some suggestions for actions that could rectify this aspect of the MAID program. Accountability and transparency are integral to the delivery of MAID and the publications of the mandated federal as well as provincial/territorial monitoring reports are one important approach to achieving confidence and trust in the program.

Keywords

medically assisted dying, euthanasia, assisted suicide, monitoring

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INTRODUCTION

As a bioethicist involved for two decades in supporting the ethical quality of various health care programs, I have been curious about the ethical quality in the delivery of medically assisted dying (MAID). With this pursuit in mind, I became fascinated by the legal and regulatory framework of the program. This paper traces the important developments of monitoring and reporting on compliance with the eligibility criteria and safeguards for MAID in Canada, from the initial court ruling through to the federal law, to regulations and to their current outcomes. It will end with suggestions for actions that could lead to a fulfillment of expectations that are set out in the law. The paper will show that unless this issue is rapidly addressed, there is a risk that the values and objectives of the court decisions and federal laws concerning assisted dying will be destabilized and the ethical foundation of the program – resting on accountability and transparency – will be undermined.

JUDGMENT OF THE SUPREME COURT OF CANADA

Until 2015, the Criminal Code of Canada held that, without exception, anyone who aids or abets a person in committing suicide commits an indictable offence and that no person may consent to death being inflicted upon them. Four individuals and a provincial civil liberties association challenged the constitutionality of these provisions. In 2015, the dispute reached the Supreme Court of Canada. The legal team for the Government of Canada defended the then existing provisions of the Criminal Code; however, the Supreme Court concluded that these sections unjustifiably infringed on guarantees in the Canadian Charter of Rights and Freedoms and therefore “are of no force or effect to the extent that they prohibit physicians-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable

medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.” (1)

When the Supreme Court of Canada delivered its benchmark ruling that made “physician-assisted dying” (an umbrella term for euthanasia and assisted suicide), under certain conditions legal, the Court was aware that such a change in law could lead to misuse and harm, but it was persuaded that “a properly administered regulatory regime is capable of protecting the vulnerable from abuse or error.” The judgement of the Court took into account, in section 25, the safeguards that were in place in other jurisdictions; and in section 27, the judges considered “the risk of permissive regime and the feasibility of implementing safeguards to address those risks” and endorsed the conclusion of the trial judge that the risk “can be identified and very substantially minimized through a carefully designed system that imposes strict limits that are scrupulously monitored and enforced.” In section 117, the Court accepted the trial judge’s conclusion that “the risk associated with physician-assisted death can be limited through a carefully designed and monitored system of safeguards” (1).

FEDERAL LAW: ELIGIBILITY CRITERIA, SAFEGUARDS, MONITORING

In response to the direction of the Supreme Court, Parliament 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. This bill reflects very closely the concerns of *Carter’s* judgment with its multiple references to safeguards, monitoring and oversight. The Preamble of the bill which came into force in June 2016 states that “robust safeguards, reflecting the irrevocable nature of ending life, are essential to prevent errors and abuse in the provision of medical assistance in dying.” It also declares that “vulnerable persons must be protected from being induced, in moments of weakness, to end their lives.” The bill (which will be referred to as MAID Law) determined in section 241.2(1) that a person may receive MAID only if they meet all of the following eligibility criteria:

1. They are eligible for health services funded by a government in Canada.
2. They are at least 18 years of age and capable of making decisions with respect to their health.
3. They have a grievous and irremediable medical condition.
4. They made a voluntary request for MAID that was not made as a result of external pressure.
5. They gave informed consent to receive MAID after having been informed of other means that are available to relieve their suffering, including palliative care.

To expand on point #3 above, the MAID Law also determined that a person has a “grievous and irremediable medical condition” only if they meet all of the following criteria:

- A. They have a serious and incurable illness, disease or disability that causes enduring suffering that is intolerable to the individual.
- B. They are in advanced state of irreversible decline in capacity.
- C. They experience enduring physical or psychological suffering that is intolerable to them and cannot be relieved under conditions that they consider acceptable.
- D. Their natural death became reasonably foreseeable.

The section of the MAID Law named ‘Safeguards’ states that before a practitioner provides a person with MAID, the practitioner must:

1. be of the opinion that the person meets all of the eligibility criteria;
2. ensure that the person’s request for MAID was made in writing, signed and dated after the person was informed that the person has a grievous and irremediable medical condition;
3. be satisfied that the request for MAID was signed and dated before two independent witnesses who also signed and dated the request;
4. ensure that the person has been informed that they may, at any time and in any manner, withdraw their request;
5. ensure that another practitioner has provided a written opinion that the person meets all eligibility criteria;
6. ensure that they and the other practitioner are independent;
7. ensure that there are at least 10 days between the day of request and the day on which MAID is provided (with a provision to shorten the interval if indicated);
8. immediately before providing MAID, give the person an opportunity to withdraw their request and ensure that the person gives expressed consent to receive MAID;
9. if the person has difficulty communicating, provide reliable means by which the person may understand and communicate their decision.¹

The MAID Law is an amendment to the Criminal Code, and as such it provides for its enforcement. Failure to comply with safeguards, forgery and destruction of documents are offenses that on conviction on indictment may lead to imprisonment of not more than five years. From our chosen perspective, it is important to know what the MAID Law states about monitoring:

¹ A bill C-7 submitted recently to the Parliament for discussion may amend the eligibility criteria and safeguards.

“The Minister of Health must make regulations that he or she considers necessary ... respecting the provision and collection, for the purpose of monitoring medical assistance in dying, of information relating to request for, and provision of, medical assistance in dying ...” Finally, and perhaps most importantly, the Bill states that regulations have to be made “respecting the use of that information, including its analysis and interpretation, its protection and its publication and other disclosure.” Failure of a practitioner to provide the required information is again an offence that could result in imprisonment of not more than two years (2).

FEDERAL INTERIM REPORTS

MAID delivery was initiated in some locations within days of Bill C-14 becoming law, so no federal regulations for reporting and monitoring could have been in place at that time. During this void, most provincial and territorial governments issued their own reporting directives. To fill the reporting gap, on April 2017, the federal Ministry of Health began to publish semi-annual Interim Reports on MAID that were based on voluntarily data provided by some provincial governments, noting that the information gathered was incomplete.

The introduction of the fourth and last Interim Report of April 2019 declared that,

(N)early all countries that permit some form of medically assisted dying consider public reporting to be a critical component to enhance transparency and to foster public trust in the application of the law. The need for the consistent collection of information and public reporting also reflects the seriousness of MAID as an exception to the criminal laws that prohibit the intentional termination of a person's life. (3)

The Report provided various statistical data, such as the age range (18-91+), average age (73 years), proportion of men and women (nearly equal) and the underlying medical circumstances of patients who received MAID (cancer is the most common), and so on. The Report failed to indicate what percentage (if any) of those persons who received MAID actually did not meet the eligibility criteria, and in how many cases (if any), the safeguards provided by the MAID Law were not respected. Clearly, this incompatibility between the rationale for the Interim Report as outlined in its Introduction and the actual content of the Report is an obstacle to achieving transparency and fostering public trust.

FEDERAL MONITORING REGULATIONS

On November 1, 2018, two years and four months after MAID delivery started, the long-awaited Regulations for monitoring of MAID by the federal Ministry of Health went into effect (4). These regulations describe a complex reporting process which differs from province to province and which will not be possible to review here. However, for the purpose of this discussion, it is important to note two topics of the Regulations which deal with reporting of practitioners and reporting of the federal government.

Firstly, practitioners involved with MAID have reporting responsibilities to the federal Ministry of Health that must include the following information: the demographic data of the practitioner who received and the patient who submitted a written request for MAID; the death resulting from MAID or other causes; the nature of the patient's suffering; if the patient required disability support services; if the patient received palliative care and for how long; and whether or not palliative care was available. These are all important data identifying circumstances in which assisted dying is taking place that will be helpful in shaping future end-of-life policies and programs in general. Even more importantly, the Regulations require reporting of compliance with each criterion of eligibility and with each safeguard, thus confirming that legal requirements for MAID delivery were satisfied.

Secondly, according to the Regulations, the federal government has the responsibility to report to the public. It specifies that the Minister of Health must cause to be published, at least once a year, a report based on the information collected. Regrettably, two key items, the data about the adherence to eligibility criteria and the adherence to safeguards (as described above), are not among the items that must be covered by the report.

An explanation for this omission can be found in the Regulatory Impacts Analysis Statement, that is not part of the Regulations but it follows Schedule 7 of the Regulations. It states that:

(T)he monitoring regime is aimed at gathering and analyzing data about medical assistance in dying from a societal perspective. ... Investigating instances of noncompliance with the eligibility criteria and procedural safeguards set out in the Criminal Code falls outside of the scope of the federal monitoring regime, and is under the purview of local law enforcement. (5)

Of course, the Criminal Code is a federal law, yet it is not unusual in Canada that the enforcement of the Criminal law is expected of 'local law enforcement', that is, agencies of provinces, territories and municipalities. In fact, most criminal cases, like murder, assault, fraud and arson are tried in provincial courts. The problem is that a fundamentally new activity like MAID can fall between the cracks of the two systems and not receive attention from either side. Is this happening? We do not know yet. To further complicate the situation, negotiations that have taken place between provincial and federal authorities resulted in two streams of monitoring data. In about one half of 13 Canadian provinces and territories, practitioners involved with MAID are expected to report to the federal government through a designated provincial or territorial body. This mechanism then

provides to these governments direct access to all data for their own investigations. In the other half of the provinces and territories, reports of practitioners go directly to the federal government. Are there provisions in place that will ensure that the federally collected monitoring data from these jurisdictions will be, as Regulation permits, regularly shared with local enforcement agencies? Will each province and territory develop their own way of analysing these reports, responding to non-compliance and to other concerns? Will Canadians be informed how the eligibility criteria and safeguards are respected in each province and territory, and what steps are being taken to deal with non-compliance? These are some of the serious questions that need to be addressed. The Canadian Medical Association recommended creating an independent national body that would receive and analyse all reports from across the country, but this recommendation has not been adopted (6). In other words, in Canada we have two different types of data collection and analysis, one to create the 'societal perspective' at the federal level and another for the use of 'law enforcement' at the provincial and territorial level. If this system is to work as intended it may require a very close, productive and publicly transparent collaboration between the federal, provincial and territorial governments.

PROVINCIAL AND TERRITORIAL MONITORING AND REPORTING

What we have learned about the federal role suggests that monitoring, analysis and reporting at the provincial and territorial level is critical in order to assure that MAID is provided only under the conditions allowed by the law. To date, no provincial or territorial government has released into the public domain a comprehensive report on the performance of its MAID program that would include this perspective. To their credit, Quebec and Ontario have provided partial data of this kind.

The province of Quebec operates their MAID program differently from other Canadian jurisdictions. The province established a commission on end-of-life care which reviews MAID reports and releases its findings annually. The commission reported in April 2019 on 1,354 cases and ruled that 13 cases (1%) did not comply with the law and in 41 cases (3%) there were missing data preventing the commission to reach a decision. The commission did not indicate what action was taken for non-compliance and in the failures to provide data, both being explicitly identified as offenses in the Criminal Code (7).

In Ontario, the Chief Coroner's office announced that their team reviewed some 2,000 cases of MAID. There were some "compliance concerns with both the Criminal Code and the regulatory body policy expectations, some of which have recurred over time." The actual number or a description of these cases was not provided. The team engaged with practitioners on a case by case basis, sharing "learning opportunities." In addition, the office of the chief coroner of Ontario released a description of a ranking system indicating how this office will react to compliance issues. For example, lack of compliance with the eligibility criterion of the requester being "capable of making decisions with respect to one's health" is classified as Level 5 and will lead to a report to the police. On other hand, lack of compliance with the requirement that a request for MAID be signed and dated in the presence of two independent witnesses is rated as Level 2 and will lead only to an "Educational Email" to the practitioner. The appropriateness of these responses to various types of non-compliance with MAID law and regulations could be debated, but it is reassuring that Ontario is developing a systematic and rational approach to the issue (8). For other provinces, there are only basic and partial statistical data available on their websites, such as for Nova Scotia (9), Manitoba (10) and Alberta (11). None of those reports refer to compliance with eligibility criteria and safeguards. Clearly, much more work must be done by provinces and territories in this area.

CURRENT MONITORING CHALLENGES

As shown, it is evident that provincial and territorial authorities are not fully engaged in their role of monitoring, enforcing and reporting on the performance of the MAID program, which they are expected to do according to the federal law and Regulations. It is also well to keep in mind that while the MAID law is in force, the Criminal Code of Canada still holds that consent does not affect the criminal responsibility of any person who inflicts death on the person who gave consent, and that counselling and assisting in suicide remain indictable offences. It is only under certain defined conditions that the MAID law provides an exemption (only) to physicians and nurse practitioners to terminate the life of a person. If these conditions were not fulfilled, then the Criminal Law would be transgressed.

The consequences of the current lack of communication about the performance of the MAID program are serious. For one, the silence of provincial and territorial bodies promotes an atmosphere of secrecy. Hospital annual reports available to the public do not provide any information about the MAID program within their institutions. Regional health authorities often have MAID coordinators or MAID teams, but there are no reports released on their activity. Combined with the scarcity of information on MAID from provincial, territorial and federal governments, this social situation leads to a lack of understanding and knowledge among professionals and the public about how the MAID program operates.

Not surprisingly, this is a worrisome scenario, especially to people living with chronic disabilities and to those who advocate for vulnerable groups of the population. The *Canadian Disability Policy Alliance* is concerned about the term 'disability' among eligibility criteria and is worried that this could be understood as an intention to permit MAID on the basis of disability alone (12). The *Coalition for Health CARE and Conscience* was gravely concerned when a woman with a disability presenting for hospital care was offered MAID (13). The *Canadian Association for Community Living* is concerned about the operation of safeguards in the MAID program and asserts that factors unrelated to patients' medical conditions can "make some people vulnerable to request an assisted death when what they really want and deserve is better treatment." The association developed, with the assistance of a large body of experts, the *Vulnerable Persons Standard* and is advocating for its use in

the MAID program (14). Expressing similar concerns, a law professor and researcher called for more robust information about medical assistance in dying in Canada in order to help protect all vulnerable patients and to provide information on equality of access (15). The *Council of Canadians with Disabilities* stated that “Canada’s MAID regulations fall short”, because among other deficiencies, they do not provide information on socio-economic factors of individuals requesting MAID, nor do they gather sufficient evidence on causes of ‘intolerable suffering’, one of the eligibility criteria for MAID. The association insists that these are critical data which, if extracted from the monitoring reports, could point to ways to improve end of life care. This 40,000 members’ association concluded that “further safeguards are urgently needed to monitor the practice of MAID” (16).

A legal scholar recently expressed concern about monitoring of MAID following growing external and internal criticism of adherence to eligibility criteria and safeguards in Belgium and Holland (17), where, like in Canada, physicians have broad discretionary powers and all information available about completed MAID cases is based on their self-reporting (18). An academic palliative care physician wrote: “I remain concerned about the lack of provincial/territorial and national reporting standards for collection of data, reporting of actions and of experiences, and the robust monitoring practices related to medical assistance in dying...” (19). A bioethics team worried that to date, little is known about how requests for MAID are situated in the broader context of end of life care. They discovered that for 80 patients requesting MAID, the palliative care consultations took place less than seven days prior to the request and for 25%, palliative care was discussed on the day of request or after the request, thus not giving patients sufficient time to consider alternatives to MAID as is expected by the MAID Law and practice guidelines. Data collected by monitoring should identify if this is a widespread problem or not. It is not surprising, then, that a recent overview of MAID practice published in the *World Medical Association Journal* by a group of Canadian physicians reported “widening and loosening of already ambiguous eligibility criteria, the lack of adequate and appropriate safeguards ... the failure of adequate oversight, review and prosecution for non-compliance with the legislation” (20).

These are some of the many voices across Canada expressing concerns or apprehension that can only be addressed effectively by a full and comprehensive reporting on the MAID program as was anticipated in the design of the program and as described above. It must be kept in mind that the enforcement of safeguard is beneficial to all involved, for obviously different reasons. Namely, the individual who does not want nor would consent to MAID; the individual requesting and consenting to MAID; the medical and nurse practitioner who wants to practice within the bounds of the law and could be pressured to provide MAID outside its bounds; to those who do not qualify; the consenting person interested in the options of postponement; finally, to all Canadians who should be able to trust the system and feel secure that their individual freedoms are respected. We all feel secure in a community where law abiding citizens respect the boundaries of the law and the government upholds them. One may not agree that a particular “stop” sign on the street is necessary, but one nevertheless complies with the rule. Even MAID assessors and providers will benefit from regular, timely analysis and reporting of MAID data because it will assure them that they have followed the protocol correctly, that they are doing only what is legally permissible, and that there can be no retroactive action taken against them in the future.

FUTURE DIRECTIONS

Considering these findings, the following three suggestions are made to rapidly address outstanding and pressing issues in monitoring and reporting of MAID and enhance the transparency of the program:

1. The provincial and territorial governments in Canada need to provide evidence that they are analysing the data collected by the federal monitoring program in their territory and produce reports summarizing the three past years of the program and then commence producing annual reports. These reports need to highlight the compliance with the MAID law and regulations regarding eligibility criteria, procedural safeguards and the administration of MAID. These reports would also indicate what actions were taken when non-compliance was detected. These provincial and territorial reports would complement the federal reports that we expect to be produced by Health Canada.
2. The federal oversight of MAID delivery ought to include on-site reviews of a certain percentage of completed MAID cases, randomly selected across the country (21). This could be set up similarly as inspections of clinical trials for human drugs that are currently conducted by Health Canada (22).
3. The institutions where medical assistance in dying is taking place or which have credentialed MAID providers, would be wise to establish an internal recording, monitoring and publishing processes. It was suggested that such reviews could best be done by a multidisciplinary local committee that would include physicians, lawyers and bioethicists (23). Such a process would not require additional reports by MAID assessors and providers; rather it could use reports that are already required by federal or provincial authorities as well as originals of MAID requests and consents, consultations, nursing notes and records of delivery of MAID, including reports of adverse events. In addition, health care institutions that are directly or indirectly operating a MAID program need to launch quality assurance and quality control programs for MAID delivery that are similar to quality programs that they operate for other activities, where the life of patients is at stake. Verification of the diagnosis of a ‘grievous and irremediable condition,’ the foremost eligibility criterion that supports a request for MAID, would appear to be a matter of due diligence and could be best done at this level. This internal review process would function best when under the oversight of boards of directors and when results will be published in the annual reports of the institutions.

CONCLUSION

The Canadian Medical Association declared that the legalisation of medical assistance in dying is “the most profound change in medical practice in modern times” (24). A close reading of the MAID Law and its regulations shows that a determined effort was made by the court and the Canadian Parliament to have this end-of-life option available to people who are competent to decide and who freely and after being advised about other options wish to give up their life, while at the same time it sets out to protect the life of those individuals who are not capable to make such a grave decision, or who would be misguided or pressured to act contrary to their desire to live. To minimize risks and harms, the program required 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 rigorous collection of data from MAID providers with analysis and interpretation of collected data, followed by its publication. Yet, those legal and regulatory efforts have yet to produce evidence that the program operates as intended.

By the end of December 2019, over 13,000 Canadians died with medical assistance (25). For almost 10,000 of those MAID cases, we have no publicly accessible evidence that the eligibility criteria and safeguards prescribed by law were respected. Therefore, it is absolutely essential that all provincial or territorial governments and their agencies responsible for oversight of MAID activities start collecting and analysing data from their territories, take appropriate actions and share their findings with the public, or where necessary, with law enforcement agencies. To assure the high performance of the MAID program, it 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, data analysis and public reporting are binding requirements of Canadian law but also can have an important educational value to health care professionals and users of health care; even more importantly, they demonstrate transparency and build trust and confidence in the MAID program. At this time, monitoring of MAID, which calls for effective collaboration of federal, provincial, territorial and local authorities, is a serious challenge that demands a response.

UPDATE

While this paper was being reviewed and awaiting publication, in July 2020 the federal government of Canada released its *First Annual Report on Medical Assistance in Dying*, which covered the period 2016-2019 (26). In reporting on the 13,946 MAID deaths, the report provides a description of the methodology of data collection, a breakdown of deaths by time periods and jurisdictions, a profile of persons who received MAID and a profile of the providers of MAID. Most important for the purpose of this discussion is section 6.0. Safeguards and Supplementary Data, which deals with both eligibility criteria and safeguards. Let us review first what the Report says or does not say about each of the five eligibility criteria as established by the MAID Law.

The First Annual Report:

1. Makes no reference at all to the first eligibility criteria listed in the law, that the person applying must be eligible for health care service in Canada.
2. Does not explicitly indicate that all those who received MAID were at least 18 years old, which is the second eligibility criterion. The table that shows the age distribution of MAID recipients starts with the category, “Age 18-45”. This may mean that there were no reports from practitioners referring to persons under age 18, but it may also mean a number of other things, such as, the number of younger persons who were given MAID was perhaps judged to be too small to be of concern.
3. Provides a very limited reference to the criterion that eligible persons “have a grievous and irremediable medical condition.” It does offer a table indicating the frequency of 11 types of intolerable suffering options from which practitioners had to choose when reporting. But the presence of “intolerable suffering” is only one of four elements that the MAID Law requires to be present in order to determine if a person has a grievous and irremediable medical condition. The Report provides no evidence if those other necessary elements were ever present. There is no indication in the Report that those who received MAID because of a “serious and incurable illness, disease or disability,” were “in advanced state of irreversible decline in capacity” and that their “natural death is reasonably foreseeable.”
4. Does not state that all those who received MAID met the eligibility criterion of having “made a voluntary request to receive medical assistance in dying;” the electronic portal for reporting only asks a practitioner to indicate why they were of the opinion that it was a voluntary request, without actually giving the practitioner an opportunity to state whether or not the request was voluntary and not made as a result of external pressure.
5. Provides no information whether or not all MAID recipients provided informed consent. In fact, the word ‘consent’ only appears in the opening section of the Report outlining the legal framework for the program.

Similarly, the First Annual Report provides an incomplete picture of how safeguards were adhered to by practitioners when providing MAID. Of the nine safeguards listed in the MAID Law, the Report touches on only two of them. One of the most elementary safeguards is that the person provides a written request, dated and witnessed. The Report offers information of whom the practitioners have received a written request from but does not actually provide any assurance that indeed all patients who received MAID completed such a written request. Another safeguard is the prescribed 10-day reflection period between the request for MAID and the execution of MAID; the Report indicates that in 34.3% of cases this safeguard was

waived (as allowed by the Law) because the person was judged to be in the imminent risk of either losing capacity to consent or dying a natural death.

The Report makes a claim in section 2.4 that “all cases of MAID are captured under the current monitoring regime,” but provides no evidence that this was indeed achieved for the reported period 2016-2019. Because pharmacists in Canada have an obligation to report each MAID drug dispensation, it would have been possible to reveal the correlation between the reports of pharmacists and those of MAID providers. The First Annual Report did not offer such correlation which could have provided some credence for the claim that no deaths by MAID were missed.

The Introduction to the First Annual Report contains the important statement that “the need for the consistent collection of information and public reporting also reflects the seriousness of MAID as an exception to the Criminal Code prohibition against the intentional termination of a person’s life.” However, in failing to report consistently and fully on the adherence to eligibility criteria and to safeguards, this Report confirms that Health Canada has no intention to assure that medically assisted deaths are always provided in such a way that makes them acceptable exceptions to the prohibition of killing as defined by Criminal Code. By default, provincial and territorial governments need to rapidly and energetically assume this role. Hence, the Conclusions and recommendations made in this paper’s section of Future Direction remain valid.

The second important event that took place while this paper was being reviewed was the submission of Bill C-7 for consideration of Parliament. This proposed legislation would expand the eligibility for MAID to include persons whose death is not reasonably foreseeable. It would also modify some safeguards of the existing law, which the Minister of Health labelled as “barriers to access” (26). This is a serious disregard of the message found in the preamble to the MAID Law which states that “robust safeguards, reflecting the irrevocable nature of ending life are essential to prevent errors and abuse in the provisions of medical assistance in dying.” Given the very unsatisfactory state of monitoring and reporting on MAID, which creates an uncertainty as to what degree the current eligibility and safeguards are respected, one must seriously ponder the question: Is this the right time to expand the current eligibility criteria and remove important safeguards in the MAID program as proposed in Bill C-7?

Reçu/Received: 04/04/2020

Remerciements

Je suis reconnaissant envers mon épouse, Louisa Pedri, pour les nombreuses discussions sur ce sujet, sa critique pertinente et son insistance sur la clarté du texte. Loretta Delea m’a beaucoup aidé en organisant les références et en m’apportant une assistance rédactionnelle.

Conflits d’intérêts

Aucun à déclarer

Publié/Published: 16/11/2020

Acknowledgements

I am grateful to my wife, Louisa Pedri, for many discussions on this topic, her incisive critique and her insistence on clarity of the text. Loretta Delea has helped me greatly by organizing references and by editorial assistance.

Conflicts of Interest

None to declare

Édition/Editors: Caroline Favron-Godbout & Aliya Afhdal

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REFERENCES

1. Supreme Court of Canada. [Carter v. Canada \(Attorney General\)](#). 2015-02-06.
2. Parliament of Canada. [Bill C-14](#). Statutes of Canada 2016. Chapter 3. Assented to June 17, 2016.
3. Government of Canada. [4th Interim Report on Medical Assistance in Dying in Canada](#); 2019.
4. Government of Canada. [Regulations for the Monitoring of Medical Assistance in Dying: SOR/2018-166](#).
5. Government of Canada. [Regulations for the Monitoring of Medical Assistance in Dying: SOR/2018-166](#). Regulatory Impact Analysis Statement. Background.
6. CMA Policy. [Medical assistance in dying](#). May 2017, s. 4.
7. Commission sur les soins de fin de vie. [Rapport Annuel d’Activites](#); 2019.
8. Office of the Chief Coroner. [Memorandum: Medical Assistance in Dying Update](#). October 9, 2018.

9. Nova Scotia Health Authority. [Medical Assistance in Dying \(MAID\) By the numbers](#); 2020.
10. Shared Health Manitoba. [Medical Assistance in Dying](#); 2020.
11. Alberta Health Services. [Data and Statistics. Medical Assistance in Dying](#); 2020.
12. Canadian Disability Policy Alliance. [Statement of January 17, 2020](#).
13. Hutchinson C. [Why are women with disabilities being given help to die, instead of help to live](#). Coalition for HealthCARE and Conscience; 2018.
14. Canadian Association for Community Living. [Safeguards in Medical Assistance in Dying](#); 2020.
15. Downie J. [An updated but incomplete picture: Maid in Canada](#). Impact Ethics. 12 October 2017.
16. Council of Canadians with Disabilities. [Canada's medical assistance in dying regulations fall short](#). 4 September 2018.
17. Miller DG, Ki YH. [Euthanasia and physicians assisted suicide not meeting due care criteria in Netherlands: a qualitative review of review committee judgements](#). BMJ Journals 2017;7:e017628.
18. Lemmens T. [Charter scrutiny of Canada's medical assistance in dying law and the shifting landscape of Belgian and Dutch euthanasia practice](#). Supreme Court Law Review 2018; (Second Series):85:459-544.
19. Wasylenko E. [Reporting and monitoring of medical assistance in dying](#). Vulnerable Persons Standard. 16 April 2018.
20. Herx L, Cottle M, Scott J. [The normalization of euthanasia in Canada: the cautionary tale continues](#). World Medical Journal. 2020;66(2):28-37.
21. Lemmens T. [Dangers of a lax assisted death regime](#). Impact Ethics. 3 March 2016.
22. Government of Canada. [About inspections of clinical trials for human drugs](#). 2015-12-09.
23. Landry JT, Forman T, Kekewich M. [Ethical considerations in the regulation of euthanasia and physician-assisted death in Canada](#). Health Policy. 2015;119(11):1490-8.
24. Government of Canada. An Act to Amend the Criminal Code (medical assistance in dying). Technical Briefing; 2020.
25. Joule a CMA Company. [Medical assistance in dying. Are you prepared?](#)
26. Health Canada. [First Annual Report on Medical Assistance in Dying](#). H22-1/6E-PDF. Ottawa; July 2020.