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REVIEW ARTICLE

Family involvement in euthanasia or Physician Assisted Suicide and dementia: A systematic review

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Abstract

Objective: To assess how families are involved in situations of euthanasia or physician assisted suicide (PAS) in dementia.**Design:** Systematic review searching literature in nine databases from inception up to October 2021. We included studies on family involvement in euthanasia from the perspective of persons with dementia and family caregivers. Themes were formulated through thematic analysis. The design was registered at Prospero (CRD42022298215).**Results:** We assessed 215 of 4038 studies in full text; 19 met the inclusion criteria of which 13 empirical studies. Themes included for people with dementia: being a burden; stage of dementia, and permissibility of euthanasia/PAS. Themes for family were the burden of care, responsibility toward the euthanasia or PAS wish, permissibility of euthanasia/PAS.**Conclusion:** The wish for euthanasia/PAS arises in situations of burdensome care and fear of future deterioration. The family feels entrusted with the responsibility to enact upon the death wish. In shaping this responsibility, four roles of family can be distinguished: carer, advocate, supporter, and performer. Family as in need of support themselves is understudied.

KEYWORDS

dementia, ethics, euthanasia, family, PAS, physician-assisted suicide

1 | INTRODUCTION

Euthanasia and physician-assisted suicide (PAS) in persons with dementia are the subject of debate. Both are currently legal in The Netherlands, Belgium, Luxemburg, Canada, Colombia, and Spain, and PAS is legal in Switzerland and in some states in the United States. Rules and regulations differ between these countries but central requirements of due care are similar (Box 1). Physical suffering due to cancer, multiple sclerosis (MS) or amyotrophic lateral sclerosis (ALS) is usu-

ally the basis for a euthanasia or PAS request. The Netherlands has 20 years of experience with a euthanasia and PAS law. The number of requests from people with dementia is rising, mostly in an early stage of dementia.¹ Dutch physicians are reluctant to perform euthanasia in dementia, particularly in more advanced stages, but public opinion tends to be more permissive.^{1,2} It is conceivable that countries that recently developed laws on assisted dying laws will see a trend of increasing requests from people with dementia in the coming years.

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BOX 1 Rules of due care

Rules of due care

- The request is voluntary, free of external pressure, well considered, and persistent.
- The suffering is unbearable and there is no prospect of improvement. In some countries this is limited to physical suffering or patients are eligible only when terminally ill with a life expectancy of <6 months.
- The patient is informed about the situation and the prospect.
- There is no reasonable alternative.

Procedural requirements:

- The physician has consulted at least one other physician who must have seen the patient and given a written opinion of the due care criteria. Some countries instigate special committees to make the final decision.
- The physician follows the procedure of due medical care and attention.

Advocates of euthanasia in dementia refer to the strong argument for individual autonomy and self-determination that underpins euthanasia and PAS legislation. In line with this, in public debates and ethical studies, family relationships are often approached as primarily problematic because of the moral complexity they entail. Family may have other priorities and interests than the person who desires euthanasia and there is also the risk of undue pressure^{3,4} or limiting of self-determination.⁵ Perhaps as a result of this, the meaning of relations and the social embeddedness of people, and of family in particular, have been overlooked and are underrepresented topics in empirical research on euthanasia.⁶

There is evidence that family does matter when it comes to decisions concerning life or death. Empirical research on the actual practice of euthanasia indicates that physicians involved in the process of euthanasia take the well-being of loved ones into consideration when they decide whether or not to grant a request.^{7,8} Family also matters to the person who is requesting euthanasia. Research shows that arguments for wanting euthanasia, besides pain relief and dignity, are also related to family. People do not want to be a burden to loved ones, do not want to become completely dependent on their care, and they feel responsible for their happiness.^{6,9–12} These studies concerning the role of family in euthanasia did not have people with dementia as their main target group. However, qualitative studies from eight countries show that relations are central to a good end of life with dementia.¹³ Relations can be complex in dementia. Dementia can have a wide range of potentially detrimental social consequences such as isolation, exclusion, and social distancing of both the person and their close family members.^{12,14–17} When the disease progresses, people become increasingly dependent upon their family, not only for their physical needs but also to sustain their identity and to speak on their

RESEARCH IN CONTEXT

1. **Systematic Review:** The authors searched nine databases for relevant literature on euthanasia, physician-assisted suicide (PAS), dementia, and family. Themes were formulated through thematic analysis.
2. **Interpretation:** Three ethical issues surfaced from the themes and finding four possible roles of family involvement in euthanasia/PAS and dementia: (1) the self-evidentness of caring, (2) the relational dimension in euthanasia/PAS, and (3) distinguishing between the personal and the general in the way family and people with dementia think about euthanasia/PAS.
3. **Future directions:** The four roles that family take on when their loved one has a euthanasia/PAS wish can inform policy and practice to improve dialogue and provide support in navigating the moral dilemmas that family, the person with dementia, and health care professionals encounter. For this, a deeper exploration of the personal perspectives of people with dementia on family-related reasons for wanting to die and the way that family is involved in the process of euthanasia/PAS is needed.

behalf when their autonomy and self-determination is reduced. This implies that family is an important factor in discussing euthanasia or PAS in dementia.

Given this importance and complexity of family involvement in euthanasia or PAS and dementia, and the observed lack of attention to this aspect in the literature, the aim of this systematic review is to provide a comprehensive overview of international literature on family involvement in euthanasia or PAS and dementia. The research question addressed in this review is: How is family actually involved in situations of euthanasia or PAS and dementia, and how do people with dementia and their family perceive this involvement? Based on the findings, we highlight ethical issues of involvement of family and discuss relevance for policy.

2 | METHOD

We take ethical issues in the broad sense of all moral aspects of the experiences of dementia and the euthanasia wish and not in the narrow sense of, for example, whether euthanasia in dementia is permissible or not. Relatives think morally when reflecting on the good life or flourishing of the other and their specific responsibility for this as family members. Topics such as health, dignity, suffering, and care are all morally charged topics for which it may be relevant to consider family involvement.

This review was registered in Prospero, registration number: CRD42022298215. To identify relevant publications, we conducted

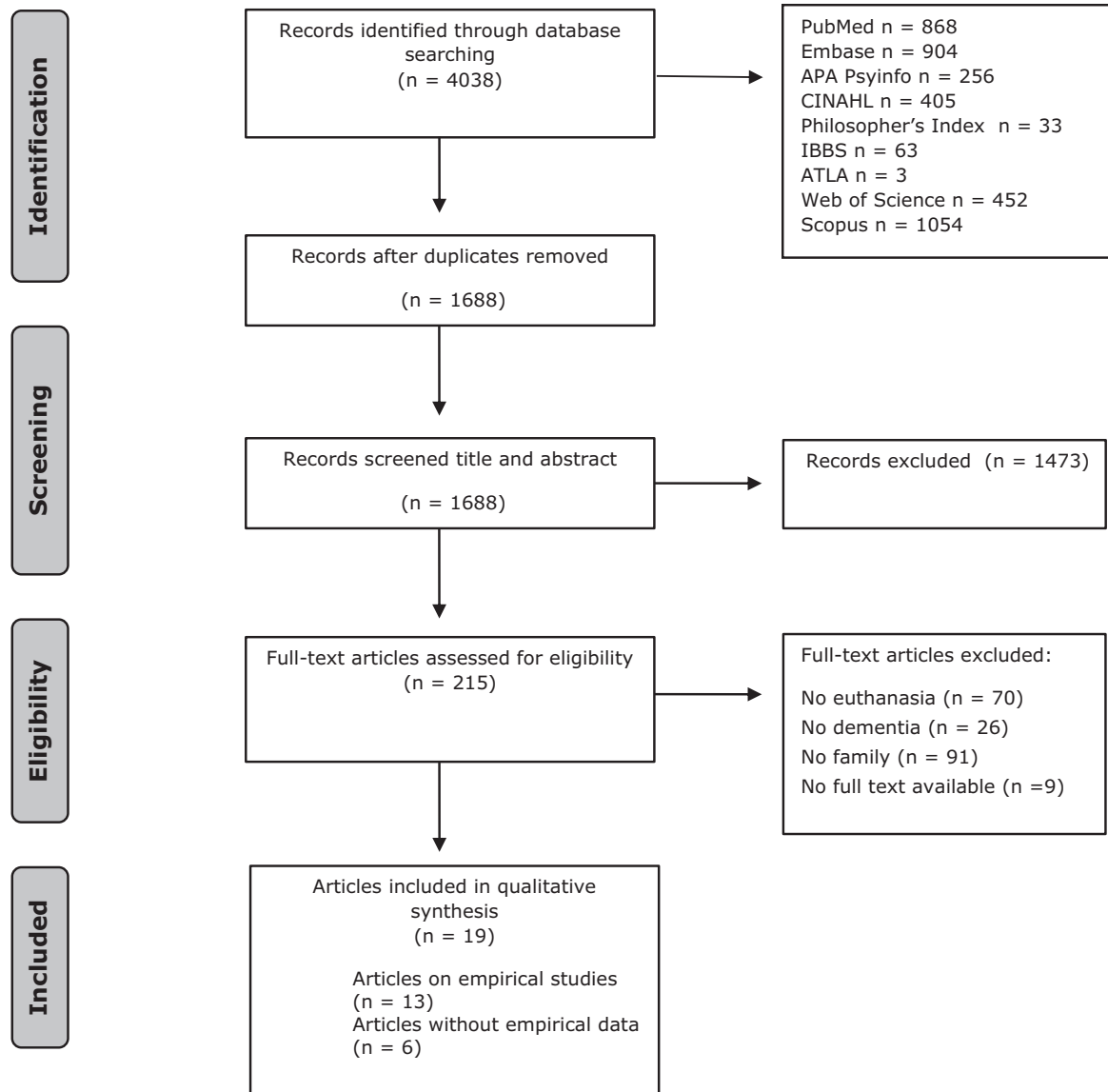


FIGURE 1 Flowchart of the search and selection procedure of articles.

systematic searches in the bibliographic databases PubMed, Embase.com, APA PsycInfo (Ebsco), CINAHL (Ebsco), Philosopher's Index (Ovid), IBSS (ProQuest), ATLA (Ebsco), Web of Science (Core Collection), and Scopus from inception up to September to October 2021 (Supplement A, search strategy and exact dates). Broad inclusion criteria were developed for a sensitive search because a pilot search indicated that studies were scarce. The following terms were used (including synonyms and closely related words) as index terms or free-text words: "Assisted suicide," "Euthanasia," "Dementia," and "Alzheimer's disease." The reference lists of the identified articles were searched for relevant publications. Languages other than English, Dutch, German, and French were excluded. This review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Figure 1).¹⁸

2.1 | Selection process

Two reviewers (TSF and AKvL, PS, or JvdS) independently screened all potentially relevant titles and abstracts for eligibility. Next, two researchers (TSF and AKvL) independently screened full-text articles for eligibility. Differences in judgment were resolved through a consensus procedure with the other researchers.

The definition of euthanasia used in this review is common in the countries that legalized euthanasia or PAS. Euthanasia is the deliberate act with the intent to end someone's life at their own request to relieve suffering. The physician carries out this request by administering lethal medication. We speak of PAS when the patients ingest the lethal medication themselves.¹⁹ The demarcation given by these two definitions means that all other end-of-life treatments, such as cardiopulmonary resuscitation, foregoing or discontinuing tube

feeding, (palliative) sedation, "passive" euthanasia or life-sustaining treatments are not considered euthanasia, and such reports are therefore excluded. Huntington's disease, AIDS, and amyotrophic lateral sclerosis (ALS) can cause symptoms of dementia but these diseases give rise to different questions concerning euthanasia or PAS and are not representative for people with dementia more generally. Therefore, we excluded such studies. Because the focus was on research that investigates the views of people with dementia and their family themselves, we also excluded research that was limited to investigating the views of health care professionals or the general public.

We included empirical studies with qualitative and quantitative data. Two reviewers (TSF and JvdS) independently evaluated the methodological quality of the full-text articles using the Mixed Method Appraisal Tool (MMAT, Supplement B). A third independent evaluation was conducted by another team member (PS) and two epidemiologists who were not involved in this review for four articles for which one author (JvdS) knew the authors. We also included non-empirical articles on ethical issues concerning the position of family in situations of euthanasia and dementia such as theoretical studies, commentaries, editorials, essays, (hypothetical) case studies, and literature studies.

Extraction of data from all articles was done by TSF; a second researcher (PS or AKvL) independently extracted the data of half of the included articles. Findings were discussed in the research group. The data were analyzed through thematic analysis²⁰ with an inductive approach to synthesize opinions, values, knowledge, and experiences of persons with dementia and their family.

3 | RESULTS

After removing duplicates, the literature search generated a total of 1688 references, of which 215 were screened in full text. A total of 19 articles met the full inclusion criteria: 12 empirical studies, 1 systematic review (Table 1), and 6 were non-empirical articles, ethical essays, background stories, and commentaries (Table 2). Four studies were from The Netherlands, and three were from the United Kingdom, four studies were from the United States, two studies were from Canada, and one each was from Switzerland, Belgium and New Zealand; two studies were conducted online and targeted English-speaking posts, mainly in the United States and the United Kingdom. The MMAT quality scores varied considerably (Table 1).

In answering the research question on how the family is actually involved in situations of euthanasia and dementia, and how people with dementia and their family perceive this involvement, we found two themes from the perspective of people with dementia and three themes from the perspective of family (Table 3).

3.1 | People with dementia

3.1.1 | Being a burden

One study shows that people with dementia do not want to be a burden to family,²¹ and in another study, being a burden is a frequently men-

tioned reason for wanting PAS.²² Ethicist Gastmans argues that the fear of becoming a burden is greater than the fear of death among people with dementia and a euthanasia wish. Especially the high emotional price of caring that loved ones have to pay weighs heavily on them.²³ The legitimacy of the fear of being a burden on one's family as motive for wanting euthanasia is heavily debated but also supported.²⁴

A study on the preferences of end-of-life care shows that the interviewed people with dementia were not aware of the burden their families were already experiencing. They spoke about being a burden as something that could happen in the future but not as something that was already a reality in the present.²¹

People with dementia seem to be content with their lives at the moment but fear the future when dementia progresses, in particular suffering and loss of dignity.^{25,26} A nominal group study (UK) shows four, central preferences regarding future end-of-life care among people with dementia: maintaining family ties, independence, feeling safe, and not being a burden.²¹ When people in favor of PAS were asked what they would consider to be good care at the end of their lives, not one mentioned PAS or euthanasia. Frequent responses were "with family around" and "at home with help."²²

In an ethnographic study,²⁶ the narrative of a future with dementia "as a life not worth living" turns out to be a driving force behind the request for euthanasia. Other research displays the fear of future suffering as fundamental to a positive attitude toward euthanasia,^{22,27} which can lead to wanting euthanasia or PAS or writing an advance directive.^{25,28} However, one qualitative study found that it is difficult for people with dementia to consider their future self and the potential burdens that their disease may generate for those around them.²¹

The actual burden of a future of living with dementia can differ from the anticipated one. Studies based on observations of people with dementia point out their ability to adapt, find meaning, and experience sufficient quality of life, which can lead to a diminishing death wish.²⁹⁻³¹ One researcher mentions that the idea of a future with advanced dementia may sometimes be more frightening for patients than the actual experience.²⁶

3.1.2 | Stage of dementia and permissibility of euthanasia or PAS

The two 1990s studies asked people with dementia directly about their opinion on PAS. The first is a US study on early stage dementia.²² It shows that more people were in favor of PAS than against it and that >50% of the patients would want to have PAS as a personal choice. The second study (UK) concerned a later stage of dementia.²⁷ The researchers asked older people if PAS is permissible in incompetent patients at the request of a relative designated in advance by the patient. Twenty-three percent of the respondents had dementia. Compared to respondents without dementia, they were more likely to oppose PAS, with an odds ratio of 3.3. Regarding the reasons for being in favor of PAS, the second most named aspect after relieving pain, was that it is a personal choice that each individual should make for themselves. In the study on end-of-life care,²¹ people with dementia do not explicitly talk about euthanasia but state that they would

TABLE 1 Articles reporting on empirical studies.

| Study | Country | Design | Population and sample size | Objective | Key results | MMAT |
|-------------------------------------|--|-----------------------|---|--|--|-------------------------|
| 1 Anderson et al. (2019) | USA and UK | Internet blogpost | Family caregivers of people with dementia, 9 blogs and 2345 blog posts | To examine expressions of suicidality and homicidality in the blogs of family carers | Complexities and high moral burden of caring for a loved one with dementia who wants to die. Concerns of family about surrogate decision-making. Thoughts of euthanasia by the care recipient and reflections on own death by the family member | 60% |
| 2 Bravo et al. (2018) | Canada | Survey | 306 Family caregivers of people with dementia | To investigate if family caregivers are open to extending MAiD to persons with dementia and exploring their arguments | Two thirds of family find MAiD acceptable for people with dementia; this is higher with a written request when competent. 65% find it likely to ask a physician to grant a close family members request for MAiD | 100% |
| 3 de Boer et al. (2011) | The Netherlands | Survey and interviews | Questionnaire 434 physicians, interviews with 11 physicians and 8 family members | To gain insight into how an advance directive for euthanasia affects resident care for people with dementia in Dutch nursing homes | Physicians and family are reluctant to adhere to an AED mostly due to the difficulties in communication. AED has a supportive role in end-of-life treatments. | Qual. 50% uan. 67% |
| 4 Daskal et al. (1999) | USA | Interviews | 26 people with dementia and 24 family members | To explore views of family and people with dementia on PAS | >50% support for euthanasia in dementia among patients and family members. Willingness among family to assist their loved one in their wish to die. | Qual. 75% uan. 87.5% |
| 5 Dehkhoda et al. (2020) | Facebook users from USA, Canada, Australia, New Zealand and the UK | Netnography | 5 Facebook communities of family members that were virtual representations of non-profit organizations that promote of advocate assisted dying laws for mentally incompetent adults | To explore how the practice of assisted dying for people with dementia is conceptualized and understood | Burden of care and the moral dilemmas that come with it. High support for assisted dying due to experiences of pain and suffering, loss of joy and dignity. Family experiences personal moral dilemmas in thinking about the death of their loved one. | 80% |
| 6 Harrison-Denning et al. (2013) | UK | Nominal group study | People with dementia (6) and their family caregivers (5), dyad of people with dementia and family caregivers (6) | To explore whether people with dementia and their family caregivers were able to generate, prioritize and influence preferences for end-of-life care | Family and people with dementia have different end-of-life care preferences and wishes. Significant for both are family contact, quality of care and dignity. The need for control over quality of care induces the request for euthanasia. People with dementia have no sense of the burden they generate on their family caregivers. | 80% |

(Continues)

TABLE 1 (Continued)

| Study | Country | Design | Population and sample size | Objective | Key results | MMAT |
|----------------------------------|-----------------|-------------------------|---|---|--|------|
| 7 Koenig et al. (1996) | UK | Survey | 168 elderly patients who were attending a geriatric specialty clinic and their accompanying family member (146) | To examine and compare attitudes of elderly geriatric patients and their family members toward PAS | 34% of patients and 55% of family is in favor of PAS for incompetent patients. Family is poor in predicting the attitude of their family member toward PAS. | 100% |
| 8 Lemos Dekker (2020) | The Netherlands | Participant observation | People with dementia, their family and professional caregivers | To examine how the request for euthanasia by people with dementia offer insight into the work of anticipation and time | People with dementia and their families fear a future with dementia, this is fundamental to a request for euthanasia. Family is very much involved in the process. | 100% |
| 9 Loizeau et al. (2019) | Switzerland | Survey | 64 physicians and 168 family members and professional guardians people with dementia | To describe and compare physicians and surrogate agreement with the use of assisted dying and CDS in advanced dementia | 47% of family members and 20% of physicians agreed with assisted dying in advanced dementia. | 67% |
| 10 Roscoe et al. (1999) | USA | Survey | 57 persons caring for a family member or friend with dementia and 46 individuals not in caring roles | To compare attitudes toward PAS and mental state of caregivers of people with dementia and non-caregivers | 40% of people caring for a family member with dementia are in favor of assisted dying. Levels of depressive symptoms and stress was not related to attitudes toward PAS | 100% |
| 11 Rurup et al. (2006) | The Netherlands | Survey | Physicians, nurses and family members | To investigate attitudes of physicians, nurses and family members toward medical en-of-life decisions concerning patients with dementia | Family attaches more importance to advance directives than physicians and have a more permissive attitude toward hastening death. 74% of family respondents finds euthanasia permissible for incompetent patients if they signed an advance directive. | 100% |
| 12 Tomlinson et al. (2015) | UK | Interviews | 16 bereaved family caregivers of people with dementia | To explore the views of bereaved family caregivers on assisted dying in dementia | Existential, physical, psychological and psychosocial suffering were identified as potential reasons for wanting euthanasia | 75% |
| 13 Tomlinson et al. (2015) | | Systematic review | Healthcare professionals, people with dementia, family caregivers and the general public | To review international literature on attitudes toward assisted dying in dementia | High support for euthanasia and PAS in dementia from family and inconsistency among people with dementia. Being white, male and non-religious are important factors for endorsing euthanasia or PAS. | |

TABLE 2 Articles without empirical data.

| | Author(s) | Title | Type of article | Key findings |
|---|-----------------------------------|--|---|---|
| 1 | Brindley, P. G. (2008) | "Good grief": what is a son—and a doctor—to do? | Commentary, personal story. Reflections of a son and physician about his mother's death leading up to an argument in favor of PAS legislation. | The moral responsibility from the patient (mother) toward the family (son) in defending her wishes. Feelings of guilt and powerlessness of not being able to relieve suffering as a son and physician. Plea for assisted death with careful regulations to ensure a dignified death. |
| 2 | Egan, T. (1990) | As memory and music faded, Alzheimer patient met death | Background story, news article. Personal story about a 54-year-old mother with Alzheimer's disease receiving PAS and the involvement and support of her family in the process. | The diagnoses of Alzheimer's disease are the reason for planning PAS. This decision is discussed and supported in the family and considered a family affair. The family belief strongly in the personal right to decide when to die if you have a terminal illness. Quality of life and dignity are contributing factors. |
| 3 | Hertogh, C.M. Ribbe, M. W. (1996) | Ethical aspects of medical decision-making in demented patients: a report from the Netherlands | Ethical essay | Distinguishment between societal and medical professional norms. Respect for autonomy is not an absolute but a reciprocal limiting principle. Family has a role in interpreting an advance directive. Adhering to an advance directive in incompetent patient is unethical and morally reprehensible because (1) it imposes a too heavy burden on family and physicians and (2) the prerequisite of unbearable suffering cannot be undoubtedly ascertained. |
| 4 | Gastmans, C., De Lepeleire (2010) | Living to the bitter end? A personalist approach to euthanasia in persons with severe dementia | Ethical essay | Overwhelming physical and mental burden of care. The fear of becoming dependent on others and becoming a burden is greater than the fear of death. Individual autonomy is more an ideal than an actual condition. In the personalist view the focus of care on relationships, personal autonomy is a prerequisite. Care is an ethical task and a calling coming from within implying an ethical demand. |
| 5 | Lewin, T. (1996) | Life and death choice splits a family | Commentary, news article. Account of a custody battle of a son over his father with dementia trying to prevent PAS. | The wish to die of a father (and physician) with Alzheimer's disease creates a profound and complex family conflict between children and parents. Family responsibility felt by some children and spouse to support the decision and by a son (and physician) to actively prevent it. Wanting PAS affects family and community. |
| 6 | Malpas, P. J. (2009) | Do those afflicted with dementia have a moral duty to die? A response to Baroness Warnock | Ethical essay | Distinguishes duties from moral duties. Family relationships bring responsibilities but little is written about duties that elderly parents have toward grown children. Especially in relation to a putative duty to die when they generate a burden of care. People cannot have a moral duty to die. But duties to others cannot be so demanding that we must give to the point of exhaustion and that our lives and goals are adversely affected. |

Abbreviations: AED, advanced euthanasia directive; MAiD, medical assistance in dying; PAS, physician-assisted suicide.

TABLE 3 Themes from the perspectives of people with dementia and family.

| | Perspective | Theme |
|---|--------------------------------|---|
| 1 | People with dementia | A. Being a burden B. Stage of dementia and permissibility euthanasia or PAS |
| 2 | Family of people with dementia | A. The burden of care B. Responsibility toward the euthanasia and PAS wish C. Permissibility of euthanasia or PAS |

"rather be dead" or "better off dead" when completely dependent on others in late-stage dementia. The most recent study²⁶ adds that people with dementia anticipate this late stage dementia with a euthanasia request but frequently postpone the actual moment of euthanasia with the real consequence that they end up in the stage they were trying to avoid.²⁶

3.2 | Family of people with dementia

3.2.1 | The burden of care

Various studies show how, in the course of the disease process, care by the family members themselves becomes increasingly difficult^{26,32,33} and affects the well-being of family and friends in general.³³ One study finds that the most important aspects in caring for their loved one is being in control, having a good quality of life, having good quality care, and having a comfortable death.²¹ An ethical study distinguishes the physical, practical burden of intense daily care from the mental burden due to grief, feelings of guilt, and shame.²³ Another study³² indicates that the burden of care can lead to "passive thoughts" of the care recipient's death, particularly when the person with dementia opposed the possibility of being a burden to their families. A nominal group study²¹ shows that spousal carers seem to accept their role more than children or siblings; the latter mention the overwhelming difficulties of caring.²¹

Experiencing the burden of care first hand makes family members reflect on their own future if they would have dementia. Family members do not want to go through the same experience, and several studies show that most of them would want euthanasia for themselves if that were the case.^{22,31-34} Two studies explicitly mention becoming a burden on their children as insurmountable and damaging the relationship.^{21,31} In a netnographic study among family, the fear of being or becoming a burden to family members is named as a relevant factor in the desire for an assisted death in dementia.³³

3.2.2 | Responsibility toward the euthanasia wish

Family members can feel a moral obligation to act on the euthanasia wish of their loved one. A Dutch study²⁹ shows that relatives or representatives are most often the ones that initiate the discussion about

an advance euthanasia directive when their loved one has become incompetent. Other studies also show that there is a willingness on the part of family to seek help²² or initiate the conversation about euthanasia when their loved one has become incompetent.³⁴ Elderly care physician and ethicist Hertogh states that a euthanasia request from family members can only be considered if there is no doubt that this is consistent with patient's actual wish, had they been competent. Yet in practice this is hardly ever the case because of emotional bonds between the patient and the family. Hertogh does, however, see an important role for family in interpreting the advance directive in particular "deciding when a situation has become one to which the patient's living will applies."³⁰

Some studies found that family members were willing to go further in supporting their loved one in their euthanasia wish than initiating the discussion. An ethnographic study shows that family members take on the role of actively structuring the process: making doctors' appointments, completing forms, and ensuring that there is a signed advance euthanasia directive, thus establishing a consistent will over time.²⁶ One older study shows that 5 of 24 family members indicated that they would be willing to actively assist their loved ones themselves.²² Experiencing moral responsibility for relieving pain and suffering and feeling guilty that they could not do so, weighed so heavily that they were willing to help their relative with dementia die,^{31,33} or felt in retrospect that they should have done so.³²

Two studies offer insight into the experiences of family members when they are implicitly or explicitly asked or even begged to end the life of a loved one. For example: "She is still looking at me intently, as if I'm hiding the key that will grant her efficient passage out of this world"³² or "When she [my mum] had moments of awareness she would beg us to end her life and we had to tell her we couldn't, it was so painful to watch and go through."³³ In one autobiographical article, this aspect, related to Being a burden (theme 1A), is briefly mentioned by family from the perspective of a person with dementia, when a mother says she feels secure because her son knows and can defend her wishes.³⁵ This moral appeal weighs heavily on family.

There are also family members who feel morally obliged to prevent euthanasia or PAS. A news article (US) on PAS, dementia, and family describes the situation of an adult child abducting his father from his mother's care and seeking legal custody to prevent an assisted suicide.²⁸ Physicians take opinions of family into consideration: de Boer et al. found that in 4.5% of 110 cases the reasons for not adhering to an advance directive was that relatives do not want euthanasia.²⁹

As dementia progresses, the involvement of family in medical decision-making increases. Family are expected to act as "proxies," making difficult and emotionally demanding decisions.²¹ Research among family shows that this is especially challenging when their views differ from professional standards or the opinions of health care professionals.³² Two studies depict family as poor in predicting the attitude of a loved one toward PAS; the ability to predict this well is of course important when the opinion of relatives counts or they have to give a substitute judgment.^{22,27}

Several studies show that, in practice, an advance euthanasia directive is often used as a guide or support tool for other medical and end-of-life care decisions on, most importantly, withholding artificial nutrition or starting palliative sedation.^{29–31} Rurup et al. found that 87% of 136 family members feel that in decisions to forgo treatment, the well-being of the patient should outweigh that of the relative.³⁶

3.2.3 | Permissibility of euthanasia or PAS

Several studies point to strong support for euthanasia and PAS among families of people with dementia. This support grows when there is an advance directive, when the person is in a terminal stage, or when there is pain or distress that cannot be relieved.^{22,31,34,36,37} Other studies, however, do not present this strong support but conclude that lack of a good quality of life and diminishing dignity due to a loss of decorum corresponds to a positive attitude toward euthanasia and PAS among some families.^{21,26,32,33} Two studies show that family prefers a limitation on life-sustaining treatments over euthanasia or PAS.^{31,36} One quantitative study³⁸ adds that being a family caregiver also influences a more positive attitude toward euthanasia.

The majority of the studies indicate that family generally values dementia negatively because of its association with being dependent on others, loss of dignity, and loss of self. For some, loss of dignity was seen as worse than death.²⁶ Words with a strongly negative connotation sometimes figure in references to people with dementia in general. They are, for example, "almost animal-like," "a lump of misery,"²⁶ "just a body,"²⁴ or "stop being a person."³² Common painful experiences of family at the basis of negative perceptions of dementia are seeing a loved one with diminishing cognition, mobility, speech, control of bodily functions, and most of all not being able to recognize family members, friends, or self.^{22,32,33,35} Nevertheless, family members also experience that a good quality of life is possible with dementia^{29,31} and that it is "not all bad."³¹

Euthanasia is foremost seen by family as a personal choice,^{22,27} and some studies speak in terms of a right of people to determine the timing and manner of their own death.^{25,31} In a Canadian study,³⁴ family was asked if every person has the right to choose how they will die—81.6% agreed. They also state that health care preferences expressed in advance of loss of capacity should be given weight equal to those voiced by a competent patient.³⁴ In line with this, family attaches considerable value to an advance directive and 73% feels that it should always be followed.³⁶ In a study from The Netherlands,³⁶

where euthanasia and PAS is legal, 74% felt that euthanasia is permissible for incompetent patients with an advance directive signed when they were still competent.

4 | DISCUSSION

Of the 19 articles included in our review, only 4 reported on first-hand accounts of the perspective of people with dementia on the involvement of family in euthanasia or PAS. These articles show that being a burden to family, especially to children, is a frequently mentioned reason for wanting euthanasia or PAS. They fear the future of living with dementia—the loss of independence and dignity that comes with late-stage dementia, which also underpins their views on euthanasia or PAS. For people with dementia, the permissibility of euthanasia or PAS depends on the stage of the disease.

Regarding the perspective of family, we found that they feel responsible for good quality care of their loved one, and at the same time, they struggle with their caring role. Caring can be physically and mentally burdensome and the moral dilemmas that present themselves in surrogate decision-making weighs heavily. They feel obliged to "do something" with the wish to die from their loved one. This can mean actively helping, supporting, or preventing death. There is strong support from families of people with dementia for euthanasia or PAS, for which they appeal to autonomy and are influenced by personal experiences and negative perceptions of dementia.

These findings raise certain ethical issues regarding the involvement of family. We discuss three of the most salient issues.

4.1 | The self-evidence of caring

The studies show a self-evidence with which family take care of their loved one with dementia; opting out is not considered. It seems to go without saying, like an inevitable moral responsibility or a mutual expectation; care can even go up to the point of exhaustion.^{21,24,32,33} Other studies^{17,39–42} also show this strong moral responsibility of family to provide good care, which may be physically challenging and mentally extremely hard, with a real risk of family members becoming overburdened and even having suicidal thoughts. However, it is hardly reflected upon.

Families struggles with their moral responsibilities for quality care and even promises made to take care of it when it is time on the one hand and their own feelings of grief, exhaustion, guilt, and legal restrictions on the other hand.^{23,43} They do not want to pass on the role of caregiver and the difficulties that come with it to their children^{31–33}; this seems contradictory to the almost natural or self-evident way they take on the caring role themselves.

Moreover, the death wish of a loved one is not something that can be ignored or set aside; family members must relate to it. They do this in different respects, from being willing to assist to preventing euthanasia from taking place. The wish for euthanasia or PAS can in itself be experienced as a burden to family.

TABLE 4 Family roles from the themes based on literature on euthanasia and PAS in dementia.

| Family role | Explanation and evolvement of roles |
|---------------|---|
| The Carer | Family starts in the role of Carer. They focus on <i>taking care of</i> the person with dementia and feel responsible for providing good quality care. The request for euthanasia or PAS can feel as an expression of the lack of good care and implicitly exposes the shortcomings of the carer. Sometimes adhering to a request is morally or legally not an option for them. When it is an option, a smaller part of Carers can become Advocates. |
| The Advocate | Advocates feel responsible to <i>be the voice</i> of the person with dementia. The latter sometimes made his/her wishes clear when still competent. Being the voice means initiating the conversation about euthanasia or PAS with physicians. The autonomy and self-determination of the person concerned is the most important value. A smaller part of Advocates, in addition to being Carers, can become active Supporters. |
| The Supporter | Supporters actively support the person with the wish to die. Here the issue of whether one agrees becomes most acute. Yet being a supporter does not necessarily mean agreeing with the death wish. They take concrete actions as an expression of their respect for the wishes of a loved one; making doctor appointments, filling in forms or writing an advance directive. A smaller part of supporters, in addition to being Carers and Advocates, can become Performers. |
| The Performer | Performers are willing, or say they are willing, to actively play a part in the (illegal) execution of euthanasia or PAS by (considering) providing or administering lethal medication themselves. |

4.2 | The relational dimension in euthanasia and PAS among people with dementia

Family is involved in the process of euthanasia in several ways. First, in practice, physicians do take the family's perspective into account, even up to the point of not granting a request for euthanasia when they feel that the family is not ready for it and in defiance of the legal criteria. Second, family is involved in the motivations for a wish to die. There is agreement among family and people with dementia that having dementia involves a terrible form of suffering, which for some justifies a euthanasia wish. The fear of being or becoming a burden to, specifically, family is a reason for wanting euthanasia. Third, regarding practical involvement, there is diversity in the nature of the involvement from family members in the process of euthanasia or willingness to do so.

Based on the themes, we distinguish four types of roles (Table 4) that family take on in situations of euthanasia and dementia: the carer, advocate, supporter, and performer.

A role that we have not found is known in palliative care as the role of family as care recipient themselves.⁴⁴ The needs of family in situations of euthanasia or PAS in dementia emerged sparingly in our review and may be overlooked. Possibly, health care professionals struggle with family also having an informal role as advocate, supporter, or performer when people with dementia request euthanasia or PAS.

Autonomy and, in particular, the individual perception of autonomy is the leading principle that underpins euthanasia legislation,⁴⁵ and the emphasis on euthanasia or PAS being a personal choice is in accordance with this.^{22,27,31,34} However, there seems to be a discrepancy with the actual reality in which the euthanasia wish is brought about amid family relationships. Euthanasia is often the result of a process and decision of patient, family, and physician together.^{7,46} The involvement of family and professional caregivers in this process is greater in people with dementia than in, for example, cancer patients, due to declining cognitive abilities and self-determination. Family of people with dementia

have to take on the role of advocate or supporter in a stage where cancer patients can still "speak for themselves."

4.3 | The personal and the general

There is a discrepancy between people's general moral views on dementia and euthanasia and PAS and the perception of what is good in the concrete situation where family is personally involved. First, the negative words that are used to describe dementia or people with dementia are generally not used to describe their own loved one.^{24,26,32} Second, family do see risks attached to (legalizing) euthanasia for people with dementia in general, for example, when there is a conflict of interest or undue pressure, but they do not relate such critical concerns to their own personal situation.^{26,31-33} This might have to do with the very general character of statements about adhering to an advance directive, the right to choose how to die, and the permissibility of euthanasia for people with dementia. Their meaning is not specified for the personal situation. Meanwhile, people with dementia and their families often subscribe to such generalized claims regarding the permissibility of euthanasia.^{22,29,31,34,36} This is backed up by other studies that show a significantly stronger positive attitude toward euthanasia and dementia among the general public and family than among physicians and nurses.^{1,36,47,48} Other research^{2,12} shows that when situations are described in less general terms, but in detail or with regard to personal situations, support decreases. The distance or proximity to the issue is fundamental to their view of what is morally good. This could also be the case in euthanasia and dementia but is not tested in any of the studies in our review.

There is a clear relational aspect to euthanasia or PAS for people with dementia. Actively involving family and offering them specific support can contribute to better care. Based on this review we can make several recommendations for policy and practice (Box 2).

BOX 2 Policy and practice

Recommendations for policy and practice

- Involve family by including (at least one) family conversation separate from the person with dementia in the rules of due care.
- Decisions on euthanasia or PAS can be supported by moral counseling guided by an independent interlocutor such as a chaplain or a spiritual caregiver.
- Offer coaching for families and physicians when there is a request for euthanasia or PAS.
- Train physicians in talking about death and dying and euthanasia or PAS to patients and their family.
- Actively support family when they are caring for a loved one with dementia to lighten the burden of care.

Implications for policy and practice

- Include people with dementia and their family in making policy.
- Recognize the position of family to improve dialogue. Family of people with dementia often feel morally obliged to be strong advocates of the wish for euthanasia or PAS of their loved one. This can be intimidating for physicians or raise suspicion regarding the family's motives.

5 | LIMITATIONS

The wide inclusion criteria employed in this review generated, in particular, non-empirical texts of a very different nature, which made comparing, analyzing and integrating the data a challenging task. However, there is little research on the ethical aspects of family involvement in euthanasia and dementia and research has a very small sample size, with variable or uncertain quality; this renders conclusions tentative.

We found few studies on first-hand experiences of opinions of people with dementia, and in particular in a later stage of the disease. Accounts of late-stage dementia depend heavily on observations of professionals or family. The reason for this seems obvious: dementia makes it difficult for people to reflect on their own situation and to express those reflections coherently to others. It requires knowledge of a person's life story to interpret it. The analysis of the perspective of people with dementia may not be saturated because of this.

5.1 | Recommendations for further research

Recent developments in The Netherlands give physicians room to interpret non-verbal behavior of people with advanced dementia

as their real wishes when they can no longer express themselves verbally.⁴⁹ Further research is needed on the moral dilemmas that this development may create for families and physicians, starting with the question of how to interpret the will and wishes of people with advanced dementia.

This research also shows that family-related reasons and the ways in which family is involved in the process of euthanasia of people with dementia have not yet been explored in depth. In particular, more research is needed that includes people with dementia to gain insight into their perspectives and experiences. Daskal et al. clearly demonstrated in his feasibility study that although people with dementia are vulnerable and require a different type of interviewing skills, it is possible and necessary to do so.^{50,51}

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [Supporting Information](#).

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