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Oncologists and medical assistance in dying: where do we stand? Results of a national survey of Canadian oncologists

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ABSTRACT

Background In June 2016, when the Parliament of Canada passed Bill C-14, the country joined the small number of jurisdictions that have legalized medical assistance in dying (MAiD). Since legalization, nearly 7000 Canadians have received MAiD, most of whom (65%) had an underlying diagnosis of cancer. Although Bill C-14 specifies the need for government oversight and monitoring of MAiD, the government-collected data to date have tracked patient characteristics, rather than clinician encounters and beliefs. We aimed to understand the views of Canadian oncologists 2 years after the legalization of MAiD.

Methods We developed and administered an online survey to medical and radiation oncologists to understand their exposure to MAiD, self-perceived knowledge, willingness to participate, and perception of the role of oncologists in introducing MAiD as an end-of-life care option. We used complete sampling through the Canadian Association of Medical Oncologists and the Canadian Association of Radiation Oncology membership e-mail lists. The survey was sent to 691 physicians: 366 radiation oncologists and 325 medical oncologists. Data were collected during March–June 2018. Results are presented using descriptive statistics and univariate or multivariate analysis.

Results The survey attracted 224 responses (response rate: 32.4%). Of the responding oncologists, 70% have been approached by patients requesting MAiD. Oncologists were of mixed confidence in their knowledge of the eligibility criteria. Oncologists were most willing to engage in MAiD with an assessment for eligibility, and yet most refer to specialized teams for assessments. In terms of introducing MAiD as an end-of-life option, slightly more than half the responding physicians (52.8%) would initiate a conversation about MAiD with a patient under certain circumstances, most commonly the absence of viable therapeutic options, coupled with unmanageable patient distress.

Conclusions In this first national survey of Canadian oncologists about MAiD, we found that most respondents encounter patient requests for MAiD, are confident in their knowledge about eligibility, and are willing to act as assessors of eligibility. Many oncologists believe that, under some circumstances, it is appropriate to present MAiD as a therapeutic option at the end of life. That finding warrants further deliberation by national or regional bodies for the development of consensus guidelines to ensure equitable access to MAiD for patients who wish to pursue it.

Key Words Medical assistance in dying, MAiD, end-of-life care, Bill C-14

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INTRODUCTION

In June 2016, when the Parliament of Canada passed Bill C-14, the country joined the small number of jurisdictions that have legalized medical assistance in dying (MAiD)[1]. Since legalization, nearly 7000 Canadians have received MAiD (as of October 2018), most of whom (65%) had an underlying diagnosis of cancer[2]. That observation is consistent with data from the Netherlands, Belgium, and Oregon, where, respectively, 71%, 69%, and 72% of deaths with MAiD occur in cancer patients[2]. Those data suggest that Canadian oncologists are likely to encounter patients who request MAiD; however, the extent to which oncologists participate in MAiD is unknown.

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Provincial regulatory bodies provide recommendations for MAiD practice; however, institutional policies, local practice patterns, and individual beliefs of oncologists might result in regional practice variation. Although Bill C-14 specifies the need for government oversight and monitoring of MAiD, the government-collected data to date have tracked patient characteristics rather than clinician encounters and beliefs. We developed a survey of Canadian oncologists to address four main study questions:

- What have been the experiences of Canadian oncologists with MAiD during the first 2 years of legalization?
- How do Canadian oncologists self-report their knowledge of MAiD policy and practice?
- How willing are Canadian oncologists to participate in MAiD?
- What do Canadian oncologists believe their role should be in introducing MAiD as an end-of-life care option?

Those questions are relevant not only in Canada, but might also assist in the conversation about MAiD in countries such as the United Kingdom, South Africa, and Australia, where consideration and debate about legalization have been occurring.

METHODS

Study Design

In this cross-sectional study, we designed and administered a novel online survey to assess the experience of Canadian medical and radiation oncologists with MAiD, self-perceived knowledge of MAiD, willingness to participate in MAiD, and perceptions of the role of oncologists in introducing MAiD as a treatment option. Notably, although surgical oncologists play a critical role in the management of cancer patients, our decision to exclude them from our study population was based on their more limited exposure and longitudinal follow-up with patients who are entering the more advanced phases of end-stage malignancy, where MAiD discussions are most likely to occur.

Survey Development

We used a rigorous process to develop our survey instrument, which measured 4 domains: exposure to MAiD, self-perceived knowledge, willingness to participate, and the perceived role of oncologists in introducing MAiD. We used the process and safeguards set out in Bill-C14 to generate a process map of MAiD, including 3 stages: initial inquiry, assessment of eligibility, and provision of MAiD. A content matrix was used to develop an initial list of survey items addressing each domain at each stage of the MAiD process, resulting in 22 items. When possible, corresponding response options were adopted from previously published Likert-scale anchors[3]. After eliminating redundant questions, the core survey was narrowed to 16 questions.

Content experts were identified on the basis of being practicing oncologists with exposure to MAiD in clinical practice and therefore deemed to be able to appreciate the relevance of the core survey questions. Additionally, members of the MAiD assessment team were included, given their understanding of and familiarity with processes and procedures in place for MAiD. A resulting group of experts, including 8 oncologists and 2 members of the MAiD team at Hamilton Health Sciences, assessed the face validity of the overall survey and the content validity of the individual survey items. Experts used a content validity index to review the survey for comprehensiveness and item relevance[4–6]. Experts rated the relevance of each item on a 4-point ordinal scale, and any item that scored less than 2 was discarded. All items were deemed to be relevant, and no new items were suggested by the content experts.

The survey was pilot-tested with 6 medical and 2 radiation oncologists from two community and two academic sites in Ontario, and after pilot-testing, the questions were refined to minimize ambiguity or bias in wording. Some questions were nested and contingent on response options from previous items. The final survey instrument is available from the authors upon request. The present study and the final survey instrument were approved by the Hamilton Integrated Research Ethics Board.

Data Collection

An electronic version of the final survey was created for e-mail distribution. We used complete sampling of members of the Canadian Association of Medical Oncologists and the Canadian Association of Radiation Oncology. After the initial e-mail invitation to complete the survey, members were sent 2 group reminder messages by e-mail. Responses were collected anonymously between March 2018 and June 2018. Consent to participate in the study was voluntary and was implied by completion of the survey, as outlined in an introductory e-mail message and form before survey completion. Physicians were not compensated for participation.

Outcomes and Data Analysis

Basic descriptive statistics summarize respondent characteristics and item responses. Reliability of the survey was assessed within each domain using the Cronbach alpha. We constructed a full multivariable regression model to uncover associations between oncologist exposure to MAiD and 3 outcomes:

- Reported knowledge of the eligibility criteria for MAiD
- Willingness to serve as an assessor of a patient's eligibility
- The role of oncologists in introducing MAiD as a treatment option

We used logistic regression analysis to examine associations between respondent demographics and those outcomes. "Exposure to MAiD" was defined as the oncologist reporting 1 or more patients approaching them about MAiD compared with no patients approaching them. Oncologists who reported "I don't know" for the number of patients approaching them were excluded from the regression analysis. Of oncologists who had at least 1 patient approach them about MAiD, "increasing exposure to MAiD" was defined as the ordinal number of patients. All tests and confidence intervals were two-sided and a p value of 0.05 or less was considered statistically significant.

TABLE I Characteristics of 224 respondents

Characteristic	Responses [*n* (%)]
Age group	
≤30 Years	7 (3.1)
31–40 Years	72 (32)
41–50 Years	57 (26)
51–60 Years	47 (21)
61–70 Years	30 (13)
≥71 Years	6 (2.7)
Prefer not to answer	5 (2.2)
Sex	
Women	100 (45)
Men	122 (54)
Prefer not to answer	2 (1)
Practice setting	
Academic	188 (84)
Community	19 (8)
Mixed	17 (8)
Specialty	
General practitioner (oncology)	2 (1)
Medical oncology	93 (42)
Radiation oncology	129 (58)
Practice duration	
≤5 Years	61 (27)
6–9 Years	39 (17)
10–14 Years	16 (7)
15–19 Years	30 (13)
20–24 Years	32 (14)
≥25 Years	46 (21)
Primary practice location	
Alberta	24 (11)
British Columbia	42 (19)
Manitoba	12 (5)
Maritimes	20 (9)
Newfoundland and Labrador	6 (3)
Ontario	88 (39)
Quebec	30 (13)
Saskatchewan	2 (1)

TABLE II Oncologist exposure to medical assistance in dying (MAiD)

Question	Responses [*n* (%)]
How many patients have approached you requesting MAiD since the passing of Bill C-14?	
0	67 (30)
1	31 (14)
2	39 (17)
3	21 (9)
4	15 (7)
≥5	40 (18)
I do not remember	11 (5)
What did you do when the patient(s) approached you about MAiD? (choose all that apply) [*n*=158]	
I provided a formal assessment of eligibility for MAiD.	38 (24)
I was not involved and referred to another physician or team.	110 (70)
I advised the patient I was not comfortable being involved with MAiD.	6 (4)
It was determined that MAiD was not the most appropriate course of action	44 (28)
How many of these patients did you formally assess for eligibility of MAiD? [*n*=38]	
0	2 (5)
1	13 (34)
2	9 (24)
3	5 (13)
4	1 (3)
≥5	8 (21)
How many of these patients were ultimately approved for and received MAiD? [*n*=38]	
0	5 (13)
1	7 (18)
2	10 (26)
3	2 (5)
4	5 (13)
≥5	5 (13)
I do not know	4 (11)

RESULTS

E-mail invitations to complete the survey were sent to 691 oncologists (325 medical oncologists, 366 radiation oncologists). Responses were received from 93 medical oncologists (28.9% response rate) and 129 radiation oncologists (35.2% response rate), representing all regions of Canada with oncology services (32.4% overall response rate, Table I). Most respondents were academic physicians (83.9%) between the ages of 31 and 60 (78.6%). The survey demonstrated good internal consistency in the domains of knowledge of MAiD and willingness to participate in MAiD, with Cronbach alphas of 0.868 and 0.708 respectively.

Exposure to MAiD

During the first 2 years of legalized MAiD, 70.1% of responding oncologists reported having at least 1 patient approach them about this option (Table II). Of those who were approached with a patient request, most (70%) referred the patient to local specialist MAiD teams or, after an initial exploration of treatment options, determined that MAiD was not the appropriate course of action (28.0%). Less commonly, they completed a formal assessment themselves (24.2%). Few of the responding oncologists (2.8%) advised patients that they were not comfortable being involved in MAiD. When oncologists completed a formal MAiD assessment, most of the requesting patients were ultimately found eligible and received MAiD (86.8%).

Knowledge

Responding oncologists were of mixed confidence in their knowledge of the MAiD eligibility criteria set out in Bill C-14 (61.5% good-to-excellent) and the assessment process for MAiD (47.8% good-to-excellent), although a substantial number indicated poor confidence in their knowledge

TABLE III Oncologist knowledge of medical assistance in dying (MAiD)

Question	Responses [*n* (%)]
How would you rate your confidence level regarding your knowledge of the eligibility criteria for MAiD? [*n*=220]	
Excellent	14 (6)
Very good	43 (20)
Good	78 (35)
Fair	61 (28)
Poor	24 (11)
How would you rate your confidence level regarding your knowledge of the assessment process or approval for MAiD as stated in Bill C-14 or provincial guidelines? [*n*=220]	
Excellent	11 (5)
Very good	32 (15)
Good	62 (28)
Fair	77 (35)
Poor	38 (17)
How would you rate your confidence level regarding your knowledge of the medications or process used for the actual administration of MAiD as stated in Bill C-14 or provincial guidelines? [*n*=220]	
Excellent	7 (3)
Very good	12 (5)
Good	22 (10)
Fair	61 (28)
Poor	118 (54)

TABLE IV Oncologist willingness to be involved in medical assistance in dying (MAiD)

Question	Responses [*n* (%)]
Now that MAiD is legal under certain circumstances, would you be willing to act as an assessor for your patient's eligibility? [*n*=218]	
I don't know	17 (8)
No	70 (32)
Yes	90 (41)
Yes, only in some cases	41 (19)
Now that MAiD is legal under certain circumstances, would you be willing to prescribe medication for a patient of yours who has been assessed and approved to receive a medically assisted death? [*n*=218]	
I don't know	22 (10)
No	120 (55)
Yes	50 (23)
Yes, only in some cases	26 (12)
Now that MAiD is legal under certain circumstances, would you be willing to directly administer medications (for example, intravenous medication) for a patient of yours who has been assessed and approved to receive a medically assisted death? [*n*=218]	
I don't know	18 (8)
No	140 (64)
Yes	39 (18)
Yes, only in some cases	21 (10)

about those areas (10.9% and 17.3% respectively, Table III). Oncologists rated their confidence in knowledge of the medications or process used in the administration of MAiD as fair-to-poor (81.3%). Logistic regression analysis (supplementary Table S1) showed strong associations of physician exposure with self-reported knowledge (odds ratio: 4.06; 95% confidence interval: 2.02 to 8.15; $p < 0.001$) and years in practice (odds ratio: 1.68; 95% confidence interval: 1.16 to 2.42; $p = 0.006$). No other factor was statistically prognostic in the multivariable model.

Willingness

Overall, 60.1% of responding oncologists reported that they would be willing to act as an assessor of their patient's eligibility for MAiD (Table IV). Willingness to write a medication prescription for self-administered MAiD or to directly administer intravenous medications for MAiD was lower at 34.8% and 27.5% respectively. Logistic regression analysis (supplementary Table S2) investigating associations between physician demographic factors and willingness to act as an assessor for patient eligibility found that no factor was predictive.

Role in Introducing MAiD

A small proportion of responding oncologists (17.4%) believed that most of their patients were aware of their right to request MAiD, with 52.8% feeling that, under some circumstances, they would advise a potentially eligible patient of their right to request MAiD. Within the latter group, 75% believed that the absence of chemotherapy, radiotherapy, or surgical treatment options, coupled with some form of patient distress (emotional, physical, existential), would warrant advising a patient of the right to request MAiD (Table V). For the 23.9% of responding oncologists who felt that such advice was inappropriate, their concern most commonly stemmed from the risk that advising patients of their right to MAiD might be construed as coercive or might damage the physician–patient relationship and from a belief that patients had a right to request MAiD, but not to be advised of it. Logistic regression analysis (supplementary Table S3) found no factor in the multivariable model to be statistically significantly prognostic for the likelihood of advising a patient about their right to request MAiD.

DISCUSSION

Ours is the first national survey of the experiences of Canadian oncologists with MAiD. Most responding oncologists reported having been approached by patients with a request for MAiD within the first 2 years of legalization. Those results are consistent with survey data from the American Society of Clinical Oncology (ASCO) in 1997, in which 62.9% of oncologists (including medical, radiation, and surgical disciplines) had received a request for MAiD over the course of their careers[7]. The ASCO survey occurred at a time when most U.S. states did not have any such legislation in place, suggesting that oncologists commonly receive requests for MAiD, regardless of its legal status. Given the high likelihood that oncologists will receive a request

TABLE V Oncologist role in introducing medical assistance in dying (MAiD)

Question	Responses [*n* (%)]
What proportion of patients do you think are aware of their right to request MAiD? [*n*=218]	
More than three quarters	17 (8)
Half to three quarters	21 (10)
One quarter to half	47 (22)
Fewer than one quarter	52 (24)
I don't know	81 (37)
Do you think that it would ever be appropriate for an oncologist to advise a potentially eligible patient of their right to request MAiD if the patient did not initiate a discussion first? [*n*=218]	
I don't know	51 (23)
No	52 (24)
Yes, under some circumstances	115 (53)
Under what situations do you believe it is appropriate to advise the patient of this right?[a] (choose all that apply)	
At the time of consultation when incurable diagnosis established	19, 1
Even while there are still palliative options available	15, 0
When there are no alternative options available and patient not symptomatic	27, 4
When there are no alternative options available and patient is symptomatic	86, 25
Other (please specify)	18, 6
Why do you believe it is inappropriate for an oncologist to advise potentially eligible patients of their right to request MAiD?[b] (choose all that apply)	
MAiD is in contradiction of the "Do no harm" principle	15, 1
May be construed as coercive	36, 6
Oncologists have not received adequate training	10, 5
Patients can request MAiD, not be advised of MAiD	19, 4
Morally opposed to the idea of MAiD	17, 5
Role is to offer hope and to improve or extend life	19, 3
Other (please specify)	9, 0

[a] Responses for those who felt that it might be appropriate to advise patients of their right to request MAiD. The number after a comma reflects the responses of physicians who initially answered "I don't know."

[b] Responses for those who felt it was inappropriate to advise patients of their right to request MAiD. The number after a comma, reflects the responses of physicians who initially answered "I don't know."

for MAiD, the novelty of MAiD, and the paucity of data about the experience of Canadian oncologists with MAiD, we were hopeful to obtain a much higher overall survey response rate. Although a one third response rate for an anonymous online survey is fair, that level of response might hurt the generalizability of the findings, despite the capture of responses from across the country. Given a limited response rate, the risk of response or volunteer bias would be high, tending to capture the attention of those who are in favour or supportive of the role of MAiD for patients or those who have more comfort with their knowledge or exposure to it. However, in our study, 35% of respondents had limited exposure to patient requests (did not receive or did not recall receiving patient requests for MAiD), and similarly, 38% of respondents reported that their confidence in their knowledge of MAiD was fair-to-poor, suggesting that, despite a limited response rate, we might have been able to capture a diverse collection of respondents.

Our responding oncologists had more confidence in their knowledge about eligibility and assessment of patients for MAiD than in their knowledge about MAiD provision. Before and after legalization of MAiD, significant effort was made by national and provincial organizations to educate about the eligibility criteria and assessment for MAiD so that physicians were equipped to handle initial patient requests. At the same time, many institutions developed specialized teams to handle the actual provision of MAiD (and, in some cases, the assessment process), involving only a small select group of physicians, which might explain the disparity in knowledge for those two components of MAiD.

Similarly, a higher proportion of oncologists reported that they would be willing to formally assess the eligibility of their patients for MAiD than would be willing to provide a prescription or administer medications. That finding suggests a possible role of oncologists as "gatekeepers" for MAiD, providing initial screening and assessment rather than comprehensive care coordination in the event of MAiD authorization. Having a larger proportion of community oncologists responding to our survey would have allowed us to get a better sense of whether that hypothesis is in fact the case. Most of our respondents worked in academic institutions and referred their patients to specialized teams for further assessment and management. Therefore, despite general support for MAiD as a treatment option, relatively few oncologists had actually provided a formal assessment. Oncologists might also face barriers such as lack of time, education, or institutional support for assessing their patients for MAiD.

Very few oncologists reported outright refusal to be involved with MAiD. Across Canada, physicians who identify as conscientious objectors to MAiD have varying care obligations. In Ontario, British Columbia, and Saskatchewan, such physicians are required by their provincial regulatory bodies to provide patients with an "effective referral" to a willing physician[8–10]. Our survey found that respondents from jurisdictions where such a policy was in place reported experience, knowledge, and willingness to participate in MAiD similar to those expressed by colleagues from areas without such a policy.

To our knowledge, our survey is the first large effort to explore clinician beliefs about advising patients of their right to request MAiD. More than half the respondents were willing to do so, usually when no effective anticancer therapy options were available and the patient was already experiencing some form of unmanageable distress. That finding is consistent with a qualitative study of general practitioners in the Netherlands which reported that physicians found it difficult to know the optimal timing to discuss MAiD and described ambivalence about initiating the conversation, but indicated a willingness to bring it up

when facing foreseeable and imminent fatal complications of disease[11].

It is striking that most oncologists in the present study reported a willingness to initiate discussion of MAiD together with other options for end-of-life care, with only a small proportion of respondents indicating that MAiD should be discussed only if prompted by the patient. Several respondents in the present study cited concerns that initiating a discussion might be construed by patients as suggesting or coercing a premature end to their lives. Data from other jurisdictions suggest that the rate of MAiD is not increased in what are traditionally identified vulnerable populations: elderly individuals, women, people of low socioeconomic status, those with mental health issues, and those belonging to racial and ethnic minorities[12]. Moreover, data from Oregon might suggest the opposite to be true: the largest proportion of those requesting and receiving MAiD are people of high socioeconomic status and high education[13]. Additionally, recent Ontario data identify a similar phenomenon: recipients of MAiD were younger, married, had higher incomes, and lived in the community as opposed to being institutionalized[14]. The variability of clinician attitudes reported in this domain suggests that oncologist practice patterns, rather than the patient preferences, might be a driver of MAiD access. Clear consensus guidelines on the role of clinicians in advising patients of the right to request MAiD might help to ensure equitable access to MAiD while also protecting the most vulnerable patients.

Our study has several strengths. We used a rigorous process of survey development, including use of a content matrix, content validity assessment, and pilot-testing before survey administration. The survey instrument demonstrated good internal consistency. Our data collection was comprehensive, and we targeted a national sample of oncologists. Conducting the survey only 2 years after legalization provided enough time for oncologists to accrue experience with MAiD, but not so much time as to limit recall.

The study also has several limitations.

First, despite efforts to reach as many oncologists as possible, with repeated reminders, we were able to achieve only a 32.5% response rate, and the generalizability of our results therefore remains uncertain. We were able to reach approximately 63% and 68.5% of all medical and radiation oncologists in the country through Canadian Association of Medical Oncologists and Canadian Association of Radiation Oncology membership lists. The low response rate from community oncologists might be attributable to lower engagement with those national organizations. Additionally, our survey was available only in English, which might have limited the number of respondents for whom English is not their first language.

Second, the cross-sectional nature of the survey means that the response data do not capture trends over time. Exposure in the 2 years since legalization in Canada was associated with oncologist confidence in their knowledge about MAiD. With increased exposure, knowledge and attitudes could continue to change in years to come. Reports of experiences in Belgium and the Netherlands show an increasing level of acceptance of MAiD over time[15,16]. Repeating the current survey at a future interval would be informative.

Third, we did not explore oncologist experience with other end-of-life care options or access to palliative care services, which are potential influences on knowledge and attitudes toward MAiD. In the 1997 ASCO survey of its members, mediators of physician practice patterns for MAiD included level of training in end-of-life care or the ability to refer to a team that could provide adequate pain and symptom control[7]. Access to specialized palliative care providers is variable by region in Canada, as evidenced by a Canadian Hospice Palliative Care Association report, which notes that only 16%–30% of dying Canadians receive palliative hospice or end-of-life care services, and that factor could influence current perceptions about, or use of, MAiD on the part of oncologists[17,18]. Interestingly, recent Ontario data demonstrate that lack of access to palliative care was not a driver to request or access MAiD; 75% of those requesting MAiD on the basis of physical or psychological suffering were engaged with palliative care services[14]. An impact on MAiD of an inability to access palliative care is not established by previously published literature.

CONCLUSIONS

In this national cross-sectional survey of Canadian oncologists, we found that requests for MAiD were common. Oncologists reported having more confidence in their knowledge of the eligibility criteria and assessment process for MAiD than of the actual administration of MAiD. Most oncologists were willing to act as eligibility assessors for their patients and, under some circumstances, to advise patients of their right to request MAiD, but would not write a prescription or administer intravenous medications for MAiD. Few oncologists reported being completely unwilling to participate in any aspect of MAiD. Future research that captures a greater percentage of oncologist responses is needed to determine practice patterns over time and to understand potential barriers to oncologist participation in MAiD.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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