Are Informal Caregivers of Persons with Dementia Open to Extending Medical Aid in Dying to Incompetent Patients? Findings from a Survey Conducted in Quebec, Canada

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Conflicts of Interest and Source of Funding: The authors have no conflicts of interest to declare. The study was funded by an unrestricted grant from the Alzheimer Society of Canada (Grant # 16 11).

Short title: Medical aid in dying for incompetent patients

Word count = 3,928

Tables & Figures = 4
ABSTRACT

Euthanasia is a controversial and complex issue, especially when involving incompetent patients. On December 10, 2015, Quebec became the first Canadian province to give access to medical aid in dying (i.e., euthanasia performed by a physician) to competent patients who satisfy strictly defined criteria. Less than two years later, Quebec is considering extending medical aid in dying (MAiD) to incompetent patients who made an advance request. With the objective of contributing scientific data to current societal debates, we conducted a survey among 471 informal caregivers of persons with dementia, reached through Alzheimer Societies. We used a series of vignettes featuring a person with Alzheimer disease to investigate respondents’ attitudes towards MAiD. The response rate was 69%. Two-thirds (68%, 95% CI, 63%-73%) found it acceptable to extend MAiD to an incompetent patient at an advanced stage of Alzheimer disease who had made a written request while competent, and 91% (95% CI, 87%-94%) found it acceptable at the terminal stage. Self-determination was the most widely endorsed argument in favor of access to MAiD for incompetent patients. Findings suggest strong support among informal caregivers for extending MAiD to incompetent patients, provided they are terminally-ill and had made a written request before losing capacity.

Key Words: euthanasia; dementia; decisional incapacity; advance directive; informal caregivers; survey; Canada
INTRODUCTION

Alzheimer disease and associated disorders affect growing numbers of people worldwide.¹ According to the Alzheimer Society of Canada, 564,000 Canadians were affected in 2016, and this number could rise to nearly one million by 2031.² Quality of life is generally good in the early stages of the disease.³ However, many dread the prospect of losing their independence and cognitive functions. Moreover, as the disease progresses, some affected individuals develop serious complications (e.g., behavioral symptoms of dementia, choking on food due to neurogenic dysphasia) that may be difficult to manage and cause enduring suffering.⁴⁻⁷

Knowledge of the unfavorable course of neurodegenerative disorders has triggered requests for assistance in dying. In the Netherlands, where this practice has been legal since 2002, 109 euthanasia requests from competent patients in the early stages of dementia were granted in 2015.⁸ The Dutch legislation allows a physician to comply with a euthanasia request made in advance by a formerly competent patient, as long as all other “criteria of due care” are met “in a corresponding way”.⁹ To date, four cases have been reported of Dutch patients who requested euthanasia while competent and through a written request, and whose requests were granted after they had become incompetent.⁸,¹⁰

On December 10, 2015, a new legislation came into effect in Quebec making it the first province in Canada to allow access to medical aid in dying (MAiD) under strictly defined circumstances.¹¹ In Quebec Bill 52, medical aid in dying is defined as “care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient’s request, in order to relieve their suffering by hastening death”. Eligibility for MAiD is restricted to competent adults from Quebec, who are at the end of their lives, have made persistent explicit requests for MAiD, and “suffer from a serious and incurable illness, are in an advanced state of irreversible decline in capacity, and experience constant and unbearable
physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable” (art. 26). In Quebec, MAiD is not accessible to patients with severe dementia who made an advance request prior to losing decisional capacity because of the competency requirement.

Current eligibility criteria to MAiD followed from a discussion paper published by the College of Quebec Physicians in 2009 and a vast consultation held by the province’s Select Committee on Dying with Dignity whose final report was filed on March 2012. The Committee heard from 32 experts in the field, and received comments from thousands of citizens and organizations through briefs, public hearings held across Quebec, and an online questionnaire. While a consensus emerged about the importance that the patient be competent at the time of the act, a number of people and organizations argued in favor of allowing MAiD in patients with severe dementia who made a written request prior to losing decisional capacity.

Whether MAiD should be accessible to incompetent patients with dementia raises complex ethical and clinical issues. These 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 impossibility for healthcare providers and families to confirm the patient’s wish to die expressed in a now-forgotten directive. The impossibility to determine whether previously expressed wishes still hold applies to all types of directives, however, including those for refusing life-sustaining interventions.

On March 24, 2017, the Quebec Minister of Health and Social Services announced his decision to ask a group of experts to reflect on whether MAiD should be extended to incompetent patients. There is currently little empirical data on this sensitive issue. With the objective of informing ongoing policy debates, we launched a large-scale study of stakeholders’ attitudes towards extending MAiD to incompetent patients. The present paper reports findings
from one group of stakeholders, namely informal caregivers of persons with dementia. In addition to investigating their attitudes regarding access to MAiD for incompetent patients, this study explored the arguments underlying informal caregivers’ position on this issue, and the value they attach to proposed safeguards. Knowledge gained from this study will be useful locally, but also more broadly as many countries are considering giving some of their citizens access to assistance in dying through new legislation.23
METHODS

Design, Population, and Sampling

The study protocol has been described in detail elsewhere and approved by the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke. Data were collected through an anonymous survey conducted in random samples of French-speaking informal caregivers of persons with dementia who were members of one of the 20 Quebec Alzheimer Societies. To protect the identity of their members, Societies randomly sampled potential participants themselves. The number of members to be drawn by each Society was proportional to the size of their membership and ranged from 14 to 75. The Alzheimer Societies also managed the survey themselves, mailing a first survey package to sampled individuals, followed by two reminders and a non-response single-page questionnaire to those who chose not to participate.

The first mailing included a personalized cover letter, multiple-page questionnaire, endorsement letter from the Federation of Quebec Alzheimer Societies, stamped return envelope, and postcard bearing the respondent’s name with instructions to mail back the postcard separately from the questionnaire. The cover letter included the Internet link to the online version of the questionnaire, and the recipient’s single-use personal access code, for those who preferred to complete the questionnaire electronically. Two weeks after the first mailing, a reminder postcard was mailed to sampled individuals who had not yet returned the questionnaire. Non-respondents received a second survey package nine weeks later. At the close of the survey, non-respondents were mailed an anonymous single-page, three-item questionnaire asking why they did not participate and eliciting their general opinions on MAiD for competent and incompetent patients.
**Questionnaire**

The questionnaire was in the form of a 8 ½ x 11 inches, 12-page color booklet containing 32 close-ended questions grouped into three main sections. It was developed with international experts in the field and pretested with 20 individuals. The cover page provided consent information and asked respondents to confirm that they were providing informal care to a person with dementia. Current eligibility criteria for MAiD, as stated in Quebec’s *Act respecting end-of-life care*, were listed on the following page. Section 1 elicited respondents’ attitudes towards MAiD and continuous deep sedation, using short clinical vignettes. The first two vignettes featured a cancer patient who was described as eligible for MAiD, while the next five described a woman moving along the dementia trajectory. Section 1 ended with a list of statements designed to capture respondents’ reasons for supporting or opposing MAiD.

Section 2 explored various related issues such as whether respondents had ever accompanied a dying relative or friend. The last section collected sociodemographic data about the respondents and about the person with dementia they were caring for.

**Data Analyses**

As a non-response analysis, we used Fisher’s exact test to compare the attitudes towards MAiD of survey participants with those of the non-participants who returned the non-response questionnaire. To describe respondents’ attitudes towards MAiD, we summarized their answers to the vignettes using proportions and associated 95% confidence intervals. Liddell’s exact test for paired proportions was used to compare respondents’ answers across vignettes. We investigated potential correlates of respondents’ attitudes with a series of logistic regressions. All reported *p*-values are two-sided. Analyses were conducted with IBM SPSS, version 24.
RESULTS

Participation rate and respondents’ characteristics

Of the 20 Alzheimer Societies based in Quebec, one was excluded a priori for serving exclusively English-speaking individuals, and 12 agreed to collaborate in the conduct of the survey. Reasons for not collaborating included unwillingness to select potential respondents at random as requested, and being uncomfortable asking members to give their opinions on such a sensitive issue. The 12 participating Societies mailed out a total of 471 survey packages. Of the potential participants, 29 identified themselves as ineligible and 306 returned the questionnaire (22 electronically), for an overall response rate of 69%.

Twenty-four of the 136 non-respondents to the full questionnaire returned the three-item non-response questionnaire. Reasons given by these 24 caregivers included one or more of the following: never received the full questionnaire, too busy to fill it out, and discomfort with having to think about the subject of our investigation. Of the 19 informal caregivers who answered items 2 and 3 of the non-response questionnaire, 14 felt it was acceptable that MAiD was currently accessible to competent patients under certain circumstances, and 16 favored extending access to incompetent patients with additional safeguards. Their opinions did not differ significantly from those of the 306 survey participants ($p = 0.088$ and 0.411, respectively).

Characteristics of the 306 respondents to the full questionnaire are reported in Table 1. Most caregivers (90%) were the spouse or an adult child of the person with dementia. Respondents were 66 years old on average, most were Canadian-born, and 72% were female. Mean score on the religiosity index was close to 6, reflecting a decline of religious activities in recent decades in Quebec. Two-thirds (67%) of respondents had accompanied a dying person until their death, a relative in 90% of these cases. When asked to imagine that they had Alzheimer disease themselves, 227 informal caregivers (77.5%) felt likely that they would write
an advance request for MAiD. Figure 1 shows conditions under which they would want their request to be carried out. The three most frequently selected conditions were physical and psychological suffering that cannot be relieved, followed by complete dependence on others for their basic needs. Caregivers were also asked to imagine that a close relative of theirs had Alzheimer disease and wrote a MAiD request. In such circumstances, 65% felt it was likely that they would ask a physician to carry out the request when the relative could no longer recognize his or her loved ones.

- Insert Table 1 and Figure 1 -

Attitudes towards continuous deep sedation and MAiD for competent and incompetent patients

Respondents’ attitudes are summarized in Figure 2, first for a patient with end-stage cancer who was described as eligible to MAiD, and second for a patient diagnosed with Alzheimer disease. Regarding the cancer patient, greater support was found among informal caregivers for MAiD than for continuous deep sedation: 88% judged MAiD somewhat or totally acceptable vs. 78% for sedation (p < 0.001). Support for MAiD for a patient at an advanced stage of Alzheimer disease was lower (at 68%, 95% CI, 63%-73%), and lower still in the absence of a written request (at 49.5%, 95% CI, 44%-55%). When the patient was described as being at the terminal stage of her disease and showing signs of distress, support for MAiD increased to 91% in the presence of a written request (95% CI, 87%-94%), and to 72% (95% CI, 66%-76%) when an advance request had not been drafted. These increases in support for MAiD from the advanced to the terminal stage are highly significant (both p-values < 0.001). The proportion of respondents who supported MAiD for the cancer patient did not differ significantly from that of respondents who favored extending MAiD to incompetent patients at the terminal stage of Alzheimer disease.
who had requested it in advance of loss of capacity (88% vs. 91%, p = 0.186). Lastly, where there is clinical evidence of distress refractory to treatment, 69% (95% CI, 64%-74%) of informal caregivers find it somewhat or totally acceptable to deeply sedate the patient until death as a means of relieving suffering. Support for sedation in terminal dementia was lower than in end-stage cancer (69% vs. 78%, p < 0.001).

Table 2 shows respondents’ levels of agreement with 13 statements aimed at uncovering their reasons for supporting or opposing MAiD, generally and for incompetent patients in particular. Answers were quite variable across respondents, with a strong majority observed for only two of the 13 statements: 248 informal caregivers (82%, 95% CI, 77%-86%) were of the opinion that every person has the right to choose how they will die (statement 2), and as many felt that healthcare preferences expressed in advance of loss of capacity should be given equal weight as given to preferences voiced by a competent patient (statement 4). Respondents who agreed with each of these two statements were in favor of extending MAiD to incompetent patients with dementia, at both the advanced and terminal stages of the disease, and whether or not the patient had written an advance request (all 8 p-values < 0.001).

Correlates of attitudes towards MAiD for incompetent patients

Lastly, to explore other correlates of respondents’ positions on MAiD for incompetent patients, we created four dichotomous dependent variables from their answers to vignettes 2.1 to 2.4, combining somewhat and totally favorable, on the one hand, and neutral, somewhat unfavorable and totally unfavorable, on the other. We then performed a series of bivariate logistic
regressions, using the variables listed in Table 1 as potential predictors. For interpreting results, we lowered the significance level at 0.01 to avoid capitalizing on chance results. We found the religiosity index to be linked to vignettes 2.1, 2.3 and 2.4 [odds ratio (OR) of 0.92, 0.87 and 0.92, respectively, \( p < 0.008 \)] but not to vignette 2.2 (OR = 0.97, \( p = 0.317 \)). Respondents who scored lower on the index (i.e. less religious caregivers) were more likely to be in favor of extending MAiD to incompetent patients with dementia at the advanced stage (with a written request) and at the terminal stage (with and without a written request). In addition, caregivers who were somewhat or extremely likely to write a MAiD request should they develop Alzheimer disease, and those somewhat or extremely likely to ask a physician to grant a MAiD request written by a close relative with Alzheimer disease, were more likely to support MAiD in all four scenarios (OR from 3.7 to 10.6, \( p < 0.001 \)). None of the other variables listed in Table 1 were associated with any of the four dependent variables, with the exception of cognitive functioning of the person with dementia, which was related to vignette 2.1 only (OR = 2.5, \( p = 0.005 \)). The lower the care recipient’s cognitive functioning, according to the caregiver, the more likely the caregiver was to support MAiD for an incompetent patient at the advanced stage of Alzheimer disease who had written an advance request while competent.
DISCUSSION

This study is the first in Canada to elicit informal caregivers’ attitudes towards MAiD for incompetent patients. It revealed strong support for extending access to MAiD to those who are at the terminal stage of their disease, show signs of suffering that the healthcare team cannot alleviate, and have made a written request for MAiD while competent. At the terminal stage, less support was found among caregivers for sedating the patient continuously until death to relieve suffering. Importantly, our analyses show that support for MAiD in the circumstances described above holds irrespective of the caregiver’s age, gender, country of origin, race/ethnicity, level of education, and financial situation. As others, we found religiosity to influence opinions to some degree. Support for extending MAiD to those at the advanced but not terminal stage of Alzheimer disease was lower, even with a written request (at 68%), which some may consider quite high.

The finding that support for MAiD varies with the stage of the disease raises the issue of determining whether a patient is at the terminal phase of life. Prognostication in dementia is often challenging in clinical practice, although recent efforts to identify prognostic indicators are promising. Well-known staging systems such as the FAST are useful for recognizing that the patient’s condition is severe but don’t include common indicators of the end stage such as increasing feeding difficulties and recurrent febrile episodes most often caused by aspiration pneumonia. Yet most people writing an advance request for MAiD may do so to avoid living for years in prolonged dementia. Their request likely reflects concerns for a diminished quality of life rather than fear of experiencing feeding difficulties and febrile episodes in the final days of life. While the presence of suffering was selected by most caregivers for triggering their own hypothetical MAiD request (cf. Figure 1), being at the terminal stage (i.e. having only a few
weeks to live) was selected by fewer respondents. Future studies could explore further whether being able to clearly distinguish the advanced vs terminal stage is indeed critical in deciding whether incompetent patients with dementia should have access to MAiD through a prior written request.

To our knowledge, only one other quantitative study has investigated the views of informal caregivers towards euthanasia.26 Conducted in the Netherlands in 2000 (thus before the legislation was passed in that country), the study involved 136 relatives of nursing home patients with dementia for whom a decision was made to start or forgo artificial nutrition and hydration. Study participants were asked the extent to which they agreed with 10 statements, one of which was “Euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent”. A majority (89%) agreed. As we observed in our survey, relatives who were more religious had more conservative attitudes towards euthanasia. Dutch caregivers were presented with two other statements similar to those we used: “Everyone has the right to decide about his/her own life and death” and “An advance directive should always be followed”. These statements were endorsed by 84% and 88% of their participants, respectively, compared to 82% of ours. Although we targeted a less restrictive population, the similarity between our findings and those of the Dutch study are striking. Both studies, however, reflect pre-implementation attitudes. de Boer and colleagues interviewed eight relatives of nursing home residents with dementia and an advance euthanasia directive who had died two to five years after the Dutch euthanasia law was passed.9 Euthanasia was not performed in any of the cases, which suggests that acting on such directives may be a difficult task for relatives.

To broaden participation, the Select Committee on Dying with Dignity offered Quebec citizens the possibility to be heard through an online questionnaire posted on the Government website.13 A total of 6,558 persons completed the questionnaire, of which 74% agreed with the
legalization of euthanasia under certain conditions. When asked who should have access to euthanasia ("with a valid reason"), 80% selected “adults capable of deciding for themselves” and 78% selected “people who make the request in advance in anticipation of incapacity”. Although comparisons with our data must be made with caution, due to differences in wording and the potential impact of having legalized MAiD for competent patients, our survey suggests that the proportion supporting euthanasia for “adults capable of deciding for themselves” is higher among informal caregivers of persons with dementia. Regarding “people who make the request in advance”, comparison is even more hazardous given that the Committee’s questionnaire did not specify the stage of the disease at which euthanasia could be granted. Yet our data clearly show that it makes a difference. Support for MAiD in those people among our respondents ranged from 68% at the advanced stage to 91% at the terminal stage.

**Strengths and limitations**

As any survey, ours has both strengths and limitations. Strengths include a survey and questionnaire designed according to the Tailored Design Method known to maximize data quality,\(^{31}\) the random selection of potential respondents, and relatively high response rate.

Limitations include the difficulty in judging whether survey participants are representative of the target population. This is always challenging, and especially when little data are available on non-respondents. Quebec Alzheimer Societies have no data on their members that would allow comparing our respondents with the population surveyed. Whether informal caregivers who are members of an Alzheimer Society differ from those who are not is unknown. A number of Societies refused to collaborate, but we have no reasons to believe that their membership differs from that of the Societies that agreed to collaborate. A small percentage of
non-respondents returned the non-response questionnaire. Their opinions on MAiD did not differ from that of respondents, but the power to detect differences was low.

Other limitations pertain to the vignettes that we used to measure caregivers’ attitudes towards MAiD. Knowing that the length of a questionnaire influences the response rate, we had to restrict the number of vignettes to only a few. At the advanced stage of Alzheimer disease, we described the patient as not being uncomfortable, whereas at the terminal stage, she was depicted as being in distress. Levels of support may have differed had we described the patient as being in distress at both stages. A case can also be made for reversing the two situations, that is, for describing a patient who showed signs of distress at the advanced stage but seemed comfortable when reaching the end-stage of the disease. The reported cases of incompetent patients with dementia who were administered euthanasic drugs in the Netherlands were not judged to be at the terminal stage. Their suffering consisted of challenging behavior that was considered as equivalent to unbearable suffering. Future studies should thus explore informal caregivers’ attitudes towards MAiD in other situations involving persons with dementia. In particular, it would be informative to add vignettes that would allow exploring separately the effect of the stage of the disease (advanced versus terminal) and presence versus absence of distress on support for MAiD. Meanwhile, Figure 1 indirectly suggests that physical and psychological suffering is indeed likely to influence caregivers’ attitudes, as these were the conditions selected by most for triggering their own (hypothetical) MAiD request.

We also chose not to explore caregivers’ attitudes towards extending MAiD to competent persons in the early stages of dementia. This decision was again motivated by the need to limit the length of the questionnaire, but additionally by the current debate in Quebec which focuses on whether MAiD should be accessible through advance requests. However, comparing support for MAiD in the early versus later stages of dementia would be of interest from an international
perspective, given that in the Netherlands, granted requests for euthanasia among people with dementia were almost exclusively restricted to the early phase when the patient was still competent to express his or her wishes.\textsuperscript{8,10} The small number of euthanasia cases among Dutch citizens with late-stage dementia has been attributed in part to the difficulty, for physicians, to determine whether the patient suffers unbearably.\textsuperscript{14-16} For some, unbearable suffering is a subjective state that only patients themselves can judge, therefore requiring competency at the time the suffering is being assessed. For others, unbearable suffering is something that others can objectively judge.\textsuperscript{4,32} For still others, an individual can state in advance of loss of capacity what circumstances he or she believes constitute unbearable suffering for him or her. Half of our respondents believed that the fear of living the advanced stages of Alzheimer disease should be considered as unbearable suffering (cf. Table 2, statement 7).

In conclusion, this study is the first to offer Canadian informal caregivers of persons with dementia the opportunity to express themselves as to whether MAiD should be accessible to incompetent patients, and if so, under which conditions. The vast majority of survey participants was open to this possibility, provided the patient is at the terminal phase of life, appears in distress, and has made a written request for MAiD. These findings, combined with upcoming results from other stakeholder groups, should be taken into account in deciding whether or not to widen the category of persons who are legally eligible to MAiD.

\textbf{ACKNOWLEDGMENTS}

We acknowledge the contribution of François Thibeault, PhD, who developed and pretested draft versions of the questionnaire in close collaboration with the coinvestigators. Special thanks are extended to the Federation of Quebec Alzheimer Societies and its members for making this study possible, as well as to all informal caregivers who took the time to fill out the questionnaire. The
authors also thank an anonymous reviewer for his or her thoughtful comments on the first version of the paper.

FIGURE LEGENDS

FIGURE 1. Conditions that should trigger the MAiD request should one develop Alzheimer disease ($n = 227$). Respondents were asked to select a maximum of three conditions among those listed and were provided space to add conditions if desired.

FIGURE 2. Attitudes towards continuous deep sedation and medical aid in dying (MAiD) for a competent patient with end-stage cancer and for an incompetent patient with Alzheimer disease ($n = 306$). Rates of missing data range from 0.3% (for Vignette 2.1) to 2.6% (for Vignette 1.1).
REFERENCES


17. de Boer ME. Advance Directives in Dementia Care: Perspectives of People with Alzheimer’s Disease, Elderly Care Physicians and Relatives. PhD Dissertation. Amsterdam: Vrije Universiteit, 2011.


TABLE 1. Respondent Characteristics ($n = 306$)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Summary statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to the person with dementia</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>144 (47.8)</td>
</tr>
<tr>
<td>Child</td>
<td>128 (42.5)</td>
</tr>
<tr>
<td>Other</td>
<td>29 (9.7)</td>
</tr>
<tr>
<td>Time since the person with dementia was diagnosed (in years)</td>
<td>5.0 ± 3.6 (1 to 21)</td>
</tr>
<tr>
<td>Physical health of the person with dementia</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>25 (8.5)</td>
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<tr>
<td>Very good</td>
<td>53 (18.0)</td>
</tr>
<tr>
<td>Good</td>
<td>108 (36.6)</td>
</tr>
<tr>
<td>Fair</td>
<td>66 (22.4)</td>
</tr>
<tr>
<td>Poor</td>
<td>43 (14.6)</td>
</tr>
<tr>
<td>Cognitive functioning of the person with dementia</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Very good</td>
<td>6 (2.0)</td>
</tr>
<tr>
<td>Good</td>
<td>40 (13.6)</td>
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<tr>
<td>Fair</td>
<td>122 (41.5)</td>
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<tr>
<td>Poor</td>
<td>126 (42.9)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>65.9 ± 11.4 (31 to 90)</td>
</tr>
<tr>
<td>Gender (Female)</td>
<td>220 (72.1)</td>
</tr>
<tr>
<td>Born in Canada</td>
<td>291 (95.7)</td>
</tr>
<tr>
<td>Race/Ethnicity (Caucasian)</td>
<td>243 (79.4)</td>
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<tr>
<td>Highest level of schooling</td>
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<tr>
<td>Description</td>
<td>Frequency</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>High school or lower</td>
<td>105</td>
</tr>
<tr>
<td>College or university degree</td>
<td>198</td>
</tr>
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Self-perceived financial situation

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<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Comfortable financially</td>
<td>141</td>
<td>47.0</td>
</tr>
<tr>
<td>Income sufficient to meet basic needs</td>
<td>142</td>
<td>47.3</td>
</tr>
<tr>
<td>Poor or very poor</td>
<td>17</td>
<td>5.7</td>
</tr>
</tbody>
</table>

Religiosity index

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has accompanied a relative or friend through the dying process</td>
<td>204</td>
<td>66.9</td>
</tr>
<tr>
<td>Has recorded healthcare preferences in the event of incapacity</td>
<td>129</td>
<td>43</td>
</tr>
</tbody>
</table>

Likely to write a MAiD request should one develop Alzheimer disease

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>(somewhat or extremely likely)</td>
<td>227</td>
<td>77.5</td>
</tr>
</tbody>
</table>

Likely to ask a physician to grant the MAiD request of a close relative who has become incompetent due to Alzheimer disease

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>(somewhat or extremely likely)</td>
<td>194</td>
<td>64.7</td>
</tr>
</tbody>
</table>

* Data shown are means ± standard deviations, with ranges in parentheses, or absolute frequencies, with percentages in parentheses. Some data were missing: from 1 (0.3%) for gender to 13 (4.2%) for the likelihood of writing a MAiD request should one develop Alzheimer disease.

† Derived from combining answers to four questions developed by Statistics Canada for the General Social Survey. Total scores range from 0 to 13 and are interpreted in three broad categories: low (0 – 5), moderate (6 – 10), and high (11 – 13).
TABLE 2. Levels of Agreement with Statements Capturing Respondents’ Values and Beliefs Regarding MAiD ($n = 306$)*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Human life must be preserved in all circumstances.</td>
<td>170 (56.0)</td>
<td>51 (16.8)</td>
<td>83 (27.3)</td>
</tr>
<tr>
<td>2. Every person has the right to choose how they will die.</td>
<td>23 (7.6)</td>
<td>33 (10.9)</td>
<td>248 (81.6)</td>
</tr>
<tr>
<td>3. Only God determines when a person dies.</td>
<td>195 (64.5)</td>
<td>50 (16.6)</td>
<td>57 (18.8)</td>
</tr>
<tr>
<td>4. Healthcare preferences expressed before losing capacity should carry the same weight as those expressed by a competent patient.</td>
<td>27 (8.9)</td>
<td>27 (8.9)</td>
<td>248 (82.1)</td>
</tr>
<tr>
<td>5. Patients at the terminal stage of Alzheimer disease do not die with dignity.</td>
<td>63 (21.0)</td>
<td>44 (14.7)</td>
<td>193 (64.3)</td>
</tr>
<tr>
<td>6. All physical pain can be alleviated at end of life.</td>
<td>78 (26.0)</td>
<td>33 (11.0)</td>
<td>189 (63.0)</td>
</tr>
<tr>
<td>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.</td>
<td>79 (26.3)</td>
<td>66 (22.0)</td>
<td>155 (51.6)</td>
</tr>
<tr>
<td>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.</td>
<td>168 (55.1)</td>
<td>22 (7.2)</td>
<td>115 (37.7)</td>
</tr>
<tr>
<td>9. It is impossible to know whether an incompetent patient has unbearable physical pain.</td>
<td>152 (49.8)</td>
<td>55 (18.0)</td>
<td>98 (32.1)</td>
</tr>
<tr>
<td>The administration of strong medications that would end life in a few minutes …</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Should be restricted to competent patients that have requested it themselves.</td>
<td>165 (55.0)</td>
<td>22 (7.3)</td>
<td>113 (37.6)</td>
</tr>
<tr>
<td>11. Should be permitted for patients who are not at the end of their lives but satisfy all other criteria of the current legislation.</td>
<td>78 (26.1)</td>
<td>50 (16.7)</td>
<td>171 (57.2)</td>
</tr>
<tr>
<td>12. Should be permitted for both competent and incompetent patients.</td>
<td>52 (17.1)</td>
<td>50 (16.4)</td>
<td>202 (66.4)</td>
</tr>
<tr>
<td>13. Should be prohibited because vulnerable individuals could receive it against their will.</td>
<td>154 (51.0)</td>
<td>78 (25.8)</td>
<td>70 (23.2)</td>
</tr>
</tbody>
</table>

* Data shown are absolute frequencies, with percentages in parentheses. To simplify presentation of the data, the first two and last two response categories on the five-point Likert scale were collapsed. Rates of missing data range from 0.3% (for statements 8 and 9) to 2.3% (for statement 13).
FIGURE 1

The bar chart shows the percentage of respondents who selected each condition among a maximum of three. The conditions are:

1. Must be admitted to long-term care
2. No longer recognizes close relatives
3. Completely dependent on others for basic needs
4. Physical pain that cannot be relieved
5. Psychological suffering that cannot be relieved
6. Only has a few weeks to live

The percentages are as follows:

- Must be admitted to long-term care: 17.2%
- No longer recognizes close relatives: 27.8%
- Completely dependent on others for basic needs: 52.0%
- Physical pain that cannot be relieved: 65.2%
- Psychological suffering that cannot be relieved: 62.6%
- Only has a few weeks to live: 41.0%
**CASE 1:** An 82 years 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.

**Vignettes 1.1:** The patient is offered continuous deep sedation. As artificial nutrition and hydration would not be provided, death should occur a few days later.

**Acceptability of providing continuous deep sedation to this end-stage cancer patient:**

**Vignettes 1.2:** The patient requests MAiD. The treating physician judges the patient eligible.

**Acceptability of providing MAiD to this end-stage cancer patient:**
CASE 2: A 75 years 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 MAiD to be carried out when she can no longer recognize her loved ones.

Vignettes 2.1 & 2.2: 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.

Attitudes toward modifying the current legislation to allow MAiD at this advanced stage of the disease, at the request of the family, in the presence of a written request (✓) or assuming that no request has ever been written (☐):

Vignettes 2.3 & 2.4: 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.

Attitudes toward modifying the current legislation to allow MAiD at this terminal stage of the disease, at the request of the family, in the presence of a written request (✓) or assuming that no request has ever been written (☐):

Vignette 2.5: Assume the patient never requested MAiD. 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.

Acceptability of providing continuous deep sedation at this terminal stage of the disease: