

# Advance Requests for Medical Assistance in Dying in Dementia: a Survey Study of Dementia Care Specialists



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## ABSTRACT

### Background

Current Canadian Medical Assistance in Dying (MAiD) legislation requires individuals to have the mental capacity to consent at the time of the procedure. Advance requests for MAiD (ARs for MAiD) could allow individuals to document conditions where MAiD would be desired in the setting of progressive dementia.

### Methods

Greater Vancouver area dementia care clinicians from family practice, geriatric medicine, geriatric psychiatry, and palliative care were approached to participate in an online survey to assess attitudes around the appropriateness of ARs for MAiD. Quantitative analysis of survey questions and qualitative analysis of open-ended response questions were performed.

### Results

Of 630 clinicians approached, 80 were included in the data analysis. 64% of respondents supported legislation allowing ARs for MAiD in dementia. 96% of respondents articulated barriers and concerns, including determination of capacity, protecting the interests of the future individual, navigating conflict among stakeholders, and identifying coercion. 78% of respondents agreed with a mandatory capacity assessment to create an AR, and 59% agreed that consensus between clinicians and substitute decision-makers was required to enact an AR.

### Conclusion

The majority of Vancouver dementia care clinicians participating in this study support legislation allowing ARs for MAiD in dementia, while also articulating ethical and logistical concerns with its application.

**Key words:** dementia, medical assistance in dying, MAiD, euthanasia, assisted suicide, autonomy, ethics

## INTRODUCTION

As the Canadian population ages, increasing numbers of older adults are developing Alzheimer's disease or other forms of dementia, with over half a million Canadians living with dementia in 2016.<sup>(1,2)</sup> Some of these individuals will retain acceptable quality of life, particularly with the provision of high quality dementia and palliative care,<sup>(3,4)</sup> while others will experience distressing neuropsychiatric and physical symptoms.<sup>(5,6)</sup>

Because of the functional deterioration associated with dementia, patients with early dementia often express anticipatory concern about their future.<sup>(7,8)</sup> Further, diminished mental capacity in dementia may impact medical decision-making as the illness progresses.<sup>(9)</sup> In response to these concerns, health-care providers and members of the public are advocating for more robust discussions around end-of-life care in people with dementia,<sup>(2)</sup> including exploring the option of Medical Assistance in Dying (MAiD).<sup>(10)</sup>

In 2016, Canada decriminalized MAiD.<sup>(11)</sup> To be eligible under current legislation, patients must have a serious medical illness that leads to grievous and irremediable suffering. Death must be reasonably foreseeable, often interpreted as within several years of the patient's anticipated natural death.<sup>(12)</sup> Legislation excludes those who do not have the capacity to consent at the time of provision, and most patients with dementia would be excluded from MAiD eligibility for the following reasons:

1. Late-stage dementia is a terminal condition that would meet criteria for MAiD as a grievous and irremediable diagnosis with a reasonably foreseeable death, but these patients lack capacity to consent.
2. Early-stage dementia is a condition where patients may have the capacity to consent to MAiD, but would not qualify as their death is not reasonably foreseeable.

The existing Canadian MAiD legislation is under review and, if passed, could allow patients with dementia greater access to MAiD. Proposed legislative changes include

removing the “reasonably foreseeable” criterion, allowing patients with early dementia who are still capable to access MAiD, with a number of new safeguards outlined, including an extended waiting period of 90 days.<sup>(13)</sup> The possibility of allowing advance requests for MAiD (ARs for MAiD) is also being evaluated, and would allow capable individuals to outline in detail, conditions where MAiD should be provided, should the loss of mental capacity later arise.<sup>(14)</sup> In a 2020 Government of Canada survey, public support for ARs for MAiD was strong, but expert stakeholders, including physicians, identified concerns and complexities with operationalizing advance requests.<sup>(15)</sup> Further research in the area, including consideration of possible safeguards, was recommended.

This survey study examines the attitudes around ARs for MAiD in physicians, nurse practitioners, and trainees who care for patients with dementia in Vancouver, Canada, adding to emerging Canadian literature in the area.<sup>(16,17,18)</sup> Further, this study contributes novel information obtained through qualitative analysis of open-ended responses, exploring participant perspectives on the ethical and logistical benefits and concerns involved with legislating ARs for MAiD, and possible safeguards such as mandatory capacity assessments and care team consensus prior to enacting ARs for MAiD.

## METHODS

### Design and Procedure

The study is a mixed quantitative and qualitative cross-sectional survey of physicians, nurse practitioners, and trainees who care for older adults with dementia in the Greater Vancouver area of British Columbia. The authors obtained ethics approval through the University of British Columbia (UBC) Behavioural Research Ethics Board.

The authors contacted department heads through the UBC School of Nursing, and the UBC Divisions of Family Practice, Geriatric Medicine, Geriatric Psychiatry, and Palliative Medicine. Department heads distributed the survey consent form and recruitment cover letter by e-mail to their division members and educational trainees. Each department head was asked to send a reminder e-mail two weeks after the initial recruitment e-mail to improve study participation.

Consent forms were included in the recruitment email and appeared again at the beginning of the survey. Consent was assumed when participants agreed to the statement at the beginning of the survey “I have read the consent letter outlining the survey study and agree to participate”. Responses were anonymous and participation was voluntary.

### Research Materials

The online survey was created with Qualtrics, an online platform available through UBC. It was a combination of quantitative and qualitative data collection with demographic information, close-ended questions, graded Likert scale questions, multiple choice questions, and a comments section with short answers (see Appendix A). Survey questions were

developed following a review of existing MAiD literature in Canada.

### Study Participants and Eligibility

Participants were eligible to complete the survey if they were 18 years of age or older, self-identified as caring for patients with dementia, English speaking, and working in the Greater Vancouver region. The study population consisted of the physician, nurse practitioner, and trainee members of the aforementioned divisions contacted, for a total of approximately 630 people (data on population size received from the division heads).

For responses to be included in the data analysis, respondents were required to complete the demographic information, and at least 75% of the survey questions (Figure 1).

### Data Analysis

The quantitative data collected was analyzed using simple percentage analysis. Subgroup analysis was not performed due to the small sample size. Thematic analysis was used to systematically organize and make inferences from the text responses provided to the two open-ended questions in the survey. Responses were individually coded by two authors, then compared and verified to ensure agreement.

## RESULTS

80 participants met our eligibility criteria and were included in the data analysis (Figure 1). We had a 56.3% (n=9/16) response rate from trainees, 27.7% (n=26/94) from specialists, 10% (n=6/60) from nurse practitioners, and 8.5% (n=39/460) from family physicians.

### Characteristics of Study Participants, Including Exposure to MAiD Education and MAiD in Clinical Practice

Table 1 summarizes the demographic details of respondents. All divisions canvassed were represented and, of the 80 respondents, the most represented specialties were physicians and trainees in family medicine (49%, n=39) and geriatric medicine (23%, n=18), with most participants working in an academic setting (46%, n=37).

Table 2 summarizes degrees of participant education and clinical experience around MAiD. Nearly all (95%, n=76) had received education regarding MAiD legislation, and half (50%, n=40) rated their knowledge in this area as good or excellent. Approximately half rated their comfort level in speaking to patients about MAiD as good or excellent (55%, n=44). Most felt their knowledge about dementia and advance care planning in dementia to be good or excellent (85%, n=68, 78%, n=62, respectively).

The majority (84%, n=67) of respondents had encountered at least one patient who had asked about MAiD, but only 35% (n=28) had been asked by a patient or 34% (n=27) by a family member about MAiD in dementia (report from survey questions 13–19, see Appendix B).

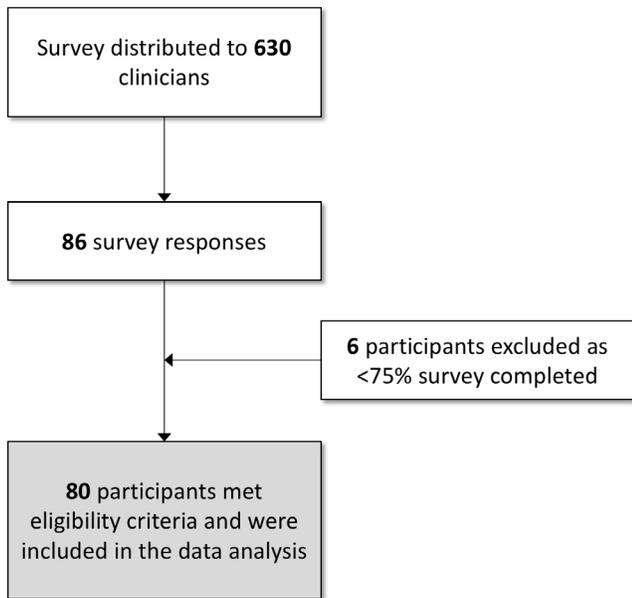


FIGURE 1. Eligible participants included in study data analysis

**Attitudes Regarding Appropriateness and Timing of Advance Requests for MAiD in Dementia (report from survey questions 20–33, see Appendix B)**

The majority of clinicians (64%, n=51) agreed or strongly agreed that MAiD should be available to patients with dementia through advanced directive (see Figure 2).

Sixty-one per cent (n=49) of participants responded that patients should be able to create an AR for MAiD during the mild stage of dementia, and 96% (n=76) responded that ARs for MAiD should be enacted in the moderate or severe stages.

Despite the majority of respondents being in agreement with ARs for MAiD, many were concerned about the potential negative impacts on patients with dementia, including concerns about their safety (see Figure 3).

**Role of Capacity Assessments (report from survey questions 34–38, see Appendix B)**

Most respondents agreed or strongly agreed that a capacity assessment should be mandatory when a patient requests MAiD (78%, n=62), or is making an AR for MAiD (78%, n=62). Sixty-four per cent (n=51) felt that enacting an AR

TABLE 1. Characteristics of study participants

Question	Response Options	N (total N= 80)	%
I identify as:	Male	35	43.75
	Female	45	56.25
	Non-binary, transgender	0	0
My age is: <sup>a</sup>	Less than 20	0	0
	20-30	7	8.86
	31-40	31	39.24
	41-50	19	24.05
	51-60	11	13.92
	61-70	11	13.92
	70 or older	0	0
I am a:	Practising physician or nurse practitioner	70	87.5
	Trainee	10	12.5
My discipline is:	Family physician who cares for older adults	39	48.75
	Geriatric Medicine physician	18	22.5
	Geriatric Psychiatry physician	6	7.5
	Nurse practitioner who cares for older adults	6	7.5
	Palliative Medicine physician	11	13.75
I have been in practice:	I am still training	9	11.25
	<1 year	6	7.5
	1-5 years	21	26.25
	6-10 years	9	11.25
	11-20 years	13	16.25
	21-30 years	10	12.5
	>30 years	11	13.75
	I am no longer practising	1	1.25
My practice/training is mainly conducted:	In an academic teaching hospital or clinic	37	46.25
	In a community hospital	14	17.5
	In a community based outpatient setting	29	36.25

<sup>a</sup>Only 79 participants provided a response for this question.

for MAiD would be difficult once capacity is lost. Most (82%, n=65) did not agree that a cognitive test (such as the Mini-Mental Status Exam (MMSE)<sup>(19)</sup> or Montreal Cognitive Assessment (MoCA)<sup>(20)</sup>) could assess capacity for MAiD as a stand-alone assessment.

### Role of the Clinical Care Team and Substitute Decision-Makers (report from survey questions 39–40, see Appendix B)

When asked who should complete MAiD assessments for patients with dementia, most respondents indicated multiple individuals, including experts in dementia (86%, n=68),

followed by the designated MAiD team assessor (71%, n=56) and physicians with the longest relationship with the patient (68%, n=54).

The majority of respondents agreed (59%, n=47) that both the substitute decision-maker and the clinical team would need to be in agreement in order to determine when an AR for MAiD should be enacted.

### Thematic Analysis of Open-Text Survey Responses

Sixty-seven participants responded to question 41, with 84% (n= 56) identifying benefits for patients with dementia should ARs for MAiD become legal. Four themes emerged from

TABLE 2.  
Study participants' exposure to MAiD education and MAiD in clinical practice

<i>Question</i>	<i>Response Options</i>	<i>N (total N= 80)</i>	<i>%</i>
How many hours of education/training have you received regarding MAiD legislation?	0 hours	4	5
	1–4 hours	52	65
	5 or more hours	24	30
I would rate my knowledge about the current Canadian legislation (eligibility criteria, referral process, assessment process) on MAiD as:	Poor	1	1.25
	Fair	12	15
	Average	27	33.75
	Good	29	36.25
	Excellent	11	13.75
I would rate my knowledge about how to access MAiD for a patient as:	Poor	2	2.5
	Fair	13	16.25
	Average	24	30
	Good	26	32.5
	Excellent	15	18.75
I would rate my comfort level in speaking to patients about MAiD as:	Poor	10	12.5
	Fair	9	11.25
	Average	17	21.25
	Good	25	31.25
	Excellent	19	23.75
I would rate my knowledge about dementia as:	Poor	0	0
	Fair	3	3.75
	Average	9	11.25
	Good	40	50
	Excellent	28	35
I would rate my comfort level about speaking to patients with dementia about advanced care planning as:	Poor	2	2.5
	Fair	7	8.75
	Average	9	11.25
	Good	34	42.5
	Excellent	28	35
The number of patients that I have encountered during my normal provision of clinical care who requested MAiD is:	0	13	16.25
	1–5	49	61.25
	6–10	6	7.5
	11–15	5	6.25
	16–20	1	1.25
	20 or more	6	7.5
I have helped refer a patient on for a MAiD assessment:	Yes	43	53.75
	No	37	46.25
I have been asked by a patient with dementia about accessing MAiD:	Yes	28	35
	No	52	65
I have been asked by a family member for a patient with dementia about accessing MAiD:	Yes	27	33.75
	No	53	66.25

analysis of the respondent comments: respecting autonomy, avoidance of suffering, reduction of anticipatory anxiety, and avoidance of premature MAiD or death (see Figure 4).

Respecting the autonomy of patients was the most frequently described benefit noted by 43% (n=29) of survey respondents. The following comment illustrates this view:

“A patient, while still cognitively intact, could make a decision based on their values. This becomes impossible as dementia progresses.”

Avoidance of suffering was identified by 40% (n=27) of respondents. One respondent described this benefit, stating:

“Like any terminal illness, it would provide some security for the person, knowing that a mechanism is in place

for helping to grant their wishes if/when they meet a point in their dementia timeline that would seem to meet their original definition of irremediable suffering from the condition.”

Reducing anticipatory anxiety was another benefit reported by over one quarter of respondents (28%, n=19). As explained by one respondent:

“Patients with dementia are often very concerned about the potential loss of dignity that can come as their disease progresses. A MAiD advance directive would give those patients control over their own dying. This would improve their QoL (quality of life) since they would not be consumed with worry over progressive decline.”

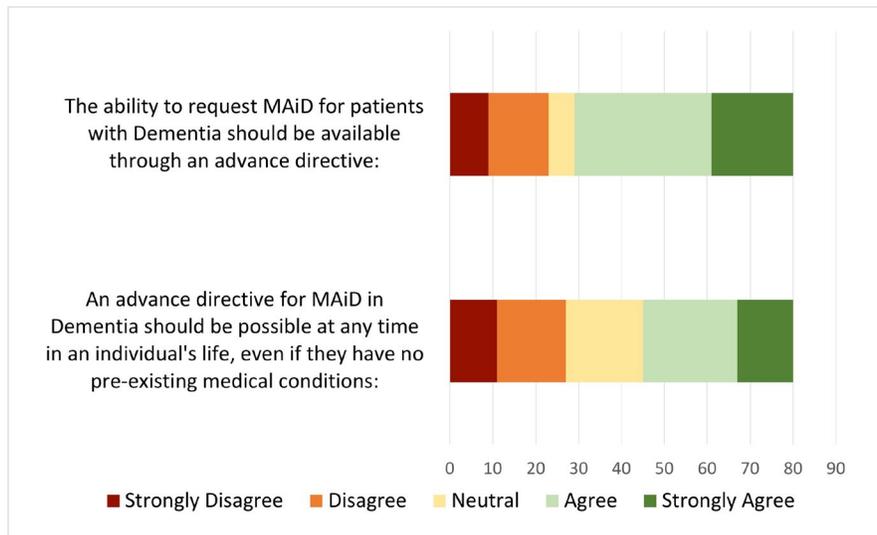


FIGURE 2. Participant responses on the appropriateness and timing of advance requests for MAiD in dementia

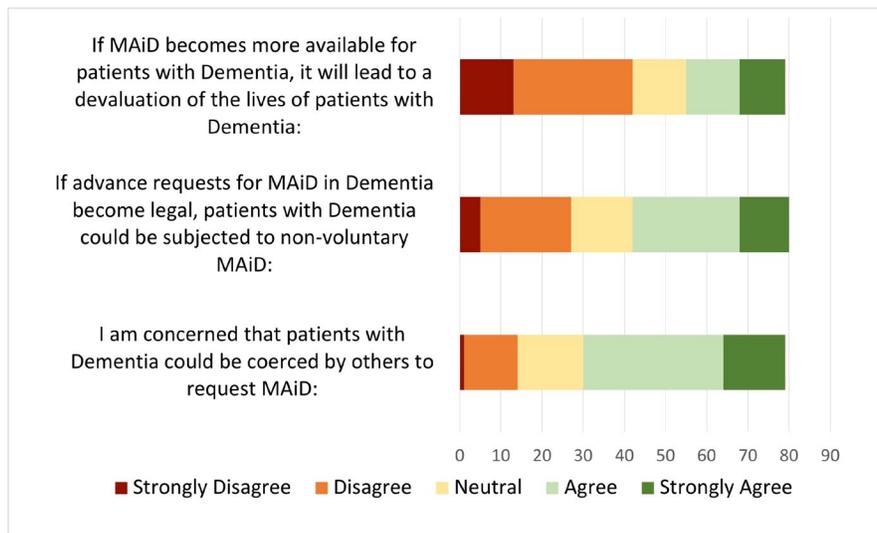


FIGURE 3. Participant concerns about negative impacts that MAiD and advance requests for MAiD will have on patients with dementia

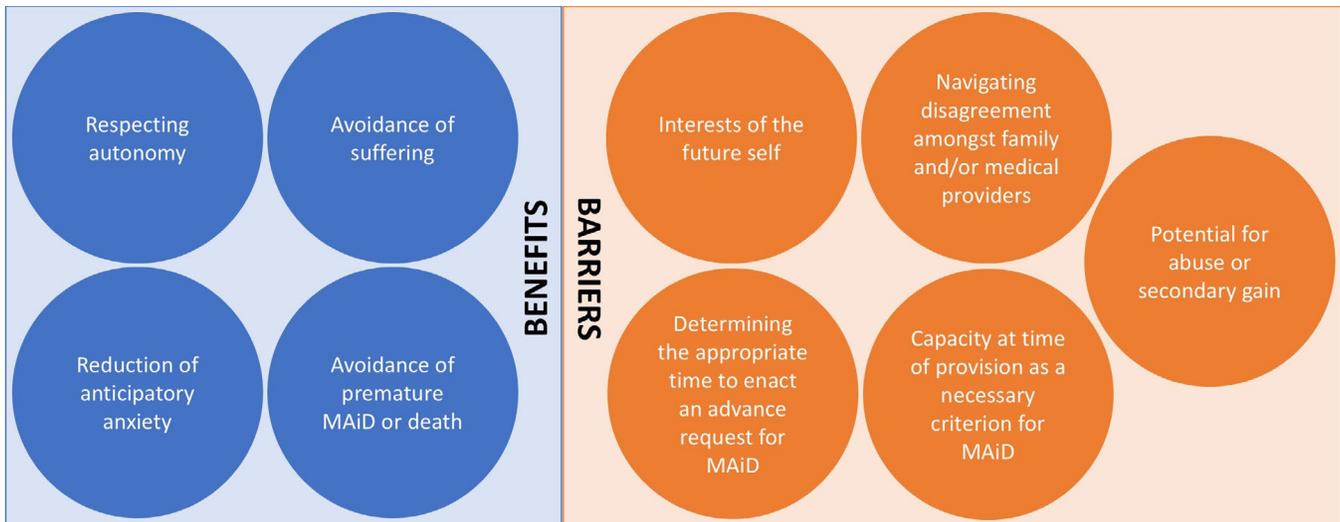


FIGURE 4. Themes arising from qualitative analysis of participant open ended responses: benefits and barriers of advance requests for MAiD in dementia

Additionally, 10% (n=7) of respondents identified avoidance of premature MAiD or death. The following comment represented this view:

“There was recently a case in popular news where a woman took her own life with mild dementia because she wasn’t allowed to make an advanced directive. This could stop that from happening.”

Eleven survey respondents (16%, n=11) did not identify any benefits for patients with dementia if ARs for MAiD were to become legal. One respondent simply stated:

“Only dangers.”

Sixty-seven participants responded to question 42, with 97% (n=67) identifying barriers or concerns with the provision of MAiD by advance directive. Five themes emerged from the analysis: interests of the future self, determining the appropriate time to enact an advance request for MAiD, navigating disagreement amongst family and/or medical providers, capacity and/or consent as a necessary requirement at time of MAiD provision, and potential for abuse or secondary gain (see Figure 4).

The most frequently identified concern, noted by more than one third of respondents (39%, n=27), was difficulty anticipating interests of the future self. As described by this respondent:

“Current health state does not predict a patient’s choices in a future health state. So while many of us in our current non-dementia state of health indicate that we wouldn’t want to live with dementia, there are many patients with dementia who appear to have a good quality of life (which they may not have anticipated they would have had when they didn’t have dementia).”

Survey respondents also acknowledged logistical challenges to enacting an advance request. Almost one third of

respondents (29%, n=20) identified challenges in determining the appropriate time to enact an advance request for MAiD. One respondent described:

“May be difficult to find the right time to ‘trigger’ the directive as the [dementia] process is gradual and insidious at times.”

Additionally, 20% (n=14) of respondents raised concerns navigating disagreement amongst family and/or care providers. As described by two respondents:

“There would also be the concern when the health-care team and SDM do not align on whether or not to provide MAiD.”

“It could also be difficult to navigate this decision if many family members are involved or if family members with opposing viewpoints are involved.”

Capacity and/or consent at the time of provision was felt by 23% (n=16) of respondents to be an important or necessary criterion for MAiD, without which MAiD would be challenging or impossible to provide. Respondents described potential challenges of providing MAiD to a patient who resists or does not understand the procedure, despite previously consenting to it. One respondent explained:

“I can’t imagine forcing a previously consented person into doing MAiD if they have no idea of what’s going on and if they are resisting the treatment.”

The potential for abuse or secondary gain was an additional challenge reported by 20% (n=14) of respondents. As one respondent stated:

“I am concerned we will enable societally driven euthanasia of dementia sufferers which will only add further stigma to the diagnosis”

## DISCUSSION

The majority (64%) of Vancouver clinicians and trainees who participated in this study support legislation allowing ARs for MAiD in dementia, similar to earlier survey findings in physicians and nurses caring for patients with dementia in Quebec.<sup>(16,17,18)</sup> Most respondents (84%) anticipated that ARs for MAiD in dementia could create opportunities for patient benefit, including preservation of autonomy, avoidance of suffering, the prevention of anticipatory anxiety about the future, and the avoidance of premature MAiD.

The Government of Canada is considering changes to the current MAiD legislation, including repealing the “reasonably foreseeable” criterion. This would allow patients with mild dementia to access MAiD while they still retain capacity.<sup>(13,14)</sup> However, even if the “reasonably foreseeable” criterion is removed, it is likely that ARs for MAiD would still be desired by some individuals with dementia. ARs for MAiD would allow an individual to more precisely outline conditions where MAiD would be desired in the later disease stages, even after capacity is lost. As indicated by this study’s respondents, ARs for MAiD may prevent some individuals from accessing MAiD earlier than they might wish, prior to the loss of capacity.

Prior studies have found that the Canadian public supports ARs for MAiD more strongly than physicians, with approval ratings around 79–91%.<sup>(15,18)</sup> Based on thematic analysis of the survey responses, we postulate that clinicians are more hesitant than members of the public because it is clinicians who will ultimately be tasked with the challenge of interpreting and enacting the AR after a patient has lost capacity. Nearly all respondents (97%) expressed significant concerns about enacting ARs for MAiD, including how clinicians might protect the interests of the future individual with dementia, navigate potential conflict among stakeholders, administer MAiD to a person lacking capacity, and identify red flags around patient coercion. Ultimately, consenting clinicians would be entrusted with the grave responsibility of providing MAiD to individuals who cannot endorse a desire for MAiD, who may appear content, or who may even resist the procedure. Some clinicians responded that they would never provide MAiD in these circumstances, regardless of a patient’s prior expressed wishes.

Understanding the concerns of clinicians helps define the potential limitations of ARs for MAiD, and may provide guidance around potential safeguards should ARs for MAiD be legislated. The majority of study respondents believed that the appropriate time to create an AR for MAiD is in early dementia, and that these requests should be supported by a mandatory capacity assessment. Most felt that decisional capacity could not be determined with a standardized cognitive test alone (i.e., MMSE, MoCA) and that individualized capacity assessments would be required. Although mandating a capacity assessment appears restrictive, prior studies suggest that a proportion of patients with early dementia have impaired decision-making capacity.<sup>(9)</sup> From this, the authors suggest that a standardized process for assessing patient capacity in dementia be created should ARs for MAiD be legislated.

Most respondents indicated that the appropriate time to enact an AR for MAiD would be in the moderate or severe stages of dementia. Further, the majority of participants felt that the clinical team and substitute decision-makers should agree that the threshold for MAiD provision, as set out in the AR, was reached. Requiring consensus is a safeguard that may improve patient safety at the expense of some patients being denied MAiD despite having completed an AR.

Creating a robust and clear AR for MAiD could be challenging, as a written directive might not capture all of the intricacies of an individual’s progressive experience with dementia. Ultimately, it will be up to clinicians and substitute decision-makers, and not the patient, to interpret the AR for MAiD in the present context.

Data from the Netherlands, where advance requests for euthanasia are fairly common, but are infrequently honoured,<sup>(21,22)</sup> demonstrate that the vast majority of patients with dementia who receive euthanasia still have decisional capacity.<sup>(14)</sup> The reasons for this phenomenon may be related to the particulars of Dutch law and policy around euthanasia, as well as ethical and logistical concerns similar to those identified by participants in this study. In the Netherlands, it is physicians and not patients who must determine whether a patient is experiencing intolerable suffering.<sup>(23)</sup> Surveys of Dutch physicians who care for patients with dementia indicate challenges in determining whether suffering is “unbearable and hopeless”, and identifying the right time to enact the AR for euthanasia.<sup>(24)</sup> Interestingly, Dutch physicians endorse a much higher degree of support for euthanasia ARs in physical illness, rather than cognitive illness.<sup>(25)</sup> This may be related to the need for “a moral appeal that is strong enough to be willing to perform euthanasia”,<sup>(26)</sup> which is challenging to obtain once a patient has lost capacity and can no longer communicate an active desire for assisted death. Finally, many Dutch nursing homes bar the implementation of ARs for euthanasia, limiting access for Dutch individuals in facility care with dementia who have completed an AR.<sup>(22)</sup>

Further work is required to understand how an AR for MAiD could be created with precision and clarity, and who should assist the patient in the process (e.g., dementia care specialists, MAiD assessors, family physicians, family and caregivers). Ideally, patients should be given all the information required to make an informed choice about the spectrum of end of life care options in dementia, MAiD being one possibility. The degree (or lack) of patient and clinician understanding around dementia trajectories may shape (mis)perceptions about the future,<sup>(27)</sup> and influence how ARs for MAiD are created and ultimately enacted. This area requires further study.

The generalizability of this study may be limited, as we had a small sample size and we limited our participants to the greater Vancouver regional area. Consequently, findings cannot be generalized to all of British Columbia or Canada. Study findings could be influenced by a selection bias, as those individuals supportive of ARs for MAiD in dementia may have been more likely to respond. This study focused on clinicians’ opinions, and did not include other important

stakeholders such as patients with dementia themselves and their caregivers. We did not include religious affiliation as a demographic variable for study respondents, which has previously been found to have a significant association with attitudes regarding MAiD in dementia.<sup>(28)</sup>

## CONCLUSIONS

The majority of Vancouver dementia care clinicians who participated in this study support legislation allowing ARs for MAiD in dementia, while also expressing concerns that ARs for MAiD will be ethically and logistically difficult to enact. Most participants endorsed mandatory capacity assessments when creating an AR for MAiD, and requiring care-team consensus at the time of enactment as potential safeguards. If ARs for MAiD in dementia are legislated, formalized support and education for the public and clinicians will be essential to ensure patients are able to make informed choices about the spectrum of end-of-life care options in dementia.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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## APPENDIX A. ONLINE SURVEY

I have read the cover letter outlining this survey study and agree to participate. (check box)

### SECTION 1

Please answer the following questions about your medical practice.

1. I identify as:
  - a. Male
  - b. Female
  - c. Non-binary, transgender
2. Age:
  - a. Less than 20
  - b. 20-25
  - c. 26-30
  - d. 31-35
  - e. 36-40
  - f. 41-50
  - g. 51-55
  - h. 56-60
  - i. 61-65
  - j. 66-70
  - k. 71-75
  - l. 75 years or older
3. I am a:
  - a. Practising physician or nurse practitioner
  - b. Trainee
4. My discipline is:
  - a. Family physician who cares for older adults
  - b. Geriatric Medicine
  - c. Geriatric Psychiatry
  - d. Nurse practitioner who cares for older adults
  - e. Palliative Medicine
5. I have been in practice:
  - a. I am still in training
  - b. Less than 1 year
  - c. Between 1-5 years
  - d. Between 5-10 years

- e. Between 11-20 years
  - f. More than 20 years
  - g. More than 30 years
  - h. I am no longer practising
6. My practice/training is mainly conducted:
    - a. In an academic teaching hospital or clinic
    - b. In a community hospital
    - c. In a community-based outpatient setting

### SECTION 2

Please answer the following questions about your prior education and knowledge regarding Medical Assistance in Dying (MAiD) and dementia in general.

7. How many hours of education/training have you received regarding MAiD legislation?
  - a. 0 hours
  - b. 1-4 hours
  - c. 5 or more hours
8. I would rate my knowledge about the current Canadian legislation (eligibility criteria, referral process, assessment process) on MAiD as:  
 (Likert Scale) – Poor, Fair, Average, Good, Excellent
9. I would rate my knowledge about how to access MAiD for a patient as:  
 (Likert Scale) – Poor, Fair, Average, Good, Excellent
10. I would rate my comfort level in speaking to patients about MAiD as:  
 (Likert Scale) – Poor, Fair, Average, Good, Excellent
11. I would rate my knowledge about dementia as:  
 (Likert Scale) – Poor, Fair, Average, Good, Excellent
12. I would rate my comfort level about speaking to patients with dementia about advance care planning as:  
 (Likert Scale) – Poor, Fair, Average, Good, Excellent

**SECTION 3**

Please answer the following questions about your prior clinical experience with patients requesting and accessing MAiD.

13. The number of patients that I have encountered during my normal provision of clinical care who requested MAiD is:
  - a. 0
  - b. 1-5
  - c. 6-10
  - d. 11-15
  - e. 16-20
  - f. More than 20
14. I have helped refer a patient on for MAiD assessment:
  - a. Yes
  - b. No
15. I believe physicians have a professional duty to refer patients for MAiD assessment upon request:
  - d. Yes
  - e. No
16. I would provide an assessment for a patient wishing to access MAiD under current legislation:
 

(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
17. I would provide provision of MAiD under current legislation for patients who meet eligibility criteria:
 

(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
18. I have been asked by a patient with dementia about accessing MAiD:
  - a. Yes
  - b. No
19. I have been asked by a family member for a patient with dementia about accessing MAiD:
  - a. Yes
  - b. No

**SECTION 4**

Please answer the following questions regarding the appropriateness of MAiD provision to patients with dementia, with and without advance directives for MAiD. See the following definitions.

Mild dementia: cognitive changes in more than one domain (memory, language, visual spatial, executive function); but patients are still able to complete all basic and some instrumental activities of daily living without assistance.

Moderate dementia: cognitive changes in more than one domain (memory, language, visual spatial, executive function); patients are able to complete most basic activities or daily living but need support for all instrumental activities of daily living.

Severe dementia: cognitive changes in more than one domain (memory, language, visual spatial, executive function); patients are unable to complete basic activities or instrumental activities of daily living and may have challenges with communication, swallowing and nutrition.

Advance directive for MAiD: a request is placed for MAiD while still capable and documented in an advance directive. MAiD will be provided at a future time when certain pre-specified conditions are met, even if the patient has lost the capacity to request or consent to MAiD at the present time.

Basic activities of daily living: toileting, mobilizing, dressing, bathing, hygiene.

Instrumental activities of daily living: shopping, cooking, housekeeping, finances, medication, transport, telephone/technology use.

20. The ability to request MAiD for patients with dementia should be available through an advance directive:
 

(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
21. An advance directive for MAiD in dementia should only be possible once a patient has been diagnosed with Dementia:
 

(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
22. An advance directive for MAiD should be possible at any time in an individual's life, even if they have no pre-existing medical conditions:
 

(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
23. At what stage of dementia should a patient be eligible for MAiD by making an active request (no advance directive) (check all that apply):
  - a. No patient with dementia should have access to MAiD
  - b. Mild dementia
  - c. Moderate dementia
  - d. Severe dementia
24. At what stage of dementia could an advance request for MAiD be completed (check all that apply):
  - a. No patient with dementia should have access to advance requests for MAiD
  - b. Mild dementia
  - c. Moderate dementia
  - d. Severe dementia
25. At what stage of dementia would it be appropriate to enact and provide MAiD via an advance directive (check all that apply):
  - a. No patient with dementia should have access to advance requests for MAiD
  - b. Mild dementia
  - c. Moderate dementia
  - d. Severe dementia

26. I think that dementia leads to physical suffering:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
27. I think that dementia leads to existential or psychological suffering:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
28. I am concerned that patients with dementia could be coerced by others to request MAiD:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
29. If advance requests for MAiD in dementia become legal, patients with dementia could be subjected to non-voluntary MAiD:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
30. If MAiD becomes more available for patients with dementia, it will lead to a devaluation of the lives of patients with dementia:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
31. MAiD should be available for patients with dementia because it respects their ability to determine meaningful quality of life:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
32. It would be unjust if patients without capacity, including those with dementia, continue to be excluded from accessing MAiD, as written in the current legislation:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
33. Even though an advance directive reflects a patient's pre-stated wish, an advance request for MAiD will be ethically difficult for a clinician to provide once a person has lost capacity:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
34. All patients with dementia should have a mandatory capacity assessment when requesting MAiD:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
35. All patients with dementia should have a mandatory capacity assessment when making an advance directive for MAiD:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
36. Do you think cognitive testing (e.g., MMSE, MoCA) is an appropriate way to assess capacity to consent to MAiD?  
a. Yes  
b. No
37. At what score do you think capacity for MAiD is likely lost and why? (MMSE: --/30, MoCA: --.30, scoring on a cognitive test cannot adequately determine capacity)  
(Short Answer)
38. What conditions would have to be met for a patient with dementia to be capable to access MAiD? (check all that apply)  
a. Ability to distinguish life from death  
b. Functionally independent for instrumental activities of daily living  
c. Functionally independent for basic activities of daily living  
d. Ability to retain relevant information with respect to their own health issues  
e. Ability to reason how the choice affects their own life  
f. Remain settled on a non-fluctuating choice  
g. Meet the BC Health Care (Consent) and Care Facility (Admission) Act criteria for consent; the adult demonstrates an understanding of the proposed treatment, the risks and benefits, the condition for which it is proposed and alternative and that it applies to their own situation  
h. Other: (Short Answer)  
\_\_\_\_\_
39. Who should complete MAiD assessments for patients with dementia? (check all that apply)  
a. Experts in dementia (Geriatric Medicine, Psychiatry, Care of Older Adults)  
b. The physician who has known the patient the longest  
c. Their most responsible physician at the time of request  
d. The designated MAiD team assessor  
e. Other: (Short Answer)  
\_\_\_\_\_

## SECTION 5

Please complete the following questions about capacity to consent for MAiD in dementia.

34. All patients with dementia should have a mandatory capacity assessment when requesting MAiD:  
(Likert Scale) – Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree
40. Who should be responsible for determining when a patient becomes eligible for MAiD based on pre-specified conditions in the advance directive? (choose one)  
a. The patient's substitute decision-maker (SDM)  
b. The clinicians involved in the patient's care  
c. The assessors and providers of MAiD  
d. Both the SDM and the clinical team must agree  
e. Other: (Short Answer)  
\_\_\_\_\_

**SECTION 6**

Please complete the following short answers in regard to advance directives for MAiD in dementia.

41. Do you perceive any benefits for patients with dementia if MAiD via an advance directive becomes legal?

(Short Answer)

42. What barriers or concerns do you perceive in the provision of MAiD by advance directive?

(Short Answer)

## APPENDIX B. PARTICIPANTS ATTITUDES TOWARDS ADVANCE REQUESTS FOR MAiD IN DEMENTIA, SURVEY RESPONSES

<i>Statement/Question</i>	<i>Response Options</i>	<i>N</i>	<i>%</i>
I believe physicians have a professional duty to refer patients for MAiD assessment upon request.	Yes	77	96.25
	No	3	3.75
I would provide an assessment for a patient wishing to access MAiD under current legislation.	Strongly Disagree	9	11.25
	Disagree	12	15.00
	Neutral	14	17.50
	Agree	22	27.50
	Strongly Agree	23	28.75
I would provide provision of MAiD under current legislation for patients who meet eligibility criteria. <sup>a</sup>	Strongly Disagree	18	22.78
	Disagree	24	30.38
	Neutral	15	18.99
	Agree	8	10.13
	Strongly Agree	14	17.72
The ability to request MAiD for patients with dementia should be available through an advance directive.	Strongly Disagree	9	11.25
	Disagree	14	17.5
	Neutral	6	7.5
	Agree	32	40
	Strongly Agree	19	23.75
An advance directive for MAiD in dementia should only be possible once a patient has been diagnosed with dementia.	Strongly Disagree	14	17.5
	Disagree	25	31.25
	Neutral	23	28.75
	Agree	17	21.25
	Strongly Agree	1	1.25
An advance directive for MAiD in dementia should be possible at any time in an individual's life, even if they have no pre-existing medical conditions.	Strongly Disagree	11	13.75
	Disagree	16	20
	Neutral	18	22.5
	Agree	22	27.5
	Strongly Agree	13	16.25
At what stage of dementia should a patient be eligible for MAiD by making an active request (no advance directive)? <sup>a</sup> (multiple responses permitted)	No patient with dementia should have access to MAiD	13	16.46
	Mild dementia	51	64.56
	Moderate dementia	32	40.51
	Severe Dementia	13	16.46
At what stage of dementia could an advance request for MAiD be completed? (multiple responses permitted)	No patient with dementia should have access to MAiD	18	22.50
	Mild dementia	49	61.25
	Moderate dementia	21	26.25
	Severe dementia	21	26.25
At what stage of dementia would it be appropriate to enact and provide MAiD via an advance directive? <sup>a</sup> (multiple responses permitted)	No patient with dementia should have access to MAiD	18	22.78
	Mild dementia	23	29.11
	Moderate dementia	28	35.44
	Severe dementia	48	60.76

NAKANISHI: ADVANCE REQUESTS FOR MAiD IN DEMENTIA

I think that dementia leads to physical suffering. <sup>a</sup>	Strongly Disagree	3	3.8
	Disagree	3	3.8
	Neutral	7	8.86
	Agree	36	45.57
	Strongly Agree	30	37.97
I think that dementia leads to existential or psychological suffering. <sup>b</sup>	Strongly Disagree	2	2.56
	Disagree	0	0
	Neutral	4	5.13
	Agree	34	43.59
	Strongly Agree	38	48.72
I am concerned that patients with dementia could be coerced by others to request MAiD. <sup>a</sup>	Strongly Disagree	1	1.27
	Disagree	13	16.46
	Neutral	16	20.25
	Agree	34	43.04
	Strongly Agree	15	18.99
If advance requests for MAiD in dementia become legal, patients with dementia could be subjected to non-voluntary MAiD.	Strongly Disagree	5	6.25
	Disagree	22	27.50
	Neutral	15	18.75
	Agree	26	32.50
	Strongly Agree	12	15.00
If MAiD becomes more available for patients with dementia, it will lead to a devaluation of the lives of patients with dementia. <sup>a</sup>	Strongly Disagree	13	16.46
	Disagree	29	36.71
	Neutral	13	16.46
	Agree	13	16.46
	Strongly Agree	11	13.92
MAiD should be available for patients with dementia because it respects their ability to determine meaningful quality of life.	Strongly Disagree	3	3.75
	Disagree	8	10
	Neutral	8	10
	Agree	36	45
	Strongly Agree	25	31.25
It would be unjust if patients without capacity, including those with dementia, continue to be excluded from accessing MAiD, as written in the current legislation.	Strongly Disagree	10	12.5
	Disagree	12	15
	Neutral	13	16.25
	Agree	27	33.75
	Strongly Agree	18	22.5
Even though an advance directive reflects a patient's pre-stated wish, an advance request for MAiD will be ethically difficult for a clinician to provide once a person has lost capacity.	Strongly Disagree	5	6.25
	Disagree	13	16.25
	Neutral	11	13.75
	Agree	27	33.75
	Strongly Agree	24	30
All patients with dementia should have a mandatory capacity assessment when requesting MAiD.	Strongly Disagree	2	2.5
	Disagree	8	10
	Neutral	8	10
	Agree	35	43.75
	Strongly Agree	27	33.75
All patients with dementia should have a mandatory capacity assessment when making an advance directive for MAiD.	Strongly Disagree	1	1.25
	Disagree	7	8.75
	Neutral	10	12.5
	Agree	34	42.5
	Strongly Agree	28	35
Do you think cognitive testing (e.g., MMSE, MoCA) is an appropriate way to assess capacity to consent to MAiD? <sup>a</sup>	Yes	14	17.72
	No	65	82.28

NAKANISHI: ADVANCE REQUESTS FOR MAiD IN DEMENTIA

What conditions would have to be met for a patient with dementia to be capable to access MAiD? <sup>a</sup> (multiple responses permitted)	Ability to distinguish life from death	66	83.54
	Functionally independent for instrumental activities of daily living	6	7.59
	Functionally independent for basic activities of daily living	15	18.99
	Ability to retain relevant information with respect to their own health issues	53	67.09
	Ability to reason how the choice affects their own life	63	79.75
	Remain settled on a non-fluctuating choice	55	69.62
	Meet the BC Health Care (Consent) and Care Facility (Admission) Act for consent; the adult demonstrates an understanding of the proposed treatment, the risk and benefits, the condition for which it is proposed and alternative and that it applies to their own proposed treatment, the risk and benefits, the condition for which it is proposed and alternative and that it applies to their own situation	53	67.09
	Other	13	16.46
Who should complete MAiD assessments for patients with dementia? <sup>a</sup> (multiple responses permitted)	Experts in dementia (Geriatric Medicine, Psychiatry, Care of the Elderly Family Physicians)	68	86.08
	The physician who has known the patient the longest	54	68.35
	Their most responsible physicians at the time of the request	27	34.18
	The designated MAiD team assessor	56	70.89
	Other	7	8.86
Who should be responsible for determining when a patient becomes eligible for MAiD based on pre-specified conditions in the advance directive? <sup>a</sup>	The patient's substitute decision maker (SDM)	5	6.33
	The clinicians involved in the patient's care	3	3.80
	The assessors and providers of MAiD	9	11.39
	Both the SDM and the clinical team must agree	47	59.49
	Other	15	18.99

<sup>a</sup>Only 79 participants provided a response for this question.

<sup>b</sup>Only 78 participants provided a response for this question.