

Medical assistance in dying for cancer patients one year after legalization: a collaborative approach at a comprehensive cancer centre

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ABSTRACT

Medical assistance in dying (MAID) is a new medical service in Canada. Access to MAID for patients with advanced cancer can be daunting during periods of declining health near the end of life. In this report, we describe a collaborative approach between the centralized coordination service and a regional cancer centre as an effective strategy for enabling interdisciplinary care delivery and enhancing patient-centred care at the end of the patient's cancer journey.

Key Words Medical assistance in dying, care coordination, collaborative care, patient-centred care

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BACKGROUND

Since July 2016, shortly after Bill C-14 received royal assent, access to medical assistance in dying (MAID) in Alberta has been available through the Alberta Health Services (AHS) MAID Coordination Service (<https://www.albertahealthservices.ca/info/page13497.aspx>), which is divided into three geographic regions: one for the Edmonton and North zones, one for the Calgary and Central zones, and one for the South Zone of the province. Each of the three MAID coordination teams comprises 1 or 2 navigators and a designated medical lead who engage the requesting patient or family and facilitate determination of MAID eligibility where appropriate. Patients and families can make direct contact with the coordination team using Alberta's Health Link (the provincial 24/7 telephone health advice service) or e-mail. Alternatively, the patient's attending physician or care provider can contact the MAID team to indicate the patient's desire to be contacted about MAID.

Within AHS, MAID service coordination is understood to be a 5-phase process (Table 1). Upon receiving a written request [Government of Alberta's Record of Request for Medical Assistance in Dying (downloadable at <http://www.health.alberta.ca/health-info/medical-assistance-dying.html>)], the MAID coordination team will identify and contact 2 physicians or nurse practitioners to perform independent eligibility assessments, as required by law. At

least 1 of the 2 should be willing to administer MAID (called "provision") for the patient.

Anticipating that a substantial proportion of MAID requests would come from patients with active cancer (70%–80% as reported by the Netherlands and Oregon^{2,3}), the Tom Baker Cancer Centre (TBCC) in Calgary, in consultation with CancerControl Alberta, designated 2 oncology physicians, part time, as service support to the MAID Coordination Service, to conduct MAID eligibility assessments and, where appropriate, to provide assisted dying. In this report, we describe the process outcomes of this collaboration for patients with cancer between January and December 2017.

METHODS

About 1.5 million people live in the catchment area of the TBCC, the single comprehensive tertiary cancer centre within the Calgary Zone. The MAID Coordination Service for the Calgary Zone ("zonal MAID team") maintains a list of AHS and non-AHS physicians and nurse practitioners who are able and willing to conduct MAID eligibility assessments and possibly to provide MAID. The MAID navigators refer patients in the pre-contemplation and contemplation phases to information available through AHS MAID Web site, and they maintain contact, often providing clarifications, as desired.

TABLE 1 Alberta Health Services: five phases of medical assistance in dying (MAID)^a

Phase	Key activities	Interdisciplinary involvement	Resources available for health providers
Pre-contemplation	<ul style="list-style-type: none"> ■ Patient exploring end-of-life options ■ Understanding prognosis, symptom management, and supportive care needs 	<ul style="list-style-type: none"> ■ Clinical oncology team ■ Palliative care services (consult or home care) ■ Psychosocial and spiritual care resources 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Web site for patients and family (FAQs and brochures) ■ CPSA training module
Contemplation	<ul style="list-style-type: none"> ■ Specific contemplation and reflection, often conversations, end-of-life options and details, including MAID 	<ul style="list-style-type: none"> ■ Clinical care teams (oncology, palliative care, and others) ■ Alberta Health Services MAID Care Coordination Service 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Web site ■ Alberta Health Services MAID Care Coordination Service ■ Government of Alberta Record of Request for MAID (form)
Determination	<ul style="list-style-type: none"> ■ Government of Alberta Record of Request form is signed ■ Two independent physicians or nurse practitioners assess for confirmation of eligibility ■ Evaluate care needs and acceptability to patient 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Care Coordination Service ■ Independent physicians or nurse practitioners from relevant clinical specialty and available physicians in community (including patient's family physician) ■ Optional or additional assessments by psychiatry, palliative care, and so on, if indicated 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Care Coordination Service ■ End-of-life conversations guide ■ Value-based self-assessment ■ MAID assessment forms (providing and independent physicians)
Action (provision)	<ul style="list-style-type: none"> ■ Planning specifics of MAID—for example, location, date, drug protocol (intravenous or oral) ■ Provision of assisted death 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Care Coordination Service ■ Clinical care team (facility patients) ■ Transfer and receiving team (off-site provision) ■ Providing physician ■ Medical examiner's office^b 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Care Coordination Service ■ Alberta Health Services MAID protocol prescription and administration record
Care after death	<ul style="list-style-type: none"> ■ Body transfer and bereavement support 	<ul style="list-style-type: none"> ■ Alberta Health Services MAID Care Coordination Service ■ Providing physician ■ Medical examiner's office^b 	<ul style="list-style-type: none"> ■ Grief and bereavement program ■ Dying with Dignity Canada support group

^a Adapted from the clinical guide for MAID published by Alberta Health Services¹.

^b The medical examiner performs the necessary examination of the body, reviews all MAID-related documentation, and issues the death certificate. FAQs = frequently asked questions.

Since January 2017, patients with cancer living in the Calgary Zone who have made contact with the MAID Coordination Service and who are ready for determination of eligibility, are referred directly to one of two TBCC oncology physicians assigned part-time for MAID support, including a radiation oncologist (JSYW) and an independent physician associate (JP), bypassing the usual cancer-clinic triaging routines. Electronic patient charts are accessed for pertinent details of cancer status and treatments. For those patients who have completed a formal written record of request (with exceptions), either of the 2 MAID-support oncology physicians, both being willing to assess and to administer protocol medications for a given patient, will perform a consultative eligibility assessment for a given patient (but, because of workload considerations, not both physicians to assess the same patient).

The MAID navigator, with input from the zonal MAID team's medical lead, identifies and contacts a second assessor for an independent assessment. The second assessor could be the attending oncologist, the family physician, another willing physician known to the zonal MAID team,

or a nurse practitioner. (A third assessor was needed on only one occasion.) No second assessor can be in a supervisory relationship with the MAID-support oncology physician who is the assessor-provider on the case.

For eligible consenting patients, MAID provision, which could be at home or at an appropriate facility, is almost always booked with the MAID-support oncology physician who conducted the eligibility assessment for the particular patient. A minimum of 2–3 days' notice through the MAID navigator is often necessary to allow time for on-site nursing to be arranged and to have the prescription filled by a participating pharmacy. All confirmed eligible patients are, as required by law, re-consented at the time of provision and offered an opportunity to rescind the request.

Of the patients included in this report, almost all were receiving active specialized palliative care through community- or facility-based services; otherwise, palliative care consultation was offered or recommended as indicated by symptom burden and end-of-life care needs.

Where decisional capacity for consent to the medical procedure is in question, referral is made to a psychiatrist

with special interest in MAID requests. Given cognizance of the health decline experienced by patients and aspects of patient-centred care, MAID assessors travelled to the patient's location, whether that was an acute-care hospital, a hospice, a long-term care facility, or the patient's home within the Calgary area. The patient's unique circumstances—including cumulative cancer experience, personal beliefs (especially those about potentially efficacious cancer or symptom-control therapies), availability and involvement of family members and their support or objection, and the patient's expectation of life quantity and quality—form the basis of the consultative MAID assessment by the oncology physician just as much as whether the request meets legislated eligibility criteria. Where concerns about care gaps or potential conflicts are identified, the MAID navigator or the consulting MAID oncology physician will revisit those issues or, as appropriate, request interdisciplinary support from any or all of palliative care, psychosocial resources (clinical psychology or social work), psychiatry, or clinical ethics.

RESULTS

In the 12-month period, 243 inquiries from patients in Calgary, or from their families or care providers, were received by the MAID Coordination Service, of which 124 (51%) were related to a cancer diagnosis. Of those 124 inquiring patients, 94 remained in the contemplation phase or proceeded to the determination phase (usually, but not necessarily, after formal written request was signed). Of those 94 included in the present analysis, 87 (93%) had died by the time the analysis was performed. Median age of this analyzed group was 70 years (range: 44–98 years); 48 (51%) were women; and their cancers affected 19 different organs or sites, the most common being gastrointestinal ($n = 20$, 21%), lung ($n = 15$, 16%), and genitourinary ($n = 14$, 15%) sites.

Of the 94 patients, 71 (76%) signed a formal written request. Eligibility was confirmed for 57 of the 71, for a MAID confirmation rate of 80%. For patients whose eligibility was not confirmed [that is, the remaining 14 (20%)], abandonment of the eligibility determination process was a result of rapid physical decline and death in half the group, often within days of the request; in the other half, abandonment was a result of a decision for alternative end-of-life care approaches, mostly in a hospice or palliative homecare setting. No patient who completed the required independent assessments was deemed not to meet the legal criteria for eligibility. Of the consultative assessments, 58% took place in the community at the patient's home or a hospice facility. Figure 1 summarizes the process outcomes of the 94 contemplating or requesting patients.

Of the 57 patients who were confirmed to be MAID-eligible, 44 (77%) had provision of assisted death using an intravenous prescription protocol. No patient chose the oral prescription option. Of the 44 patients who had an assisted death, 17 (39%) had their provision at home; 12 (27%), in an acute-care hospital; and 15 (34%), in other care facilities.

Most MAID-contemplating patients had recently received a consultation or follow-up visit with a TBCC oncologist (81 of 94, 86%), with or without having received

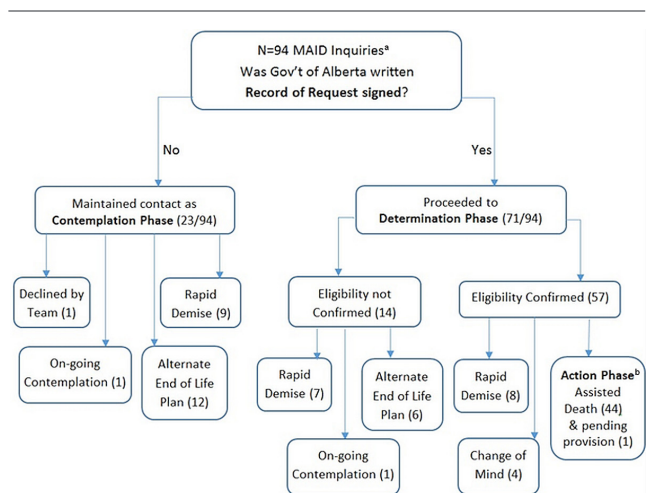


FIGURE 1 Process outcomes after patient contact with the Alberta Health Services MAID (medical assistance in dying) Coordination Service. Only inquiries from patients in the contemplation phase or those leading to a subsequent determination are included. Final outcomes at the time of death or last follow-up are illustrated; dynamic decisional pathways are not shown. ^aOf 94 inquiries, 30 (32%) were made during hospital admission and 21 (22%), while in hospice. ^bOf 44 assisted deaths, 12 (27%) were in hospital, and 17 (39%), in the patient's home.

cancer-specific treatments. Of the 81 patients with recent oncologist contact, 61 (75%) submitted their MAID request within 90 days of their last cancer care encounter, with most requests being submitted within 30 days of a TBCC oncology visit (45 of 61, 74%). Those 61 patients were seen or managed by 39 different attending cancer specialists from medical, radiation, and surgical oncology.

DISCUSSION

In Canada, MAID is a new health care service. In Alberta, centralized coordination provides patients with a standardized process, including informative Web-based reading materials, available eligibility assessors, location arrangements, and for eligible and consenting patients, a protocolized prescription for MAID. The MAID service requirement for patients with active cancer was unknown in January 2017. The collaborative service pilot described here was therefore conducted for patient support and institutional learning and feedback.

Data for the first 6 months of 2017 reported by Health Canada showed that, of all assisted deaths in Alberta, 49% were cancer-related, a rate that was lowest compared with the 60%–70% rates of cancer-related assisted deaths in other provinces⁴. Potential reasons for the discrepancy are speculative and not further elaborated for this report. Notably, 25% of MAID provisions in Alberta took place in the patient's home and 37% in a hospital.

In contrast, the present series for the Calgary Zone's cancer-centre MAID service pilot recorded more assisted deaths at home (39%), with a large proportion of the requesting patients having recently received cancer centre treatment or services. Almost two thirds of written requests

for MAID (45 of 71) occurred within 30 days after a cancer-centre contact. That degree of recent clinical care and attention could justify and motivate the active involvement of cancer centre staff in supporting MAID-related services, facilitating conversations and transitioning from a disease-oriented focus to end-of-life care concerns or other advance care planning issues. In addition, cancer clinicians have a vital role as clinical specialists to clarify prognosis, available treatment options, and care goals—elements that are essential for the MAID-contemplating patient with progressing or newly diagnosed cancer. Interdisciplinary involvement, especially with palliative care specialists, has been integral to the MAID process. As a function of coordination and collaboration, the MAID navigators and the oncology physicians routinely discuss the need for supportive and comfort care with the patient and family caregivers, and encourage the ongoing involvement of palliative specialist services to acknowledge or ensure that physical, mental, social, and existential domains of suffering are reassessed and addressed to the best extent possible.

Whether they consist of contemplative conversations, eligibility assessments, provision, or after-death care, MAID-related services are new to clinical practice in Canada. Assigning the role of consultative MAID eligibility determination and provision to specific individuals (2 senior oncology physicians in this service region) helped in the development of a collaborative relationship between the centralized coordination team and clinical oncology care providers. The formalized role also enabled interdisciplinary communication (particularly with palliative care services) and provided support to other oncologists encountering MAID inquiries. The 2017 pilot through the TBCC has established some practice standards for the regional cancer service and begun building capacity to help sustain a high-quality, patient-centred approach to end-of-life care, for which MAID is now one of the accepted options.

With respect to limitations, the collaborative service model has been limited to the contemplation, determination, and action phases, and does not include bereavement support or contact with surviving families or caregivers about their experiences. An information booklet with contact numbers for grief and bereavement services (routine care through AHS) and support for family published by Dying with Dignity Canada is given to the family at the end of each provision, but the extent to which grief support is needed or accessed is unclear.

Because MAID provision is deemed an elective procedure, time for provision is limited to standard workdays and hours, and the lack of on-call or after-hours provision was a limiting factor for some patients. Given that navigators have a wide range of tasks and that patient conditions can change unpredictably, real-time communications with family caregivers can be challenging. At times, the expectations of patients, family, or caregivers have exceeded service capacity. Even so, the consistent gratitude, case after case, expressed by family and caregivers to the

team at the end of the assisted death, affirms the value and quality of services provided. Provincially, the MAID Coordination Service has prepared, but not yet implemented, a post-MAID questionnaire to survey and evaluate the family and caregiver experience of the MAID process, including an invitation for those who received both palliative care and MAID services to participate in focus group discussions. The need for additional resources or strategies to enhance interdisciplinary communication, as well as communication between the MAID team and patients or family caregivers, will likely be identified or clarified.

CONCLUSIONS

In Canada, MAID is a new medical service. Accessing MAID can be daunting for patients with advanced cancer as their health declines near the end of life. A centralized coordination service, in collaboration with the regional cancer centre, appeared to be an effective strategy to enable interdisciplinary care delivery and to enhance a patient-centred approach at the end of the patient's cancer journey.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare the following interests: SV has received fees as an advisory board member for Amgen, AstraZeneca, Eli Lilly, Novartis, Pfizer, Roche, and Seattle Genetics. The remaining authors have no conflicts to disclose.

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