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Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada

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An aging population and shifts in Western societies toward secularism, populism, and an emphasis on individual autonomy and personal control have fueled the movement to legalize assisted dying. It has now been legalized in some form in five European countries (the Netherlands, Belgium, Switzerland, Germany, and Luxembourg), six U.S. states (Oregon, Washington, Vermont, Montana, California, and Colorado), Colombia, and most recently Canada.[1]

Medical assistance in dying, referred to as MAiD in Canada, was decriminalized by the Canadian Supreme Court on February 6, 2016,[2] and a bill that specified the conditions under which MAiD could be legally provided was passed by parliament on June 17, 2016.[3] These legal milestones brought resolution to a long-running, contentious debate in this country about the permissibility of assisted dying — but left much ambiguity regarding its implementation.[4] With relatively little guidance or coordination at the national or provincial levels and without any specified funding mechanism, health care institutions and the medical community were obliged to implement MAiD, ensuring timely access and balancing the rights of patients and health care providers.

The only published report on the implementation of an assisted dying program is that of the Death with Dignity program at Seattle Cancer Care Alliance,[5] which provides only assisted suicide (the prescribing of lethal medications that patients self-administer) outside the hospital setting. At the time that report was published, 24 patients had died from a self-administered lethal dose of secobarbital over almost 2 years, representing 21% of those who had inquired about the program and 60% of those who were prescribed the drug. Assisted suicide may allow patients to feel a greater sense of autonomy, and health care providers to feel less responsibility and moral conflict, than they do with euthanasia (the administration of a lethal substance by another person).[6]

The Canadian MAiD law allows either assisted suicide or euthanasia for a requesting person who meets specified criteria. We recently implemented a hospital-based MAiD program at the University Health Network (UHN) in Toronto, and as other U.S. states and countries such as Australia, France, South Africa, Japan, and the United Kingdom consider legalizing MAiD, they may find our institution's experience valuable. Provision of MAiD in a health care facility imposes specific institutional obligations to ensure effective and appropriate delivery, support and protect families and health care providers, and educate staff about the practice.

Institution-based delivery and the hospital-wide education process surrounding it have brought assisted dying more prominently into the public space of medical care. These circumstances have enhanced transparency and accountability regarding the range of medical practices at the end of life and have encouraged more open conversation about wishes, fears, and preferences. It has been noted that such open discourse, which has been called "public dying,"[7] may diminish stigma and fear about the end of life and may help break down the barrier of silence and isolation between dying people and the world to which they have belonged. Most health care providers participating in MAiD believe they have a moral obligation to provide compassionate care and uphold the legal rights of the terminally ill. There has been general support for their participation, although some concerns have been expressed about the ad-

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verse personal and professional repercussions they might experience.

UHN consists of four tertiary care teaching hospitals that collectively provide care to nearly 40,000 inpatients and support more than 1.1 million ambulatory care visits per year. The Department of Supportive Care at Princess Margaret Cancer Centre, which offers psychosocial oncology and palliative care services, assumed operational responsibility for MAiD at UHN because of its staff members' expertise in responding to patients' and families' suffering, assessing suicidality, and managing end-of-life care. Other clinical departments were unwilling to be formally associated with MAiD in this way, citing concerns ranging from conscientious objections of staff, to potential stigmatization of their practice area, to concern about obscuring their specialty's role in protecting life.

The responsibility for implementing MAiD required the creation of an institutional framework for patient assessment and provision of the service and a plan for educating staff about engaging in conversations with patients about it. A website (www.uhn.ca/healthcareprofessionals/MAID) and an e-learning module were developed to support new staff members and program sustainability. The UHN MAiD framework (Fig. 1) was structured to provide equitable access to MAiD and to ensure that the substantive procedural safeguards required by Canada's law (Table 1) would be upheld.

UHN's MAiD Framework

Early in the framework's development, UHN chose to limit MAiD to the intravenous administration of lethal medications in the hospital. This decision was based on the predictability of the outcome with this method, the lower complication rate than with oral administration of drugs,[8] and the structure of medical care at UHN, which is largely hospital-based. For patients seeking oral options or provision of MAiD at home, physicians were directed to contact a community provider through a referral service of the Ontario Ministry of Health and Long Term Care. To respect conscientious objection and the personal discomfort of some staff, and to meet the law's requirement that MAiD be provided with "reasonable knowledge, care and skill,"[9] UHN adopted a three-team model consisting of clinical, assessment, and intervention teams (Fig. 1).

The clinical team consists of all health care providers involved in usual care for the patient, including nurses, allied health professionals, consultant physicians, and the attending or most responsible physician (MRP). The assessment and intervention teams are constituted entirely of physicians and nurse practitioners who have volunteered to participate. This approach has largely circumvented the anticipated problem of conscientious objection, although some health care providers are still unwilling to make effective referrals to willing providers.

The assessment team comprises two physicians skilled in assessing patients' prognosis, suffering, and capacity to provide informed consent. Disagreements between these two assessors are resolved through discussions involving the two MAiD program leaders. The intervention team includes a physician or nurse practitioner who conducts a final evaluation and ensures that the patient retains capacity before obtaining informed consent and providing the intervention. Although designating a specific and consistent location for MAiD delivery has logistical advantages, a distributed model was adopted because no clinical unit was willing to be identified as the de facto "MAiD unit."

UHN takes measures to diminish potential adverse effects of MAiD on the families of the deceased and on staff. These include ensuring that psychosocial care clinicians are available to provide short-term support to family members as needed and conducting debriefing sessions for staff before and after the intervention. Most family members have been supportive of patients' wishes and appreciative of our process. Distress has largely been associated with a struggle to accept the inevitable death of their loved one, rather than a response to MAiD itself. Finally, a multidisciplinary UHN MAiD quality committee provides oversight, reports performance on MAiD metrics annually to the medical advisory committee, and stewards MAiD data for use in quality assessment and research (with Research Ethics Board approval).

UHN's MAiD Statistics

UHN began receiving patient inquiries about MAiD in March 2016, soon after assisted dying was decriminalized. Table 2 shows the process metrics and clinical characteristics of referrals from March

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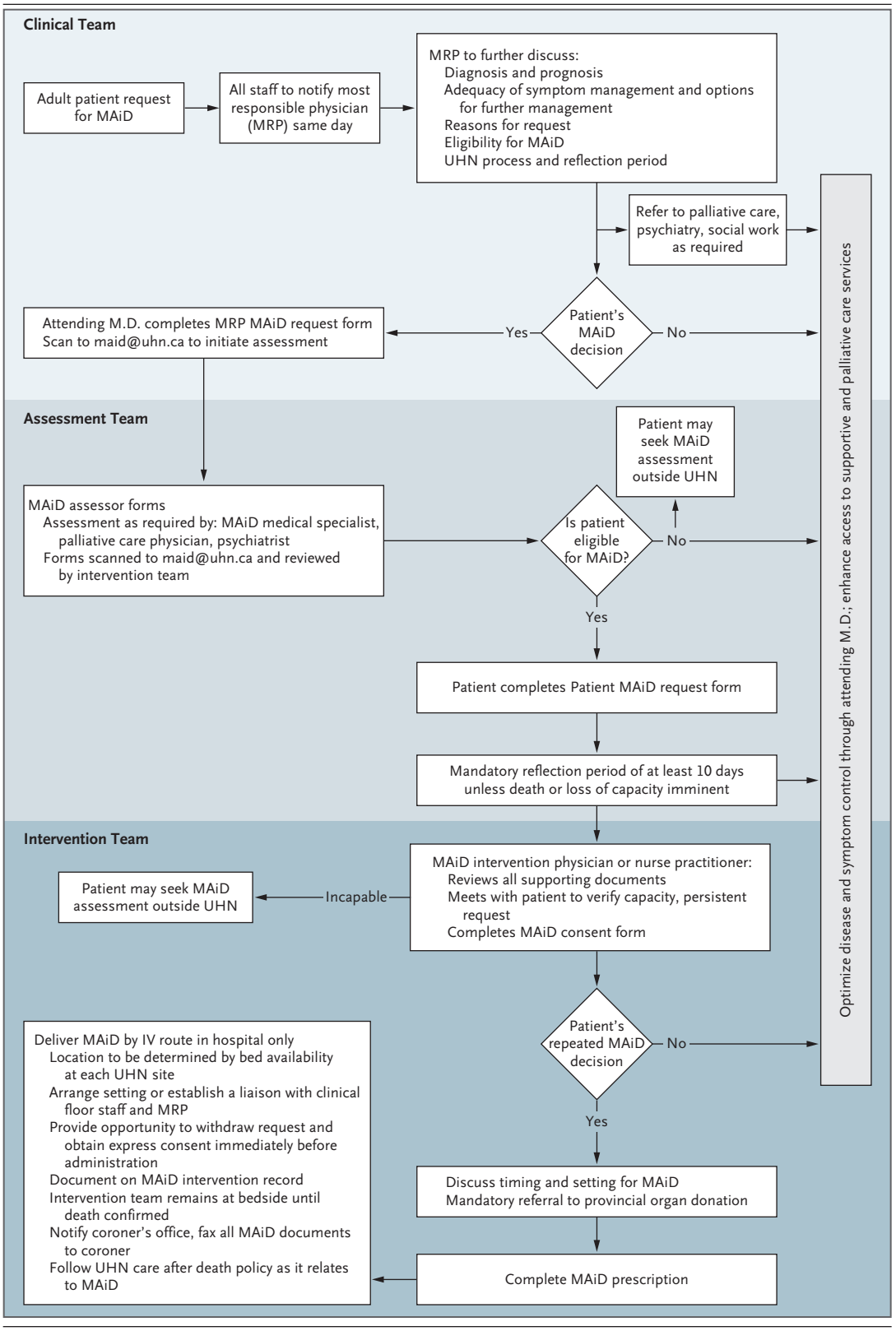

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Figure 1 (facing page). The UHN MAiD Framework.
Supportive care may include any combination of spiritual care, social interests, occupational therapy, physiotherapy, physiatry, psychology, and psychiatry.

8, 2016, to March 8, 2017. There were 74 MAiD inquiries during that period, 74% of which were for patients whose primary diagnosis was cancer. Other diagnoses included neurologic conditions (amyotrophic lateral sclerosis, stroke, neurofibromatosis, multiple sclerosis, cortical basal degeneration, myasthenia gravis, and Parkinson's disease) and lung conditions (chronic obstructive pulmonary disease, bronchiectasis, and interstitial lung disease); there were also single cases of short gut syndrome and depression. (Mental illness was a condition potentially eligible for MAiD between February 6, 2016, and June 17, 2016, after which it was excluded by legislation.) This remains a contested area subject to future constitutional review.

Of patients who inquired about MAiD, 39% (29 of 74) proceeded to assessment. Reasons for not proceeding included withdrawal of the request by the patient, primary mental illness, delirium, and active dying, with a concomitant inability to participate in an assessment. Among the patients who underwent assessment, 86% (25 of 29) were approved for MAiD; 97% (28) of these patients were already receiving specialty palliative care services, but only 52% (15) were receiving specialized psychosocial care. Reasons for denial of approval included lack of capacity to provide informed consent and indecision about receiving MAiD at the time of the eligibility assessment. Among patients granted approval, 76% (19 of 25) have received MAiD. The reason for not proceeding to MAiD was natural death in some cases, and a change in the patient's decision in others. Just prior to delivery of MAiD, all patients who reached this stage were evaluated by intervention-team physicians to determine whether they currently met criteria for informed consent. Of those who retained capacity to consent, none rescinded their intent to proceed. In all cases, death occurred within minutes after injection of intravenous drugs for MAiD.

Overall, 26% of the patients (19 of 74) who inquired about MAiD received the intervention. Those who received MAiD tended to be white and relatively affluent and indicated that loss of autonomy was the primary reason for their request (Table 2). Other common reasons included the wish to avoid burdening others or losing dignity and the intolerability of not being able to enjoy one's life. Few patients cited inadequate control of pain or other symptoms.

CURRENT STATUS AND FURTHER CONSIDERATIONS

The degree to which MAiD has become normalized within UHN and throughout Canada was unexpected, particularly in view of the controversy preceding its legalization. Nevertheless, participating physicians are still being advised to seek legal advice on each case in which they participate. This recommendation highlights persistent concerns regarding medical liability, although such close and ongoing legal consultation for the purpose of defending and protecting physicians does not necessarily encourage the optimal balance between the rights of health care providers and those of patients.

We discovered relevant practical and emotional needs among members of virtually every hospital department throughout our implementation process. We found that education and support are required for staff members directly involved in MAiD, including those providing nursing, pharmacy, and translation services, but also for those indirectly involved, such as those in housekeeping, transportation, and medical records departments. Fears that there could be overzealous delivery of MAiD may have been diminished by checks and balances in our framework, by the broad and inclusive approach we took to education, and by the fact that institutional leaders had not taken a position of either advocacy for or opposition to MAiD. It has been consistently communicated that the program's goal is to provide patient-centered care that meets the institution's legally mandated obligations, while safeguarding the rights and interests of both patients and staff.

Our early experience with MAiD has demonstrated that many patients who request MAiD do not receive it because death or loss of capacity supervenes. That occurred most often with requests made when the patient was within hours or days from natural death. We have now taken the position in our MAiD program that it is neither desirable nor practically feasible for MAiD to be delivered on an emergency basis at the very end of

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Table 1. Key Substantive and Procedural Safeguards in Canadian MAiD Law.

Substantive Safeguards

A person may receive MAiD only if all the following eligibility criteria are met:

1. The person is eligible — or but for any applicable minimum period of residence or waiting period would be eligible — for health services funded by a government in Canada;
2. The person is at least 18 years of age and capable of making decisions with respect to his or her health;
3. The person has a grievous and irremediable medical condition:
   a. The person has a serious and incurable illness, disease, or disability;
   b. The person is in an advanced state of irreversible decline in capability;
   c. The illness, disease or disability, or state of decline causes enduring physical or psychological suffering that is intolerable to the person and cannot be relieved under conditions that the person considers acceptable; and
   d. The person's natural death has become reasonably foreseeable, when one takes into account all medical circumstances, without a prognosis necessarily having been made as to the specific length of time remaining;
4. The person has made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
5. The person gives informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve his or her suffering, including palliative care.

Procedural Safeguards

A medical practitioner or nurse practitioner must satisfy the following requirements before providing MAiD:

1. Ensure that the person's request for MAiD was made in writing, signed and dated by the person or by an authorized third person if the person desiring MAiD is unable to sign, after being informed of his or her grievous and irremediable medical condition;
   a. The authorized third person must be at least 18 years of age, understand the nature of the request for MAiD, and not be a beneficiary under the person's will or a recipient in any other way of other material benefit resulting from the person's death;
2. Ensure that the request was signed and dated by two independent witnesses:
   a. Witnesses must be at least 18 years of age and understand the nature of the request for MAiD;
   b. Witnesses must not be a beneficiary under the person's will or a recipient in any other way of other material benefit resulting from the person's death;
   c. Witnesses must not be an owner or operator of a health care facility at which the person is being treated or resides; and
   d. Witnesses must not be directly involved in providing health care services or personal care to the person;
3. Ensure that the person has been informed that, at any time and in any manner, the person may withdraw the request;
4. Ensure that another independent medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all MAiD eligibility criteria; both practitioners must meet the following requirements:
   a. Practitioners are not in a mentoring or supervisory relationship with one another or connected in any other way that would affect their objectivity; and
   b. Practitioners are not a beneficiary under the patient's will or a recipient in any other way of other material benefit resulting from the patient's death;
5. Ensure that there are at least 10 full calendar days between the day on which the request was signed by the person and the day on which MAiD is provided or — if both practitioners are of the opinion that the person's death or loss of capacity to provide informed consent is imminent — any shorter period that is appropriate in the circumstances;
6. Immediately before providing MAiD, give the person an opportunity to withdraw the request and ensure that the person gives express consent to receive MAiD;
7. If the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided and communicate his or her decision;
8. Provide MAiD with reasonable knowledge, care, and skill in accordance with any applicable provincial laws, rules, or standards; and
9. Inform the pharmacist that the substances being prescribed are for the purpose of providing MAiD.

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Table 2. UHN MAiD Process Metrics and Clinical Characteristics (March 8, 2016, to March 8, 2017).*

Process Metrics	Data	
Disciplines of assessment team members	N=17: psychiatrist (7), palliative care physician (4), family physician (1), oncologist (2), neurologist (1), internist (1), surgeon (1)	
Disciplines of intervention team members	N=12: anesthesiologist (3), intensive care unit physician (1), emergency department physician (1), family physician (1), internist (1), oncologist (1), nurse practitioner (4)	
Total MAiD inquiries by month	N=74: March (2), Apr. (1), May (0), June (8), July (4), Aug. (13), Sept. (12), Oct. (3), Nov. (5), Dec. (11), Jan. (4), Feb. (11)	
Location of MAiD assessments	N=29: outpatient (7), inpatient (22)	
MAiD approvals	N=25	
Location at activation of approval of MAiD intervention	N=19: outpatient (3), inpatient (16)	
Mean time from receipt of request to assessment (range) — days	3.2 (0–10)	
Mean time from approval to intervention (range) — days	10.4 (0–62)	
Mean recommended reflection period (range) — days	7.7 (0–20)	
Clinical Characteristics	**No Intervention**	**Intervention**
Assessed patients (N=29)	10	19
Median age (range) — yr	67 (27–92)	70 (47–91)
Sex — no. (%)		
Female	3 (30)	9 (47)
Male	7 (70)	10 (53)
Race — no. (%)†		
White	6 (60)	18 (95)
Asian	4 (40)	1 (5)
Married (including common law) — no. (%)	6 (60)	11 (58)
Average median annual household income — $*	64,000	76,000
Cancer diagnosis — no. (%)	8 (80)	18 (95)
Percent citing loss of autonomy as reason for MAiD request	80	95
Receiving palliative care — no. (%)	9 (90)	19 (100)
Receiving psychosocial care — no. (%)	3 (30)	12 (63)

* Average median annual household income was estimated by postal-code proxy on the basis of the 2011 Statistics Canada Census.
† Race was determined by the assessment team.

life. Indeed, the initiation of the MAiD process in actively dying patients may compromise symptom management, since patients may refuse opioids in order to retain capacity for consent; such late initiation also needlessly consumes the limited energy and time of patients and their families at the very end of life. Palliative sedation is available as an alternative for intolerable suffering that cannot otherwise be relieved in actively dying patients.

The discrepancy in numbers between MAiD requests and delivery may occur in part because the Canadian law does not allow MAiD to be approved as a form of advance care planning. Patients must be able to provide informed consent just before the intervention is delivered, presumably to protect them from its unwanted imposition when they are incapable of making their own decisions. This stipulation, however, has unintentionally caused some patients to feel pressured to re-

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quest MAiD prematurely or to accept the risk of becoming incapacitated and thereby losing the right to receive MAiD.

As in the United States[10] and Europe,[11] the primary reason for which patients in our setting sought MAiD was to relieve distress over the loss of autonomy and to experience a sense of personal control over the circumstances of dying. Approval for MAiD had this effect in some patients, even when they were uncertain about whether and when they would actually pursue it. As in other jurisdictions,[10,12] many patients changed their minds about pursuing MAiD after making the request and receiving approval. The lack of provision in the Canadian legislation for such reversals may cause distress in people who want certain and timely access to MAiD but are not yet prepared to receive it. Modification of the legislation to permit advance care planning and consent for MAiD by a substitute decision maker would allow the prior wishes of competent patients to be fulfilled, whether or not they retain capacity at the time of delivery. That approach is already possible with such measures as withdrawal of life supports.

The UHN MAiD program is resource-intensive, but it has been established and maintained largely by the utilization or diversion of existing resources in a publicly funded health care system. MAiD care teams were deployed through workload redistribution, and physicians conducting assessments and performing interventions can claim fees from the provincial health insurance plan for the services provided. Hospital funding was provided for development of the educational materials and for the recruitment of a MAiD clinical care coordinator. However, the time spent by many volunteer health care providers in delivering MAiD, providing education related to it, and participating in the required case reviews and legal documentation is largely uncompensated. Funding mechanisms are needed to ensure safe and effective delivery of MAiD in settings that may not be able to mobilize adequate internal resources.

Just as advocacy from outside mainstream medicine brought palliative care "from the margins to the center,"[13] so has it brought MAiD into the mainstream of medicine. It is now clear that MAiD education must be included in undergraduate medical education curricula in Canada and in the training for a variety of specialties, including general medicine, family medicine, oncology, neurology, respirology, palliative care, pharmacy, psychiatry, social work, spiritual care, and bioethics. Whether the legalization of MAiD in Canada will contribute to its wider availability in other parts of the world remains to be seen, as does the answer to the question of whether this "brave new world" will ultimately be regarded as enlightened[14] or dystopian.[15]

Disclosure forms provided by the authors are available at NEJM.org.

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