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**Comparing the attitudes of four groups of stakeholders from Quebec, Canada,
towards extending medical aid in dying to incompetent patients with dementia**

(Running title: Medical aid in dying for patients with dementia)

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CONFLICT OF INTEREST

None to declare

ABSTRACT

Objective: The Canadian province of Quebec has recently legalized medical aid in dying (MAID) for competent patients who satisfy strictly defined criteria. The province is considering extending the practice to incompetent patients. We compared the attitudes of four groups of stakeholders towards extending MAID to incompetent patients with dementia.

Methods: We conducted a province-wide postal survey in random samples of older adults, informal caregivers of persons with dementia, nurses, and physicians caring for patients with dementia. Clinical vignettes featuring a patient with Alzheimer disease were used to measure the acceptability of extending MAID to incompetent patients with dementia. Vignettes varied according to the stage of the disease (advanced or terminal) and type of request (written or oral only). We used the generalized estimating equation (GEE) approach to compare attitudes across groups and vignettes.

Results: Response rates ranged from 25% for physicians to 69% for informal caregivers. In all four groups, the proportion of respondents who felt it was acceptable to extend MAID to an incompetent patient with dementia was highest when the patient was at the terminal stage, showed signs of distress and had written a MAID request prior to losing capacity. In those circumstances, this proportion ranged from 71% among physicians to 91% among informal caregivers.

Conclusion: We found high support in Quebec for extending the current MAID legislation to incompetent patients with dementia who have reached the terminal stage, appear to be suffering and had requested MAID in writing while still competent.

Key words: euthanasia, dementia, decisional incapacity, advance directive, attitude, survey, law, Canada

Key points:

- Medical aid in dying is a controversial practice, even more so when involving patients unable to consent at the time of the act.
- The governments of Quebec and Canada are both considering extending the practice to such patients.
- We measured the attitudes of older adults, informal caregivers, nurses, and physicians on this issue for a patient with Alzheimer disease.
- Over 70% of the respondents were open to this possibility, provided the patient is at the terminal stage of the disease, shows signs of distress, and had requested aid in dying in writing prior to losing capacity.

INTRODUCTION

As a result of the global rise in life expectancy, the number of individuals living with dementia is growing rapidly worldwide. In 2017, this number was believed to be close to 50 million, with an estimated 9.9 million new cases of dementia each year.¹ Alzheimer disease, a common cause of dementia in elderly people, is one of the most feared life-threatening diseases among Americans over 65 years of age.² No cures are currently available and none are foreseen in the near future. Most affected individuals will live for years with dementia,³ gradually losing their cognitive and functional abilities to carry out activities that they value. While people living with dementia may still have a lot of things to enjoy, research also shows that they may experience burdensome symptoms as the disease progresses.⁴

Some authors contend that most people will eventually adjust to a dementia diagnosis.⁵⁻⁷ Others have found that anticipated experiences of patients living with dementia are often more negative than their actual experiences.⁸ Nonetheless, increased awareness of the challenges of living with dementia can result in some diagnosed people seriously contemplating a hastened death.^{9,10} Such thoughts may trigger formal requests for physician-assisted suicide or euthanasia, to be carried out either early in the disease trajectory (while still competent) or later when decisional capacity has been lost. In the Netherlands, where the law on assisted death imposes no limit on life expectancy, physicians can provide assistance in dying at both the early and late stages of dementia, provided the legal requirements are met. The number of Dutch people with dementia who were granted assistance in dying has steadily increased since the legislation was introduced in 2002, from 1 in 2004 (0.05% of all cases) to 169 in 2017 (2.6%).^{11,12} In 2017, all but three cases were at the early stage of the disease and still competent to confirm their request for euthanasia.

In this paper, we report an integrated and comprehensive analysis of the attitudes of four groups of Quebec stakeholders towards giving incompetent patients with dementia access to

euthanasia. In December 2015, Quebec became the first province in Canada to legalize euthanasia, called “medical aid in dying” (MAID) in the legislation.¹³ In Bill 52, MAID 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 residing in 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”. The requirement of being competent and at the end of life implies that most patients with dementia cannot receive MAID. Unlike the Netherlands, Quebec does not allow incompetent patients to receive MAID through a request written prior to losing capacity. However, the Quebec Government recently tasked a panel of experts to reflect on whether MAID should be extended to incompetent patients, and if so, under what conditions.¹⁴ Another expert panel was recently given a mandate to review the evidence on this issue by the Government of Canada who decriminalized medical assistance in dying six months after Quebec’s legislation came into force.¹⁵

Little empirical data are currently available in Canada to inform the work of these panels.¹⁶ Research conducted in other countries shows that acceptance of death-hastening practices has increased in the last decades,^{17,18} especially for terminally-ill but still competent patients who suffer unbearably from an incurable disease. Euthanasia in patients with dementia who are no longer competent is more controversial and continues to be debated, even in the Netherlands where the practice is legal in some circumstances.¹⁹

With the objective of informing public debates and policy developments on this highly sensitive and complex healthcare issue, we measured the attitudes of different Quebec stakeholders towards extending MAID to incompetent patients with dementia in specific circumstances. Four

groups of stakeholders were targeted: 1) informal caregivers of persons with dementia, 2) nurses and 3) physicians likely to be involved in end-of-life decision-making, and 4) adults aged 65 and over presumed free of cognitive impairment. Findings from the first three groups have recently been published.²⁰⁻²² Herein, we first report older adults' attitudes on the issue, and second compare attitudes across the four targeted groups. Based on findings from other countries,^{16,23} we expected older adults and informal caregivers to have more permissive attitudes than nurses and physicians towards extending MAID to incompetent patients with dementia. We further expected support for extending MAID to such patients to be stronger for those who are at the end of life and appear to be suffering, two requirements that are part of the current Quebec legislation.

METHODS

Design, Populations and Sampling

The study protocol has been published elsewhere.²⁴ In brief, we conducted a province-wide postal survey on representative samples of French-speaking Quebec residents belonging to one of the four groups of stakeholders. A random list of adults aged 65 and over was drawn from the administrative database of the Quebec universal health insurance plan. Residents of long-term care facilities were excluded a priori, given the high prevalence of cognitive impairment in these settings. Random samples of informal caregivers of persons with dementia were drawn by local Alzheimer Societies, while random lists of nurses and physicians were provided by their respective professional association. Eligibility for nurses and physicians was restricted to those who were caring for patients with dementia at the time of the survey.

Sampled individuals received a first survey package containing a personalized cover letter, the questionnaire, an endorsement letter from the Federation of Quebec Alzheimer Societies, a stamped return envelope, and a postcard bearing the respondent's name to be returned separately from the questionnaire. A reminder postcard was mailed two weeks after the first mailing, and a second complete survey package nine weeks later. Respondents had the option of filling out the paper questionnaire or its online version using a personal identifier that was provided in the cover letter. Responses were anonymous. The survey ran from September 2016 to December 2017. It was approved by the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke (file #2016-623). Consent information was provided on the cover page of the questionnaire, and consent inferred from sampled individuals who returned the questionnaire.

Survey questionnaire

The questionnaire was developed with international experts in dementia care and pretested for length, clarity of the questions, and comfort with the content through cognitive interviews.²⁵ The questionnaire consisted of three main sections preceded by the list of current eligibility criteria for MAID as stated in Bill 52. Section 1 included five clinical vignettes designed to measure respondents' attitudes towards MAID and continuous deep sedation (CDS; cf. Figure 1). While the focus of the survey was on MAID, we felt it was important for all respondents to be aware that other options exist for relieving suffering at the end of life. The vignettes featured a woman with Alzheimer disease moving from the early stage of her disease to the advanced and then terminal stage. Respondents were asked to indicate the extent to which they find it acceptable that a physician grants the patient's request for MAID or deeply sedates the patient continuously until death. Responses were provided on a five-point Likert-type scale ranging from *totally unacceptable* to *totally acceptable*.

Section 2 explored various related issues, including whether respondents would request MAID for themselves should they have Alzheimer disease. Sections 1 and 2 were identical across groups, allowing direct comparisons of their attitudes towards MAID and CDS. Section 3 was specific to each group, collecting sociodemographic characteristics and, for health professionals, work-related information.

Statistical analysis

Older adults' attitudes towards MAID and CDS were summarized using proportions and compared across vignettes using a test for correlated data.²⁶ We relied on the generalized estimating equation (GEE) approach to compare attitudes across groups and vignettes, controlling for age, gender and religiosity.²⁷ Model construction began by testing interaction terms, with results guiding subsequent analyses. GEE analyses were conducted with SAS Proc GENMOD (SAS Institute Inc., Cary, NC), version 9.4. To ensure adequate cell sizes for

comparative analyses, responses were dichotomized, comparing respondents who considered an end-of-life practice to be acceptable in a given scenario (*somewhat* or *totally*) with those who did not. All reported *p*-values are two-sided. GEE results are expressed using odds ratios (ORs) and 95% confidence intervals (CI). As detailed in Bravo *et al.*²⁴, using nQuery Advisor 7.0, we estimated a priori that 621 older adults, 527 informal caregivers of persons with dementia, 614 nurses, and 653 physicians should be invited to take part in the survey.

RESULTS

Participation rates and respondent characteristics

Of the 621 randomly selected older adults, 36 were not eligible due mainly to cognitive impairment and 317 returned the questionnaire (10 electronically), for a response rate of 54%. Seniors who returned the questionnaire were 2 years younger, on average, than the Quebec population aged 65 and over, but similar with respect to gender.²⁸ Characteristics of the 317 senior respondents are summarized in Table 1. When asked to imagine that they had Alzheimer disease, 76% indicated being *somewhat* or *extremely likely* to write a MAID request for themselves; 74% would be *somewhat* or *extremely likely* to ask a physician to grant the MAID request of a close relative diagnosed with Alzheimer disease. The condition most often selected for triggering their own (hypothetical) MAID request was *physical pain that cannot be relieved* (chosen by 60% of the senior respondents) whereas *admission to a long-term care facility* was the condition least often selected (by 17%).

- Insert Table 1 -

Characteristics of the three other groups of respondents have been reported elsewhere.²⁰⁻²² Excluding sampled individuals who identified themselves as non-eligible, response rates were 69% for informal caregivers ($n = 306$), 59% for nurses ($n = 291$), and 25% for physicians ($n = 136$). The mean age (\pm SD) was 66 ± 11 for informal caregivers, 52 ± 9 for nurses and 49 ± 12 for physicians; 72% of informal caregivers, 82% of nurses and 60% of physicians were female. The average religiosity index was highest among informal caregivers (5.9 ± 4) and lowest among physicians (3.5 ± 3.5). Should they be diagnosed with Alzheimer disease, 77% of informal caregivers, 79% of nurses and 56% of physicians would be likely to write a request for a hastened death; 65% of informal caregivers and nurses, and 55% of physicians would ask a physician to grant the MAID request of a close relative. Conditions for triggering one's own MAID request were similar across groups, with most selecting *physical pain that cannot be relieved*

(from 65% of informal caregivers to 73% of nurses and physicians) and fewer selecting *admission to a long-term care facility* (from 16% of nurses to 18% of physicians).

Seniors' attitudes towards MAID and CDS

The extent to which seniors found MAID and CDS to be acceptable end-of-life practices for an incompetent patient with Alzheimer disease is shown in Figure 1. Acceptability of MAID was higher at the terminal stage than at the advanced stage, both in the presence of a prior written request (90% of the senior respondents found it *somewhat* or *totally acceptable* at the terminal stage vs. 76% at the advanced stage, $p < 0.001$) and in its absence (75% vs. 64%, $p < 0.001$). At the terminal stage of Alzheimer disease and in the presence of a prior written request for MAID, support for MAID was higher than for CDS (90% vs. 79%, $p < 0.001$). As we reported previously,²⁰⁻²² informal caregivers and nurses also favored MAID over CDS in those circumstances (both p -values < 0.001), whereas physicians were equally likely to judge MAID and CDS as acceptable practices to relieve the patient's apparent suffering (71% vs. 68%, $p = 0.623$).

- Insert Figure 1 -

Comparing groups on attitudes towards MAID

Figure 2 shows, for each group, the proportions of respondents who felt it was acceptable (*somewhat* or *totally*) for an incompetent patient with Alzheimer disease to receive MAID in the four scenarios investigated. The two graphics suggest a strong *Group* effect, with support highest among older adults and lowest among physicians. A *Stage* effect is also apparent in all four groups, with support higher at the terminal stage. Figure 2 further suggests stronger support in the presence of a prior written request, at both the advanced and terminal stages of Alzheimer disease.

- Insert Figure 2 -

We used the GEE approach to formally test the *Group*, *Stage* and *Type-of-request* effects on respondents' attitudes. We began by estimating a model that included the three-way interaction term (that is, the *Group* by *Stage* by *Type-of-request* effect), in addition to their lower terms and the three potential confounders (age, gender and religiosity). As the three-way interaction was significant ($p = 0.006$), subsequent analyses were conducted separately for the advanced and terminal stages of Alzheimer disease. The two-way interaction involving the *Group* and *Type-of-request* effects was also significant at the advanced stage ($p < 0.001$), with older adults and informal caregivers being less influenced by the type of request than the health professionals. The two-way interaction was not significant at the terminal stage ($p = 0.461$). Consequently, at the advanced stage, separate models were estimated for each type of request, while a single model was estimated at the terminal stage.

Final results are reported in Table 2. All tested effects are highly significant. Compared to physicians (the reference group), older adults and informal caregivers had between 3.5 and 7.7 higher odds of finding acceptable that the incompetent patient be given access to MAID, whereas nurses' odds were about twice higher (ORs from 1.7 to 2.4). At the terminal stage, respondents had 3.9 higher odds of supporting this practice when a request had been made in writing, as compared to only orally. Regarding the three potential confounders (data not shown in Table), the effect of gender was never significant and that of age was inconsistent across models. The effect of religiosity was highly significant in all three models, confirming previous findings.^{16,17} A 5-point decrease in the index of religiosity (pointing towards less religious people) nearly doubles the odds of finding it to be acceptable that MAID be extended to the incompetent patient with Alzheimer disease (ORs from 1.5 to 1.9 across the three models).

- Insert Table 2 -

DISCUSSION

Knowledge of the attitudes of stakeholders on sensitive issues plays a pivotal role in informing public policy developments. Conducted among four major groups of stakeholders, our survey shows high support in Quebec for extending MAID to incompetent patients with dementia, provided they are at the terminal stage, appear in distress, and had made a written request for MAID prior to losing capacity. Support was especially high among older adults and informal caregivers, at over 90% in both groups. Confirming earlier findings from other countries,^{9,16} and our first hypothesis, support for MAID in those circumstances was lower – but still relatively high – among nurses and physicians, at 83% and 71%, respectively. Support was significantly lower in the other situations investigated, especially among nurses and physicians, when the patient was at the advanced rather than terminal stage and had not documented her request for MAID.

More permissive attitudes towards euthanasia among the general population relative to health professionals have been attributed to differing knowledge of care options for patients with dementia, and differing roles in the decision-making process and delivery of care.^{23,30} A more negative view of dementia is another plausible explanation. In all four groups, support for extending MAID to an incompetent patient was higher than found in other countries, perhaps due to differences in legal frameworks, culture and level of religiosity.¹⁶ Higher support in Quebec may also reflect a general trend towards greater support over time,^{16,31} or be the result of having conducted the survey at a time when both levels of government are considering extending MAID to incompetent patients under certain conditions. Media attention to this emotionally charged issue has brought some people to publicly oppose extending the current legislation to these patients, arguing that it would put a heavy burden on physicians and the risk vulnerable patients being abused. Many others, however, have voiced the opposite view, arguing that it is discriminatory to deprive incompetent patients of a right now afforded to those who remain competent until the end of life. They have also argued that it may compel individuals to seek MAID earlier than they otherwise would in order not to lose the opportunity for MAID.

Our findings also confirm our second hypothesis that support for extending MAID to incompetent patients with dementia would be greater for those who appear to be suffering and have reached the end of their lives. Currently, unbearable suffering and being at the end of life are two of the conditions that a competent patient must meet to receive MAID under the Quebec legislation. This may have influenced respondents' answers to the survey. We cannot disentangle the separate influence of these two factors, because they were confounded in the vignette (that is, at the terminal stage, the patient was described as being in distress). Of the 1050 respondents, 759 indicated being likely to write a MAID request should they have Alzheimer disease. Of those, 67% selected *physical pain that cannot be relieved* as one of three conditions for triggering their request, compared to 40% for *having only a few weeks left to live*. These data suggest that evidence of suffering may have weighed more heavily in the respondents' support for extending MAID to the incompetent patient than her being at the end of life. Future surveys could formally test this hypothesis by including vignettes in which the two factors vary independently.

The Dutch legislation on euthanasia requires unbearable suffering (as judged by physicians) but imposes no restriction on life expectancy. Stressing the difficulty for physicians to judge whether an uncommunicative patient is suffering unbearably, some commentators have argued that the Dutch legislation's emphasis on suffering as a necessary condition is not the appropriate legal framework in cases of advanced dementia.³²⁻³⁴ According to Menzel,³³ avoiding suffering is not the primary reason why most people decide to draft an advance MAID request. Rather, it is out of fear of future loss of dignity, control and independence in daily activities and bodily functions. Whether suffering should be included as a requirement in any extension of MAID to incompetent patients and, if so, how it should then be defined, are challenging issues facing policy makers. Many persons' greatest concerns about living long into dementia are losing the ability to recognize friends and loved ones, and becoming unaware of their own existence. In our survey, we did not investigate whether the definition of suffering should be broadened to encompass

such widespread concerns. This should be pursued in future investigations to further inform policy discussions on whether incompetent patients should have access to MAID through an advance directive.

Continuous deep sedation (CDS) is an alternative to MAID for alleviating a patient's suffering. In the context of end-stage dementia, in none of our samples was CDS preferred to MAID based on a written request. While this finding may reflect a lack of knowledge of CDS, it may also suggest that many people see little value in extending the dying process at this stage. An alternative explanation is linked to our vignette mentioning that CDS would be provided without artificial nutrition and hydration (as is usually done). Qualitative studies are warranted to better understand why MAID is preferred over CDS in end-stage dementia.

In our survey, over 75% of older adults, informal caregivers, and nurses, and one out of two physicians, indicated that they would request MAID for themselves should they develop Alzheimer disease. Actual behaviors may differ from stated intentions. Nonetheless, these relatively high rates suggest that many people could request MAID in advance of loss of capacity, should this option be legalized. As people may change their minds as their disease progresses, it would then be important to raise awareness of the need to revise their advance requests while they still have the capacity to do so.

Strengths and limitations

To our knowledge, this study is the first in Quebec and Canada to survey four groups of stakeholders on the question of whether MAID should be extended to incompetent patients. The study has a number of strengths, including its timeliness, the relevance of the surveyed groups, random selection of group members, diverse characteristics of the respondents, use of a common set of questions enabling between-group comparisons, and anonymity of the answers

that counters response bias. Response rates are relatively high, except among physicians for which it is comparable to that of other surveys on end-of-life practices.³⁵

Limitations should also be considered. First, as for any survey, the possibility that respondents differ from non-respondents cannot be ruled out. Opinion surveys have been found to carry less risk of bias than surveys of activities.³⁶ Nonetheless, the rate of support that we observed in our survey, especially among the physicians, likely reflects an upper bound. Second, individuals with mild dementia were not surveyed, because we felt it was inappropriate to mail them our questionnaire. As a result of the disability paradox, their attitudes may differ from those of older adults presumed free of cognitive impairment. A qualitative study is currently underway, in which people with early dementia are interviewed face-to-face. Forthcoming results will complement those from the survey. Third, not all clinical situations of interest could be covered by the questionnaire, and vignettes cannot capture the complexity of real-life decisions. In particular, treatment-limiting decisions, such as stopping artificial nutrition and hydration, were not presented as an option. Conceivably, some respondents' support for MAID may have been weaker had they been offered the option to select other means of hastening the patient's death. Forth, although our data strongly suggest that the respondents did distinguish between the "advanced" and "terminal" stages of progressive dementia, we acknowledge that "having only a few weeks left to live" (the specification we gave for the terminal stage) would in practice be difficult to establish reliably. Lastly, quantitative surveys provide limited information on why respondents answered as they did and should be complemented with qualitative interviews.

CONCLUSION

The above limitations notwithstanding, this study reveals that over 70% of the respondents felt it to be acceptable to extent MAID to an incompetent patient with Alzheimer disease who has reached the terminal stage, shows signs of distress, and had requested MAID in writing prior to losing capacity. Support dropped considerably, in all four groups of respondents, when the

patient was described as being at the advanced rather than terminal stage, or as not having made a request in writing. How high support should be to justify extending the legislation to currently excluded patients, and whether any extension would require high support in all stakeholder groups, remain unsettled. We found significant variation in stakeholder groups' support for extending MAID to incompetent patients with dementia. Democratic deliberation (DD) has been shown effective in helping people "reason together", through expert education and dialogue, to arrive at a collectively reasoned policy position on morally complex questions.³⁷⁻⁴⁰ We are currently designing a study to test the efficacy of a DD approach in helping older adults, informal caregivers, nurses, and physicians reach a group decision on whether MAID should be available to incompetent patients, and if so, in which circumstances.

FIGURE LEGENDS

- Figure 1.** Acceptability of medical aid in dying (MAID) and continuous deep sedation (CDS) for an incompetent patient with Alzheimer disease among the 317 senior respondents. Less than 2% of data were missing across scenarios.
- Figure 2.** Group-specific acceptability levels of medical aid in dying (MAID) for an incompetent patient with Alzheimer disease, stratified by the stage of the disease and the presence (in black) or absence (in grey) of a prior written request. Data for informal caregivers, nurses and physicians were first reported in Bravo *et al.*²⁰⁻²²

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Table 1. Characteristics of the 317 senior respondents

Characteristics	Descriptive statistics [†]
Age (in years)	72.7 ± 5.9 (65 to 89)
Gender (female)	166 (52.5)
Born in Canada	306 (96.8)
Race/Ethnicity (Caucasian)	244 (77.2)
Religiosity Index [‡]	5.9 ± 4.2 (0 to 13)
Highest level of schooling	
High school or lower	182 (60.7)
College or university degree	118 (39.3)
Self-rated financial situation	
Comfortable financially	108 (35.2)
Income sufficient to meet basic needs	177 (57.7)
Poor or very poor	22 (7.2)
Self-perceived health compared to others of the same age	
Excellent	48 (15.5)
Very good	121 (39.0)
Good	95 (30.6)
Fair	37 (11.9)
Poor	9 (2.9)
Has recorded healthcare preferences in the event of incapacity	138 (44.2)
Personally knows someone with Alzheimer disease or a related disorder	235 (74.1)
Has accompanied a dying relative or friend through the dying process	221 (69.7)

Likely to write a MAID request should one develop Alzheimer disease (<i>somewhat or extremely likely</i>)	236 (75.9)
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Conditions that should trigger their own MAID request (*n* =236)[§]

Admission to a long-term care facility	40 (16.9)
No longer recognizing loved ones	116 (49.2)
Being completely dependent on others for basic needs	122 (51.7)
Physical pain that cannot be relieved, according to the healthcare team and close relatives	141 (59.7)
Psychological suffering that cannot be relieved, according to the healthcare team and close relatives	117 (49.6)
Having only a few weeks left to live, according to the healthcare team	98 (41.5)
Likely to ask a physician to grant the MAID request of a close relative who would have written one after being diagnosed with Alzheimer disease (<i>somewhat or extremely likely</i>)	224 (74.2)

† Data shown are means ± standard deviations with ranges in parentheses, or absolute frequencies with percentages in parentheses, derived from valid cases. Few data were missing: between 1 for gender, country of origin and race/ethnicity, to 23 for one or more of the four items involved in deriving the religiosity index.

‡ The religiosity index is derived from combining answers to four questions developed by Statistics Canada for the General Social Survey.²⁹ Total scores range from 0 to 13 and are interpreted in three broad categories: low (0 – 5), moderate (6 – 10), and high (11 – 13).

§ Respondents were asked to select a maximum of three conditions among those listed.

Table 2. Final GEE results from testing one between-subject factor (*Group*) and two within-subject factors (*Stage* and *Type of request*) on attitudes towards MAID for an incompetent patient with Alzheimer disease, controlling for age, gender and religiosity

ADVANCED STAGE			
EFFECT	Odds ratio	p-value	95% confidence interval
Written request			
Group			
Older adults	4.9	< 0.001	2.8 – 8.7
Informal caregivers	3.5	< 0.001	2.1 – 5.8
Nurses	1.7	0.014	1.1 – 2.7
Physicians (reference)	1		
Oral request only			
Group			
Older adults	7.7	< 0.001	4.1 – 14.4
Informal caregivers	5.1	< 0.001	2.9 – 9.1
Nurses	2.4	0.003	1.3 – 4.2
Physicians (reference)	1		
TERMINAL STAGE			
Group			
Older adults	5.4	< 0.001	3.1 – 9.4
Informal caregivers	4.8	< 0.001	2.9 – 8.0
Nurses	2.0	0.001	1.3 – 3.0
Physicians (reference)	1		
Type of request			
Written	3.9	< 0.001	3.3 – 4.7
Oral only (reference)	1		

Case overview 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 1 & 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.

Vignettes 3 & 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.

Vignette 5 Assume the patient never requested MAID. The family asks for CDS to alleviate the patient's distress. As artificial nutrition and hydration would not be provided, death should ensue within a few days.

Acceptability of modifying the current legislation to allow MAID at this advanced stage of the disease, in the presence of a prior written request (in black) or assuming (in grey) that the patient had made repeated requests orally but never in writing

Acceptability of modifying the current legislation to allow MAID at this terminal stage of the disease, in the presence of a prior written request (in black) or assuming (in grey) that the patient had made repeated requests orally but never in writing

Acceptability of providing CDS at this terminal stage of the disease

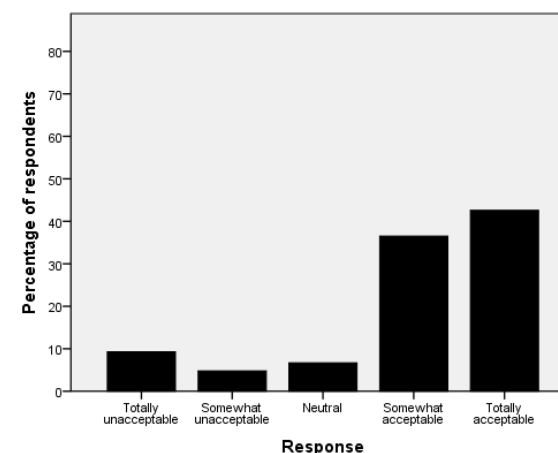
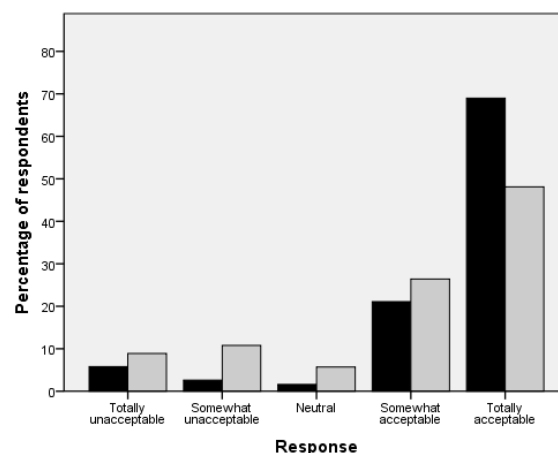
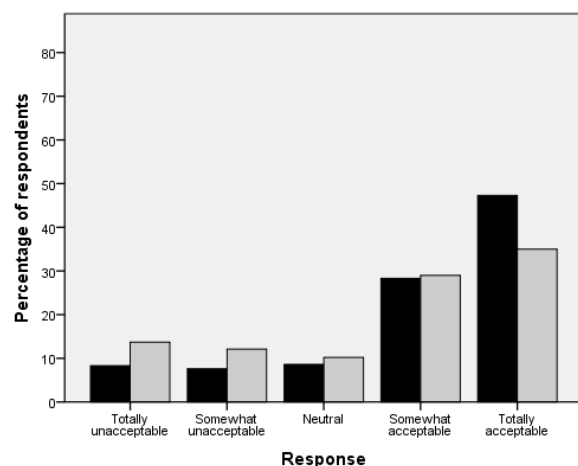
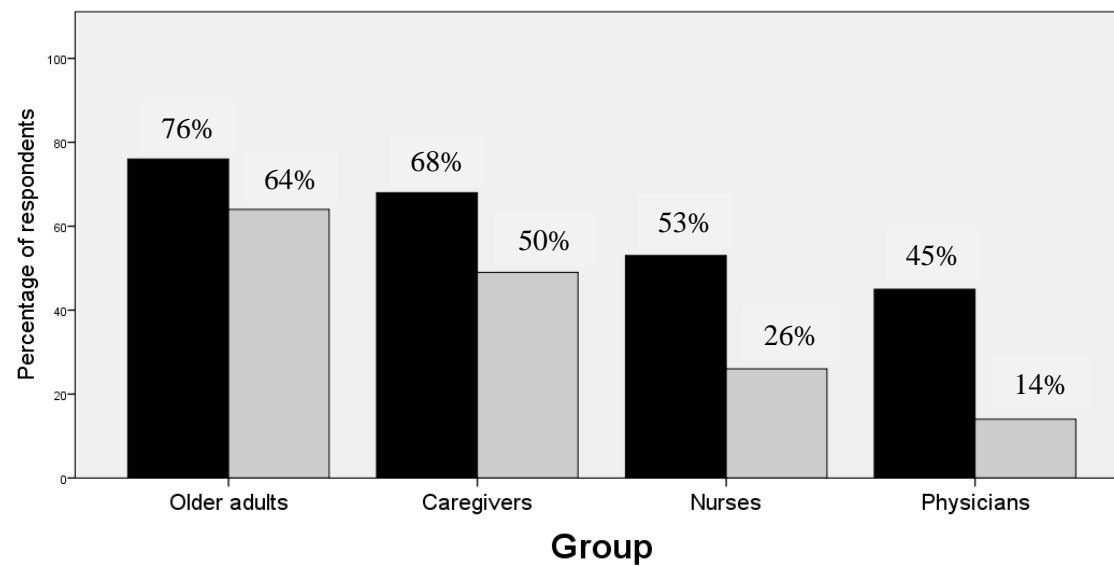


Figure 2

ADVANCED STAGE



TERMINAL STAGE

