Quebec physicians' perspectives on medical aid in dying for incompetent patients with dementia

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Abstract

Objectives To elicit Quebec physicians' attitudes towards extending medical aid in dying (MAiD) to incompetent patients and to compare the attitudes of family physicians to those of other medical specialists.

Methods We conducted a postal survey among physicians caring for patients with dementia. We used hypothetical vignettes to elicit their attitudes towards MAiD and continuous deep sedation (CDS) to relieve suffering at end of life. Two patients were depicted in the vignettes: one with cancer eligible for MAiD and one with dementia. The generalized estimating equation approach was used to investigate factors associated with attitudes, including the stage of the illness (advanced vs terminal dementia) and the presence or absence of a prior written request.

Results A total of 136 physicians out of 653 returned the questionnaire. Physicians favoured CDS over MAiD for relieving suffering in the cancer vignette (93% vs 79%; $p = 0.002$). In advanced dementia, 45% of physicians supported giving the patient access to MAiD with a written request and 14% without such request. At the terminal stage of dementia, these proportions increased to 71% and 43%, respectively ($p < 0.001$), reaching 79% and 52% among family physicians. Support for CDS in terminal dementia was lower than in end-stage cancer (68% vs 93%; $p < 0.001$) and equal to MAiD with a written request (68% vs 71%; $p = 0.623$).

Conclusion Many Quebec physicians support extending MAiD to incompetent patients with dementia to relieve suffering at the terminal stage. This finding will inform current deliberations as to whether MAiD should be extended to these patients.

Résumé

Objectifs Mesurer les attitudes des médecins du Québec face à l'idée d'étendre l'aide médicale à mourir (AMM) à des patients inaptes et comparer les attitudes des médecins de famille à celles d'autres médecins spécialistes.

Méthodes Nous avons mené une enquête postale auprès de médecins qui soignent des patients avec démence. Les attitudes face à l'AMM et à la sédation palliative continue (SPC) ont été mesurées au moyen de vignettes faisant intervenir un patient atteint de cancer qui est admissible à l'AMM et un second patient atteint de démence. Des équations d'estimation généralisée ont servi à

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étudier l'influence de facteurs sur les attitudes, dont le stade de la maladie (avancé vs terminal) et la présence ou non d'une directive écrite.

Résultats 136 médecins parmi les 653 sollicités ont retourné le questionnaire. Les médecins préférèrent la SPC à l'AMM pour soulager la souffrance d'un patient atteint de cancer (93 % vs 79 %; $p=0,002$). Au stade avancé de la démence, 45 % des médecins appuient l'idée de donner au patient accès à l'AMM avec une directive écrite, et 14 % sans une telle directive. Au stade terminal, ces proportions augmentent à 71 % et 43 % respectivement ($p<0,001$), atteignant 79 % et 52 % chez les médecins de famille. Toujours au stade terminal, l'appui à la SPC en contexte de démence est moindre qu'en contexte de cancer (68 % vs 93 %; $p<0,001$) et égal à l'AMM avec directive écrite (68 % vs 71 %; $p=0,623$).

Conclusion Nombre de médecins du Québec appuient l'idée d'étendre l'AMM à des patients inaptes, qui sont au stade terminale d'une démence, pour soulager leur souffrance. Ce constat informera les discussions en cours visant à déterminer si l'AMM devrait être étendue à ces patients.

Keywords Euthanasia · Decisional incapacity · Dementia · Advance directive · Physician · Survey

Mots-clés Euthanasie · Incapacité décisionnelle · Démence · Directive anticipée · Médecin · Sondage

Introduction

As the Canadian population ages, growing numbers of older adults are developing Alzheimer disease or other forms of dementia that gradually erode their decision-making capacity. Nearly one million Canadians could be affected by dementia some 15 years from now (Alzheimer Society of Canada 2016). Using data from the UK, Brayne et al. (2006) estimated that one third of people over the age of 65 die with dementia. Many of these people will have lived with the disease for several years (Xie et al. 2008). Quality of life is generally good in the early stages of dementia, and many affected individuals will progress to the advanced stages without appearing to experience distressing symptoms (van Kooten et al. 2017). Others, however, will suffer a range of symptoms that may be difficult to manage and cause enduring suffering, including pain, dyspnea, dysphasia, recurrent infections, shortness of breath, and mood disorders (Canadian Institute for Health Information 2016; Hendriks et al. 2015; Husebo et al. 2008; Midlbust et al. 2018; Mitchell et al. 2009; Vandervoort et al. 2013; van Kooten et al. 2017).

Aware of the possible clinical complications of advanced dementia and apprehending losing their independence and cognitive functions, some people do not want their lives to extend into prolonged dementia. Few options are available to these individuals (Menzel and Chandler-Cramer 2014). In the early stages of the disease, they can voluntarily stop eating and drinking or attempt suicide. Both options amount to sacrificing valuable years of life. They can sign an advance directive in anticipation of decisional incapacity, in which they refuse all life-sustaining interventions. However, they may never find themselves in a situation where such interventions are needed and can be refused to hasten their death. Menzel and Chandler-Cramer (2014) propose using an advance directive to request that food and fluids by mouth be withheld when

dementia becomes sufficiently severe. They argue for following the directive, provided doing so respects the person's critical interests and does not cause distress from not being fed. According to the authors, death by cessation of food and water is relatively comfortable when properly overseen and would lead to death in a few weeks.

Three countries—the Netherlands, Belgium, and Luxembourg—offer their citizens the option of completing an advance euthanasia directive. Euthanasia is usually defined as the termination of life by a physician who administers lethal drugs at the patient's request (Rietjens et al. 2009a). In Belgium and Luxembourg, decisionally incapacitated patients can access euthanasia through a prior written request, provided they are in a state of irreversible coma. The Dutch legislation imposes no such restriction. To date, a few cases have been reported of Dutch patients at an advanced stage of dementia whose written requests for euthanasia were granted after they had become incompetent (Regional Euthanasia Review Committees 2017).

Following a landmark decision from the Supreme Court of Canada in *Carter*, Bill C-14 came into effect on June 17, 2016, making medical assistance in dying (MAiD) legal in Canada for patients who meet the legal requirements (Parliament of Canada 2016). Six months earlier, a MAiD legislation had come into force in the province of Quebec (Bill 52 2014). Definitions and eligibility criteria for MAiD are not identical in the two jurisdictions (Online Resource 1). However, both require that the person be competent at the time of provision of MAiD.

At both levels of government, legislation was preceded by some discussions as to whether MAiD should also be accessible to incompetent patients on the basis of a request made in advance of decisional incapacity. Neither government chose to give incompetent patients access to MAiD through a prior written request. Instead, they each tasked a group of experts to reflect on the issue. These groups would benefit from knowledge of

stakeholders' positions of the issue. Little empirical data relevant to the current Canadian context are currently available to support their work (Tomlinson and Stott 2015). Against this background, we launched a large-scale survey among major groups of Quebec stakeholders, including physicians, to uncover their attitudes towards expanding MAiD to incompetent patients (Bravo et al. 2017). In this paper, we describe Quebec physicians' attitudes towards extending MAiD to incompetent patients with dementia, and their willingness to be involved should it be legal. As a secondary objective, we compare the views of two groups of physicians (family physicians vs other medical specialists) whose involvement in MAiD is known to differ. In the Netherlands, for instance, 85% of euthanasia cases were performed by general practitioners in 2016 (Regional Euthanasia Review Committees 2017).

Methods

Design and sample

As previously described in more detail elsewhere (Bravo et al. 2017), we conducted an anonymous province-wide postal survey in a random sample of French-speaking, currently active physicians. The sample was provided by the *Collège des médecins du Québec* and restricted to the following specialties more likely to be involved in end-of-life decision-making: family medicine, geriatrics, internal medicine, neurology, psychiatry, and intensive care. The survey was further restricted to physicians who were caring for patients with Alzheimer disease or a related disorder. Sampled physicians were asked whether they satisfied this last eligibility criterion on the cover page of the questionnaire.

Potential respondents received a first survey package in September 2016, followed by two reminders. Non-respondents were mailed a single-page 3-item questionnaire in January 2017, asking for their reasons for not participating and their general attitudes towards MAiD. The survey was closed on March 1st, 2017. The survey was approved by the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke (file #2016-623).

Questionnaire

The questionnaire consisted of three main parts, preceded by consent information and the list of current eligibility criteria for MAiD as stated in Quebec's Bill 52. Part 1 used hypothetical clinical vignettes to elicit respondents' attitudes towards MAiD and continuous deep sedation (CDS), first for a terminally ill patient with cancer who was described as eligible for MAiD, and second for a patient with Alzheimer disease (Box 1). CDS involves the use of medications to relieve refractory symptoms by

Box 1 Overview of clinical vignettes used in the survey

CASE 1 (a patient with end-stage cancer): an 82-year-old competent patient with advanced colorectal cancer, who can no longer be cured, suffers unbearably, and has a few weeks to live according to the treating physician.

The patient is offered continuous deep sedation. As artificial nutrition and hydration would not be provided, death should occur a few days later.

Vignette 1.1: Respondents were asked the extent to which they consider it acceptable that a physician provides continuous deep sedation to the patient.

The patient requests medical aid in dying. The treating physician judges the patient eligible.

Vignette 1.2: Respondents were asked the extent to which they consider it acceptable that a physician provides medical aid in dying to the patient.

CASE 2 (a patient with Alzheimer disease): a 75-year-old retired teacher, diagnosed with Alzheimer disease, who writes an advance directive in which she refuses all life-prolonging interventions should she be incompetent and explicitly requests medical aid in dying to be carried out when she can no longer recognize her loved ones.

The patient is now 81, unable to care for herself, and lives in a long-term care facility. She can no longer make decisions but does not seem uncomfortable.

Vignette 2.1: Respondents were asked the extent to which they are in favour of modifying the current legislation to allow medical aid in dying at this advanced stage of the disease, at the request of the family, in the presence of a written request.

Vignette 2.2: Respondents were asked the extent to which they are in favour of modifying the current legislation to allow medical aid in dying at this advanced stage of the disease, at the request of the family, assuming that the patient had made repeated requests orally but never in writing.

The patient must now be spoon-fed, shows signs of distress and cries a lot. All efforts to control symptoms have failed. The treating physician believes the patient has a few weeks to live.

Vignette 2.3: Respondents were asked the extent to which they are in favour of modifying the current legislation to allow medical aid in dying at this terminal stage of the disease, at the request of the family, in the presence of a written request.

Vignette 2.4: Respondents were asked the extent to which they are in favour of modifying the current legislation to allow medical aid in dying at this terminal stage of the disease, at the request of the family, assuming that the patient had made repeated requests orally but never in writing.

Assume the patient never requested medical aid in dying. The family asks for continuous deep sedation to alleviate the patient's distress. As artificial nutrition and hydration would not be provided, death should occur a few days later.

Vignette 2.5: Respondents were asked the extent to which they consider it acceptable that a physician provides continuous deep sedation at this terminal stage of the disease.

rendering the patient unconscious until death. It is usually reserved for patients with a life expectancy of 2 weeks or less. CDS and MAiD are both interventions intended to relieve the patient's suffering, but with MAiD, the means used to do so is to end the patient's life (Collège des médecins du Québec 2016). Clinical vignettes were followed by a set of 13 attitudinal statements aimed at uncovering respondents' reasons for supporting or opposing MAiD. Part 2 asked general questions on related

issues, such as whether respondents would be willing to administer MAiD to an incompetent patient should it be legal. Background variables were collected in part 3.

Statistical analyses

We summarized respondents' attitudes towards MAiD and CDS using proportions and 95% confidence intervals. We used the generalized estimating equation (GEE) approach to investigate the effects of various factors on acceptability of a given end-of-life practice (Agresti 2002). Factors investigated included the illness (cancer vs Alzheimer), end-of-life practice (MAiD vs CDS), stage of Alzheimer disease (advanced vs terminal), prior written request (present vs absent), and specialty (family medicine vs other). All models initially included interaction terms involving investigated factors (e.g., disease $\times$ end-of-life practice), but as none were significant they were subsequently dropped. GEE analyses were conducted using SAS Proc GENMOD (SAS Institute Inc., Cary, NC; version 9.4). All reported p values are two-sided.

Results

Characteristics of the respondents

Of 653 sampled physicians, 119 reported not currently caring for patients with dementia and were therefore not eligible. A total of 136 physicians returned the questionnaire, for a response rate of 25.5%. Twenty-eight of the 398 non-respondents returned the non-response 3-item questionnaire. Lack of time was the reason given by most physicians for not participating in the survey. Two of the 28 physicians who returned the non-response questionnaire did not answer the second and third items eliciting their general attitudes towards MAiD. Of the 26 others, 20 felt that the current MAiD legislation (which requires competency) was *somewhat* or *totally acceptable*; 7 were *somewhat* or *totally favourable* to extending MAiD to incompetent patients.

Of the 136 respondents, 62 were family physicians and 74 had other specialties (Table 1). These proportions do not differ significantly from those in the random sample provided by the *Collège* ($p = 0.859$). In the year preceding the survey, 59% had received a (likely informal) request to be helped to die from one or more patients; 51% had received a corresponding request from one or more patients' families. When asked the likelihood that they would write a MAiD advance request for themselves should they have Alzheimer disease, 74 (56%) answered *somewhat* or *extremely likely*. These 74 respondents were invited to select conditions that they would want to trigger their advance request. Those most often selected were physical pain and psychological suffering unsuccessfully relieved, and complete dependence on others for basic

needs. Half of the respondents (55%) reported being *somewhat* or *extremely likely* to ask a physician to grant the MAiD request of a close relative diagnosed with Alzheimer disease.

Attitudes towards CDS and MAiD

Competent patient with cancer

Respondents' attitudes towards CDS and MAiD for the patient with end-stage cancer are shown in Table 2, first for all physicians combined, and then separately for family physicians and the other medical specialists. Overall, 93% of physicians felt that deeply sedating the patient until death was *somewhat* or *totally acceptable*, and 79% felt it was acceptable that a physician administer MAiD to this patient who we depicted as eligible. Acceptability of sedation was higher than for MAiD ($p = 0.002$; OR = 3.4, 95% CI: 1.6–7.4). Attitudes towards these two practices did not differ significantly between family physicians and the other specialists ($p = 0.119$). Of the 136 physicians, 106 (78%) reported caring for patients like the one depicted in the vignette. Assuming that the patient was one of their own, 49% of these 106 physicians indicated being *somewhat* or *extremely likely* to administer MAiD themselves at the patient's explicit request. This proportion was higher among family physicians than among the other specialists (60% vs 39%; $p = 0.033$).

Incompetent patient with Alzheimer disease

Table 3 summarizes respondents' attitudes towards MAiD and CDS for the patient with Alzheimer disease, first when the patient is at the advanced stage of her disease (part A) and second when she is at the terminal stage (part B). At the advanced stage, 45% (95% CI, 37%–53%) of physicians were in favour of giving the patient access to MAiD if there was a request written while she still had capacity, and 14% (95% CI, 9%–21%) assuming repeated requests had been made orally over the years but not in writing. Of the 121 physicians who indicated caring for patients with advanced dementia, 31% (95% CI, 23%–41%) would be *somewhat* or *extremely likely* to administer MAiD themselves in the presence of a written request and 14% (95% CI, 9%–21%) with oral requests made while still competent.

At the terminal stage (Table 3, part B), the proportion of physicians who were in favour of giving the patient access to MAiD increases to 71% (95% CI, 62%–78%) in the presence of a written request and to 43% (95% CI, 35%–51%) in its absence (still assuming repeated requests had been made orally before losing capacity). The effects of the two factors that vary across vignettes (i.e., presence vs absence of a prior written request and advanced vs terminal stage of dementia) are both highly significant ($p < 0.001$ for each factor; OR = 3.6,

Table 1 Characteristics of the 136 physicians who returned the questionnaire

Characteristics	Summary statistics ^a
Age (in years)	49.2 ± 12.5
Gender (female)	79 (59.8)
Religiosity Index ^b	3.5 ± 3.5
Trained in Canada	130 (95.6)
Has some training in palliative care	70 (51.9)
Speciality	
Family medicine	62 (45.6)
Geriatrics	33 (24.3)
Internal medicine	9 (6.6)
Neurology	7 (5.1)
Psychiatry	12 (8.8)
Intensive care	3 (2.2)
Double speciality	3 (2.2)
Other/unspecified	7 (5.1)
Years of medical practice	
10 or less	43 (31.6)
11 to 20	37 (27.2)
21 to 30	22 (16.2)
More than 30	34 (25.0)
Practice setting(s) ^c	
Private practice	26 (19.5)
Group practice	35 (26.3)
Hospital	75 (56.4)
Long-term care facility	33 (24.8)
University Hospital Centre	51 (38.3)
In the last 12 months, number of patients who expressed to the physician the desire to be helped to die in order to relieve their suffering	
None	55 (40.7)
Less than 10	71 (52.6)
10 or more	9 (6.7)
In the last 12 months, number of families who expressed to the physician the desire that a loved one be helped to die in order to relieve his or her suffering	
None	66 (48.9)
Less than 10	59 (43.7)
10 or more	10 (7.4)
Has accompanied a relative through the dying process	81 (59.6)
Likely to write a MAiD request should one develop Alzheimer disease (<i>somewhat or extremely likely</i>)	74 (56.1)
Conditions that should trigger their own MAiD request (<i>n</i> = 74) ^d	
Admission to a long-term care facility	13 (17.6)
No longer recognizing loved ones	31 (41.9)
Being completely dependent on others for basic needs	39 (52.7)
Physical pain that cannot be relieved, according to the healthcare team and close relatives	54 (73.0)
Psychological suffering that cannot be relieved, according to the healthcare team and close relatives	47 (63.5)
Having only a few weeks to live, according to the healthcare team	19 (25.7)
Likely to ask a physician to grant the MAiD request of a close relative who would have written one after having been diagnosed with Alzheimer disease (<i>somewhat or extremely likely</i>)	71 (54.6)

^a Data shown are means ± standard deviations, or absolute frequencies with percentages in parentheses, derived from valid cases. Few data were missing: between 1 for training in palliative care and 8 for age

^b Derived from combining answers to four questions developed by Statistics Canada for the General Social Survey (Clark and Schellenberg 2006). Total scores range from 0 to 13 and are interpreted in three broad categories: low (0–5), moderate (6–10), and high (11–13)

^c More than one answer could be given

^d Respondents were asked to select a maximum of three conditions among those listed

95% CI: 2.6–4.9 and OR = 3.4, 95% CI: 2.5–4.7, respectively). Of the 112 physicians who reported caring for patients with terminal dementia, 54% (95% CI, 45%–63%) would be *somewhat* or *extremely likely* to administer MAiD themselves in the presence of a written request and 32% (95% CI, 24%–42%) in its absence. At the terminal stage of the illness, 68% of physicians

(95% CI, 60%–75%) felt it was acceptable to sedate the patient continuously until death as a means of relieving the patient's persistent distress. Support for this practice in end-stage cancer was higher than in terminal dementia (93% vs 68%, *p* < 0.001; OR = 5.9, 95% CI: 3.2–10.9). In terminal dementia, physicians were equally likely to judge CDS and MAiD based

on a written request as acceptable practices to relieve the patient's apparent suffering (68% vs 71%, $p = 0.623$).

Table 3 further reveals that family physicians always judged MAiD to be more acceptable than did the other specialists, at both the advanced and terminal stages of dementia, and whether or not a written request had been made by the patient while she was still competent. Controlling for the presence or absence of a written request, the difference in support for MAiD between family physicians and the other specialists was statistically significant at the terminal stage ($p = 0.028$; OR = 2.0, 95% CI: 1.1–3.9) and of borderline significance at the advanced stage ($p = 0.055$; OR = 1.9, 95% CI: 0.99–3.6). Should the patient be one of their own, family physicians were also more likely than the other physicians to administer MAiD themselves in each of the four scenarios. Here again, the difference between the two groups of physicians was statistically significant at the terminal stage ($p = 0.002$; OR = 3.2, 95% CI: 1.5–6.5) and of borderline significance at the advanced stage ($p = 0.056$; OR = 2.1, 95% CI: 0.98–4.5), still controlling for the presence or absence of a written request. Greater support for CDS was also found among family physicians than among the other specialists (75% vs 62%), but the difference was not significant ($p = 0.102$).

General statements

Physicians' levels of agreement with 13 general statements are shown in Table 4. Views varied considerably between physicians, except for four statements that were endorsed by over 70% of the respondents. These include statement 3 that *only God determines when a person dies*: 73% of the respondents disagreed with this statement, reflecting a relatively low level of religiosity among the respondents (cf. Table 1). Concordant with findings from Table 3, most respondents valued preferences expressed by patients in anticipation of incapacity (statements 4 and 8). Most respondents also felt that it is possible to determine whether an incompetent patient has unbearable physical pain (statement 9).

Of the 13 general statements, all but two (statements 8 and 9) were associated with the physicians' responses to vignette 2.3 (where the patient was at the terminal stage of her disease and had made a prior written request for MAiD) (p values from < 0.001 to 0.037), and always in the expected direction. For instance, physicians who felt MAiD was acceptable (*somewhat* or *totally*) in that specific situation tended to agree that "Every person has the right to choose how they will die" (statement 2, $p < 0.001$), that "The fear of living the advanced stages of Alzheimer disease or related disorders should be considered as unbearable suffering for those at the early stage"

Table 2 Attitudes of physicians towards continuous deep sedation (CDS) and medical aid in dying (MAiD) for a competent terminally ill patient with cancer^a

	Overall	Family physicians	Other medical specialists
Vignette 1.1: acceptability of CDS			
	$n = 136$	$n = 62$	$n = 74$
Totally unacceptable	3 (2.2)	2 (3.2)	1 (1.4)
Somewhat unacceptable	2 (1.5)	1 (1.6)	1 (1.4)
Neutral	5 (3.7)	1 (1.6)	4 (5.4)
Somewhat acceptable	44 (32.4)	17 (27.4)	27 (36.5)
Totally acceptable	82 (60.3)	41 (66.1)	41 (55.4)
Vignette 1.2: acceptability of MAiD			
	$n = 135$	$n = 61$	$n = 74$
Totally unacceptable	8 (5.9)	1 (1.6)	7 (9.5)
Somewhat unacceptable	16 (11.9)	5 (8.2)	11 (14.9)
Neutral	5 (3.7)	3 (4.9)	2 (2.7)
Somewhat acceptable	38 (28.1)	15 (24.6)	23 (31.1)
Totally acceptable	68 (50.4)	37 (60.7)	31 (41.9)
Likelihood of administering MAiD themselves to a similar patient of their own			
	$n = 106$	$n = 52$	$n = 54$
Extremely unlikely	27 (25.5)	8 (15.4)	19 (35.2)
Somewhat unlikely	17 (16.0)	9 (17.3)	8 (14.8)
Neutral	10 (9.4)	4 (7.7)	6 (11.1)
Somewhat likely	27 (25.5)	15 (28.8)	12 (22.2)
Extremely likely	25 (23.6)	16 (30.8)	9 (16.7)

^a Data shown are absolute frequencies with percentages in parentheses

Table 3 Attitudes of physicians towards medical aid in dying (MAiD) and continuous deep sedation (CDS) for an incompetent patient with Alzheimer disease^a(A) At the advanced stage of the disease

	Overall	Family physicians	Other medical specialists
Vignette 2.1: acceptability of allowing MAiD in the <u>presence</u> of a written request			
	<i>n</i> = 134	<i>n</i> = 62	<i>n</i> = 72
Totally unacceptable	25 (18.7)	7 (11.3)	18 (25.0)
Somewhat unacceptable	36 (26.9)	16 (25.8)	20 (27.8)
Neutral	13 (9.7)	7 (11.3)	6 (8.3)
Somewhat acceptable	39 (29.1)	17 (27.4)	22 (30.6)
Totally acceptable	21 (15.7)	15 (24.2)	6 (8.3)
Vignette 2.2: acceptability of allowing MAiD in the <u>absence</u> of a written request			
	<i>n</i> = 134	<i>n</i> = 62	<i>n</i> = 72
Totally unacceptable	54 (40.3)	19 (30.6)	35 (48.6)
Somewhat unacceptable	44 (32.8)	18 (29.0)	26 (36.1)
Neutral	17 (12.7)	12 (19.4)	5 (6.9)
Somewhat acceptable	12 (9.0)	8 (12.9)	4 (5.6)
Totally acceptable	7 (5.2)	5 (8.1)	2 (2.8)
Assuming it were legal, likelihood of administering MAiD themselves to a similar patient of their own, in the <u>presence</u> of a written request			
	<i>n</i> = 121	<i>n</i> = 54	<i>n</i> = 67
Extremely unlikely	43 (35.5)	14 (25.9)	29 (43.3)
Somewhat unlikely	29 (24.0)	12 (22.2)	17 (25.4)
Neutral	11 (9.1)	7 (13.0)	4 (6.0)
Somewhat likely	26 (21.5)	14 (25.9)	12 (17.9)
Extremely likely	12 (9.9)	7 (13.0)	5 (7.5)
Assuming it were legal, likelihood of administering MAiD themselves to a similar patient of their own, in the <u>absence</u> of a written request			
	<i>n</i> = 121	<i>n</i> = 54	<i>n</i> = 67
Extremely unlikely	68 (56.2)	24 (44.4)	44 (65.7)
Somewhat unlikely	29 (24.0)	13 (24.1)	16 (23.9)
Neutral	7 (5.8)	5 (9.3)	2 (3.0)
Somewhat likely	13 (10.7)	8 (14.8)	5 (7.5)
Extremely likely	4 (3.3)	4 (7.4)	0 (0)

(B) At the terminal stage of the disease

	Overall	Family physicians	Other medical specialists
Vignette 2.3: acceptability of allowing MAiD in the <u>presence</u> of a written request			
	<i>n</i> = 136	<i>n</i> = 62	<i>n</i> = 74
Totally unacceptable	17 (12.5)	4 (6.5)	13 (17.6)
Somewhat unacceptable	15 (11.0)	6 (9.7)	9 (12.2)
Neutral	8 (5.9)	3 (4.8)	5 (6.8)
Somewhat acceptable	37 (27.2)	16 (25.8)	21 (28.4)
Totally acceptable	59 (43.4)	33 (53.2)	26 (35.1)
Vignette 2.4: acceptability of allowing MAiD in the <u>absence</u> of a written request			
	<i>n</i> = 136	<i>n</i> = 62	<i>n</i> = 74
Totally unacceptable	33 (24.3)	11 (17.7)	22 (29.7)
Somewhat unacceptable	24 (17.6)	9 (14.5)	15 (20.3)
Neutral	21 (15.4)	10 (16.1)	11 (14.9)
Somewhat acceptable	36 (26.5)	17 (27.4)	19 (25.7)
Totally acceptable	22 (16.2)	15 (24.2)	7 (9.5)

Table 3 (continued)

Assuming it were legal, likelihood of administering MAiD themselves to a similar patient of their own, in the <u>presence</u> of a written request			
	<i>n</i> = 112	<i>n</i> = 49	<i>n</i> = 63
Extremely unlikely	28 (25.0)	5 (10.2)	23 (36.5)
Somewhat unlikely	15 (13.4)	8 (16.3)	7 (11.1)
Neutral	8 (7.1)	3 (6.1)	5 (7.9)
Somewhat likely	29 (25.9)	13 (26.5)	16 (25.4)
Extremely likely	32 (28.6)	20 (40.8)	12 (19.0)
Assuming it were legal, likelihood of administering MAiD themselves to a similar patient of their own, in the <u>absence</u> of a written request			
	<i>n</i> = 111	<i>n</i> = 48	<i>n</i> = 63
Extremely unlikely	44 (39.6)	10 (20.8)	34 (54.0)
Somewhat unlikely	18 (16.2)	8 (1.7)	10 (15.9)
Neutral	13 (11.7)	6 (12.5)	7 (11.1)
Somewhat likely	24 (21.6)	14 (29.2)	10 (15.9)
Extremely likely	12 (10.8)	10 (20.8)	2 (3.2)
Vignette 2.5: acceptability of CDS			
	<i>n</i> = 135	<i>n</i> = 61	<i>n</i> = 74
Totally unacceptable	9 (6.7)	3 (4.9)	6 (8.1)
Somewhat unacceptable	16 (11.9)	7 (11.5)	9 (12.2)
Neutral	18 (13.3)	5 (8.2)	13 (17.6)
Somewhat acceptable	59 (43.7)	28 (45.9)	31 (41.9)
Totally acceptable	33 (24.4)	18 (29.5)	15 (20.3)

^a Data shown are absolute frequencies with percentages in parentheses

(statement 7, $p = 0.004$) or that “The administration of a strong medication that would end life in a few minutes ... [s]hould be

permitted for both competent and incompetent patients” (statement 12, $p < 0.001$). Conversely, they tended to disagree

Table 4 Levels of agreement with general statements aimed at uncovering respondents’ values and beliefs regarding medical aid in dying ($n = 136$)^a

Statement	Disagree ^b	Neutral	Agree ^b
1. Human life must be preserved in all circumstances.	83 (61.5)	27 (20.0)	25 (18.5)
2. Every person has the right to choose how they will die.	34 (25.0)	20 (14.7)	82 (60.3)
3. Only God determines when a person dies.	99 (73.3)	25 (18.5)	11 (8.1)
4. Healthcare preferences expressed before losing capacity should carry the same weight as those expressed by a competent patient.	23 (16.9)	14 (10.3)	99 (72.8)
5. Patients at the terminal stage of Alzheimer disease do not die with dignity.	41 (30.1)	34 (25.0)	61 (44.9)
6. All physical pain can be alleviated at end of life.	48 (35.3)	20 (14.7)	68 (50.0)
7. The fear of living the advanced stages of Alzheimer disease or related disorders should be considered as unbearable suffering for those at the early stage.	63 (46.3)	25 (18.4)	48 (35.3)
8. Health care to be provided to an incompetent patient should always be based on his/her current situation, irrespective of preferences he/she may have expressed while still competent.	108 (79.4)	15 (11.0)	13 (9.6)
9. It is impossible to know whether an incompetent patient has unbearable physical pain.	114 (83.8)	11 (8.1)	11 (8.1)
The administration of a strong medication that would end life in a few minutes ...			
10. Should be restricted to competent patients that have requested it themselves.	54 (40.0)	15 (11.1)	66 (48.9)
11. Should be permitted for patients who are not at the end of their life but satisfy all other criteria of the current legislation.	63 (46.3)	20 (14.7)	53 (39.0)
12. Should be permitted for both competent and incompetent patients.	50 (36.8)	19 (14.0)	67 (49.3)
13. Should be prohibited because vulnerable individuals could receive it against their will.	89 (65.9)	25 (18.5)	21 (15.6)

^a Data shown are absolute frequencies, with percentages in parentheses

^b Combines *somewhat* and *totally*

with statement 13 that “The administration of a strong medication that would end life in a few minutes ... [s]hould be prohibited because vulnerable individuals could receive it against their will” ($p < 0.001$).

Discussion

With the objective of informing current and future legislative reflection, we surveyed Quebec physicians on whether MAiD should be extended to incompetent patients. We started by eliciting their attitudes towards the current legislation, to establish baseline levels of support towards MAiD. Nearly 80% of the respondents approved the active ending of life at the explicit request of an end-stage cancer patient with severe pain. Acceptance of MAiD in those circumstances was higher than found in other countries (Hendry et al. 2013). This finding may reflect a response bias or a general trend towards more tolerant attitudes over time (Bolt et al. 2015; Kouwenhoven et al. 2013). One in two participants (and 60% of family physicians) would be willing to fulfill a MAiD request from a similar patient of their own. Family physicians’ greater openness to performing euthanasia has been reported by others and explained by their long-standing care relationships with their patients (Bolt et al. 2015).

In the case of the patient with end-stage cancer and severe pain, surveyed physicians favoured CDS over MAiD. Arguably, respondents considered CDS to be more compatible with their role in caring for patients. CDS is increasingly being used internationally to prevent further suffering in patients with a very short life expectancy and refractory symptoms, most often while forgoing artificial nutrition and hydration (Raus et al. 2011). It has been argued that the availability of palliative sedation obviates the need for assisted death. Yet, research indicates that the two practices differ in many respects, being applied to different patient populations and addressing quite different clinical problems (Raus et al. 2011; Rietjens et al. 2006). Moreover, the availability of palliative sedation did not prevent requests for euthanasia in permissive countries (Hendry et al. 2013). These facts suggest that CDS and MAiD are alternative means to alleviate otherwise intractable suffering in dying patients.

The majority of physicians who participated in our survey opposed extending MAiD to incompetent patients with dementia—even in the presence of a written request—and would refuse to be involved themselves, except in cases where the patient is at the terminal stage, had made a written request before losing capacity, and shows signs of distress. In those circumstances, 71% of the respondents felt that MAiD was acceptable, and 54% would be willing to provide MAiD themselves to one of their patients who matched the above description. These proportions were slightly higher among family physicians, at 79% and 67%, respectively. Bolt and

collaborators (Bolt et al. 2015) also found family physicians to be significantly more likely to perform euthanasia in controversial cases, including dementia.

Support for extending MAiD to incompetent patients in distress with terminal dementia, and willingness to be involved, were higher among Quebec physicians than found in other countries (Tomlinson and Stott 2015), even in the Netherlands where such patients could qualify for access (Kouwenhoven et al. 2013). The latter study was conducted 8 years after the Dutch euthanasia law came into effect, but before the first reported case of euthanasia in an incompetent patient with advanced dementia. One third of the surveyed physicians supported euthanasia in advanced dementia based on a written directive. This relatively low level of support among Dutch physicians may reflect greater awareness of the difficulties of determining whether a patient meets the legal requirements, including unbearable suffering (which, unlike in Canada, is not a purely subjective matter to be determined by the patient), and of providing MAiD to those judged eligible. These difficulties likely explain the very small number of cases of euthanasia performed to date in Dutch patients with advanced dementia, in comparison to the large number of Dutch citizens who have filled out an advance euthanasia directive. Active ending of life, even at the patient’s request, is certainly emotionally disturbing for physicians (van Marwijk et al. 2007). Even greater negative emotions would likely be experienced in cases of patients with whom direct communication is no longer possible, but who are not unconscious and still interact with their environment. Patients with advanced dementia might not fully understand what is happening to them during the euthanasia procedure and resist injections (Bolt et al. 2015). In their last annual report, the Dutch Regional Euthanasia Review Committees (2017) acknowledged the difficulty of correctly interpreting resistance in incompetent patients who had made a valid request for euthanasia while competent. They recommended erring on the side of caution and blamed a physician for not halting the procedure in an incompetent patient who pulled her arm away when the physician tried to inject the drugs.

Limitations

Study findings must be interpreted in light of its limitations. Short vignettes inevitably simplify complex situations, and actual decisions would in practice be based on much more information (Rietjens et al. 2009b). Only a few situations could be covered by the questionnaire. Other situations of interest could be explored in the future, such as that of a patient with advanced (rather than terminal) dementia who shows sign of distress, or one suffering from a concomitant painful disease. As found in other surveys (Fédération des médecins spécialistes du Québec 2009; Marcoux et al. 2016), the response rate was low, despite following experts’

recommendations aimed at maximizing response rates and data quality (Dillman et al. 2014). Our response rate is possibly underestimated, however, because the questionnaire was sent to all physicians in pre-specified specialties, including a likely significant number who did not care for patients with dementia and therefore were not eligible. Nonetheless, we cannot exclude the possibility that nonresponse has to some extent biased our findings. Still, while a precise estimate cannot be provided, our results suggest that hundreds of Quebec physicians favour extending MAiD to incompetent patients in some circumstances. Moreover, many would be willing to provide MAiD themselves to an eligible patient of their own, should it become legal.

Conclusion

This study suggests that a majority of Quebec physicians favour extending MAiD to incompetent patients with dementia through a prior written request as a means of relieving suffering at the terminal stage, despite the complexities involved. Much less support was observed at the advanced stage, a stage in which an affected individual may live for many years. In practice, determining whether a patient has reached the terminal stage of dementia is challenging. Common clinical indicators include increasing feeding difficulties and recurrent febrile episodes most often caused by aspiration pneumonia.

To further inform the debate on whether MAiD should be extended to incompetent patients, other clinical situations should be explored, namely situations involving patients whose decisional incapacity is due to causes other than dementia. Qualitative studies are also warranted to better understand *why* physicians favour or oppose extending MAiD to incompetent patients. Finally, more data are needed on the complex ethical and clinical issues raised by providing MAiD to incompetent patients. Such issues include patients' potential to adapt to their disease as it progresses, practical difficulties in choosing the right moment to carry out the request, and the difficulty for physicians and families to confirm the patient's wish to die.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest. Jocelyn Downie is member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying (Mental Disorders Working Group).

Ethical approval “All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.”

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