



End-of-life discussions in practice: survey among Canadian radiation oncologists

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Background: Early end-of-life (EOL) discussions improve patient satisfaction, quality of care, and the cost-effectiveness of care. However, some US studies show that radiation oncologists (ROs) are unlikely to discuss EOL issues until the patients develop significant symptoms or the families initiate the discussion. There have been no prior studies describing the patterns of EOL discussions among Canadian ROs. The objectives of this study were: (I) to describe the patterns of EOL discussions among Canadian ROs; (II) to identify the barriers to EOL conversation among Canadian ROs; (III) to assess the attitudes of Canadian ROs toward Medical Assistance in Dying (MAiD).

Methods: The 22-question online survey was distributed to the members of Canadian Association of Radiation Oncologists (CARO). Demographics, EOL discussion patterns, perception of EOL discussions, barriers, and the impact of MAiD were evaluated.

Results: Sixty ROs responded out of 326. Prognosis (57%) and goals of care (58%) were routinely discussed, while advanced directive (40%) and planned site of death (12%) were not. More than 90% felt that early EOL discussions with palliative patients were important. The amount of palliative discussion training was correlated with confidence in EOL discussion ($P<0.01$), perceived importance of RO role in EOL ($P=0.006$), and the frequency of planned site of death discussion ($P=0.041$). The most frequently identified barriers were lack of time, uncertainty about prognosis, and concern for patient disappointment. Many ROs provided MAiD information upon request or case-by-case, but only 3% provided the information routinely.

Conclusions: Canadian ROs recognize the importance of EOL discussions, but they do not routinely incorporate advanced directive or site of death in their discussions. ROs with more palliative discussion training were more confident in EOL discussion and likely to engage in them earlier. Short structured training may improve the confidence and quality of EOL discussion. Time constraint is the number one barrier that may be alleviated by delegation of tasks and patient education tools. Discussion about MAiD is supported but not routine among Canadian ROs.

Keywords: Radiation oncology; oncology; palliative; survey

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Introduction

End-of-life (EOL) discussions improve patient satisfaction, quality and cost-effectiveness of care (1,2). Guidelines and educational objectives are available to help clinicians engage in quality EOL discussions (3,4). However, many radiation oncologists (ROs) are unlikely to discuss EOL issues until patients develop significant symptoms or families initiate the discussion (5,6). Previously described barriers among oncologists include limited knowledge or training, sense of failure in not being able to provide curative treatment, belief that patient's outcome will be negatively impacted, uncertainty about the prognosis, ambiguity about the responsible physician, and lack of time.

ROs need to be proficient in discussing EOL issues. 40–50% of radiotherapy is given with palliative intent, and many patients in a RO practice have a short life-expectancy (7–9). Discussion of goals of care, patient values, and prognosis helps to direct care, especially in the setting of incurable or advanced cancers (6). At the end of their lives, many cancer patients encounter oncologists on a frequent basis; therefore, leaving EOL discussions to general practitioners may be inappropriate. Mack *et al.* showed that the majority of patients who died from cancer during a study period were cared for primarily by oncologists, but only 27% had an EOL discussion with their oncologist (10). In a survey performed in an inpatient unit, most patients preferred to discuss EOL issues with their oncologists rather than with their primary care physician (11).

With the passing of the bill C14 in Canada, and the legalization of Medical Assistance in Dying (MAiD), EOL care and decision making are becoming more complex. There is lack of clear consensus regarding how to approach MAiD requests among ROs.

To date, there are no publications describing whether EOL discussions take place specifically in the setting of radiation oncology practice in Canada. Given the volume of patients receiving palliative radiotherapy, it is important to understand the landscape of palliative discussions by ROs and the potential barriers. In addition, opinions of ROs regarding how EOL care discussions are changing as MAiD requests become commonplace in their practice is of great interest.

The objective of this study is to describe the frequency and content of EOL discussions among Canadian ROs and to identify barriers to these discussions.

Methods

Ethics approval was obtained from University of British Columbia (UBC) research ethics board (No. H18-00496), and informed consent was obtained from all of the responders. An email survey was sent to all board-certified ROs that are members of the Canadian Association of Radiation Oncology (CARO) (n=326). A second reminder request was sent 4 weeks later.

The survey (supplementary) consisted of 22 questions with 5 questions for basic demographic data and 17 questions soliciting practice pattern information and opinions regarding palliative care and MAiD. The secured Vancouver Coastal Health (VCH) Checkbox 6 program was used to create the questionnaire. The survey questions were devised to reflect previously identified important EOL topics for palliative patients (3,4). Some of the surveys from published studies were also referenced (6,12–14). The questions were reviewed by 4 independent investigators for suitability and face validity. They were designed to take only 10 minutes to complete. Two investigators were asked to comment on the survey regarding the content, clarity, and brevity. Once a consensus was reached, the survey was sent to the next investigator for comments and revisions. The same process was repeated until the fourth investigator agreed on the final revisions. The questionnaire covered topics such as experience with palliative care, EOL discussion patterns, MAiD, and suggestions for improvements. Responders were also asked to rank the perceived barriers to EOL discussions, and scores were tabulated based on ranking of the barriers. All responses were voluntary and anonymous.

Descriptive statistics and analytical statistics were performed on SPSS ver 22. Nonparametric Spearman's correlations and Mann-Whitney U test were performed to assess association of basic demographic information and response outcomes. Kuskal-Wallis Test was performed to evaluate the association between self-reported amount of training in EOL discussion and the frequency, perception of, and confidence in such discussions.

Results

Demographic information is presented in *Table 1*. Sixty ROs responded out of 326 (19%). Average age was 45 (range: 32–76) years, average years in practice was 13 (range: 1–44), and 63.3% were male. The responses were represented by

7 provinces, with the highest representation from Ontario (30.0%). Most common specialty sites were GI (11.9%), GU (11.9%), lung (11.3%), head and neck (11.3%), and breast (10.1%). The least common specialty sites were hematologic (4.2%), skin (4.2%), sarcoma (2.4%), and pediatrics (1.8%). In terms of formal palliative care training, 16.0% had a rotation during medical school, 45.0% had a rotation during residency, 32.0% had 3 or more lectures.

Table 1 Survey response demographics and practice pattern data

Characteristics	Value (N=60)
Sex, n (%)	
Male	38 (63.3)
Female	22 (36.7)
Average years in practice [range]	45 [32–76]
Average age [range]	13 [1–44]
Region of practice, n (%)	
British Columbia	15 (25.0)
Alberta	5 (8.3)
Saskatchewan	2 (3.3)
Manitoba	4 (6.7)
Ontario	18 (30.0)
Quebec	10 (16.7)
Nova Scotia	5 (8.3)
Others	1 (1.7)
Number of patients seen in a typical month (consults and follow ups), n (%)	
10–19 patients	2 (58.0)
20–29 patients	10 (16.7)
29–39 patients	13 (21.0)
40 or more patients	32 (53.3)
Others/no response	3 (5.0)

Only 5.0% had less than 3 lectures or no formal training.

Over 50% of ROs reported that 25–50% of their practice consisted of palliative intent treatment, and 30% of ROs had greater than 50% palliative case load. Nearly 75% of ROs responded that more than 50% of the patients that receive palliative therapy would be expected to pass away within a year (Table 2).

Figure 1 shows RO survey response for frequency of EOL discussion topics. In a typical month of practice with patients starting palliative intent treatment, prognosis (57%) and goals of care (58%) were discussed more than 50% of the time. In contrast, advanced directive (40%) and planned site of death (12%) were discussed more than 50% of the time. There was no significant association between physician gender and the frequency of prognosis, site of death preference, advanced directive, and goals of care discussions ($P=0.665, 0.513, 0.525, 0.268$ respectively). There was no direct association between physician age and the frequency of EOL discussions ($P=0.955, 0.800, 0.267, 0.482$ respectively). However, there was significant association between the higher level of EOL discussion training and the frequency of the site of death preference discussion ($P=0.041$).

Figure 2 shows ROs opinion on aspects of EOL discussions. More than 90% of responders felt that the EOL discussions for palliative patients who were feeling otherwise well were important to very important. More than 60% of responders said role of RO is important in EOL discussion. Less than 50% of responders felt that they had adequate training in EOL discussions, and less than 60% said they were confident in engaging in the discussions. There were no significant association between gender and the rating of importance of palliative discussion in well patients, confidence in EOL discussion, importance of role of RO, or the amount of training in discussion

Table 2 Frequency of palliative intent treatment and perception of their life expectancy

Proportion of treated patients	% of radiation oncologists response	
	In an average year, what percentage of patients in your practice received palliative intent radiation?	Out of the patients receiving palliative radiation, what percentage of them would you not be surprised if they died in the following year?
Less than 25% of patients	18%	9%
25–50% of patients	53%	18%
50–75% of patients	23%	46%
More than 75% of patients	7%	28%

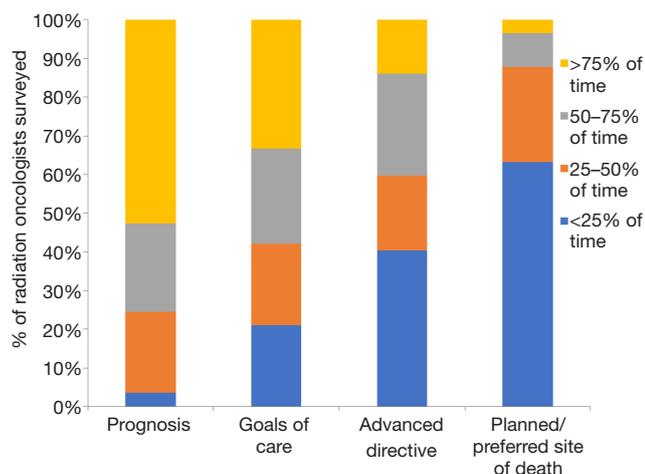


Figure 1 Frequency of palliative topic discussions with patients starting palliative radiation therapy.

($P=0.618, 0.182, 0.896, 0.080$ respectively). There were no direct association between age and the above ratings ($P=0.529, 0.234, 0.464, 0.444$ respectively). There was significant association between the level of EOL discussion training and increased perception of the importance of RO role in EOL ($P=0.006$), importance of discussing EOL when the patient is otherwise well ($P=0.039$), and increased confidence in EOL discussion ($P<0.01$).

The most frequently identified barrier to EOL discussion was lack of time, followed by uncertainty about prognosis, concern for disappointment or hopelessness in patients, and uncertainty about the physician responsible for the discussion (*Table 3*). Other factors not listed in the questionnaire were hesitation to give too much information at once and appropriateness of the first consult as an opportunity to broach EOL discussion.

The most frequent preference for support to facilitate EOL discussion was interdisciplinary meetings with palliative care physicians ($n=39$), followed by more time for consultation/follow ups ($n=33$), formal educational seminars ($n=32$), access to allied health members such as general practitioners in oncology (GPO) or nurse practitioners (NP) ($n=26$), fee structure for EOL discussion ($n=22$), resource and reference materials ($n=22$), and online training module ($n=18$) (*Figure 3*).

MAiD was only routinely discussed by 3% of ROs. The majority (56%) of ROs said they provide information about MAiD only when requested, 15% said they provide information about MAiD on a case by case basis, 15% said

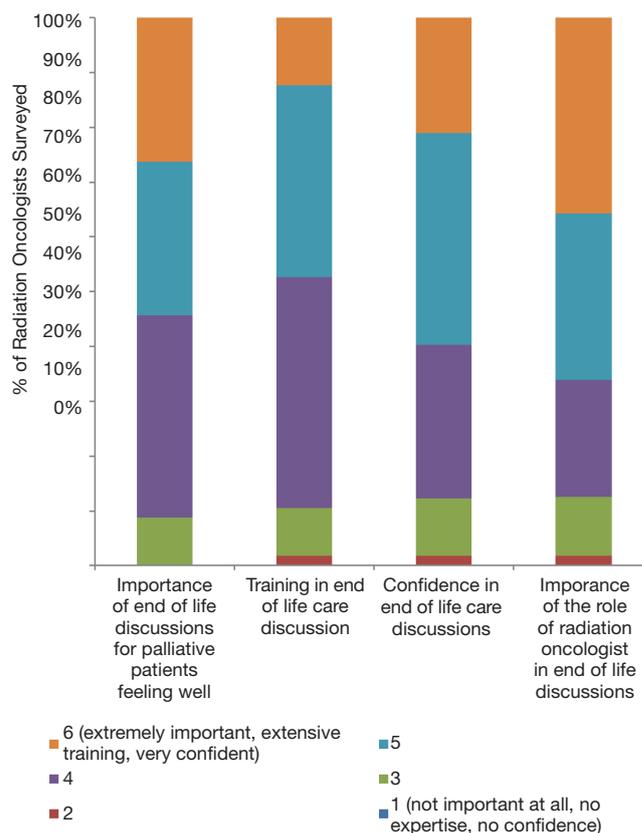


Figure 2 Rating of importance of, level of training in, and confidence in end of life discussion.

they do not provide any information but refer to another colleague who is familiar with MAiD process, and 5% said they do not talk about MAiD at all.

Discussion

EOL discussions should occur with any patients facing serious and life-threatening illness, such as an incurable malignancy, or for any patients whose physicians would not be surprised if the patient died in the next year (4). This population consists of the majority of patients receiving palliative radiation therapy.

Strengths of this study are that it is the first survey of EOL care discussion practices among ROs in Canada. Participants represented a wide range of age, regions of practice, treatment sites, and radiation oncology residency rotation. In contrast, previous studies consisted of sampling of oncologists in confined regions, specialties, or treatment sites (13,14).

In our study, about 50% of ROs reported that they

Table 3 Ranking of barriers to the end of life discussions

Barrier	Rank
Lack of time	1
Uncertainty about prognosis	2
Concern for disappointment or hopelessness in patients	3
Uncertainty about the physician responsible for the discussion	4
Patient is uncomfortable with the discussion	5
Physician is uncomfortable with the discussion	6
Lack of expertise or training	7
Uncertainty about cultural appropriateness of discussion	8
Concern that such discussion may lead to poorer outcome for patients	9
Lack of translator	10
Compromise of MD patient relationship	11
Physician's sense of personal failure	12
Others	13
Appropriateness given he or she will only meet the patient once	
Hesitation to give too much information at once	

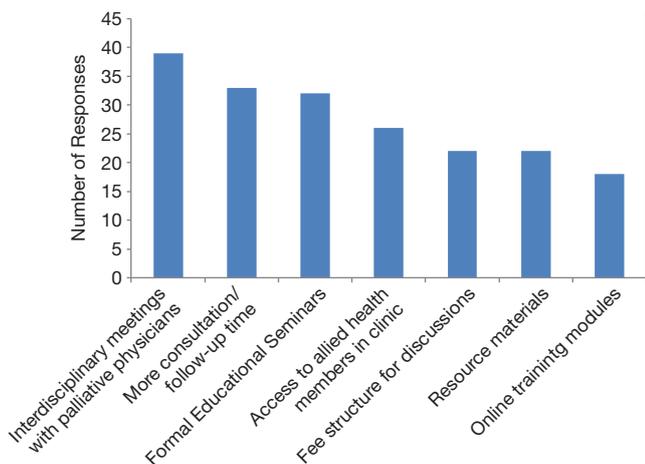


Figure 3 Responses to how radiation oncologist could be supported to engage in end of life discussion.

discuss prognosis more than 75% of the time that they evaluate patients for palliative intent treatment. This is consistent with previous literature which estimates about 50–70% rate of routine prognosis discussion with palliative

patients (6,15). However, less than 10% of surveyed ROs discussed preferred or planned site of death routinely. This is unfortunately consistent with a study by Keating *et al.* that suggested the rate of discussion regarding hospice or site of death with terminally ill patients was low overall among medical practitioners, but it was significantly lower among ROs and surgeons compared to medical oncologists (5). Early discussion of site of death or hospice is recognized as an important part of EOL discussion (16,17). Many studies have suggested that patients prefer to die at home rather than in hospital, and hospice care at the EOL has been associated with better pain relief, quality of life, and potentially reduced cost of care (18–20). Such discussions occur too late in disease trajectory, and patients often miss the opportunity to die at home or at hospice as they wished (21–23). Therefore, exploring a patient’s preferred site of death or desire for hospice care should be an integral part of early EOL discussions.

Conversation about advance directive is also a crucial part of EOL discussion. In our study, less than 40% of ROs reported that they routinely discuss advance planning for patients undergoing palliative radiation. Advance directive reduces the cost of care and the frequency of aggressive treatments such as ventilation, intensive care admission, and resuscitation at the EOL (24,25). In turn, aggressive treatments are associated with worse patient quality of life and higher rate of major depressive disorder among the caregivers (24). Moreover, early advance care planning increases the likelihood that the patient wishes are known and followed (26,27). Recently, there have been many guidelines that advocate for routine advance directive discussion as part of quality oncology care, and advance directive should be part of routine EOL discussion (28,29).

Our study demonstrated that ROs recognize the importance of their role in early EOL discussion. More than 50% of the sampled oncologists felt that EOL discussion is important for palliative patients otherwise feeling well, and more than 60% felt that ROs are an important part of such discussions. However, less than 50% of the survey participants felt that they had enough training in it. Similarly, Tseng *et al.* found that ROs were somewhat or less confident in their ability to discuss prognosis and were less likely to engage in EOL discussion than medical oncologists (6).

In this study, ROs who reported more extensive EOL discussion training also had higher level of confidence in such discussion. They were also more likely to recognize the importance of engaging in EOL discussion earlier in the disease trajectory, planned site of death discussion, and RO’s

role in EOL discussion. These results are not surprising, and more training will likely lead to better EOL discussions. Formal education in palliative care and EOL discussion is varied across training programs. In Canada, Royal College of Physician curriculum for radiation oncology program consists of only 1 month of palliative care (30). In the US, there is lack of formal instruction for palliative care as part of oncology curriculum (31,32). One solution may be an intense but short coaching for clinicians to better facilitate EOL discussion. A randomized trial by Bernacki *et al.* is currently enrolling clinicians to undergo 2.5-hour intense training to better utilize Serious Illness Conversation Guide (SICG) (33). Although results are not yet published, primary outcomes will be rate of goal-concordant care and patient peacefulness at EOL. Also, a study by Schenker *et al.* suggested that a 2-day intense training session led by a palliative care physician for oncology nurses was sufficient to improve symptom management and advanced planning for palliative patients (34). Another solution may be to increase formal palliative training during the residency, such as structured didactic teaching, utilization of standardized patients, formal feedback and evaluation sessions to increase resident comfort with routine EOL topics (32).

Other identified barriers to the EOL discussion were lack of time, uncertainty about prognosis, and concern for hopelessness and disappointment in patients. Similarly, a survey of Canadian medical oncologists identified lack of time, brief therapeutic relationship with patients, uncertainty in estimating prognosis, and desire to maintain hope as barriers in EOL (13). There may be several strategies to alleviate the time constraint for EOL discussions. One would be the use of educational tools, such as a pamphlet or a guidebook, in combination with clinician delegates for efficient discussion of EOL. Stein *et al.* demonstrated that for patients with metastatic cancer, the use of pamphlet containing information regarding communication and planning for future, as well as a psychologist to guide them through the decision making, resulted in earlier placement of advance directive, less likelihood of death in hospital, and less caregiver burden (35). Other studies demonstrated that the collaboration with an oncology nurse and the distribution of advance care guidebook to patients significantly increased the advance plan documentation in stage IV cancer patients (34,36). In addition, studies have shown that regular interdisciplinary palliative care meetings consisting of medical, radiation, surgical oncologists, as well as palliative physicians and nurses are feasible and may significantly improve quality of life, symptoms, and distress (37,38). It may be beneficial to have palliative care physician and a nurse at cancer-specific

multidisciplinary rounds.

MAiD in Canada was first introduced in June 17th, 2016, after the passage of Bill C-14. Its implementation is in nascent stage, and the process requires fulfilment of stringent set of criteria. There have been mixed physician opinions about introduction of MAiD, reflecting the controversies regarding the logistics, ethics, and eligibility criteria surrounding it. Canadian Medical Association (CMA) survey in 2016 showed that 61% of physicians were unwilling to participate in MAiD, and 40% were not even comfortable referring the patient for MAiD (39). In contrast, among palliative physicians that were surveyed in 2017, 53% referred the patient for assessment for MAiD, 75% provided information about MAiD, and 80% explored the request themselves (40). Our study shows that ROs are very likely to either provide information about MAiD or refer to someone who is more knowledgeable about MAiD upon request. Although the survey cannot assess detailed opinions about MAiD from RO perspective, it demonstrates overall support for MAiD among ROs when patients request it.

The study is limited by a potential response bias due to the voluntary nature of the survey. However, if most of the study responders consisted of ROs actively engaging in EOL discussions already due to the response bias, then it would further strengthen the need for improvement in EOL discussion among all ROs. Also, the overall response rate was low at 19% and represents a small survey sample size compared to the total number of practicing ROs. This is an expected finding, as response rates of previous electronic surveys to ROs eliciting the supportive care practice patterns have been consistently below 20% (41,42). Many factors may account for the low response rate, such as lack of remuneration offer, selective interest in palliative care topics, and survey fatigue. Generalizability may be limited as regions of practice were not proportionally sampled. Yet, given the uniformity of radiation oncology training across Canada, trend would be expected to be similar across the provinces.

Conclusions

Canadian ROs recognize the importance of their role in EOL care discussion. While prognosis and goals of care are discussed frequently, advanced directive and planned site of death are not routinely discussed. ROs who have more extensive EOL discussion training not only have more confidence in EOL discussion, but also engage in such discussions earlier and more frequently. Structured short clinical training in EOL discussion among ROs may

increase the quality and frequency of EOL discussions. Effective delegation of roles and patient education tools may alleviate the time constraint. Currently, MAiD is supported but not routinely discussed by ROs.

Acknowledgments

None.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The study was approved by University of British Columbia (UBC) research ethics board (No. H18-00496) and written informed consent was obtained from all patients.

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Survey for the study “End-of-Life Discussions in Practice: Survey Among Canadian Radiation Oncologists”

Your age

Your gender

- Male
- Female
- Other:

Which province do you practice in?

British Columbia

Where did you do your radiation oncology residency?

University of British Columbia

Specialty sites

- Breast
- CNS
- Head and neck
- Hematologic
- GI
- GU
- Gynecologic
- Lung
- Pediatrics
- Sarcoma
- Skin
- Palliative
- Other

Number of years in practice

In a typical month, how many patients do you see (including consults and follow ups)?

Select:

What training/education have you had in palliative care?

- Rotation during medical school
- Rotation during residency
- Year of added competency
- Less than 3 lectures/seminars
- Greater than 3 lectures/seminars
- None
- Other

In an average year, what percentage of patients in your practice receive palliative therapy?

Select:

Out of the patients receiving palliative therapy, what percentage of patients would you not be surprised if they died in the following year?

Select:

A number of topics may come up during the treatment of palliative patients. In a typical month, what percentage of patients who were starting palliative treatment have you engaged in a discussion regarding:

Prognosis

Select:

Preferred/planned site of death

Select:

Advanced directive conversation

(General discussion about care goals, values, and wishes, designated decision maker, or power of attorney in case the patient is incapacitated)

Select:

Goals of care

(Discussion about medical order used to describe and communicate level and focus of care)

Select:

What would you identify as a barrier to such a discussion? Please rank the following (drag and drop, with the biggest barrier on top)

- Lack of time
 - Concern for disappointment or hopelessness in patients
 - Concern that such discussion may lead to poorer outcome for patients
 - Uncertainty about prognosis
 - Uncertainty about the physician responsible for the discussion
 - Physician is uncomfortable with the discussion
 - Patient is uncomfortable with the discussion
 - Lack of expertise or training
 - Physician's sense of personal failure
 - Uncertainty about cultural appropriateness of discussion
 - Lack of translator
 - Compromise of MD patient relationship
 - Others
- Please comment on potential other barriers



How important do you think end of life discussions are for palliative patients feeling otherwise well?

- Not important at all
-
- 1
-
- 2
-
- 3
- Occasionally important
-
- 4
-
- 5
-
- 6
- Very important

Do you think you have enough expertise and training to be able to have an effective end of life care discussions?

- No training
-
- 1
-
- 2
-
- 3
- Some training
-
- 4
-
- 5
-
- 6
- Very extensive training

How confident are you in having end of life care discussions?

- Not confident at all
-
- 1
-
- 2
-
- 3
- Somewhat confident
-
- 4
-
- 5
-
- 6
- Very confident

How important is engaging in end of life discussions in the role of a radiation oncologist?

Not important at all



1



2



Occasionally important

3



4



5



6

Very important

Please select or comment on how MAID features in end of life conversations in your practice.

- I routinely provide information about MAID as one of potential options as part of the conversation
- I provide information about MAID as I see appropriate for select patients
- I provide information about MAID only when requested by patients
- I don't provide information about MAID but refer to another colleague
- I won't talk about MAID at all
- Other/comment (please check the box)

Please check the following boxes on how radiation oncologists could be supported to engage in a quality end of life conversation.

- Formal educational seminars
- Interdisciplinary meetings with palliative care physicians
- Resource/reference materials
- Online training modules
- More time for consultations/follow-ups
- Fee structure for advanced directive, goals of care discussion, etc.
- Access to allied health members in clinic, ex. GPO, NP
- Other/comment (please check the box)

Many patients have not had end of life discussions. How often do you think radiation oncologists should be engaging in an end of life care discussion (prognosis, site of death, goals of care, or advanced directives) with patients starting palliative intent treatment?

Select:

Final comments: