Hastening death for people with dementia: An exploratory literature review

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Executive Summary

Final Exit Network (FEN) provides education and support to those who want choice in dying. FEN staff have reported that people facing dementia frequently seek information about the possibility of hastening death, and FEN polls suggest that substantial proportions of the public support choice in dying for individuals facing dementia. However, approaches to hastened death, including Medical Aid in Dying (MAiD), in the context of dementia have received relatively limited attention. The purpose of this project was to 1) explore the scientific literature on peoples' attitudes and beliefs related to hastening death in the context of dementia, 2) support FEN's efforts to provide educational resources to these individuals, their families, and the public, and 3) support training for FEN volunteers who are working with individuals with dementia.

The research team conducted multiple exploratory reviews of peer-reviewed scientific literature and used artificial intelligence assistance to explore patterns and connections across a wide range in the literature. After several iterations, we identified twelve articles that were relevant to our goals. These articles addressed key themes related to reasons for seeking a hastened death (autonomy and control, dignity and respect for persons, and concern for social burden), issues with timing of a hastened death, and recommendations for improving education and planning related to hastening death.

The literature that we identified was limited in some critical ways. Most articles focused on ethical issues or the acceptability of choosing a hastened death, rather than expanding upon the many complex issues that individuals must consider. With few exceptions, the literature focused on medically-supported forms of hastening death, such as MAiD or VSED. This fails to acknowledge the lack of access to MAiD for persons with dementia in the U.S., and it ignores other mechanisms that people may use to hasten their death. Overall, we found a strong tendency for considerations of hastening death to be stigmatized or pathologized in the literature as suicidal ideation. And finally, the few articles that focused on dementia tended to ignore individuals' own perceptions and experiences, instead they described the perceptions of family caregivers and health care providers.

Several issues, if addressed, would contribute constructively to the gaps we identified in the research and also would serve FEN's goals. First, the perspectives of people facing dementia should be prioritized as much as possible. Next, to improve our support for this population, we must understand the complex aspects of anticipated suffering experienced by people facing dementia, the nuances of their perceptions of being a social burden, and the complicated issue of timing for those who choose a hastened death. We recommend a small-scale research project that will leverage the experience of FEN's volunteers, particularly those who work directly with individuals who are considering hastened death, to explore these issues systematically.

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With the advancements of medicine and diagnostic assessments, as well as an increasing global life expectancy, the prevalence of dementia has been increasing[1,2]. According to the World Health Organization[3], 57 million people worldwide had dementia in 2021. The importance of appropriate care for people at all stages of dementia has been well documented[4,5,6,7]. That said, medical aid in dying and hastening death has received limited attention in the context of dementia, particularly when compared to the ways in which these issues have been explored in the context of other illnesses[8].

Final Exit Network (FEN) is an organization whose mission is "to educate and support those who want choice in dying"[9]. In 2021, FEN in collaboration with YouGov conducted a poll exploring people's level of support for the option to hasten one's own death when faced with dementia. Their results indicated that a majority (53%) of the 1,148 U.S. adults surveyed agreed that a person in early-stage dementia who expressed a desire to use the mechanism of voluntarily stopping eating and drinking (VSED) to hasten their deaths once they entered late-stage dementia should have their wishes supported. Additionally, a substantial minority (44%) of poll respondents supported the idea that people with dementia should have access to a means to end their life peacefully in early-to-moderate stages of the disease, i.e., before they lose the ability to care for themselves[10]. This substantial level of support for access to a chosen death for people faced with dementia is consistent with FEN's mission and with the experience of its program volunteers, many of whom speak regularly with individuals and families facing dementia diagnoses and who understand the logistical and emotional complexities of these decisions. We have partnered with FEN to explore the scientific literature regarding people's attitudes and beliefs related to hastening death in the context of dementia, with the long-term goal of supporting FEN's efforts to identify information and support needs for these individuals and their families, develop educational resources on this topic, and provide additional support and training to FEN volunteers who may be working with individuals with dementia.

Medical Aid in Dying

Medical Aid in Dying (MAiD) is a treatment option that centers around respecting individual autonomy, dignity, and humanity at the end of life[11], governed by a legislative process. Other terms that are associated with MAiD are "hastening death," "death with dignity," and "physician assisted suicide." Hastening death is a broader term, compared to MAiD, because it is not restricted by legal systems[12]. Although MAiD is a globally recognized term, in the U.S., MAiD is legal in only 11 states (i.e., California, Colorado, Delaware, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington). To be eligible for MAiD in the U.S., the person must to be 1) an adult (i.e., 18+ years), 2) terminally ill, with a prognosis of six months or less, 3) mentally capable of making their own decisions, and 4) physically capable to

self administer the oral medication prescribed by the physician[13,14]. Additionally, two different health care providers must confirm the person's prognosis, the person must make two separate requests for MAiD, and the person must be aware of all possible options for end-of-life care[11]. The majority of MAiD recipients in the U.S. are white, educated, older adults, and dying from cancer[15,16]. Of note, in the U.S., MAiD medications must be self-administered, and not everyone who is prescribed MAiD decides to hasten their death by taking the medication they receive[16].

Overall, MAiD is controversial and often debated regarding the ethical practices, policy regulations, and interpretations of research[17,18]. Despite the fact that a majority of respondents in surveys of healthcare workers, informal caregivers, and the general public express support for MAiD[19,20], conversations regarding MAiD are stigmatized, institutional support is limited, and barriers exist to accessing MAiD[21]. Our goal is not to argue whether MAiD is acceptable, but rather to understand the perspectives, concerns, and educational needs of people who are considering a hastened death in the context of a dementia diagnosis.

MAiD and Dementia

Although people with dementia who wish to hasten their death may receive MAiD services in Canada, Switzerland, Netherlands, or Belgium[22,23,24], only Switzerland allows non-citizens to use their healthcare system for this purpose, and the logistical and financial barriers to doing so are significant for United States' residents. As stated earlier, MAiD requirements in the U.S. include the person must be cognitively competent and be considered within six months of their death. People with dementia almost never meet these criteria simultaneously. People in early to moderate stages of dementia are not eligible for MAiD because prognoses at these stages exceed six months. By the time a dementia prognosis approaches six months, the person's cognitive functioning hinders their ability to make their own decisions and they may be declared incompetent to do so[25]. Employing VSED to accelerate a six-month terminal prognosis and thereby becoming eligible for MAiD earlier in the course of dementia has been explored[25]. However, this strategy is controversial[26]. Thus, in the U.S., MAiD is largely inaccessible to individuals with a dementia diagnosis who wish to hasten their deaths.

Purpose of This Review

The goal of this review is to explore recent literature and provide a conceptual analysis of the attitudes toward hastening death, in the context of dementia. We hope to support FEN's work to identify information and support needs for those in this group who are considering a hastened death option. To address our goal, we identified three key questions:

- For people with dementia, what are their attitudes (e.g., fears, concerns, worries) towards MAiD or other forms of hastened death?
- For people with dementia, what information do they need or desire that could best support their decision-making?

- What information, resources, or education are needed for family members or loved ones of those with dementia who are considering hastening their deaths?

Methods

Our team (an epidemiologist, a bioethicist, and two psychologists) conducted multiple exploratory reviews of the peer-reviewed scientific literature, discussed our findings, sought consensus on next steps, and hand-selected relevant articles.

Exploratory Literature Reviews

Our first search of multiple databases (including but not limited to, PsycINFO, MEDline, and PubMed) focused on concepts and constructs within our key questions (i.e., people with dementia, caregivers, attitudes, MAiD and hastened death, and educational supports) yielded over 8,500 articles. We then filtered irrelevant terms such as staff, nurses, and included only peer-reviewed studies in the U.S. and Canada within the last five years (see Table 1). Of the 255 studies selected, we determined that very few articles directly addressed our key questions. In a second exploratory review, we widened our inclusion of relevant terms and narrowed our search by excluding non-relevant diseases (e.g., cancer, HIV/AIDs, and COVID-19) and non-relevant populations (e.g., adolescents or pediatrics; see Table 2), and limited it to the last 3 years. The second review resulted in 275 articles, within which we again found little to no cohesion.

Artificial Intelligence: ResearchRabbit

To find more relevant literature we turned to an artificial intelligence tool to explore patterns and connections in the collective literature. ResearchRabbit is a free online tool that uses citation analysis and artificial intelligence to help researchers explore academic literature[27]. By starting with a few "seed" or "best fit" papers, ResearchRabbit then identifies papers in the broad scientific literature that are most likely to be related to those "seed" papers based on citation networks and thematic similarities. We, as a team, identified twelve "seed" papers that consistently appeared across our two exploratory reviews, were commonly cited across reviews, or were determined to be relevant to our goals. ResearchRabbit generated a map of these twelve papers (see Figure 1), which highlighted two distinct areas of research: ethical debate of hastening death and end-of-life care for individuals with dementia. Unfortunately, ResearchRabbit did not connect these areas of research, signaling to us that the literature has not directly addressed our goals; rather, the literature has captured aspects of our goals, but separately.

Results

We identified three central themes in the twelve "seed" articles: reasons for seeking a hastened death, issues with timing of a hastened death, and recommendations for improving educational and planning services related to hastening death. We also identified three sub-themes

within reasons for seeking a hastened death: autonomy and control, dignity and respect toward persons, and concern for social burden.

Reasons for Seeking a Hastened Death

Eight out of the 12 articles focused on reasons why people with dementia or cognitive impairment may seek hastening death: autonomy and control, dignity and respect toward persons, and concern for social burden.

Autonomy and Control. Five articles focused on autonomy and control; those articles included scope reviews[28,29], systematic reviews[30], and survey data[31,32]. The articles included older adults in long-term care[28], people with dementia[29], and people with irremediable health conditions[30,31,32] and consistently found that people prioritize having a sense of autonomy and control, especially toward the end of life. The sense of control may come from the ability to accelerate the timeline of an impending death and avoid future losses[31], as well as to maintain control over the physical, psychological, existential, spiritual, and social dimensions of daily life[30,31,32].

Blake[31] investigated the moral locus of control in people with irremediable health conditions who were considering hastening their death. Blake[31] described an intuitive moral comfort level with the choice to end one's life when faced with irremediable health conditions, which is distinct from the social impediments and public ethical controversies to doing so. He positioned and separated the choice of individuals within the social and legal arguments about such a choice, and found that people who were planning to hasten their death had different personal, spiritual, and moral perspectives than the general population. He reported on education, spiritual identity, belief in an after-life, source of moral authority and locus of control. However, he did not assess participants by diagnosis, so while Blake[31] provided relevant background information about those with terminal diagnoses who are planning a hastened death, his results were not specific to people with dementia.

Rodríguez-Prat and colleagues[30] described anticipated suffering as affecting attitudes toward hastening death in those with life-threatening illnesses, however, they did not specifically address the ways in which anticipated suffering may differ depending on diagnosis (e.g., for persons with cancer versus dementia), but did note that anticipated suffering included fears related to pain and hopelessness, which may lead to distress, loss of control, or burden to loved ones. Rodríguez-Prat and colleagues[30] characterized individuals' wishes to hasten their deaths as an expression of a desire to limit the duration of their suffering, to exert autonomy and self-control to the end of life, and to take affirmative action to reduce the anticipated suffering of their loved ones.

Anderson and colleagues[29] explored the feasibility and acceptance of advanced care planning in older adults with dementia. They found that persons over 65 years of age diagnosed with dementia were generally accepting of MAiD to maintain autonomy, quality of life, and independence, and to avoid physical impairments and future suffering. They also found that informal caregivers say they would request MAiD, if they were themselves diagnosed with

Alzheimer's disease. Additionally, people with cognitive impairment were more likely to have Do Not Resuscitate (DNR) orders, in comparison to people without cognitive impairment[29].

Dignity and Respect toward Persons. Four articles identified dignity and respect towards persons: a survey of informal caregivers on their attitudes toward MAiD[33], a systematic review[34], and a meta-ethnography of people with life-threatening illnesses who wish to hasten death[30], and qualitative interviews of caregivers on their attitudes toward hastened death for those with dementia[35].

Bravo and colleagues[33] focused on Canadian caregivers' attitudes towards MAiD and the controversy surrounding advanced requests for MAiD as the disease progresses. (For more information on the difference between "advance requests" and "advanced directives," see the Council of Canadian Academies[36].) They provided the informal caregivers with a hypothetical scenario of Mrs. Jackson, who had recently witnessed her father die of dementia and was now diagnosed with dementia herself. The participants followed Mrs. Jackson's decision-making process, while being prompted to articulate their own attitudes towards MAiD in the context of Mrs. Jackson's experience. For example, 89% of informal caregivers agreed with the statement: "Many patients at later stages of dementia do not die with dignity"[33]. One caregiver, in particular, explained: "I do not understand why we take away someone'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" [33]. The emphasis of "someone's right to decide" and "honouring their wishes" acknowledges the unique decision-making process of the person.

The systematic reviews conducted by Rodríguez-Prat and colleagues[30] and Rodríguez-Prat and colleagues[34] identified patients' perspectives on reasons to seek a hastened death in the context of life-threatening illnesses (e.g., cancer or HIV/AIDS). Having a terminal illness threatens a person's sense of identity, thus, seeking a hastened death is a way to regain a person's dignity[34]. Rodríguez-Prat and colleagues[34] argued that people may seek to hasten death when their basic needs as a person are unmet. Even individuals who perceive hastening death as acceptable centered their reasoning on the fact that they are "still a person"[35], suggesting a need for preserving a sense of self, which is potentially threatened when someone is close to death. Tomlinson and colleagues[35] identified a consistent tension among participants, particularly on the rights of the individual versus the common good. Participants supported improved autonomy for individuals, yet were concerned with the overall need for support in dementia care (e.g., treatment options), noting that dying people often are dependent on other people and systems, which may lead to personal devaluation[30].

Concern for Social Burden. Four articles highlighted concerns for social burden: a survey of informal caregivers[33], a meta-ethnography of patient experiences[30], and qualitative interviews of informal caregivers[35,37]. Two of these articles explored hastening death in the context of people with dementia[33,35]. Social burden was examined as a multidimensional construct (i.e., social, psychological, physical, and financial domains). One participant from Bravo and colleagues[33] unpacked the complexity of social burden: "My father's dementia is draining us physically,

emotionally and financially…My father would be horrified to know the grief he caused…I cannot stress in strong enough terms how angry I am with the medical system…I do not support MAiD. At the same time, I would definitely choose MAiD if I had dementia…I could not put my children through it…" Similarly, the family caregivers interviewed by Tomlinson and colleagues[35] emphasized the ways in which family burden could influence an individual facing dementia. In the words of one participant: "How would I react if somebody said, 'Your children have got to care for you, we cannot provide a home, your children must cope'."

Smolej and colleagues[37] explored the roles of family caregivers in the context of MAiD and referenced caregiver burden specifically in this context. Many caregivers described the process of seeking information about MAiD from their health care team as cumbersome, and they expressed a desire for more transparency from the medical team about the option. They expressed strong support for their loved ones' autonomy in deciding to use MAiD, and explained that MAiD allowed them to focus on spending the last moments with their loved ones, rather than being distracted with caregiving responsibilities, because it gave their loved one a feeling of relief from indignities and suffering.

Timing of a Hastened Death

Four out of the 12 articles discussed timing in relation to a hastened death, specifically in the context of people with dementia[8,30,35,38]. These articles included a commentary[8], systematic reviews[30,38], and a qualitative study[35]. Cain and Quill[8] was the only article we found that focused substantially on timing issues. They described how historical changes in end-of-life care imposed a six-month standard time frame for terminal illness, which is still embedded in care and reimbursement practices and policies, though that timeframe has become outdated in many situations due to advancements in medicine. People with dementia are estimated on average to have a prognosis of six to eight years, meaning people with early dementia are often *too early* to begin decision-making about hastening death, but then *too late* as the disease progresses to make those decisions because of competence issues[8].

Although the other articles did not directly address the timing of decisions, they captured features of why timing is especially salient for people with dementia. Tomlinson and colleagues[35] focused on caregivers' attitudes toward hastening death for those with dementia and emphasized the complexities that caregivers describe when considering this option from the frontlines. Timing was described as a general part of the complexity of decision making, but specific references to time from diagnosis or to expected death were not addressed. Rodriguez-Prat and colleagues[30] identified a key theme of "lived experience of a timeline towards dying and death," which encompassed a paradoxical sense of time. For example, when a person has a terminal illness, they are aware that time in general is running out, yet due to the broader context of the illness (e.g., inability to engage in previous activities) time may feel slow and drag on. One participant described time as "waiting and waiting, too often, extended, prolonged, so long, on and on…"[30]. Similarly, Tomlinson and colleagues[35] noted most people who wished to hasten their death described themselves as "waiting for death."

Tomlinson and Stott[38] included attitudes toward assisted dying in those with dementia. Interestingly, they reported the differentiated acceptability in physician assisted suicide, depending on what stage of dementia a person has. They found that the public perceived physician assisted suicide acceptable for people with severe dementia when those individuals requested this when they still had cognitive capacity (i.e., advance request). In contrast, they found that people with dementia and caregivers were hesitant about physician assisted suicide in advanced stages, but were supportive of physician assisted suicide during early stages of dementia.

Education and Planning Services Related to a Hastened Death

Four out of the 12 articles focused on recommendations for improving education and planning services for people who may seek a hastened death: a scope review of available resources for professionals and family caregivers[28], qualitative studies of caregivers[37,39], and a meta-ethnography of patient perspectives[30]. Although hastening death in the context of dementia diagnosis was not directly addressed, the articles explored advanced care planning for people with dementia.

These articles consistently acknowledged the need for better communication and education for end-of-life decisions. In terms of communication, Alford and colleagues[28] highlighted the importance of more "frequent" and "in-depth" end-of-life conversations. Most of the responsibility to initiate death-related conversations (e.g., advanced care planning) is on the individual to explore, rarely was the conversation initiated from the healthcare worker[37]. Smolej and colleagues[37] proposed having a liaison to explain the different legal aspects. Additionally, Alford and colleagues[28] found a positive association between utilization of resources and frequency of conversations among families and health care physicians, suggesting the need for more formalized resources to facilitate conversations. Former caregivers revealed their frustration with the lack of training and stigmatization healthcare professionals may have with end-of-life conversations[35], and expressed a desire for healthcare professionals to initiate these conversations more readily with patients and families[37].

Bavelaar and colleagues[39] described an adaptive, informative booklet – *Comfort Care Booklet* – published in Canada 2005 and modified for several other European settings. The adaptations differed in the types of treatment addressed, in particular tube feeding, euthanasia, and spiritual care, with some countries' booklets excluding at least one of these topics entirely. The booklets also vary across countries in their emphasis on patients' previously expressed wishes regarding medical decisions, and on existential dilemmas at the end of life. The authors identified core elements (i.e., typology of treatment and symptoms, patient and family rights and wishes, typology of decisions at end of life, indirect and explicit messages, descriptions of prognosis, and the relationship between healthcare worker and family caregivers) of end-of-life care to family caregivers of people with dementia in an effort to define optimal palliative care in dementia.

Gaps and Limitations

The main goal of our review was to provide information that would help FEN in their support for people who wish to hasten their death in the context of dementia. We identified three central themes and three sub-themes from selected literature that we believe address some important issues relevant to this goal. However, although our search was exhaustive, we noticed substantial gaps and limitations in the relevant literature. These gaps and limitations are fourfold: the literature 1) mainly focuses on the acceptability and ethical issues surrounding a hastened death, 2) avoids non-medically mediated approaches to hastened death, 3) stigmatizes "suicidal" ideation, and 4) heavily ignores individual perspectives to a hastened death.

Focuses on Acceptability and Ethical Issues

Within our searches, most articles on attitudes about hastened death in dementia tended to focus on the acceptability and ethical issues surrounding the issue[29,33,35,38,40]. Although individuals and their families certainly wrestle with issues of acceptability or ethics of choosing a hastened death, very few articles addressed the psychological, social, and existential questions that are often at the core of a desire for a hastened death, such as "How can I put my children through this?"

Avoids Non-Medically Mediated Approaches

The literature we identified focused almost exclusively on medically-mediated approaches to hastening death, such as physician assisted suicide[41] and MAiD[42]. This also included VSED[26], given that medical providers are typically involved to monitor the patient and provide supportive medications[25] (e.g., anxiolytics). The literature is essentially silent regarding non-medically mediated approaches to hastening death, including the inert gas method or other approaches. The literature also is silent about the limits on access to VSED and MAiD in many assisted living or nursing care facilities, even though these limits add significant complexity to patients' decisions about a hastened death.

Stigmatizes and Misconceptions of Suicide

The focus in the literature on medically-mediated and legally sanctioned approaches to hastening death may be related to a similar limitation we observed in the literature, namely the tendency to characterize and pathologize a desire to hasten one's death as a "suicidal" impulse or ideation. We found several articles characterizing end of life decisions as "suicide" or "suicidal ideation"[43,44,45]; and Tomlinson and colleagues[35] noted that some individuals in their study were hesitant about even inquiring about options for a hastened death for fear that they would be "pathologized as depressed." Although no evidence has supported concerns that access to MAiD could increase rates of suicide[46,47,48], the frequent conflation of suicide with hastened death has limited our understanding of the careful thought and complexities that go into a decision to hasten death for many people, including those with a dementia diagnosis.

Ignores Individuals' Perspectives

It was challenging to find articles specific to individuals' perspectives as most articles focused on other populations of interest, such as nurses, general public, or informal caregivers[33,35,37,38]. This may be due to the challenges with researching "vulnerable" populations[18], as well as related to the other gaps and limitations addressed above (e.g., if a research team's focus is on acceptability and ethics, then collecting data from the public and authority figures is appropriate because they are informing political decisions; if their focus is on medical approaches, then collecting data from medical professionals is appropriate because they are directing and managing these interventions). Although we recognize the valuable perspectives from healthcare professionals, informal caregivers, stakeholders, and the general public, these perspectives cannot speak to the lived experiences of individuals who are facing dementia and considering a hastened death.

Discussion

The gaps and limitations discussed above substantially limit the existing literature's usefulness for FEN's goal of supporting people with dementia in exploring their choices, including the choice to hasten their death. Due to the insufficient evidence to address issues people with dementia may have when navigating the possibility of a hastened death, the literature cannot adequately support those who seek to assist them, be they informal caregivers, healthcare workers, or organizations such as FEN.

Although suffering is not unique to people with dementia, it may be qualitatively distinct from other terminal diagnoses. The reviewed literature highlighted suffering due to a terminal illness as a factor that may influence the decision to hasten death. However, few articles examined the heightened or extended experiences of suffering that could be associated with a dementia diagnosis. A dementia diagnosis can vary in terms of its trajectory and the progressive loss of functioning; that is, suffering may be specific to each person's experience. Living with dementia often involves a form of anticipated suffering that was not well-explored in the literature. People are often aware in the early stages of the disease that they will, at multiple undefined points in the future, experience changes and losses in their mental and physical functioning; simultaneously, they are aware that there are few meaningful and accessible dementia-related treatments. Thus, people with dementia can feel relatively helpless in the face of these changes, which compound and accumulate over time. These experiences of compounded helplessness are related to themes we identified in our review of the literature, such as personal control, dignity and respect, and social burden, but none explored the perceptions and experiences of people living with dementia and how these issues influence their thoughts and choices regarding a hastened death.

Although the literature identified concerns about social burden as a potential factor related to hastened death, the meaning of social burden is especially complex and salient for individuals facing dementia. For example, a person who strongly fears being a burden to their

loved ones may be more likely to seek a hastened death, regardless of their diagnosis. But dementia has a unique trajectory, including many years in which people are unable to live independently and will require increasingly intensive caregiving; this is in comparison to other terminal illnesses (e.g., cancer), in which a person may have a longer period of being independent and shorter timeframe of intensive care. People facing dementia may have nuanced, detailed, and particularly emotionally driven concerns related to being a burden to others. These concerns may include the desire to avoid creating burden *for others* (i.e., avoiding the stigma or shame of depending on others), the desire to not be a burden *at all*, independent of its effects on others (i.e., the strong intrinsic value some hold for independence or autonomy), and the desire to not burden *loved ones* (i.e., caregiving often means the loss of functioning and self is both a witnessed and shared experience). These issues may be further complicated by accessibility and affordability of formal structures to provide care (i.e., assisted living, "care homes," or nursing facilities), as well as cultural expectations of independence and autonomy. These complex issues related to perceived burden were not well-addressed in the literature.

The literature also did not address the issue of timing of the decision to hasten death, nor did it explore the ways in which dementia may affect individuals' perspectives of timing. Cain and Quill[8] were the only authors who addressed timing explicitly, in terms of how traditional frames of "terminal prognosis" (i.e., a prognosis of six months or less) are problematic for those facing dementia. Yet more specific timing issues may be particularly crucial for people facing dementia; that is, the stage of diagnosis and time to expected death. Between these separate time points is the unknown rate of cognitive decline, which affects decision making, independence, type of care and burden on informal caregivers and systems. Earlier diagnoses could extend the time frame for those who want to consider a hastening death. Additionally, there have been improvements in diagnostic tools, such as identifying genetic risk factors and testing for other biomarkers, which could lead to more people receiving earlier diagnoses. FEN's opinion poll[10] revealed that a substantial proportion of the general public support the desire to hasten one's death for people with dementia, even prior to losing the ability to make medical decisions for themselves. Although informative, these opinions are not of people with dementia or who are at risk for dementia. Therefore, it is unclear the perspectives and decision-making timeline for people with dementia regarding a hastened death.

Future Directions

This literature review provides insight and guidance in the shaping of future research, which could address the identified gaps and provide support to the individuals and families who are making decisions related to dementia care and hastening death. Below we outline a qualitative research project that could provide insight into the issues that would be helpful for FEN's educational efforts and contribute to a neglected aspect of the scientific literature.

Title: FEN Exit Guides' perspectives on the decision to hasten death among persons with dementia: An interpretive phenomenological analysis.

Purpose: To explore and define the issues that are most salient to clients and families who are facing dementia and considering a hastened death, based on the experiences of volunteers who have been tasked with educating and supporting them.

Participants: Individuals who are serving as Exit Guides for FEN or who have served as Exit Guides in the past (to be included, we recommend that participants have served as an Exit Guide for at least two FEN clients within the last 18 months).

Method: Four to five semi-structured focus groups of approximately four guides each, using an interpretive phenomenological analysis (IPA) approach. IPA is a qualitative research method that is participant-oriented and that emphasizes the lived experiences of individuals who have experienced similar events or phenomena[49]. Although IPA was originally conceptualized as an approach to be used with individual interviews, we concur with Love and colleagues[50], who argue that IPA can be used in focus groups successfully, particularly when such groups can "[capitalize] on the peer-to-peer interactions and rapport, especially in an homogeneous sample with shared experiences on sensitive and stigmatizing topics."

The structure and size of the focus groups ensures that every participant has a full opportunity to share their perspectives and experience, in keeping with the IPA approach. Focus groups would invite participants to share their general experience with the questions and concerns about hastened death that are expressed by FEN clients and their families; then to share clients' and families' perceived benefits of, barriers to, and/or concerns regarding hastened death. Facilitators would then ask participants to consider how dementia shapes these same issues – questions and concerns regarding perceived benefits and barriers – specifically for clients with dementia and their families. In keeping with the themes and gaps identified in this literature review, follow-up questions would focus on the ways in which participants perceive issues of autonomy, control, dignity, perceived burden, and timing affecting the decisional processes of clients and their families. Focus groups would be audio recorded and transcribed; and key codes would be identified, using an inductive coding approach assisted by qualitative coding software. Initial themes identified after the first two focus groups, would be validated or revised based on subsequent focus groups.

Time: 18 to 24 months, including IRB review and approval, recruitment and training of student assistants, recruitment and scheduling of focus groups, completion and transcription of focus groups, and data analysis. The timeline does NOT include writeup of study results for dissemination to academic conferences or journals. The research team would collaborate with FEN to determine dissemination plans for the results, including in FEN press releases, presentations at scientific meetings, or articles in scientific journals.

Cost: Costs will be primarily related to the research team's time (15-20% time for a principal investigator to lead the research, 50% time for a graduate or undergraduate assistant, and $15,000

for senior research advisors, if needed), $400 for transcription software, $750 for qualitative analysis software, and $2,000 for travel costs associated with presenting results at a national scientific conference. We estimate that total direct costs for this project would be approximately $60,000. Indirect costs would be set by the university with which FEN chooses to contract, and these may depend on whether FEN has set a policy on indirect cost limits.

Importance/implications of results: Results will provide insight into the key issues and themes that FEN Exit Guides encounter as they support the educational and decisional processes of clients, who are considering a hastened death in the context of dementia. The project would be a unique contribution to the existing research literature. It would also provide detailed guidance for shaping the questions that would be most useful to explore in future research, which could include collection of qualitative or survey data focused on attitudes and concerns regarding end-of-life issues from individuals in very early stages of dementia. Projects could also include a survey of family members or loved ones of those living with dementia regarding these issues. Other research questions may emerge that are of interest to FEN leadership as well.

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Table 1. *First exploratory review to examine hastening death in the context of dementia.*

Topics	Inclusion Terms	Exclusion Terms
Population	"early stage dementia" or "cognitive impairment"	"staff," "physician," "stakeholders," "nurses," or "nursing"
Perspectives	"patient perspectives"	"ethics" or "ethical"
Procedure	"Medical aid in dying" or "hastened death"	

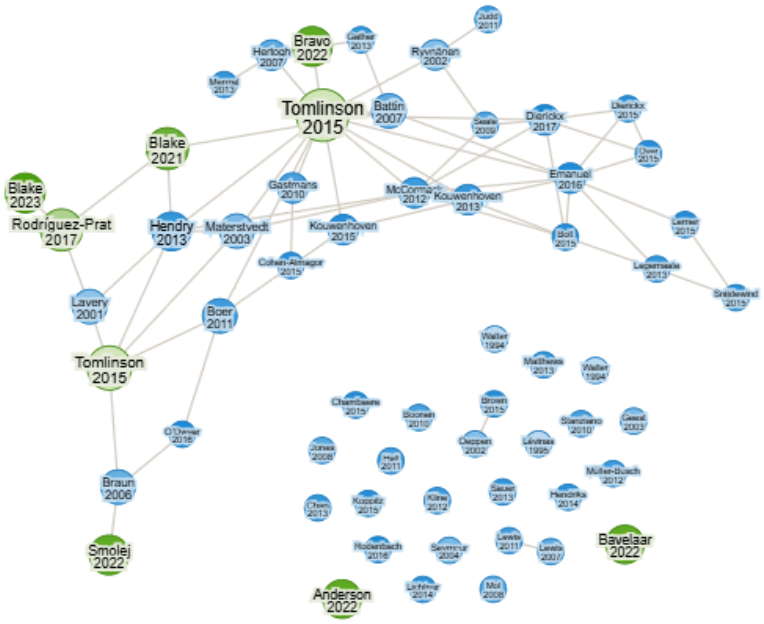
Note. We narrowed the search to be published in the U.S. or Canada, as well as be peer-reviewed and published within the last 5 years.

Table 2. *Second exploratory review to examine hastening death in the context of dementia.*

Topics	Inclusion Terms	Exclusion Terms
Population	"early stage dementia," "cognitive impairment," or "dementia"	"staff," "physicians," "expert," "social worker," "stakeholders," "nurses," or "nursing"
		"cancer" "kidney" "HIV" "COVID-19," or "diabetes"
		"adolescents" or "pediatric"
Perspectives	"patient," "perspectives," "attitudes," "fears," or "suicide"	"ethics" or "ethical"
Procedure	"Medical aid in dying," "medical assistance in dying," hastened death," "end-of-life care," or "death conversations"	

Note. We narrowed the search to be published in the U.S. or Canada, as well as be peer-reviewed and published within the last 3 years.

Figure 1. *ResearchRabbit generated literature mapping.*



Note. The green circles are our "seed" articles and the blue circles are the similar works generated by ResearchRabbit. The connected lines are establishing "reference to" work. The content from the upper cluster is mainly debating the controversy on MAiD being acceptable and ethical. And the content from the lower cluster is outlining the needs of people living with dementia.