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Informal care-givers' attitudes towards medical assistance in dying for persons with dementia

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Abstract

Medical assistance in dying (MAID) is legal in Canada but cannot be accessed through an advance request. Some data suggest that informal care-givers of persons with dementia support the legalisation of advance requests for MAID. Opponents argue that care-givers' support is due to society's failure to address their well-documented burden and unmet needs. To our knowledge, this assumption has never been tested. To fill this knowledge gap, we conducted a survey among 204 Canadian informal care-givers of persons with dementia to (a) elicit their attitudes towards allowing no longer competent adults to access MAID through an advance request, and (b) test the hypothesis that attitudes are in part driven by the level of burden experienced by care-givers and unmet needs for support. Attitudes were elicited with a clinical vignette involving a woman with Alzheimer's disease who requests MAID while still competent, or through an advance request for the time after she would lose decisional capacity. Informal care-givers' support for MAID ranged from 60 per cent in the scenario where the person is still competent and likely has several more years to live, to 87 per cent when she is depicted as no longer competent, in severe distress and close to death. Quality-of-life considerations and the value of self-determination were key arguments in support of legalising advance requests for MAID. Using multivariable logistic regression, we found no evidence that burden and unmet support needs influence attitudes towards advance requests for MAID, after controlling for other determinants. These findings contribute new insights into people's attitudes towards the sensitive issue of whether MAID should be extended to persons with dementia-induced decisional incapacity.

Keywords: informal care-giver; dementia; mental incompetence; euthanasia; assisted suicide; survey

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Introduction

According to the World Health Organization (2020), 152 million people could have dementia by 2050. Currently, there are no effective ways to prevent or cure neuro-degenerative disorders causing dementia. As a result, a growing number of people die with dementia, often after having lived with this syndrome for several years (Joling *et al.*, 2020).

Palliative care has much to offer people living with dementia and their loved ones, from diagnosis onwards (Murray *et al.*, 2017; Froggatt *et al.*, 2020; Gilissen *et al.*, 2021). It could improve their quality of life through timely identification of declining health, assessment of physical, psychosocial and spiritual needs, management of pain and other symptoms, advance care planning and family support (Murray *et al.*, 2017). While high-quality evidence of the effectiveness of palliative care in the context of dementia is still lacking (Kochovska *et al.*, 2020; Gilissen *et al.*, 2021), recent studies highlight benefits in several domains across different settings, including symptom assessment and management, quality of care and dying, and reduced costs of end-of-life care (Senderovich and Retnasothie, 2020; Miranda *et al.*, 2021).

Despite these promising findings, dementia still ranks among the most feared clinical conditions, ahead of cancer and contagious diseases such as COVID-19 (UsAgainstAlzheimer's, 2021). Volicer *et al.* (2019) attribute dementia fear to misconceptions about the consequences of a dementia diagnosis. They point out that many people are unaware that they can enjoy and appreciate life for years after the onset of dementia, especially during the mild and moderate stages. Nonetheless, even people with good knowledge of dementia dread the prospect of losing their capacity to interact meaningfully with their loved ones and closest friends, in addition to becoming totally dependent on others for their most basic needs. Moreover, some people have deeply held convictions that prolonged dementia is a bad end to a life, whether one ends up being a 'happy demented person' or one who is 'terribly frightened and anxious' (Menzel and Chandler-Cramer, 2014).

Few options are available to those who want to avoid living with advanced dementia (Menzel and Chandler-Cramer, 2014; Volicer et al., 2019). While still competent, they can voluntarily stop eating and drinking, or take their own lives. Both options could deprive affected individuals of several years of valuable life. They can record their wish to forgo all life-sustaining interventions after they have lost decision-making capacity. However, they may never be in a situation where such interventions are required to sustain life and could be withheld to hasten death. In late-stage dementia, individuals are dependent upon others for feeding and hydration. In some jurisdictions, including most Canadian provinces (Downie, 2018; Mader and Apold, 2019), a competent person's advance directive can instruct others not to provide food and fluid by mouth or artificially when they can no longer eat or drink independently (Volicer et al., 2019; Pope, 2021). Death under those circumstances is generally thought to be peaceful and comfortable with proper oral care (Wax et al., 2018). Lastly, in a few countries (e.g. the Netherlands), people can make advance requests for assistance in dying (or euthanasia) to be provided after they have lost decision-making capacity (Council of Canadian Academies, 2018). In the Netherlands, a growing number of people

with dementia have drawn up an advance euthanasia directive (Schuurmans *et al.*, 2020). The number of Dutch citizens with dementia who received euthanasia is also rising, although most granted requests involved people who still had capacity to consent (Evenblij *et al.*, 2019).

Following a landmark ruling from the Supreme Court of Canada in Carter v. Canada (2015), Bill C-14 came into effect in June 2016, enacting exemptions from criminal liability for medical and nurse practitioners who provide medical assistance in dying (MAID)¹ to persons meeting the legal requirements (Government of Canada, 2016). Six months earlier, MAID had been legalised in the Canadian province of Quebec under conditions defined in the *Act Respecting End-of-life Care* (Government of Quebec, 2014). In both jurisdictions, access to MAID was initially restricted to competent adults, who have a serious and incurable condition, are in an advanced state of irreversible decline in capacity, and experience enduring, intolerable and irremediable suffering. In addition, patients had to be at the end of life (Quebec) or at a point where their 'natural death had become reasonably foreseeable' (the rest of Canada).

On 17 March 2021, the Canadian Parliament passed Bill C-7 (Government of Canada, 2021), further amending the Criminal Code with respect to MAID. Amendments include repealing the 'reasonably foreseeable death' eligibility criterion (or end-of-life criterion in Quebec) and introducing a two-track approach to procedural safeguards for eligible persons whose natural death is or is not reasonably foreseeable. Bill C-7 further allows a form of advance consent for MAID relevant to this paper. It can be provided to eligible persons whose natural death is reasonably foreseeable and who have lost the capacity to consent before MAID is provided if they had entered into a written arrangement with the medical or nurse practitioner prior to losing capacity.² By introducing a 'final consent waiver', this change to Canada's MAID regime allows some people with dementia to live longer than they would have under the old law, because they do not have to seek MAID earlier than they want to just for fear of losing capacity to consent (Downie and Green, 2021). However, MAID is not an option for many people with dementia, specifically those who lose decision-making capacity before their suffering has become intolerable (Downie, 2020). Indeed, Canada's current legislation does not allow requests for MAID to be made in advance of meeting all eligibility criteria, e.g. shortly after having been diagnosed with dementia. A bill that would legalise advance requests for MAID was tabled on 25 May 2022, by the National Assembly of Quebec (2022). Discussions surrounding the bill will resume in autumn 2022, following the upcoming provincial elections.

Whether, and under what conditions, advance requests for MAID might be justified is a complex health-care issue that requires balancing several interests and societal values (Council of Canadian Academies, 2018). Arguments in favour include the value of individual choice; the inability to relieve suffering in some cases; the absence of a moral distinction between withholding/withdrawing potentially life-sustaining treatment (*e.g.* antibiotics) and MAID; and the claim that allowing advance requests for MAID could reduce anticipatory anxiety and prevent premature death (from MAID or suicide) (Nakanishi *et al.*, 2021).

Counterarguments include the need to protect vulnerable populations from abuse; concerns about the 'slippery slope'; the risk of impeding the development

of palliative care; and ethical tensions faced by health-care professionals who object to MAID on moral grounds but could feel pressured to be involved (Dumont and Maclure, 2019; Downie and Schuklenk, 2021; Mathews *et al.*, 2021; Panchuk and Thirsk, 2021). Additional arguments against advance requests for MAID include the difficulty of anticipating the interests of one's future self; patients' potential to adapt to their disease as it progresses; the impossibility of engaging in meaningful conversations with patients who lack decisional capacity to confirm their wish to die; and practical difficulties in assessing suffering, balancing current preferences against earlier wishes and choosing the right moment to carry out the request (Nakanishi *et al.*, 2021).

Initiated some years ago (*e.g.* Government of Quebec, 2012; Special Joint Committee on Physician-Assisted Dying, 2016), discussions as to whether advance requests for MAID ought to be legalised are still ongoing in Canada (Government of Canada, 2020; National Assembly of Quebec, 2022). With the objective of informing public policy development in this area, we conducted Quebec-wide anonymous surveys on stakeholders' attitudes towards extending MAID to persons lacking decisional capacity (Bravo *et al.*, 2019). The first group surveyed were informal care-givers of persons with dementia. Of the 306 respondents, 91 per cent were in favour of giving no longer competent patients access to MAID through an advance request, provided they are at the end of life and show signs of intractable distress (Bravo *et al.*, 2018a).

Reacting to this finding,³ some people argued that this high level of support reflects informal care-givers' heavy burden and many unmet support needs. To our knowledge, there is no evidence supporting this statement. As pointed out by Wiebe *et al.* (in press), MAID is not meant to address structural inequities in our society. Surely, widening access to MAID through advance requests cannot be justified by society's failure to address informal care-givers' needs and the short-comings of health and social care systems. As the Quebec survey did not query informal care-givers about their care-giving responsibilities and impact on their daily lives, no data were available to test formally the hypothesis that care-giver burden and unmet support needs somehow 'explain' care-givers' attitudes towards extending MAID to no longer competent persons. Given the policy implications of confirming or invalidating this hypothesis, and having restricted our previous survey to Quebec, we extended the survey to informal care-givers from the rest of Canada, adding questions to measure burden and needs for support.

Hence, consistent with our previous survey, the first objective of this study was to investigate informal care-givers' attitudes towards MAID for persons with dementia, and the beliefs underlying them. A second objective was to explore factors associated with these attitudes, with a focus on care-giver burden and unmet support needs. Based on findings from the Quebec survey, we expected support for extending MAID to no longer competent persons to be high generally, and to increase as the person approaches the end of life. We further expected self-determination and quality-of-life considerations to be main arguments voiced by care-givers in support of widening MAID access. To our knowledge, no study has yet investigated whether attitudes towards advance requests for MAID are associated with burden and support needs. *A priori*, we hypothesised that attitudes would be driven mainly by care-givers' sociodemographic characteristics (*e.g.*)

religiosity) and health-related characteristics of the person with dementia for whom they were caring (*e.g.* evidence of suffering), and hence that care-giver burden and unmet support needs would not be strongly associated with attitudes once other determinants have been considered.

Methods

Design and population

The current cross-sectional survey ran from 12 February to 31 May 2020, thus before the 'reasonably foreseeable death' eligibility criterion was removed from the MAID legislation. The survey was designed for people who have a close relationship with a person living with dementia, either in the community or in a long-term care facility. Potential respondents were reached through provincial Alzheimer Societies (excluding Quebec), all but one of which agreed to publicise the survey among their members. Interested Society members were invited to contact the research assistant to receive the survey package or a single-use personal password to access the questionnaire online.

Survey questionnaire

The questionnaire comprises 56 closed-ended questions, grouped into five main sections described below. These are preceded by consent information and the list of eligibility criteria for MAID that applied at the time of the survey. The questionnaire ends with space for the respondent's comments. Informed consent was assumed on return of the questionnaire (Canadian Institutes of Health Research *et al.*, 2018).

Sections 1 and 2 investigate respondents' attitudes towards MAID for persons with dementia, and underlying beliefs (objective 1), whereas Sections 3–5 supply data to explore associated factors (objective 2). The first two sections were modelled on the questionnaire developed for Quebec, enabling comparisons between that province and the rest of Canada. Content of the other sections was based on prior research (Koneke, 2014; Stolz *et al.*, 2015, 2017; Tomlinson and Stott, 2015) and on the clinical knowledge of the research team, given the paucity of studies directly on the topic. This led to a conceptual framework of factors possibly associated with respondents' attitudes (*see* Figure 1). Postulated factors relate to the respondent, the person with dementia with whom they are involved and the care-giving context. Items for capturing these various factors were mostly taken from the General Social Survey (GSS) – Caregiving and Care Receiving (Statistics Canada, 2019). The GSS aims to better understand and respond to the needs of Canadians who provide care to family and friends living with long-term health conditions. The GSS has been launched by Statistics Canada every five years since 1998.

Specifically, Section 1 of the questionnaire includes a series of hypothetical vignettes (*see* Appendix) used to elicit respondents' attitudes towards MAID in the context of dementia. The vignettes feature a 75-year-old retired teacher, Mrs Jackson, moving along the dementia trajectory, from the early stage when she communicates her wishes for future health care to the end stage. In writing, Mrs Jackson explicitly requests that a doctor end her life through a lethal injection when she no longer

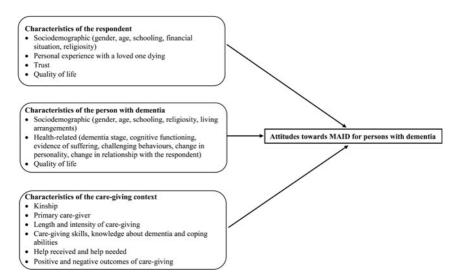


Figure 1. Conceptual framework of potential correlates of respondents' attitudes towards medical assistance in dying (MAID) for persons with dementia.

recognises her loved ones. Questions then focus on three specific stages defined in the questionnaire:

- Stage A, where Mrs Jackson is still able to make health-related decisions.
- Stage B, where she is no longer able to make such decisions but might still have years to live.
- Stage C, where she is still unable to make health-related decisions and is considered close to death.

For each stage, respondents are asked the extent to which they find it acceptable that a doctor be allowed to administer to Mrs Jackson a substance that would cause her death. For Stages B and C, the question is repeated, this time assuming that Mrs Jackson has been showing persistent signs of severe distress that the health-care team is unable to alleviate. Thus, five scenarios were investigated in all.

Section 2 begins with 12 statements designed to uncover respondents' reasons for supporting or opposing MAID in general and for patients unable to consent. Reasons include religious objections, respect for patient autonomy and concerns for vulnerable populations. These are followed by general questions on related issues, including respondents' support for the (then) current MAID legislation, whether they would write an advance MAID request for themselves should they have dementia and whether they would ask a doctor to comply with such a request drafted by the person with dementia with whom they are involved.

Section 3 collects sociodemographic (*e.g.* gender, age, living arrangements) and health-related data (*e.g.* dementia stage, change in personality, overall quality of life) about the person with dementia. Section 4 begins by asking the respondent whether he or she currently provides care or help to that person and, for those who do,

explores their care-giving context, as well as positive and negative effects of caregiving. Section 5 collects sociodemographic data on the respondent (*e.g.* gender, age, importance of religious or spiritual beliefs) and self-rating of quality of life.

Statistical analysis

We first describe the respondents, using means and standard deviations or counts and percentages. Next, attitudinal items are summarised using proportions, and compared across vignettes using an exact test for paired data (Liddell, 1983). Lastly, we performed logistic regressions to determine whether burden and unmet support needs are associated with attitudes, after adjusting for characteristics of the respondent, the person with dementia and the care-giving context. To ensure convergence of the estimation process, some variables measured on Likert-type scales were summed into composite scores, and others were dichotomised, before investigating their associations with the outcomes.

Examples of composite scores include those used to quantify the positive and negative effects of care-giving. The *positive outcome of care-giving* score results from summing a respondent's ratings on five items suggested by Yu *et al.* (2018) (*e.g.* a sense of personal accomplishment or growth), while its negative counterpart is derived from eight items taken from the GSS that assess the impact of care-giving on the respondent's physical and mental health, social life and finances. Dichotomised variables include responses to the vignettes: those who considered MAID to be acceptable in a given scenario (somewhat or totally) were grouped separately from the others.

Logistic regression analyses focused on three scenarios: Stage A; Stage B without evidence of distress (as an illustration of the 'happy demented person'); and Stage C with evidence of severe distress (illustrating the 'terribly frightened and anxious' person) (Menzel and Chandler-Cramer, 2014). Repeatedly for each scenario, we proceeded in four steps. First, we conducted univariable analyses to identify factors associated with attitudes at the 0.15 significance level. Second, we discarded any factor that was too multicollinear with others (based on the variance inflation factor (VIF)) or precluded convergence of the model (due to empty cells). Third, retaining the remaining factors for possible inclusion in multivariable models, we added in one factor at a time, until adding more did not improve the model at the 0.05 significance level (forward approach). Lastly, we added our indicators of burden and unmet support needs to each model to determine whether they further distinguish respondents in favour of or opposed to MAID in the scenario. All reported *p*-values are two-sided. Analyses were conducted with IBM SPSS for Windows, version 25.

A few of our respondents left comments at the end of the questionnaire. A thorough thematic analysis of comments left by 420 responders to our previous surveys has recently been published (Bravo *et al.*, 2021). In the present paper, rather than repeating the analysis on a new set of similar comments, we selected representative comments from informal care-givers that we have included in the Discussion to illustrate how some respondents justified their views on MAID for people with dementia.

Sample size considerations

Estimating the true population proportion (objective 1) requires 196 subjects when the margin of error is set at 5 per cent, the confidence level at 95 per cent and the likely sample proportion at 85 per cent (based on our prior findings). Testing the significance of a single dichotomous predictor (objective 2) using a multivariable logistic regression requires 201 subjects when the significance level is set at 5 per cent, power at 80 per cent, the between-group difference in proportions at 0.10 and the correlation of the predictor with potential confounders at 0.10. Combining these considerations, we aimed for around 200 survey respondents.

Results

Respondent characteristics

Of the 271 Alzheimer Society members who contacted the research assistant for access to the questionnaire, 204 (75%) returned it. The respondents are described in Table 1. Most (79%) were female, with age ranging from 29 to 89 years. Roughly half had a university degree and felt comfortable financially. Two-thirds had experienced the death of a loved one (67%) and 62 per cent reported having documented their health-care wishes in the event of incapacity. Importance of religious or spiritual beliefs was quite variable across respondents, as were self-ratings of quality of life. Three-quarters of the respondents (76%) supported the MAID legislation that was in effect at the time of the survey. Slightly more (83%) would write a MAID request for themselves should they develop dementia, and 76 per cent would ask a doctor to comply with such a request made by the person with dementia with whom they were involved. Half of the respondents were the spouse or partner of that person, and 74 per cent (150) reported providing care or help to him or her.

Statistical analyses investigating respondents' attitudes towards MAID in the context of dementia (objective 1) use the entire sample of 204 respondents, while those exploring associated factors (objective 2) are restricted to the 150 respondents who identified themselves as 'care-givers'.

Attitudes towards MAID for persons with dementia

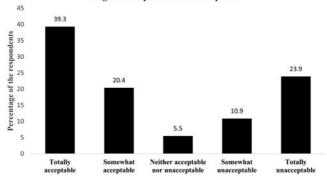
Figure 2 shows respondents' ratings of the acceptability of MAID in the context of dementia, under each of the five scenarios investigated. Sixty per cent felt it was acceptable (somewhat or totally) to give the depicted person access to MAID when she is still able to provide contemporaneous consent (Stage A). Support increases to 70 per cent (p < 0.001) when the person is no longer competent, may still have years to live and shows no signs of distress (Stage B, grey bars), increasing further to 84 per cent (p < 0.001) when she is close to death (Stage C, grey bars). In Stage B, support for MAID increases with evidence of severe distress (85% *versus* 70%, p < 0.001), whereas this has no effect in Stage C (87% *versus* 84%, p = 0.109).

As shown in Table 2, most of the 12 general statements were endorsed by over 70 per cent of the respondents (some by over 80%), and always in the direction consistent with the relatively high levels of support for MAID observed through the vignettes. For instance, 83.2 per cent agreed that people have the right to choose how they will die (S2); and 87.5 per cent that the fear of going through the later

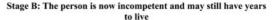
Descriptive Characteristics statistics Gender (female) 147 (78.6) 65.0 (11.0) Mean age (SD) Born in Canada 173 (93.0) Highest level of schooling: High school or lower 31 (16.7) College 53 (28.5) University 102 (54.8) Financial situation: Comfortable financially 87 (48.1) Income sufficient to meet basic needs 80 (44.2) Poor or very poor 14 (7.7) Importance of religious or spiritual beliefs: Very important 56 (29.9) Somewhat important 54 (28.9) Not very important 35 (18.7) Not important at all 42 (22.5) Personal experience with a loved one dying 131 (66.8) Have documented their health-care wishes in the event of incapacity 121 (62.1) Quality of life: Excellent 27 (14.6) Very good 69 (37.3) Good 56 (30.3) Fair or poor 33 (17.8) Favourable (somewhat or totally) to the (then) current federal legislation on 150 (75.8) MAID Likely (somewhat or extremely) to write a MAID request for themselves 164 (83.2) should they develop dementia Likely (somewhat or extremely) to ask a doctor to comply with the MAID 145 (75.9) request of the person with dementia (assuming MAID was legal in such cases) Kinship to the person with dementia: Spouse/partner 99 (52.9) Daughter/son 73 (39.0) Other 15 (23.1) Provide care or help to the person with dementia 150 (73.5)

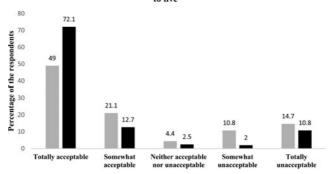
Table 1. Description of the respondents

Notes: N = 204. Data are counts with percentages in parentheses except for mean age with standard deviation (SD) in parentheses. The number of missing data ranges from 6, for support for the (then) current federal legislation on medical assistance in dying (MAID), to 19 for quality of life.

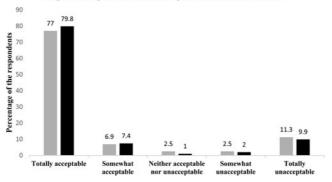


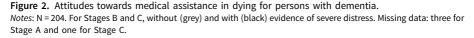












stages of dementia may cause intolerable suffering for those at the early stage (S7). Respect for prior-expressed wishes (S4 and S8) was also endorsed by most (85.7 and 77.5%, respectively). Somewhat surprisingly, 76.8 per cent of the respondents felt that all suffering can be alleviated at the end of life (S6), suggesting that,

Statem	nent	Moderately or strongly disagree	Moderately or strongly agree
S1	Human life must be preserved in all circumstances	151 (76.3)	47 (23.7)
S2	Every person should have the right to choose how they will die	33 (16.8)	164 (83.2)
S3	Only God or another divine entity determines when a person dies	146 (76.0)	46 (24.0)
S4	Health-care preferences expressed before losing capacity should carry the same weight as those expressed by a patient who still has capacity	27 (14.3)	162 (85.7)
S5	Many patients at later stages of dementia do not die with dignity	21 (11.0)	170 (89.0)
S6	All suffering can be alleviated at the end of life	43 (23.2)	142 (76.8)
S7	The fear of going through the later stages of dementia may cause intolerable suffering for those at the early stage	24 (12.5)	168 (87.5)
S8	Health care to be provided to patients unable to make health-related decisions should be based on their current quality of life, ignoring preferences they may have expressed while still able to do so	148 (77.5)	43 (22.5)
S9	It is impossible to know whether a patient unable to communicate verbally is suffering	133 (68.6)	61 (31.4)
The ad	Iministration of strong medications that cause de	eath:	
S10	Should be restricted to patients able to give consent, who have requested it themselves and satisfy all other legal requirements for medical assistance in dying	135 (70.3)	57 (29.7)
S11	Should be permitted for patients unable to give consent who requested it while still able to do so and satisfy all other legal requirements for medical assistance in dying	23 (11.7)	174 (88.3)
S12	Should not be extended to patients unable to give consent because they could receive it against their will	119 (63.0)	70 (37.0)

Table 2. Respondents' values and beliefs regarding medical assistance in dying

Notes: N = 204. Data are counts with percentages in parentheses. The number of missing data ranges from six for S1 to 19 for S6.

among our respondents, self-determination may be a stronger motive for the extension of MAID to persons unable to consent than considerations of suffering. Lastly, although 88.3 per cent agreed with extending MAID to decisionally incapable persons in general (S11), 37 per cent expressed some concern that people might receive it against their will (S12).

Correlates of attitudes towards MAID for persons with dementia

Table 3 reports the results of investigating which factors, related to the respondent, the person with dementia or the care-giving context, distinguish respondents in favour of MAID from those opposed, in each of the three scenarios analysed. Of the 35 potential predictors investigated, eight were statistically significant (at the 0.15 level) under all three scenarios (religiosity of the care-giver and personal experience with a loved one dying, co-residency, evidence of psychological suffering in the care receiver, worsened relationship between the care-giver and care receiver, quality of life of the care receiver, kinship and help received by the care-giver), six were never significant (schooling of the care-giver, trust in doctors, care receiver's gender, length of care-giving, help needed and knowledge of dementia), whereas the association of the 21 other factors varied with the scenario.

Setting aside our indicators of burden and unmet support needs (the negative outcome of care-giving score and help needed), 14 factors were found to distinguish respondents favourable to MAID in the context of dementia from those opposed at Stage A, 20 at Stage B and 17 at Stage C. No factor was too strongly multicollinear with others (largest VIF = 4.9). However, at Stage C, two factors related to the respondent (religiosity and coping) had to be discarded due to empty cells. Of the respondents who opposed extending MAID at Stage C, all had rated their religious or spiritual beliefs as somewhat or very important, and all had reported not coping well at all with their care-giving responsibilities. All other predictors were carried over to the next, multivariable step of the analysis to determine whether burden and unmet support needs are associated with attitudes, after adjusting for potential confounders. Final results of these analyses are reported in Table 4.

Our forward approach resulted in four characteristics of the respondent (gender, religiosity, trust in people and trust in the health-care system) and two characteristics of the person with dementia (evidence of psychological suffering and worsened relationship with the respondent) being included in the model predicting attitudes towards MAID at Stage A. When added to this model, help needed was statistically significant (p = 0.022), whereas the negative outcome of care-giving score was marginally significant (p = 0.066). The respondent's gender and religiosity, as well as evidence of psychological suffering in the person with dementia, also predicted attitudes at Stage B (without distress). Two other predictors ended up in the model: quality of life of the person with dementia and care-giving skills. Neither the negative outcome of care-giving score nor help needed was significant (p =0.653 and p = 0.118, respectively) when added to the model. Lastly, three predictors were included in the model at Stage C, all related to the person with dementia (religiosity, co-residency and worsened relationship with the respondent). As for Stage B, the negative outcome of care-giving score and help needed provided no additional prediction power (p = 0.651 and p = 0.527, respectively) once the three predictors were included. The Hosmer-Lemeshow chi-square test provided no evidence of lack of fit for the three final models, with p-values ranging from 0.415 to 0.523.

Table 3. Results from univariable analyses of factors associated with attitudes towards medical a	assistance in dying for persons with dementia
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		Stage A ¹		Stage B without distress ² Stage C with			with severe dist	th severe distress ³	
Factors	Favour (N = 88)	Oppose (N = 61)	p^4	Favour (N = 107)	Oppose (N = 43)	p ⁴	Favour (N = 131)	Oppose (N = 18)	p ⁴
Characteristics of the respondent	t:								
Gender (female)	88.5	72.4	0.014	87.7	67.5	0.006	82.8	82.4	0.963
Mean age	63.7	67.3	0.043	64.1	67.8	0.051	65.0	65.5	0.855
Highest level of schooling (university)	54.7	60.3	0.498	56.2	57.5	0.887	55.1	70.6	0.218
Financial situation (comfortable)	44.6	53.6	0.298	46.1	52.6	0.490	45.9	64.7	0.144
Importance of religious or spiritual beliefs (very or somewhat important)	48.3	74.1	0.002	51.9	77.5	0.004	53.1	100	0.001
Personal experience with a loved one dying	72.4	55.7	0.036	72.6	48.8	0.006	67.7	50.0	0.147
Trust:									
In people	85.9	73.8	0.069	82.7	76.7	0.410	82.0	72.2	0.342
In doctors	90.5	93.3	0.536	92.2	90.7	0.773	92.1	88.9	0.661
In the health-care system	64.4	80.3	0.033	68.9	76.7	0.330	70.0	77.8	0.486
Quality of life (fair or poor)	17.6	20.7	0.649	20.2	17.5	0.712	20.6	5.9	0.102
Characteristics of the person wit	h dementia:								
Gender (female)	50.0	51.7	0.842	47.7	57.1	0.297	51.5	38.9	0.313
Mean age	80.9	78.7	0.230	80.2	79.4	0.676	80.6	75.2	0.060

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Table 3. (Continued.)

		Stage A ¹		Stage B without distress ² Stage C w			with severe dist	vith severe distress ³	
Factors	Favour (N = 88)	Oppose (N = 61)	p ⁴	Favour (N = 107)	Oppose (N = 43)	p ⁴	Favour (N = 131)	Oppose (N = 18)	p ⁴
Highest level of schooling (university)	28.7	39.0	0.197	26.0	48.8	0.008	32.0	38.9	0.567
Importance of religious or spiritual beliefs (very or somewhat important)	52.3	68.9	0.042	55.1	67.4	0.163	55.0	88.9	0.003
Co-residency	31.3	50.8	0.019	31.0	58.1	0.002	34.7	72.2	0.003
Type of dwelling (LTC facility)	62.8	52.5	0.211	61.0	53.5	0.404	62.0	33.3	0.021
Dementia stage (moderate or severe)	88.5	82.0	0.265	88.7	79.1	0.139	89.2	61.1	0.005
Cognitive functioning (poor)	63.6	59.0	0.569	67.3	48.8	0.037	64.1	44.4	0.113
Evidence of physical suffering	48.9	27.9	0.009	47.7	23.3	0.005	42.7	27.8	0.216
Evidence of psychological suffering	65.9	42.6	0.005	64.5	34.9	0.001	60.3	27.8	0.009
Exhibits challenging behaviours (daily)	34.1	28.8	0.502	37.0	21.4	0.064	33.9	17.6	0.159
Change in personality	67.0	59.0	0.317	69.2	51.2	0.040	65.6	50.0	0.203
Worsened relationship with the respondent	63.6	36.1	0.001	62.6	27.9	0.001	56.5	27.8	0.021
Quality of life (poor)	33.0	21.3	0.116	35.5	11.6	0.002	31.3	5.6	0.010
Characteristics of the care-giving	context:								

Kinship (spouse/partner)	45.5	65.6	0.015	46.7	72.1	0.004	50.4	77.8	0.024
Primary care-giver	78.4	80.0	0.815	75.7	88.1	0.080	77.1	94.1	0.068
Mean length of care-giving (years)	6.6	5.7	0.240	6.5	5.4	0.192	6.3	5.7	0.623
Intensity of care-giving (≥20 hours per week)	34.9	44.8	0.231	35.2	50.0	0.106	38.8	40.0	0.926
Mean help received (0–4)	1.3	1.6	0.110	1.3	1.6	0.150	1.3	2.0	0.013
Mean help needed (0–7)	2.0	2.1	0.920	2.0	2.3	0.406	2.1	1.8	0.625
Care-giving skills (fair or poor)	18.4	10.2	0.164	19.0	4.8	0.016	15.5	11.8	0.677
Knowledge of dementia (fair or poor)	7.0	3.4	0.339	6.7	2.4	0.259	5.5	5.9	0.945
Coping (not well at all)	23.0	15.5	0.265	22.1	14.3	0.271	22.7	0	0.004
Mean positive outcome of care-giving (0–11)	4.3	5.0	0.205	4.2	5.6	0.019	4.5	5.1	0.478
Mean negative outcome of care-giving (0–17)	10.7	8.8	0.023	10.0	9.7	0.698	10.0	8.9	0.357

Notes: N = 150. Except for the three *p*-value columns, data are percentages unless otherwise specified. Factors with p < 0.15 (bold) were candidates for the next, multivariable step. LTC: long-term care. 1. The person with dementia is still able to make health-related decisions. 2. The person with dementia is now incompetent, does not show signs of distress and may still have years to live. 3. The person with dementia is still incompetent, does show signs of severe distress and is close to death. 4. From univariable logistic regressions.

Table 4. Final results from multivariable analyses investigating the associations of burden and unmet support needs with attitudes towards medical assistance in dying for persons with dementia, after adjusting for potential confounders

	St	age A ¹	Stage B wi	ithout distress ²	Stage C with severe distress ³					
Model	Factors included	Odds ratio (95% CI)	Factors included	Odds ratio (95% CI)	Factors included	Odds ratio (95% CI)				
1	Characteristics of the	respondent:								
	Gender	6.0 (1.9–18.9)	Gender	12.2 (2.9–52.2)						
	Religiosity	0.2 (0.09–0.57)	Religiosity	0.2 (0.05–0.48)						
	Trust in people	8.7 (2.2–33.7)								
	Trust in the health-care system	0.3 (0.10-0.83)								
	Characteristics of the person with dementia:									
	Evidence of psychological suffering	4.0 (1.6–9.9)	Evidence of psychological suffering	4.7 (1.7–12.9)	Religiosity	0.11 (0.02–0.58)				
	Worsened relationship with the respondent	3.2 (1.4–7.8)	Quality of life	7.5 (1.7–32.9)	Co-residency	9.8 (2.6–37.5)				
					Worsened relationship with the respondent	4.0 (1.1–15.0)				
	Characteristics of the care-giving context:									
			Care-giving skills	13.1 (1.5–112.7)						
	Adding indicators of burden and unmet needs to Model 1	Odds ratio (95% CI)	Adding indicators of burden and unmet needs to Model 1	Odds ratio (95% CI)	Adding indicators of burden and	Odds ratio (95% CI)				

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					unmet needs to Model 1	
2	Negative outcome of care-giving	1.1 (0.99–1.22)	Negative outcome of care-giving	0.97 (0.87–1.09)	Negative outcome of care-giving	0.97 (0.85–1.11)
	Help needed	0.77 (0.62–0.96)	Help needed	0.83 (0.66-1.05)	Help needed	1.1 (0.82–1.48)

150. CI: confidence interval. 1. The person with dementia is still able to make health-related decisions. Fourteen predictors were initially included in the model: six related to the nt (gender, age, religiosity, personal experience with a loved one dying, trust in people, trust in the health-care system), six related to the person with dementia (religiosity, co-residency, of physical suffering, evidence of psychological suffering, worsened relationship with the respondent, quality of life), and two related to the care-giving context (kinship, help received). son with dementia is now incompetent, does not show signs of distress and may still have years to live. Twenty predictors were initially included in the model: four related to the nt (gender, age, religiosity, personal experience with a loved one dying), ten related to the person with dementia (schooling, co-residency, dementia stage, cognitive functioning, of physical suffering, evidence of psychological suffering, exhibits challenging behaviours, change in personality, worsened relationship with the respondent, quality of life) and six the care-giving context (kinship, length of care-giving, intensity of care-giving, help received, care-giving skills, positive outcome of care-giving). 3. The person with dementia is still ent, does show signs of severe distress and is close to death. Fifteen predictors were initially included in the model: three related to the respondent (financial situation, personal experience with a loved one dving, quality of life), nine related to the person with dementia (age, religiosity, co-residency, type of dwelling, dementia stage, cognitive functioning, evidence of psychological suffering, worsened relationship with the respondent, guality of life) and three related to the care-giving context (kinship, primary care-giver, help received).

Discussion

This study found a majority of Canadian informal care-givers to be in favour of enlarging access to MAID through advance requests, with support increasing as the person with dementia approaches the end of life. No evidence was found to support the claim that positive attitudes towards advance requests for MAID are driven by care-giver burden and unmet needs for support. Rather, attitudes seem more strongly determined by care-giver characteristics, the importance they attach to respecting previously expressed wishes and quality-of-life considerations, as will be illustrated below with extracts from comments left by respondents at the end of the questionnaire.

Attitudes towards MAID for persons with dementia

As expected from our previous survey (Bravo *et al.*, 2018a) and polls conducted in the general Canadian population (Bronskill, 2020; Government of Canada, 2020), support for extending MAID to persons lacking decisional capacity was relatively high, ranging from 70 per cent when the person shows no signs of distress and likely has several more years to live, to 87 per cent when she is in distress and has reached the end of her life. These percentages are close to those observed in the Quebec sample of informal care-givers (68 and 91%, respectively) (Bravo *et al.*, 2018a). To our knowledge, no other study has investigated these stakeholders' attitudes towards this issue in the Canadian legal context. Some years ago, Rurup *et al.* (2006) reported that 89 per cent of 136 Dutch relatives of nursing home residents with dementia agreed that euthanasia should be accessible to 'incompetent patients if they signed an advance euthanasia directive when they were still competent'. High support for legalising advance requests for assistance in dying has also been found among persons with mild dementia (Thériault *et al.*, 2018b, 2018c).

In their comments, some of our respondents reaffirmed their strong support for giving people who want to die access to MAID, for instance:

I think it is entirely cruel to make a person live when they do not want to. My mom tells me on a daily basis how she would like to leave the world and why does someone else get to decide how and why she should live ... She tells me what is happening and how she is terrified losing her memory ... She says she lived her whole life to become someone and made it through so many things ... She said she kept going and lived because she knew there would be light at the end of the tunnel but she knows there is no light at the end of this tunnel. (ID 194)

When first diagnosed my husband asked me to not let them 'Wheel me into the sunroom'. While he is not there yet, there is ample evidence in his LTC [long-term care] home of people who are at that point. It is very stressful knowing I will not be able to legally act on that request. I do not understand why we take away some-one's right to decide. I thought the whole point was to protect the vulnerable person. In my view this means honouring their wishes and not forcing them into a situation they don't want. I get the potential for abuse – surely we can set up and agree on a system that is fair to the patient. (ID 71)

In addition to the value of self-determination, poor quality of life was another reason voiced for supporting enlarging MAID access to persons with severe dementia, as illustrated below:

We are told that dementia care focuses on living in the moment, which is a great ethos when the patient is participating as best as they can in daily activities. But I don't want to sit in a chair sleeping all day. I don't want to have to sit in my own feces waiting for staff to have time and resources to change me. I don't want to play games as if I am a 5 year old. I don't want to be stuck watching daytime talk shows because that is what the staff put on. (ID 137)

While not strongly against giving decisionally incapacitated persons' access to MAID, some respondents underscored how difficult it would be for their loved ones – or themselves – to carry out a MAID request:

I could never ask someone to enact assisted dying on my behalf. That is, even if I filled out the paperwork I could never ask one of my daughters or my husband to put that into action. I feel that giving them that task would be overwhelming no matter what my physical state. Personally, even if my Mom had that in place I'm not sure I could follow through. Sure, there are days when I would feel like it but in the long run I don't think it would sit well with me. (ID 28)

In their comments, other respondents reiterated their strong opposition to MAID, generally or specifically for persons lacking decisional capacity:

Under no circumstances would I ever consider assistance in dying for myself or anyone else. It is wrong and if that is the best the government has to offer baby boomers we are in a sorry state. (ID 56)

MAID at Stage A, for a still-competent person with dementia who dreads the prospect of an unavoidable deterioration (*see* Appendix), was endorsed by 60 per cent of our respondents.⁴ Still-competent Canadians with dementia as the sole underlying medical condition can qualify for MAID (Canadian Association of MAID Assessors and Providers, 2019) and some have received MAID (CBC Radio, 2019; Grant, 2019; Frangou, 2020). Yet, the person in the vignette was not described as being in an advanced state of irreversible decline in capability or experiencing enduring, intolerable and irremediable suffering (eligibility criteria for MAID) and so would not qualify for MAID. Lesser support for MAID at Stage A among our respondents (60%), compared to Stages B and C (70 and 87%, respectively), could reflect discomfort with ending life at an early stage of dementia, or the belief that 'the prospect of an unavoidable deterioration' does not make suffering unbearable.

Impact of burden and unmet needs on attitudes

Our hypothesis that care-giving burden and unmet needs for support would have little influence on attitudes towards advance requests for MAID after adjusting for potential confounders was confirmed. At Stages B and C, we found no statistically significant associations between attitudes and our indicators of burden and unmet support needs (Table 4). This finding is in line with that of others showing that most people requesting MAID can access the support they need (Health Canada, 2021; Wiebe *et al.*, in press), invalidating the claim that people choose MAID because of society's failure to provide for them (Wiebe *et al.*, in press). We did find, however, that the extent of help needed influenced attitudes at Stage A, *i.e.* in early stage dementia where the person is still able to make health-related decisions. Help needed was, however, the least significant predictor among the eight factors included in the model. Overall, Table 4 suggests that negative effects of the disease (*e.g.* psychological suffering, change in relationship, poor quality of life) and some sociodemographic characteristics of the care-giver (*e.g.* gender and religiosity) are stronger correlates of attitudes than are burden and needs. Nonetheless, comments left at the end of the questionnaire do suggest an impact for some individuals:

My father's dementia is draining us physically, emotionally and financially. The quality of life of the rest of the family, including the grandchildren has been deeply impacted. We have witnessed the most unspeakable treatment of people living with dementia in the care home ... Should I be unlucky enough to get dementia I have told my kids, friends and family that I never, ever, ever, EVER want to live in care facility or require home care. My father would be horrified to know the grief he has caused. If we could have provided a dignified medically assisted death we would have done so years ago. I would not wish this hell on anybody. (ID 72)

My major concern is that people will choose MAID because they don't want to be a burden on their caregivers. I was my father and my husband's caregiver. Both had dementia. In both cases, I felt that home supports and proper medical care were not in place. As a caregiver, I struggled on a continuous basis to get assistance or information from the health care system. I cannot stress in strong enough terms how angry I am with the medical system for not providing enough support. I fear that people like my father or my husband would choose MAID for no other reason than they feared they were a burden – emotionally, physically, and financially. For that reason, I do not support MAID. At the same time, I would definitely choose MAID if I had dementia because after having been a caregiver, I could not put my children through it. This should not be the case. I believe that if the medical system was working properly, it is only in rare cases that MAID should be a viable choice. (ID 75)

Hence, although no relationship was detected (statistically) at the group level, burden and help needed may influence some individuals' attitudes towards MAID for persons lacking decisional capacity. A qualitative approach, complementing our quantitative study, could shed more light on this issue.

Limitations

First, we relied on a volunteer sample, from which self-selection may have occurred based on favourable feelings about the topic. Second, we do not know how many

Alzheimer Society members received the invitation to participate in the survey and so cannot estimate the response rate. In contrast, the Quebec survey was based on a random sample of informal care-givers, allowing the response rate to be established (69%) (Bravo *et al.*, 2018a). While sampling mechanisms differed between the two surveys, attitudes towards advance requests for MAID were similar. Third, survey participants might differ from informal care-givers who are not members of an Alzheimer Society, especially with regards to unmet needs for support. Yet, there is no reason to assume that the correlates of attitudes would differ across samples. Fourth, our sample lacks diversity with respect to race/ethnicity, precluding investigating their associations with attitudes.

Fifth, to avoid lengthening the questionnaire, standardised tools were not used to measure care-giver burden, and some types of help needed might have been missed. Still, items used to measure burden and help needed were drawn from a national survey that has been conducted repeatedly since 1996 (Statistics Canada, 2019). Sixth, when conducting quantitative analyses to identify correlates of an outcome of interest, low statistical power and residual confounding can rarely be ruled out. Moreover, informal care-givers' written comments about their burden and dissatisfaction with the health-care system suggest the need to complement our quantitative approach with in-depth interviews to elucidate further the role of burden and unmet support needs in care-givers' attitudes towards MAID for people with dementia. Lastly, our survey was conducted in a country that has recently legalised MAID, and at a time when its possible extension to decisionally incapable persons was being actively debated. Attitudes and their correlates may differ in jurisdictions where MAID is prohibited in all forms or not a hot topic.

Conclusions

We found considerable support among Canadian informal care-givers of persons with dementia for extending the MAID legislation to persons lacking decisional capacity, with support increasing as the person approaches death. The likelihood of a poor quality of life in advanced dementia and respect for previously expressed wishes were main arguments voiced for widening access to MAID through advance requests. We found no evidence that burden and unmet needs for support were major determinants of informal care-givers' attitudes towards this delicate issue.

Many challenges lie ahead for legislatures that would allow advance requests for assistance in dying, including how to assess suffering and to determine when to carry out the request. Quebec's recently tabled Bill 38 provides that

With the assistance of [a competent]⁵ professional, the patient must describe in detail in the request the constant and unbearable physical or psychological suffering ... that will determine, when the patient has become incapable and when a competent professional finds that the patient is experiencing such suffering due to their illness, the time from which the patient considers it appropriate to obtain [MAID].

In the request, the patient may also designate trusted third persons 'who, when of the opinion that the patient is experiencing the suffering described in the request, must notify a competent professional'. The professional who concludes that the patient is indeed experiencing the suffering described in the request must 'ensure that the process for administering [MAID] continues' and 'inform every third person designated in the request of the conclusion' before administering MAID. Despite these provisions, many uncertainties remain about how the MAID process would evolve in practice when triggered by the content of an advance request.

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Author contributions. The first six authors designed the study and secured funding. GB, LVdB and JD designed the survey questionnaire, whereas LT performed the statistical analyses. GB wrote the paper, which was critically reviewed by all co-authors. All co-authors approved the final version of the paper.

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Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. The study received ethical approval from the Research Ethics Board of the CIUSSS de l'Estrie – CHUS (file #2020-3397).

Notes

1 As per Section 241.1 of the *Criminal Code*, 'MAID' is an umbrella term which includes: (a) the administration by a medical practitioner or nurse practitioner of medication that will cause a person's death at their request and (b) the prescription or provision by a medical practitioner or nurse practitioner of medication that a person can self-administer to cause their own death.

2 The second form of advance consent is for circumstances involving failed self-administration by a competent adult.

3 See e.g. Martin (2017).

4 Attitudes towards giving a person with dementia access to MAID at Stage A were not explored in the Quebec survey because it was conducted some years before the end-of-life and death-reasonably-foreseeable criteria were repealed.

5 Defined in Bill 38 as a medical or specialised nurse practitioner.

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Appendix: The vignettes

Mrs. Jackson is a 75-year-old retired teacher who was recently diagnosed with dementia. A few years earlier, Mrs. Jackson's father had died with dementia. Although Mrs. Jackson knows that her quality of life could be good in the early stages, she fears losing her dignity and the capacity to care for herself as her condition worsens. She also knows that there is no cure for her disease.

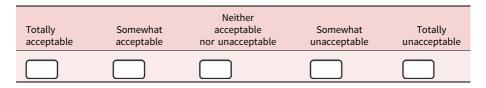
Together with her loved ones and doctor, Mrs. Jackson discusses the health care that she would or would not want to receive when she is no longer able to make health-related decisions. Next, she records her wishes in a document. In this document, she refuses all medical interventions that would prolong her life after she is no longer able to make health-related decisions. She also explicitly requests that a doctor end her life through a lethal injection when she no longer recognizes her loved ones.

She gives copies of her document to her loved ones. In the following years, she often reminds them and her doctor of the wishes she expressed in the document. Her loved ones agree to plead for the respect of her wishes if necessary.

Stage A: Still able to make health-related decisions

Mrs. Jackson is still able to make decisions about her care and treatment but increasingly dreads the prospect of an unavoidable deterioration. After discussing with her family, she asks her doctor to end her life by administering a substance that would cause her death.

1. To what extent do you find it acceptable that the current legislation be changed to allow a doctor to administer to Mrs. Jackson, *at this stage of her disease*, a substance that would cause her death?

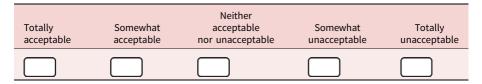


Stage B: No longer able to make health-related decisions and may still have years to live

Six years later, Mrs. Jackson, now 84, cannot take care of herself anymore. She now lives in a long-term care home and is no longer able to make health-related decisions. She is in relatively good physical health and is not expected to die in the years to come. She interacts well with other residents, but she does not seem to recognize her loved ones anymore and she walks away from them when they visit.

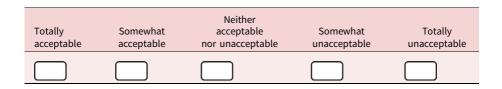
As instructed by Mrs. Jackson, her loved ones show her doctor the document in which she asked that a doctor end her life when she could no longer recognize her loved ones.

2. To what extent do you find it acceptable that the current legislation be changed to allow a doctor to administer to Mrs. Jackson, *at this stage of her disease*, a substance that would cause her death?



In the above situation, assume that for some time now, Mrs. Jackson has been *showing signs of severe distress*. She seems terrified and cries a lot, even when surrounded by her loved ones. All efforts by the healthcare team to alleviate her anxiety have failed.

3. To what extent do you find it acceptable that the current legislation be changed to allow a doctor to administer to Mrs. Jackson, *at this stage of her disease* and *in the context of severe distress*, a substance that would cause her death?

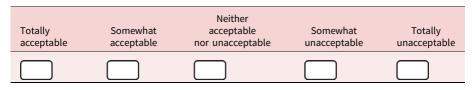


Stage C: Still unable to make health-related decisions and is close to death

Mrs. Jackson is still unable to make health-related decisions and her physical health has seriously deteriorated. She is frail, bedridden and has developed a serious lung infection. She refuses to eat or drink, even when assisted by a health professional. Based on these signs, Mrs. Jackson is expected to die soon should it be decided not to treat her infection. However, Mrs. Jackson *shows no signs of distress.*

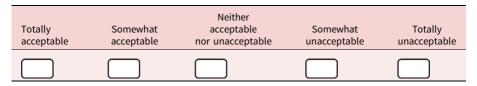
Mrs. Jackson's loved ones remind her doctor of the document in which she refused all life-prolonging treatments and asked that a doctor end her life when she could no longer recognize her loved ones.

4. To what extent do you find it acceptable that the current legislation be changed to allow a doctor to administer to Mrs. Jackson, *at this stage of her disease*, a substance that would cause her death?



In the above situation, assume that for some time now, Mrs. Jackson has been *showing signs of severe distress*. She seems terrified and cries a lot, even when surrounded by her loved ones. All efforts by the healthcare team to alleviate her anxiety have failed.

5. To what extent do you find it acceptable that the current legislation be changed to allow a doctor to administer to Mrs. Jackson, *at this stage of her disease* and *in the context of severe distress*, a substance that would cause her death?



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