

Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec

Vincent Thériault, Diane Guay and Gina Bravo

Volume 4, Number 2, 2021

Éthique et AMM
MAiD Ethics

URI: <https://id.erudit.org/iderudit/1084452ar>

DOI: <https://doi.org/10.7202/1084452ar>

[See table of contents](#)

Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

[Explore this journal](#)

Cite this article

Thériault, V., Guay, D. & Bravo, G. (2021). Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 4(2), 69–77. <https://doi.org/10.7202/1084452ar>

Article abstract

Background: In Quebec, medical aid in dying (MAiD) is legal under certain conditions. Access is currently restricted to patients who are able to consent at the time of the act, which excludes most people with dementia at an advanced stage. However, recent legislative and political developments have opened the door to an extension of the legislation that could give them access to MAiD. Our study aimed to explore the attitudes of people with early-stage dementia toward MAiD should it become accessible to them. **Methods:** We used a qualitative descriptive design consisting of eight face-to-face semi-structured interviews with persons living with early-stage Alzheimer's disease, followed by a thematic analysis of the contents of the interviews. **Results and Interpretations:** Analysis revealed three main themes: 1) favourable to MAiD; 2) avoiding advanced dementia; and 3) disposition to request MAiD. Most participants anticipated dementia to be a painful experience. The main reasons for supporting MAiD were to avoid cognitive loss, dependence on others for their basic needs, and suffering for both themselves and their loved ones. Every participant said that they would ask for MAiD at some point should it become available to incompetent patients and most wished that it would be legal to access it through a request written before losing capacity. **Conclusion:** The reasons for which persons with Alzheimer's disease want MAiD are related to the particular trajectory of the disease. Any policy to extend MAiD to incompetent patients should take their perspective into account.

© Vincent Thériault, Diane Guay and Gina Bravo, 2021



This document is protected by copyright law. Use of the services of Érudit (including reproduction) is subject to its terms and conditions, which can be viewed online.

<https://apropos.erudit.org/en/users/policy-on-use/>



This article is disseminated and preserved by Érudit.

Érudit is a non-profit inter-university consortium of the Université de Montréal, Université Laval, and the Université du Québec à Montréal. Its mission is to promote and disseminate research.

<https://www.erudit.org/en/>

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec

Vincent Thériault^a, Diane Guay^a, Gina Bravo^a

Résumé

Contexte : Au Québec, l'aide médicale à mourir (AMM) est légale sous certaines conditions. L'accès est actuellement limité aux patients qui peuvent donner leur consentement au moment de l'acte, ce qui exclut généralement les personnes atteintes d'un trouble neurocognitif majeur en stade avancé. Cependant, de récents développements législatifs et politiques ouvrent la porte à une extension de la législation qui pourrait leur donner accès à l'AMM. Notre étude vise à explorer le point de vue de personnes atteintes de la maladie d'Alzheimer en stade léger envers l'AMM dans l'éventualité où celle-ci leur serait accessible. **Méthode :** Nous avons employé un devis qualitatif descriptif consistant en huit entretiens semi-structurés avec des patients atteints de la maladie d'Alzheimer, suivis d'une analyse thématique du contenu des entretiens. **Résultats et interprétation :** L'analyse a révélé trois thèmes principaux : 1) favorable à l'AMM ; 2) éviter les stades avancés de la maladie ; et 3) disposition à demander l'AMM. La plupart des participants anticipent que la maladie d'Alzheimer sera une expérience souffrante. Les principales raisons de soutenir l'AMM étaient d'éviter la perte cognitive, la dépendance vis-à-vis des autres pour leurs besoins de base et la souffrance tant pour eux-mêmes que pour leurs proches. Tous les participants ont indiqué qu'ils demanderaient éventuellement l'AMM si elle devenait accessible aux patients inaptes et la plupart souhaiteraient qu'il soit possible d'y accéder via une directive anticipée avant de perdre sa capacité. **Conclusion :** Les raisons pour lesquelles les personnes atteintes de la maladie d'Alzheimer souhaitent l'AMM sont directement liées à la trajectoire particulière de la maladie. Toute politique visant à étendre l'AMM à des patients inaptes devrait prendre en compte leurs points de vue.

Mots-clés

euthanasie, démence, qualitatif, AMM, incompétence, directive anticipée

Abstract

Background: In Quebec, medical aid in dying (MAiD) is legal under certain conditions. Access is currently restricted to patients who are able to consent at the time of the act, which excludes most people with dementia at an advanced stage. However, recent legislative and political developments have opened the door to an extension of the legislation that could give them access to MAiD. Our study aimed to explore the attitudes of people with early-stage dementia toward MAiD should it become accessible to them. **Methods:** We used a qualitative descriptive design consisting of eight face-to-face semi-structured interviews with persons living with early-stage Alzheimer's disease, followed by a thematic analysis of the contents of the interviews. **Results and Interpretations:** Analysis revealed three main themes: 1) favourable to MAiD; 2) avoiding advanced dementia; and 3) disposition to request MAiD. Most participants anticipated dementia to be a painful experience. The main reasons for supporting MAiD were to avoid cognitive loss, dependence on others for their basic needs, and suffering for both themselves and their loved ones. Every participant said that they would ask for MAiD at some point should it become available to incompetent patients and most wished that it would be legal to access it through a request written before losing capacity. **Conclusion:** The reasons for which persons with Alzheimer's disease want MAiD are related to the particular trajectory of the disease. Any policy to extend MAiD to incompetent patients should take their perspective into account.

Keywords

euthanasia, dementia, qualitative, MAiD, incompetence, advance request

Affiliations

^a Faculty of Medicine and Health Sciences, Université de Sherbrooke, Sherbrooke, Canada

Correspondance / Correspondence: Vincent Thériault, vincent.theriault3@usherbrooke.ca

INTRODUCTION

In 2017, it was estimated that close to 50 million people worldwide had Alzheimer's disease, a common cause of dementia, and this number could reach 131.5 million in 2050 (1). The disease is still incurable to this day and its progression gradually affects cognitive functions and the ability to carry out activities of daily living. In the advanced stage, patients can suffer greatly physically and/or psychologically and most are unable to consent to care (2-5). Many of these people fear the state in which they may eventually find themselves, even more than the suffering they may endure at the end of their lives (6-7). At that point, some care options are available, such as refusing life-sustaining interventions and palliative sedation (8). But for those who do not wish to go through the advanced stages of dementia, the only options are then to voluntarily stop eating and hydrating themselves or to take their own life (9). That last option is problematic because the disease eventually leads to an altered awareness state and makes it increasingly difficult to plan a suicide (10). Another option is thus increasingly considered across the world: voluntary euthanasia.

Voluntary euthanasia is legal in Quebec under certain conditions since December 10, 2015. Called medical aid in dying (MAiD) in the legislation, it was originally restricted to, among other conditions, those who are able to consent at the time of the act and who are at the end of their lives, which excludes most people with dementia. It also excludes people living with the disease

who want to access MAiD through an advance request made before losing capacity. Some commentators described this situation as discriminatory; others saw it as necessary to protect vulnerable people (11). In 2017, the government of Quebec opened the door to an expansion of the legislation to some incompetent patients and commissioned an expert panel to reflect on the issue. The expert panel proposed, among other things, to allow the formulation of an advance request for MAiD in anticipation of the inability to consent (12). During that time, a landmark case would also cause the “end of life” criteria to be deemed unconstitutional by the Superior Court of Quebec (13). A bill by the federal government aimed at making changes to MAiD is currently under review (14). If the bill passes, people living with dementia could access MAiD if they are competent at the time of the procedure and are suffering unbearably, but there is no provision to authorize advance requests.

MAiD in the context of dementia involves various specific issues that make it more complex compared to when the ability to consent is still present. Allowing MAiD at the beginning of the disease while the person is still competent risks ending life prematurely, while at the terminal stage it may be impossible to ensure that the person really wants to die due to their inability to communicate clearly (15-16). Some further argue that an advance request for MAiD should not be carried out because the person with dementia could have adapted to their situation or changed their mind (17-25). Moreover, health care professionals and families will likely have difficulty determining when the time has come to administer MAiD (2,18). Finally, some question whether an advance request should ever have authority in the decision to terminate the life of a person who has lost the ability to consent (18,26-28).

Considering that people living with dementia would be the most directly affected by a change in legislation, not taking their opinion into account would be unjust. However, the vast majority of the studies of attitudes toward MAiD in the context of dementia are survey-based and target either physicians, nurses, caregivers of persons with dementia or the general public (29-33). Also, while surveys are valuable for capturing the views of these types of stakeholders, a qualitative approach seems more appropriate to in-depth study of the attitudes, perceptions and emotions of people with cognitive impairment. To our knowledge, only one qualitative study directly investigated this question with participants who had dementia themselves. Daskal *et al* (34) used qualitative interviews to study the attitudes of patients and their caretakers toward hastening death in Illinois, a US state where no euthanasia law was passed at the time or since. Half of their patient sample (n=26) were in favour of euthanasia. The main reasons for support were the desire to have freedom of choice, to avoid suffering and to avoid being a burden to their family, whereas the reasons for not supporting euthanasia were generally related to religious beliefs. The authors concluded that interviewing patients with mild dementia about their opinion regarding euthanasia was feasible and therefore they should be included in these kinds of discussions. In line with this recommendation, and given the paucity of data on this topic, we explored the attitudes of people with early-stage dementia toward MAiD should it become accessible to them.

METHODS

Design

A qualitative descriptive design was chosen for the study. This design entails collecting narrative data to obtain a comprehensive description of individuals' perspectives and allows flexibility to use or not a particular theory or framework (35). Although this design retains an important part of interpretation, it produces results that are closer to the data compared to other qualitative designs (35). This study was approved by the Research Ethics Board of the CIUSSS Estrie-CHUS (file # 2018-2567) and signed informed consent was obtained from all participants.

Participants and procedures

The study took place between February and December 2018. At that time, the expert panel previously mentioned had not submitted their report and the “end of life” criteria was still present in the law. The study was conducted among French-speaking patients admitted at the Memory Clinic of the CIUSSS Estrie-CHUS, in Sherbrooke, Quebec, using a list of previously signed consent authorizing researchers to contact them. To be eligible, participants had to be diagnosed with Alzheimer's disease and still be at the early stage, which was operationalized by a score above 18 on Folstein's Mini-Mental State Examination (MMSE) and/or above 17 on the Montreal Cognitive Assessment (MoCA) test (36,37), recorded in the patient's medical chart within the last two years. All potential participants were previously deemed capable of making decisions for themselves, including giving consent to participate in research.

Following this medical chart review, a letter introducing the study was mailed to potentially eligible participants who were contacted by telephone one week later to gauge their interest in participating. Patients were excluded if the information present in the medical chart or the telephone call revealed potential incapacity or vulnerability that would make it inappropriate to solicit their participation. An interview guide (Box 1) was developed and tested with 3 persons. Zanna and Rempel's revised tripartite model of attitudes was used as an inspiration for its development and also to guide the data analysis process (38). This model postulates that attitudes are based on cognitive (knowledge, beliefs), affective (feelings, emotions), and conative (willingness to act, intentions) information.

Box 1: Interview guide

1. What do you know about MAiD? ^a
2. What do you think of it?
3. How do you feel about the possibility that people with dementia have access to MAiD?
4. What do you think about the possibility of having this choice, personally? How does it make you feel?
5. What would make you consider it? ^b or What would make you not consider it?
6. What should your condition be like for you to request MAiD? ^b
7. How would you expect your decision to be carried out? ^b

a. The interviewer provided necessary explanations to participants who misunderstood the legislation in effect at the time.

b. Asked only to participants who expressed the desire to request MAiD.

Demographic data were collected at the beginning of the interview, which were conducted by the first author (VT), an experienced geriatric nurse. Attitude data was gathered using digitally recorded, semi-structured, face-to-face in-depth interviews with open-ended questions (39). The questions were not necessarily asked exactly as they appeared in the interview guide, nor necessarily always in that order. The interview process was fluid, iterative, and left room for improvisation. Sub-questions and clarification questions were frequently asked depending on the flow of the conversation. Considering their vulnerability and the sensitivity of the topic, participants were given the choice to be accompanied by a person of their choosing to act in a supportive role. All interviews were manually transcribed by VT. In order to enhance the scientific rigor of the study, field notes and reflexive memos were kept to add descriptions of the context of the interviews, record impressions and give insights for the analysis process (40). As the research topic was considered sensitive, information about services available from the local Alzheimer Society was provided, should a participant require further support.

Data analysis

A thematic analysis was conducted to extract key themes from transcripts (41). No analysis software was used. Transcripts were initially coded by VT according to the three components of the revised tripartite model of attitudes and then reviewed by a team member (DG) until consensus was reached. Next, subthemes were clustered together and compared to generate branching categories and ultimately a thematic tree. This process, along with iterative data collection, continued until thematic saturation was reached, that is when further coding added no new relevant themes (42). A thematic journal was used to document thoughts on the formulation of subthemes, thematic groupings and any other element related to data analysis.

RESULTS

Of the 76 medical charts consulted, a total of eight participants were interviewed before reaching thematic saturation. Eight potentially eligible participants refused to participate and 60 were excluded. The latter were excluded mainly because their conditions were more advanced than previously believed, making the interview impossible, or presented a significant vulnerability that could potentially make the interview risky for their psychological well-being. The majority of participants were female (5/8) and their age ranged from 57 to 84 years. The interviews took place at participants' homes and lasted between 30 and 50 min. All but two participants chose to be interviewed in the presence of a close relative. Participant characteristics are presented in Table 1.

Table 1: Participant demographic data

Participant (Fictional name)	Gender	Age	MMSE ^a	MoCA ^a	College or university degree	Accompanied by a close relative	Knows / has known someone close with dementia	Religiosity ^b
Alice	F	84	24	23	Yes	No	Yes	Catholic, believer and actively practicing
Bernard	M	81	23	18	No	Yes	Yes	Catholic, believer and actively practicing
Celine	F	57	25	19	Yes	Yes	No	Catholic, believer but rarely practicing
Denise	F	77	30	26	Yes	Yes	No	Catholic, believer but rarely practicing
Estelle	F	80	26	24	No	Yes	Yes	Catholic, believer and actively practicing
Fernand	M	73	26	22	No	Yes	No	Nonbeliever
Ginette	F	73	26	25	No	No	Yes	Catholic, believer but rarely practicing
Henri	M	66	25	20	Yes	Yes	Yes	Catholic, believer but rarely practicing

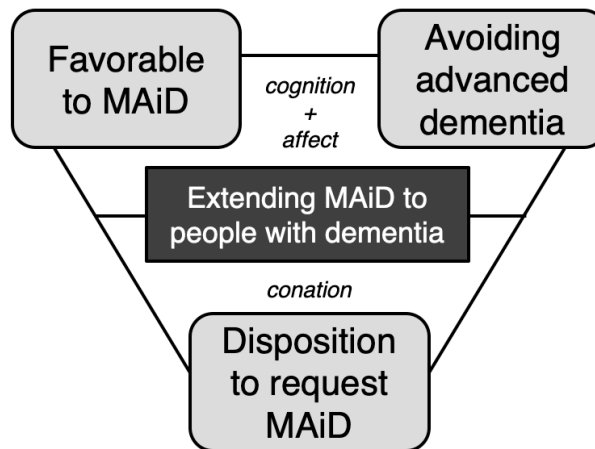
a. on a scale from 0 to 30. Lower scores imply greater cognitive impairment; b. in a population (Quebec) where approximately 75% of people are catholic (43).

MMSE: Mini-Mental State Examination; MoCA: Montreal Cognitive Assessment

Analysis of the transcripts revealed three main thematic categories: 1) favorable to MAiD; 2) avoiding advanced dementia; and 3) disposition to request MAiD. As shown in Figure 1, considering the findings, we grouped the cognitive and affective components of the revised tripartite model of attitudes under two themes because they often emerged together. The third theme corresponds to the conative component. Each theme will be described below and illustrated with verbatim extracts.

Verbatim were translated from French to English by the authors for the purposes of this paper. The translation has been kept as literal as possible.

Figure 1: Main themes



Cognitive & affective components: Favorable to MAiD

All participants expressed positive opinions and feelings toward MAiD in general. They thought it was a good thing to not unnecessarily stretch an unavoidable death, especially if there is suffering. One even viewed MAiD as a favour: “You know...you’re there. It’s a favour if he [a physician] helps you die. You will die anyway.” (Alice) Another participant said that MAiD was preferable to “traditional” suicide because it was painless: “You get a shot and you go. That doesn’t hurt. Instead of going over a bridge and throwing yourself off, or something.” (Fernand) Every participant felt the same way about MAiD in the context of dementia, and so thought that it should be accessible to this population. “If the law was extended to people who probably have the disease or are going to, [...] I think it’s very good.” (Ginette)

Considering the unpredictable progression of dementia, two participants expressed that they would personally be relieved if they could consent to MAiD in advance. “Free from this worry. Relieved that we can move on.” (Henri) The other one echoed that feeling but emphasized the positive impact that advance requests could have for their loved ones: “I could do it in advance for them. Because it’s going to be hard to decide, you know? My family...If I did it in advance, I feel it would be easier.” (Alice)

Cognitive & affective components: Avoiding advanced dementia

Participants had differing reasons for supporting MAiD, but there was a common thread: to avoid the negative consequences that come with advanced dementia. Those reasons were closely related to the particular trajectory of the disease.

Loss of autonomy

Although most participants were still quite independent, the first category of consequences was related to the loss of autonomy in basic functions and dependence on others for their needs. For example, being unable to drive, to speak clearly, to eat by themselves, go to the toilet or just being unable to take care of themselves in general. One participant expressed this loss of independence by her recently revoked driving license: “I had a nice little car. For the last two years I was dragging a little. This year, they [her family] decided it was the end. That, I found hard.” (Denise)

Cognitive impairment

Another category of consequences had to do with the cognitive losses commonly brought on by dementia. All participants already had some degree of cognitive impairments, usually related to their memory, but the severity of impairments varied. However, no matter how advanced they were, participants feared that it would get worse. Most evoked a general fear of cognitive loss, but others were more specific in what they feared. One participant feared the moment when they would no longer recognize their loved ones anymore: “You know, if I can’t recognize the people around me, I do not belong here anymore.” (Alice) Three participants feared that they would get “disconnected”, meaning that they could not really interact with anything or anyone anymore: “Why let them [people with advanced dementia] not be aware of anything? That’s not a life.” (Estelle) Two felt angst at the prospect of not totally being themselves anymore: “Their personality can change. They can perhaps become aggressive. Or they are suffering. [...] I do not want to live when I have no more knowledge, when I will not be myself anymore.” (Ginette)

When the subject of taking a decision for a future-self that may not correspond to the present-self was brought up by the interviewer, that last participant made it clear that the medical team and her family should give priority to what she expressed in her advance request if she was no longer able to make a decision: “[...] when the disease is very advanced, that I am no longer myself and I change my mind. [...] they should listen to me now.” (Ginette)

Suffering of loved ones

Another reason to want MAiD reported by six out of eight participants was to avoid hurting their loved ones or be a burden. It could be related to witnessing their deterioration and/or having to take care of them. “If I keep going, they’re the ones who are going to stay, who are going to have...they are going to have to go through this.” (Bernard) One of these participants seemed even more concerned about the suffering he could be causing to his loved ones than about his own suffering: “I don’t have too much trouble with pain [...]. It’s more for the others.” (Henri)

Personal suffering

Despite generally prioritising the suffering of their loved ones, five participants also feared their own potential suffering, although they were often unclear about what kind of suffering they feared. One participant evoked something akin to an existential suffering: “What would be the value that I would have in life? None.” (Fernand) Another seemed to fear actual physical pain: “I would have to be sick, but really sick, you know? And have pain, especially pain.” (Denise)

Social repercussions

One participant went even further in the consequences that might be avoided with MAiD and inferred that it could bring a social benefit. “Please. We as a society, these people, can we take them to their last rest, and then give the time to people who really need it?” (Henri)

Ultimately, considering that they were all in the early stage of the disease, most participants said that they were not currently suffering that much. But they were aware of the progression of the disease, and all were convinced that the suffering would eventually come for them and their loved ones. “In my mind, which is still there [laugh], I know that at some point it will be worse. For my spouse too...” (Celine)

Conative component: Disposition to request MAiD

All participants made it clear that not only were they in favour of MAiD, but they would personally ask for it at some point should it become available to incompetent patients. They also wanted the opportunity to consent themselves in advance while they still could. “[...] I want to consent while my decision is still in my mind, and I am not too much demented to accept it. [...] It’s good that I decide while I’m lucid. And that I decide for myself.” (Ginette)

One participant noted that he would like to consent himself specifically to spare his family from having to make the decision: “I’d rather that it would be me who decides to leave, so that they do not feel guilty” (Bernard) That being said, all participants made it clear that they would not wish to have MAiD at the point where they were currently in the disease. But *when* they would want to receive it varied widely. For two participants, the time would come when they would be near the end of their life, even though they probably would not be able to consent by themselves anymore. “If there is no more treatment possible, I feel myself deteriorating and there is no coming back. [...] That is, the end is coming.” (Ginette)

In one case, the participant specifically placed the responsibility to determine the right time on the medical team: “When the doctor thinks that there is nothing more to do, it’s time.” (Bernard) For others, MAiD should come much earlier, when the incapacities would become more pronounced. A participant even mentioned that he would ask for MAiD only if he did not have to wait until the end of his life, otherwise he would commit suicide: “Because if I could see myself at such a point [at the advanced stage of the disease], maybe I would kill myself before I get there.” (Fernand)

Two participants mentioned that they would request MAiD when they “get there”, but when that was wasn’t entirely clear. “For me, I would agree. It would be a good thing. When I get there!” (Alice) One of these two participants observed that it was hard to know for sure when exactly MAiD requests ought to be carried out. When asked how far she would let the disease progress, she answered: “How far ... I really can’t say. But what comes to me is that I cannot know for sure.” (Denise)

Considering that MAiD requests would be carried out after they had lost their ability to consent, all participants were confident that either the medical team, their loved ones or both would be able to determine the appropriate moment. “With all the people who are going to be involved in this, I’m not worried about them, they’ll make the right decision. I’m not worried.” (Henri)

DISCUSSION

To our knowledge, this is the first qualitative study to provide insight into the perspectives of persons living with early-stage dementia about MAiD in a jurisdiction where this practice is legal, but as yet only for competent patients. This confirms, as Daskal *et al* (34) concluded, that it is possible although difficult to recruit and interview people with early-stage dementia and so learn their views. The main difficulty was related to the progression of Alzheimer’s disease and the small window of time open for recruitment. It was often found that the potential participants were past the early stage of the disease or had even died since their last cognitive test, which explains in part the low participation rate. For a few participants, the interview process was more challenging due to hearing or speaking difficulties. Some were also a bit nervous, and their discourse was therefore more limited than others. And some had difficulty clarifying their thoughts precisely, so the depth of the discussions varied. However, all participants were able to complete the interview and communicated their appreciation of the experience.

To summarize, every participant wished that it would be legal for them to access MAiD. The reasons for which participants supported MAiD were all related to the negative consequences of dementia, such as suffering and being a burden to loved ones, as found by Daskal *et al.* (34). Participants also expressed that they would personally ask for MAiD at some point, though the moment when the request should be carried out varied. Findings from this small sample concur with those from other stakeholders and the general population in whom high support was found in Quebec for extending MAiD to incompetent patients (30-33,44). In a systematic review of factors influencing opinions on this issue, Tomlinson and Stott (29) found a strong association between being a religious person and being against MAiD. This does not appear to be the case in our sample. Despite almost all our participants reporting that they were religious, none mentioned any argument related to their religious beliefs for supporting or opposing MAiD. Several reported personally knowing someone with advanced dementia, and for some, this seemed to be decisive in them wanting to access MAiD in the future. Clarke *et al.* (45) found that experiencing similar illness in relatives and friends increased the probability of expressing a preference to access “measures to help die peacefully” among different end-of-life care options. This seems consistent with our results.

The main reasons reported for supporting MAiD echo those mentioned by Menzel (46), namely, not wanting to go through severe dementia and what it brings. Most participants viewed living with dementia as a painful experience, but this suffering seems to stem more from the fear of what is to come, as de Beaufort and van de Vathorst (23) argue. In a qualitative study about the expectations of living with dementia, Read *et al.* (47) found that their participants mainly feared the loss of control over their life and the prospect of being a burden to their loved ones. Almost all our participants expressed similar fears. However, a gradual loss of awareness of the disease and its impacts typically comes with dementia (21,48). Moreover, referring to the disability paradox, some authors argue that expected experiences of dementia patients are often more negative than actual experiences (17,20). As such, their case is distinct from that of patients who currently have access to MAiD in Quebec since these mainly base their requests on their current suffering (49,50).

The participants mostly favoured making advance requests rather than letting someone else decide whether and when they would have MAiD. In the Netherlands, where it is legal to carry out advance euthanasia requests in some circumstances, van Wijngaarden *et al.* (25) found that people with dementia who made such a request viewed this as a way to keep some control over their life. However, it also led to some anxiety when they considered issues such as potential changes over time in their desire to die, the possibility of disagreement between the people involved and the difficulty to determine the right moment to carry out the request. Although studies on treatment preferences at the end of life report some stability over time, those preferences tend to be more persistent when they come from individuals with a stable health condition, implying that advance directives would be more difficult to execute in the context of dementia (51,52).

Furthermore, very few physicians agree to carry out advance euthanasia requests in the Netherlands (2,53). The reasons are mainly related to the difficulty of assessing suffering in these patients and the impossibility of confirming their wish to die (53). In Quebec, Bravo *et al.* (30) found considerable support (71%) among physicians to extend MAiD in the terminal stage of the disease, but much less (45%) in cases where the incompetent patient may still have several years to live. This contrasts with the views of most of our participants who not only thought that they should have access to MAiD *before* the latter stages of the disease, but also trusted that the medical team would carry out their request. However, they did not agree themselves on when exactly they should have access to MAiD, which could make it difficult for their family, the medical team and legislators to determine the right time. Regarding this issue, the Dutch legislation allows for competent patients with dementia to draw up an advance request setting out their conditions to carry out euthanasia, as long as it is compatible with the law (16). This can still cause problems, as demonstrated by the criminal trial of a doctor in the Netherlands who administered euthanasia to a patient with dementia whose request could be interpreted in different ways, one of which suggested that she wanted to consent to euthanasia herself when she was still competent (16). Our participants made it seem much more straightforward than what practical experience elsewhere suggests.

STRENGTHS AND LIMITATIONS

This study has several strengths, including its relevance in the current legislative context, the use of a theoretical framework guiding the data collection and analysis, and the study population composed of people living with dementia. People with dementia are most directly concerned by the possible expansion of MAiD to incompetent patients, yet their views have rarely been investigated (29). We therefore believe that this study contributes to a certain social justice, considering that people living in a vulnerable situation have now been heard by public decision-makers. Limitations must also be acknowledged. Although thematic saturation was reached, our sample was homogeneous with regard to ethnicity and religion, which are two factors known to be associated with attitudes toward MAiD (29,54). It is conceivable that other themes would have emerged from participants with different cultural backgrounds. This possibility should be explored in future studies. There is also the possibility of a volunteer bias, meaning that those who chose to participate in the study could be more inclined to support MAiD. We do not know whether eligible persons who refused to participate (n=8) were in favour or not. Furthermore, the wording of some of our questions could be interpreted as being more positive than neutral, for instance when we refer to the fact that MAiD could be a “choice” to which participants would have “access”. Moreover, some authors recommend conducting a validation of the themes with the participants after the analysis to increase internal validity, although others question the true value of doing so (55-57). Considering the declining memory of our participants, which would have potentially decreased the benefit anyway, coupled with their vulnerability and the sensitivity of the research topic, we elected not to do such a validation. Lastly, another potential limit of our study is that attitudes toward alternative end-of-life treatments to MAiD were not explored. We do not think, however, that doing so would have significantly changed the results, for two main reasons. First, most participants were not

worried about physical pain, but rather feared the various losses associated with the disease as well as its impact on their loved ones. Consequently, they would ask for MAiD well before the terminal stage of the disease. Second, Bravo *et al.* (30-33) found high levels of support for extending MAiD among various stakeholder groups (excluding people with early-stage dementia) who were presented with two other end-of-life care options, namely the withholding of antibiotics should the patient develop a life-threatening pneumonia and continuous deep sedation. Nonetheless, future studies could explore whether discussing these options with people with early-stage dementia changes their views on MAiD. Future studies could also probe participants on a scenario in which their future selves' wishes would seem to contradict their current wishes with regard to MAiD, like the example in the Netherlands mentioned earlier.

CONCLUSION

This study explored the views of eight persons living with early-stage Alzheimer's disease related to the possible expansion of the Quebec legislation to give them access to MAiD. While we of course cannot generalize this sample to the entire population in a quantitative sense, our participants' views are favourable, in general as well as for themselves. The participants would personally ask for MAiD at some point if it were legal to do so in order to avoid the negative consequences of dementia. People who are in favour of MAiD generally wish to avoid suffering at the end of life, while people with dementia seem to have other reasons that are related to the particular trajectory of the disease. Indeed, most participants wanted to avoid the multiple losses associated with advanced and terminal dementia and wished to have access to MAiD much earlier. This position differs from that of physicians, who are much less in agreement with the extension of MAiD to incompetent patients who may still have many years to live. Future studies should explore ways to reconcile these views. In the meantime, any policy to extend MAiD to incompetent patients should consider the perspective of all those directly concerned, including people living with dementia.

Reçu/Received: 28/11/2020

Remerciements

Nous remercions tous les participants pour leur temps généreux. Nous remercions également le personnel de la Clinique de la Mémoire du CIUSSS Estrie-CHUS pour leur collaboration. Cette étude faisait partie d'un programme de recherche plus vaste dirigé par GB et financé par la Société Alzheimer du Canada (subvention #16-11).

Conflits d'intérêts

Aucun à déclarer

Publié/Published: 1/12/2021

Acknowledgements

We are grateful to all the participants for their generous time. We also thank the staff of the Memory Clinic of the CIUSSS Estrie-CHUS for their collaboration. This study was part of a larger research program directed by GB and funded by the Alzheimer Society of Canada (grant #16-11).

Conflicts of Interest

None to declare

Édition/Editors: Nico Nortjé & Aliya Afddal

Les éditeurs suivent les recommandations et les procédures décrites dans le [Code of Conduct and Best Practice Guidelines for Journal Editors](#) de COPE. Plus précisément, ils travaillent pour s'assurer des plus hautes normes éthiques de la publication, y compris l'identification et la gestion des conflits d'intérêts (pour les éditeurs et pour les auteurs), la juste évaluation des manuscrits et la publication de manuscrits qui répondent aux normes d'excellence de la revue.

Évaluation/Peer-Review: Andrew Stumpf & Johan Bester

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateurs n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la [Revue canadienne de bioéthique](#) assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

The editors follow the recommendations and procedures outlined in the COPE [Code of Conduct and Best Practice Guidelines for Journal Editors](#). Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

Reviewer evaluations are given serious consideration by the editors and authors in the preparation of manuscripts for publication. Nonetheless, being named as a reviewer does not necessarily denote approval of a manuscript; the editors of the [Canadian Journal of Bioethics](#) take full responsibility for final acceptance and publication of an article.

REFERENCES

1. ADI, Wimo A, Ali G-C, et al. [World Alzheimer Report 2015: The Global Impact of Dementia: an Analysis of Prevalence, Incidence, Cost and Trends](#). London: Alzheimer's Disease International (ADI); 2015.
2. Rurup ML, Onwuteaka-Philipsen BD, et al. [Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands](#). *Journal of the American Geriatrics Society*. 2005;53(7):1138-44.
3. Herrmann N, Gauthier S. [Diagnosis and treatment of dementia: 6. Management of severe Alzheimer disease](#). *Canadian Medical Association Journal*. 2008;179(12):1279-87.
4. Vandervoort A, Van den Block L, van der Steen JT, et al. [Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying](#). *Journal of the American Medical Directors Association*. 2013;14(7):485-92.
5. Midtbust MH, Alnes RE, Gjengedal E, Lykkesler E. [A painful experience of limited understanding: healthcare professionals' experiences with palliative care of people with severe dementia in Norwegian nursing homes](#). *BMC Palliative Care*. 2018;17:25.

6. Menzel PT, Steinbock B. [Advance directives, dementia, and physician-assisted death](#). *Journal of Law, Medicine and Ethics*. 2013;41(2):484-500.
7. Oregon Public Health Division. [Annual Report 14: Oregon's Death with Dignity Act—2011](#).
8. Arcand M. [End-of-life issues in advanced dementia: Part 2: management of poor nutritional intake, dehydration, and pneumonia](#). *Canadian Family Physician*. 2015;61(4):337-41.
9. Menzel PT, Chandler-Cramer MC. [Advance directives, dementia, and withholding food and water by mouth](#). *Hastings Center Report*. 2014;44(3):23-37.
10. Conejero I, Navucet S, Keller J, et al. [A complex relationship between suicide, dementia, and amyloid: a narrative review](#). *Frontiers in neuroscience*. 2018;12:371.
11. Committee on Health and Social Services. [Special consultations and public hearings on Bill 52, An Act respecting end-of-life care](#). Quebec National Assembly; 2013.
12. Ministère de la Santé et des Services sociaux. [L'aide médicale à mourir pour les personnes en situation d'inaptitude : le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence](#). n° 19-828-04W; 2019.
13. [Truchon c. Procureur général du Canada](#), 2019 QCCS 3792.
14. [Loi modifiant le Code criminel \(aide médicale à mourir\), projet de loi n° C-7](#), (dépôt et 1^{re} lecture – 5 octobre 2020), 2^e sess., 43^e légis. (Can.).
15. Cohen-Almagor R. [First do no harm: euthanasia of patients with dementia in Belgium](#). *The Journal of Medicine and Philosophy*. 2016;41(1):74-89.
16. Miller DG, Dresser R, Kim SYH. [Advance euthanasia directives: a controversial case and its ethical implications](#). *Journal of Medical Ethics*. 2019;45(2):84–9.
17. de Boer ME, Hertogh CMPM, Dröes R-M, et al. [Suffering from dementia - the patient's perspective: a review of the literature](#). *International Psychogeriatrics*. 2007;19(6):1021-39.
18. de Boer ME, Hertogh CMPM, Dröes R-M, et al. [Advance directives in dementia: issues of validity and effectiveness](#). *International Psychogeriatrics*. 2010;22(2):201-8.
19. Dees M, Vernooij-Dassen M, Dekkers W, van Weel C. [Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review](#). *Psycho-Oncology*. 2010;19(4):339-52.
20. Hertogh CMPM, de Boer M., Dröes R-M, Eefsting J. [Beyond a Dworkinean view on autonomy and advance directives in dementia. response to open peer commentaries on "Would we rather lose our life than lose our self? lessons from the Dutch debate on euthanasia for patients with dementia."](#) *American Journal of Bioethics*. 2007;7(4):4-6.
21. Hertogh CMPM. [The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia](#). *Journal of Medical Ethics*. 2009;35(2):100-3.
22. Mishara BL, Weisstub DN. [Premises and evidence in the rhetoric of assisted suicide and euthanasia](#). *International Journal of Law and Psychiatry*. 2013 Sep;36(5-6):427-35.
23. de Beaufort ID, van de Vathorst S. [Dementia and assisted suicide and euthanasia](#). *Journal of Neurology*. 2016;263(7):1463-7.
24. Woien S. [Conflicting preferences and advance directives](#). *American Journal of Bioethics*. 2007;7(4):64-5.
25. van Wijngaarden E, Alma M, The A-M. ['The eyes of others' are what really matters: The experience of living with dementia from an insider perspective](#). *PLoS ONE*. 2019;14(4):e0214724.
26. Alvargonzález D. [Alzheimer's disease and euthanasia](#). *Journal of Aging Studies*. 2012;26(4):377-85.
27. Dresser R. [Dworkin on dementia. Elegant theory, questionable policy](#). *The Hastings Center Report*. 1995;25(6):32-8.
28. Jaworska A. [Respecting the margins of agency: Alzheimer's patients and the capacity to value](#). *Philosophy and Public Affairs*. 1999;28(2):105-38.
29. Tomlinson E, Stott J. [Assisted dying in dementia: a systematic review of the international literature on the attitudes of health professionals, patients, carers and the public, and the factors associated with these](#). *International Journal of Geriatric Psychiatry*. 2015;30(1):10-20.
30. Bravo G, Rodrigue C, Arcand M, et al. [Quebec physicians' perspectives on medical aid in dying for incompetent patients with dementia](#). *Canadian Journal of Public Health*. 2018;109(5-6):729-39.
31. Bravo G, Rodrigue C, Arcand M, et al. [Nurses' perspectives on whether medical aid in dying should be accessible to incompetent patients with dementia: findings from a survey conducted in Quebec, Canada](#). *Geriatric Nursing*. 2018;39(4):393-9.
32. Bravo G, Rodrigue C, Arcand M, et al. [Are informal caregivers of persons with dementia open to extending medical aid in dying to incompetent patients? findings from a survey conducted in Quebec, Canada](#). *Alzheimer Disease and Associated Disorders*. 2018;32(3):247-54.
33. Bravo G, Trottier L, Rodrigue C, et al. [Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia](#). *International Journal of Geriatric Psychiatry*. 2019; 34(7):1078-86.
34. Daskal F, Hougham G, Sachs G. Physician-assisted suicide: interviews with patients with dementia and their families. *Annals of Long Term Care*. 1999;7(8):293-8.
35. Sandelowsk M. [What's in a name? Qualitative description revisited](#). *Research in Nursing & Health*. 2010;33(1):77-84.
36. Folstein MF, Folstein SE, White T, Messer MA. *MMSE-2 User's Manual*. Lutz, FL: Psychological Assessment Resources. 2010

37. Nasreddine ZS, Phillips NA, Bédirian V, et al. [The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment](#). *Journal of the American Geriatrics Society*. 2005;53(4):695-9.
38. Zanna MP, Rempel JK. Attitudes: A new look at an old concept. In: Bar-Tal D, Kruglanski AW, eds. *The Social Psychology of Knowledge*. Cambridge, UK: Cambridge University Press; 1988. p. 315-34.
39. Savoie-Zaic L. Chapitre 12 : L'entrevue semi-dirigé. In: Gauthier, B. *Recherche sociale. De la problématique à la collecte des données*. Presses de l'Université du Québec; 2003. p. 293-316.
40. Colorafi KJ, Evans B. [Qualitative descriptive methods in health science research](#). *HERD*. 2016;9(4):16-25.
41. Paillé P, Mucchielli A. *L'analyse qualitative en sciences humaines et sociales*. Armand Colin; 2016. (Collection U. Sciences humaines et sociales).
42. Weller SC, Vickers B, Bernard HR, et al. [Open-ended interview questions and saturation](#). *PLoS ONE*. 2018;13(6):e0198606.
43. Statistics Canada. [National Household Survey \(NHS\) Profile](#). 2011.
44. Leger Marketing. [L'aide médicale à mourir dans les cas de maladie de type Alzheimer au stade avancé ; L'opinion des canadiens. Survey report](#). April 2019.
45. Clarke G, Fistein E, Barclay M, Theimann P, Barclay S, Holland A. [Preferences for care towards the end of life when decision-making capacity may be impaired: A large scale cross-sectional survey of public attitudes in Great Britain and the United States](#). *PLoS ONE*. 2017;12(4):e0172104.
46. Menzel PT. [AEDs are problematic, but Mrs A is a misleading case](#). *Journal of Medical Ethics*. 2019;45(2):90-1.
47. Read ST, Teye C, Wynaden D. [Experiences and expectations of living with dementia: A qualitative study](#). *Collegian*. 2017;24(5):427-32.
48. van Delden JJM. [The unfeasibility of requests for euthanasia in advance directives](#). *Journal of Medical Ethics*. 2004;30(5):447-51.
49. Wiebe E, Shaw J, Green S, Trouton K, Kelly M. [Reasons for requesting medical assistance in dying](#). *Canadian Family Physician*. 2018;64(9):674-9.
50. Seller L, Bouthillier M-É, Fraser V. [Situating requests for medical aid in dying within the broader context of end-of-life care: ethical considerations](#). *Journal of Medical Ethics*. 2019;45(2):106-11.
51. Auriemma CL, Nguyen CA, Bronheim R, et al. [Stability of end-of-life preferences: a systematic review of the evidence](#). *JAMA Internal Medicine*. 2014;174(7):1085-92.
52. Hertogh CPM. [The misleading simplicity of advance directives](#). *International Psychogeriatrics*. 2011;23(4):511-5.
53. de Boer ME, Dröes R-M, Jonker C, Eefsting JA, Hertogh CPM. [Advance directives for euthanasia in dementia: Do law-based opportunities lead to more euthanasia?](#) *Health Policy*. 2010;98(2):256-62.
54. Williams N, Dunford C, Knowles A, Warner J. [Public attitudes to life-sustaining treatments and euthanasia in dementia](#). *International Journal of Geriatric Psychiatry*. 2007;22(12):1229-34.
55. Tracy SJ. [Qualitative quality: eight "big-tent" criteria for excellent qualitative research](#). *Qualitative Inquiry*. 2010;16(10):837-51.
56. Morse JM. [Critical analysis of strategies for determining rigor in qualitative inquiry](#). *Qualitative Health Research*. 2015;25(9):1212-22.
57. Sandelowski M. [Rigor or rigor mortis: the problem of rigor in qualitative research revisited](#). *Advances in Nursing Science*. 1993;16(2):1-8.