

Completion of Medical Certificates of Death after an Assisted Death: An Environmental Scan of Practices

Produire un certificat médical de décès dans les cas
d'aide médicale à mourir : analyse du contexte des
pratiques



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Abstract

Policies and practices have been developed to operationalize assisted dying processes in Canada. This project utilized an environmental scan to determine the spectrum of assisted death reporting practices and medical certificate of death (MCD) completion procedures both nationally and internationally. Findings suggest medically assisted dying (MAiD) is represented on the MCD inconsistently nationally and internationally. Related factors include

the specifics of local assisted death legislation and variations in death-reporting legislation, variation in terminology surrounding assisted death and designated oversight agency for assisted dying reporting.

Résumé

Au Canada, des politiques et des pratiques ont été élaborées pour opérationnaliser les processus d'aide médicale à mourir. Ce projet analyse le contexte afin de déterminer le spectre des pratiques pour la déclaration des décès assistés ainsi que les procédures pour les certificats médicaux de décès (CMD), aux niveaux national et international. Les résultats font voir que l'aide médicale à mourir n'est pas représentée de façon cohérente sur les CMD, et ce, aux niveaux national et international. Les facteurs concernés comprennent les précisions quant à la législation locale concernant l'aide à mourir ainsi que les variations dans la législation sur la déclaration des décès, une variation dans la terminologie connexe et les agences de surveillance désignées pour la déclaration de l'aide médicale à mourir.

MEDICALLY ASSISTED DYING (MAiD) IS AN END-OF-LIFE OPTION THAT HAS become available to eligible Canadians since the passing of Bill C-14 by the federal government in 2016. Because of the jurisdiction of provincial governments over matters concerning health, there is significant variability in both policies and procedures across the 10 provinces and three territories of Canada. The completion of the medical certificate of death (MCD) after MAiD profoundly impacts the families of the deceased and the tracking and analyzing population-level data. MCDs are important to families as they provide closure, peace of mind and documentation of cause of death to family members (Department of Health and Human Services 2003). Additionally, the MCD may reveal sensitive information about deceased individuals including cause, manner and location of death and significant medical history (Boles 2012). This project utilized an environmental scan to determine the current Canadian and international practices regarding MCD completion post-assisted death. An environmental scan was conducted according to a process suggested by Albright (2004). The process followed the steps of 1) identification of need, 2) gathering the information, 3) analyzing the information, 4) communicating the results, and 5) facilitating and encouraging the making of informed choices. This paper represents partial fulfillment of step 4.

An environmental scan is an appropriate methodological choice to analyze a practice environment to identify emergent issues, review the impact of significant events, guide future plans, review quality improvement opportunities, raise issue awareness, initiate a broader project and inform decision-making (Albright 2004; Graham 2008; Guion 2010; Wilburn 2016). It is an especially useful process after regulatory and legal changes, as these may have

significant impact on government agencies and health delivery organizations, who may utilize the resulting information in forming evidence-based policies and informing strategic planning (Albright 2004). Within the Canadian context of this environmental scan, federal Bill C-14 legalized MAiD necessitating provinces and territories, who have jurisdiction through provincial/territorial legislation, to develop policies and procedures for MCD completion and death reporting standards.

Every country has a system for reporting cause and manner of deaths and issuing of death certificates (Das 2005). It is generally accepted that the cause of death is “the disease, injury or poison responsible for the death of a person” (Das 2005: 193), whereas the manner of death is a description of the circumstances of how the death occurred with the usual manner of death categories including natural, accident, suicide, homicide or undetermined (Das 2005; Hanzlick et al. 2002). Downie and Oliver (2016) reported on the MCD of 12 Canadian provinces and territories. Each available provincial MCD made a determination of cause of death (immediate, antecedent and underlying) and specified a manner of death from a selection of pre-set categories. There was some variation province to province in the manner of death categories.

Natural deaths are deaths solely or near solely related to the disease and/or the aging process (Hanzlick et al. 2002), and within the Canadian context, this information is provided on the MCD in accordance with the World Health Organization’s guidelines and classified in accordance with the international classification of diseases, injuries and causes of death (Office of the Registrar General 2010). Within most Canadian jurisdictions, the most responsible practitioner (i.e., physician or nurse practitioner) is tasked with determining the cause of death in such situations (Wetmore 2007). When the manner of death is deemed non-natural, the death is typically reported to an oversight agency, such as the coroner’s office or medical examiner’s (ME) office (Canadian Medical Protective Society 2016). Cause and manner of death is guided by both legislation and principles. Within the Canadian context, each province has its own death investigation or reporting legislation resulting in provincial/territorial practice differences.

Within the Canadian context, the MCD constitutes the legal record of an individual’s death that may be utilized to settle issues of estate, insurance claims, matters of pension, and genealogy (Brooks and Reed 2015; Office of the Registrar General 2010; Swain et al. 2005). Nationally, the MCD is also used as a key source of mortality data. These statistical data are used to a) assess and monitor for changes and identify regional differences in population health status, b) to monitor trends in infant and maternal mortality, infectious diseases, accidents and suicides, c) to anticipate health research and healthcare priorities, and health facilities, services and manpower, and d) to plan prevention, screening and health promotion programs (Office of the Registrar General 2010; Swain et al. 2005). International evidence suggests errors on MCDs have been reported, including errors in recording the immediate and underlying cause of death, incomplete or inaccurate recording of contributing disease processes, MCDs with incomplete or incorrect sections (i.e., place of death), and incorrect

manner of death classification (Hunt et al. 1993; McGivern 2017; Mieno et al. 2015; Nielsen et al. 1991; Smith Sehdev and Hutchins 2001). Given the vast utilization, and far reaching impacts, of the MCD data, ensuring accuracy and a measure of consistency in reporting is paramount.

Identifying the Need

MAiD is an end-of-life option available to eligible Canadians since the passing of Bill C-14. Section 3.1 of Bill C-14 states the Minister of Health, after consultation with provincial governments, will establish guidelines regarding MCD completion in cases where MAiD has been provided (Government of Canada 2016). The Government of Canada (2017) followed with non-binding guidelines suggesting the immediate cause of death be listed as toxicity of the drugs administered and the precipitating medical condition as the underlying cause of death. They further suggest 1) MAiD be recorded as contributing to the death, but not part of the sequence of events, and that 2) specification be provided if MAiD was practitioner- or self-administered, and 3) that the manner of death should be recorded as natural if that option exists. Downie and Oliver (2016) reflected on two of the factors in death reporting post-assisted death, that of privacy and insurance concerns, and offered first principles with regards to completion of MCDs after an assisted death. They suggest physician-assisted death (now termed “medically assisted death,” as nurse practitioners may also provide this) be recorded as the manner and the underlying medical condition as the cause of death.

In absence of binding national directions, provincial jurisdictions bear the responsibility of determining how the MCD is completed post-assisted death. This responsibility includes death investigation and registration oversight, while balancing accuracy and both health practitioner and care recipient sensitivities. Because MAiD became legally accessible June 2016, it is important to review the current pan-Canadian and international practice of recording assisted death on MCDs. The objective of this project was to determine and compile current practices in the completion of the MCD in Canadian and international jurisdictions related to assisted dying.

Gathering the Information

Information on MCD completion post-assisted death, specifically cause and manner of death and related assisted death reporting recommendations, was sought from all the Canadian provinces and territories, the American states of Vermont, Oregon, Washington State, California and Colorado and internationally from Belgium, the Netherlands and Switzerland. Within the United States of America, there is no federal assisted death legislation and development of assisted death legislation is under the purview of individual states. The American states chosen for inclusion in the environmental scan are states with state-level assisted death legislation with operationalized frameworks, policies and procedures. The international jurisdictions of Belgium, the Netherlands and Switzerland were included in the environmental scan as these nations have legalized assisted death.

Web-based searches were conducted for data in relation to MCD completion post-assisted death. Search terms included (in a variety of combinations) MAiD, assisted death, death certificates, medical certificates of death, vital statistics, Office of the Chief Coroner, Medical Examiner, names of assisted death legislation (i.e., Death with Dignity Act), provincial physician associations, Dignitas, EXiT, assisted death reporting, and Death with Dignity. Documentation was utilized if it was available in English. Within the Canadian context, e-mail communication was sent to available provincial and territorial agencies (provincial/territorial Vital Statistics, offices of provincial/territorial Coroners/Medical Examiners [ME], and physician associations), as well as known end-of-life researchers and MAiD providers, for information solicitation with regards to cause and manner of death and related assisted death reporting recommendations and for validation of online documents. Canadian data were reported if at least two data sources reported the same information or if information was obtained from a provincial agency representative.

American state information was obtained from a variety of sources including state Dying with Dignity agencies, State annual reports, State Health Departments (website and e-mail communication), as well as by review of State assisted dying legislation. Practice information from Belgium, the Netherlands and Switzerland was obtained from e-mail communication with Dignitas, EXIT, World Right to Die Federation, various end-of-life researchers (known through authors' professional connections and via communication with authors of peer reviewed journal articles regarding assisted death in the included international countries), and review of available English translated federal laws pertaining to assisted death.

Analyzing the Information

Within Canada, there is variability in MCD completion. Twelve jurisdictions are represented in Table 1 (available online at longwoods.com/content/25685). One jurisdiction is not reported due to lack of available online documents and/or non-response from identified provincial organizations (Vital Statistics Offices, ME/Coroner's Offices, physician associations). Four jurisdictions closely approximate the Health Canada MCD completion guidelines (Government of Canada 2017), while no jurisdictions fully subscribe to the first principles suggested by Downie and Oliver (2016). Of the reporting jurisdictions, eight classify the manner of death as natural, three jurisdictions document the manner as unnatural (one as a suicide, one as unclassified and one as MAiD) and in one jurisdiction the manner is not explicitly stated. Involvement with the provincial coroner's office or ME's office depends on three factors: 1) designation (or not) as the oversight agency for assisted deaths, 2) designation (or not) of the assisted death as a natural death, and 3) if there was an unnatural antecedent event precipitating the assisted death (i.e., spinal cord injury due to an accident).

Within the American states included in this review, there is consistent application of cause and manner of death; cause of death is the underlying precipitating illness and the manner of death is natural (Table 2 – available online at longwoods.com/content/25685).

In most states there is clear language embedded in their legislation to protect the privacy of the individual care recipient choosing an assisted death and, in most cases, prohibits reference to either the medications used or suicide as the manner of death. Internationally, the availability of English documentation limited the depth of information that was able to be obtained. The practice in reporting assisted deaths has a varied process with one country reporting assisted deaths as natural and two countries reporting deaths as non-natural (Table 3 – available online at longwoods.com/content/25685). In the countries where death is reported as non-natural (the Netherlands and Switzerland), the manner of death is consistent with their legislated terminology (i.e., euthanasia in the Netherlands; assisted suicide in Switzerland). European jurisdictions have a variety of practices to ensure the laws and related practice safeguards are upheld. Due to the variations in practice, and the limitations on the available data, the European information will not be considered in the section entitled “Facilitating and Encouraging the Making of Informed Choices.”

Communicating the Results

Project results will be shared through the authors’ professional networks with the goal of supporting planning and policy decision-making within the Canadian context. A number of stakeholders who provided insight and information to the regional practices have asked to be informed of the project results, which will be facilitated through sharing publication information. Additionally, results will be shared through existing academic knowledge translation processes including relevant conferences and presentations.

Facilitating and Encouraging the Making of Informed Choices

An environmental scan is helpful in an environment after regulatory change and may assist in forming evidence-based policies and strategic planning (Albright 2004). As assisted death is a newly available care option, precipitated by a national law change, with provincial authority over operationalization of practice, variation in policy is understandable. Based on the current state of Canadian practices and the experiences of other jurisdictions, the authors recommend a) a consistent provincial approach in MAiD reporting in Part 1 and Part 2 of the MCD, b) a consistent provincial reporting of manner of death post-assisted death and, c) a designated process for MAiD oversight.

In the reviewed American states, where both assisted death legislation and death reporting is at the state level, binding MCD completion standards are possible. As the Canadian federal parliament does not have the power to legislate consistent MCD completion requirements, these choices are left to the purview of the Canadian provinces and territories. Consistency in death reporting Part 1, Part 2 and the manner of death on the MCD may require re-examination and/or amendment of provincial/territorial death investigation/reporting legislation. These discussions should occur in a timely, coordinated, sensible approach. Additionally, finding a balanced approach regarding the information provided on

the MCD and the information further provided to families (should they request it) on the death certificate is further warranted to balance reporting needs and care recipient and practitioner sensitivities.

The most appropriate agency (Coroner's Office, ME Office or other) to oversee assisted death reporting processes should not be determined by the classification of the death as natural or unnatural. MAiD is a unique, sensitive, practice area and dedicated reporting and oversight of all MAiD-related deaths to facilitate practice review is paramount. The government of Canada (2017) has proposed a federal monitoring regime to support accountability, transparency and the protection of vulnerable individuals, as well as identification of trends, legislation monitoring and collection of quality and consistent data (2017). Provincial resultant practices should align such that MCD completion and oversight standards are consistently applied while being cognizant of reporting duplication and client, family and provider sensitivities. This is critical not only for consistency in recording and reporting of the data but, most importantly, to ensure upholding of assisted death safeguards embedded in both legislation and local policy. The importance of a consistent approach to reporting and oversight cannot be understated.

Conclusion

The goal in this project was to undertake an environmental scan of the practice of MCD completion in assisted death nationally and internationally. Assisted death is represented on the MCD inconsistently across the scanned jurisdictions. Related factors include the overarching assisted death legislation and variations in death investigation/reporting legislation, variation in assisted death terminology and the designated oversight agency for assisted dying reporting. Within the Canadian context, striving for consistent application of cause and manner of assisted death reporting is important for accurate, sensitive and pan-Canadian consistent statistical reporting. Further discussion at both the federal and provincial level is encouraged to determine the most appropriate process and/or agency to review medically assisted deaths in Canada. These measures would support the continued development of a consistent, transparent and respectful assisted death reporting system in Canada.

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