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A family affair: Repeated interviews with people with dementia and a euthanasia wish and their families

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ABSTRACT

This study examines the reasons of people with dementia request euthanasia and how these reasons change over time with a special focus on reasons related to family. In addition, it examines how family relates to their loved one's euthanasia wish. Seven people with dementia and a euthanasia wish in the Netherlands were interviewed, and three years later, two of them and five family members were interviewed again. Four themes were identified using thematic analyses: (1) Protecting the relationship from the impact of dementia; (2) Private domain as the primary setting to discuss euthanasia; (3) Implicit expectation to respect and agree with the euthanasia wish; (4) Experienced responsibilities of family regarding the euthanasia wish. Professionals should be aware of the position of family and the interrelatedness of the person's concern for family happiness and families' moral commitment to agree and support the wish.

Introduction

Recent evaluation of the euthanasia and Physician Assisted Suicide (PAS) law in the Netherlands shows that 36% of the general public think it is important that family participates in the decision-making process (Heide van der & ZonMw, 2023). Legally, this is not permitted and family has no decision-making power. Physicians are, as a part of the due care criteria (Box 1), obliged to ensure that there is no undue pressure from family members or conflict of interests, and that the request for euthanasia is voluntary, well considered and persistent. In the case of dementia, it is more difficult to rule out undue family pressure because abilities of self-expression and self-determination decrease when dementia progresses to a more advanced stage. An Advance Euthanasia Directive (AED) is sometimes written to replace the oral request in case of diminished self-determination due to illness, but in dementia this is rarely the case and it is heavily debated amongst physicians (Coers et al., 2023; Den Hartogh, 2018; RTE Jaarverslag 2020, 2023).


Box 1. Rules of due care in the Netherlands

A person can only request euthanasia for themselves.

- The request is voluntary, free of external pressure, well considered, and persistent.
- The suffering is unbearable with no prospect of improvement.
- The patient is informed about the situation and the prospect and understands the information.
- There is no reasonable alternative to relieve the situation.
- The physician has consulted at least one other physician who must have seen the patient in person and provide an independent written opinion regarding the due care criteria.
- The physician follows the procedure of due medical care and attention.

Perhaps due to the absence of the family in official law and regulation, this perspective is also overlooked and underrepresented in research on euthanasia and PAS, which focuses on healthcare professionals or public opinion (Goldberg et al., 2021; Snijdewind et al., 2014; Variath et al., 2020). Furthermore, people with dementia are also rarely involved in these studies (Tomlinson & Stott, 2015). The few studies that have been conducted on the subject show that family is an

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important factor in the reasons for euthanasia and PAS and that family participates in the process of considering euthanasia or PAS (Boer, 2021; Scheeres-Feitsma et al., 2023; Snijdewind et al., 2014). The more intense involvement of relatives in the case of dementia and the pressure from family that physicians experience to perform euthanasia, make it all the more important to fill this gap in the research (Roest et al., 2019; Snijdewind et al., 2014; Van Der Steen et al., 2023). The Netherlands has had euthanasia legislation for decades. Although euthanasia for people with dementia is rare (approximately 3.6% of all instances of euthanasia in 2023) it is increasing every year (RTE Jaarverslag 2023). Physicians are reluctant to perform euthanasia for people with dementia, while public opinion is more permissive (Brinkman-Stoppelenburg et al., 2020).

All the factors mentioned lead to establishing the following research questions:

- What reasons do people with dementia have for their euthanasia request and do reasons change over time?
- Does family play a role in the reasons for wanting euthanasia?
- How do families of people with dementia experience their responsibilities regarding their loved one's euthanasia request?

Methods

Procedure

Fourteen interviews were conducted in two series with a three-year interval. In the first series (September–November 2019), seven people with dementia and a euthanasia wish were interviewed. They were asked about their images of dementia and the reasons for wanting euthanasia. Participants were invited to bring someone to the interview if they wished. This resulted in a family member being present at six interviews, in one case a son and in five interviews a spouse. On occasion, these family members participated in the conversation, for example, to clarify something that the person with dementia said. But the main focus of the interview was on the person with dementia. In analyzing the data of the first series, relationships and family relationships in particular stood out as important themes, regarding the image of dementia as well as the reasons for euthanasia. Because of this prominence of family-related themes, relationality and family became new focal points in the follow-up interviews.

The second series of interviews were conducted between October 2022 and February 2023. Individual interviews were conducted with five of the family members who were present at the first interview. Two persons with dementia from the first series were interviewed again in the presence of their spouses. One interview was conducted a few days before the person in question received euthanasia, the other was with a person for whom the right time had not yet arrived. All interviews with family members took place after the interviews with the participant with dementia. The names used in this article are pseudonyms.

The Consolidated Criteria for reporting Qualitative Studies (COREQ) checklist was followed to present the data (Tong et al., 2007).

Participants

The participants for the study were approached in the Netherlands via open calls on social media, personal contact by a physician and through brochures distributed in Alzheimer cafes; a support meeting for people with dementia and their families (Vandenbulcke et al., 2022). The inclusion criterion was to have an active wish for euthanasia based on dementia. All participants initiated contact with the researcher (TSF) themselves. A total of 7 participants consented to participate in the study. The participants with dementia (Table 1) were between 53 and 88 years old, four of them were male and three were female. One participant was widowed, the other participants were married and living with their spouse in their own homes. All participants had grown up children, the children of the youngest participant still lived at home. Participants had been diagnosed with dementia six months to three years prior to the date of the first interview. All but one participant with dementia had a written advance directive. Two of the participants with dementia were interviewed for a second time after a period of three years. With one of the participants only email contact was established. He indicated that he had withdrawn his euthanasia request because of the birth of grandchildren. Three family members indicated that their loved one with dementia was no longer able to be interviewed.

The first author took the initiative for the second series of interviews with family members individually. Five family members were willing to participate. One family member agreed to a short telephone call but declined to be interviewed in-depth because she felt it would be too stressful. With one participant only email contact was established.

Table 1. Participants.

Participant	Interviewed in	AED ^a	Context	Situation is 2023
Victor	2019, 2022	Yes	Victor was a 76-year-old man and married for the second time. He had two children with his first wife. He was a managing director of a large international company. He traveled a lot for work as well as privately. He had always been pro euthanasia. He had had an advance directive for many years, which he updated when he was diagnosed with dementia. Victor lived with his wife in a small city. He received euthanasia in 2022. It was performed by his general practitioner, in his own home surrounded by his family. He donated his brain for scientific research. <i>Main reasons^b:</i> Autonomy, self-determination and taking responsibility not to burden his family.	Received euthanasia in 2022
Marie Harry	2023, 2019, 2022	No	Wife of Victor. Present during first and second interview and interviewed individually shortly after Victor's death. Harry is a 71-year-old retired police officer who lives with his wife in small village in a rural area. They have three children. When Harry was diagnosed with dementia, he immediately told his wife that he wanted euthanasia. A close friend who lived in a nursing home functioned as a negative example. However, he did not write an advance directive. Harry discussed his wishes with his physician once and feels that this is sufficient. He is letting life run its course and expects his wife to give the signal when it is time for euthanasia. <i>Main reasons:</i> Not wanting to be a burden to his wife and fear of deterioration and being dependent on others.	The right time for euthanasia has not yet arrived
Thea Toos	2022, 2019	Yes	Wife of Harry. Present during first and second interview and interviewed individually. Toos was a 68-year-old retired nurse. She was married and had one son. She lived at home with her husband and in the last year of her life she visited a recreational daycare center twice a week. When diagnosed with a progressive type of dementia and aphasia, she immediately discussed euthanasia with her husband and wrote an advance directive. As a former nurse she was very aware of legislation and how it would affect her situation. She connected with the 'end-of-life expertise center', which provided support to her and her husband. She received euthanasia in 2021 in a hospital and donated her organs. <i>Main reasons:</i> Unnecessary suffering, self-determination and not wanting to be a burden to her family.	Received euthanasia in 2021
Harm Stien	2022, 2019	Yes	Husband of Toos. Present during first interview and interviewed individually a year after Toos' death. Stien is an 88-year-old woman. She comes from a long line of ministers and was married to a minister. Religion is important to her, also in how she perceives euthanasia. The topic of death was always freely and openly talked about in the family. It is something to look forward to and not something to fear. She has four sons and has been widowed for five years. Her husband suffered a sudden and progressive disease that also caused dementia. Stien has always had a liberal view on euthanasia, but the traumatic experience of her husband's illness contributed to her writing an advance directive with the help of her sons. During the first interview, Stien lived at home with help from family, neighbors, and church members. Three years later, she was admitted to a nursing home because her increasing care needs could no longer be met by her large network. <i>Main reasons:</i> unnecessary suffering, self-determination, and no hope for a cure.	Too late to meet the required rules of due care
Ralph Mark	2023, 2019	Yes	Son of Stien. Present during first interview and individually interviewed. Mark is a 68-year-old retired owner of an agricultural family business. He is married and has three children. When he was diagnosed with dementia, he decided he wanted euthanasia and talked about it with his wife. At a later stage, they involved their children in the discussion. There is a great fear of a future with (progressing) dementia. Together with his wife he wrote an advance directive, discussed it with his physician and dementia case manager and joined a Right-to-Die association. When contacted after three years, Mark was still living at home with his wife. He had withdrawn his request for euthanasia. His wife stated that life proved to be difficult, especially for her, but also bearable. The wish to die had faded. <i>Main reasons:</i> self-determination, self-awareness, and fear of not recognizing his family.	Withdrew euthanasia request
Alies Marion	–, 2019	Yes	Wife of Mark. She and a son were present during the interview. Only brief telephone contact in 2022. Marion is a 75-year-old retired preschool director. She is married and lives at home with her husband in a large city. They have two daughters. When Marion was diagnosed with Alzheimer's disease, she immediately said to her husband that she wanted euthanasia. Together with their daughters they wrote an advance directive. When reconnecting after three years, Marion still lived at home but was visiting a daycare center for people with dementia twice a week. Because Marion appeared to be happy and enjoying life, her family decided that euthanasia was no longer an option or necessary.	Family decided not to bring up the euthanasia request again
Jan Ton	2023, 2019	Yes	<i>Main reasons:</i> self-determination, fear of losing decorum, and of not recognizing her children. Husband of Marion. Present during first interview and interviewed individually. Ton is a 53-year-old unemployed factory worker. He is married and has two children. Ton plays the organ in his local church and conducts the church choir. He found it difficult to hold on to a job because he forgot so much and made mistakes. After a period of diagnostic uncertainty, he was diagnosed with Alzheimer's disease. Almost immediately after his diagnosis he wrote an advance directive. He describes people with dementia as 'lumps of meat with no identity'. The prospect of unintentionally being nasty to his wife and not being able to communicate with people around him was unbearable. When (email) contact was made again after three years, Ton had withdrawn his euthanasia request. He wrote that the birth of two grandchildren had made his wish to die disappear. <i>Main reasons:</i> being independent, fear of losing communication and of not recognizing wife and children, not wanting to be a burden to family.	Withdrew euthanasia request
Jannie	–	–	Wife of Ton, not present at the interview.	–

^aAED advance euthanasia directive.^bPresentation of main reasons, not necessarily in order of importance.

Two of the seven people with dementia died of euthanasia in the three-year interval. Two persons withdrew their euthanasia request in consultation with their family. For one person, the right time had not yet arrived and for another person, the right time had passed and she no longer met the criteria. In one case, the family had decided it was best not to bring up the euthanasia request again.

Data collection

Fourteen semi-structured in-depth interviews, lasting between 45 and 60 min, were conducted at the participant's home. In the first series (Supplement 1) of interviews the following topics were addressed and elaborated on: (a) their reasons for wanting euthanasia, (b) their general opinion on and their perception of euthanasia and dementia, and (c) their ideas on the euthanasia wish or advance directive. In the second interview with the two people with dementia (Supplement 2), the topic of family and expectations toward family and euthanasia was discussed. The topics from the first interview were revisited.

Interviews with family members individually were conducted only in the second series (Supplement 3) and focused on (a) opinions and feelings regarding the euthanasia wish, (b) expectations and responsibilities regarding the euthanasia wish, and (c) involvement in the period prior to euthanasia.

All interviews were conducted by the first author, a female ethicist and PhD researcher. Field notes were made during the interviews. Before the second series, the first interviews were re-read by the researcher to identify specific questions or points of interest. Participants received a summary of the interview to adjust or correct information; in one case a minor remark was made, which was added.

Ethics

The regional ethical review committee for patient-related research at the Medical Center Leeuwarden in the Netherlands concluded that the study was exempt from the Medical Research Involving Humans Subjects Act (WMO, reference RTPO NWMO 1056, 11 January 2019). Participation was voluntary. All participants received written information about the research beforehand, and this was repeated verbally at the start of the interview. All participants with dementia were competent at the time of the interview and fully understood what they were consenting to, as were the family members who were present. All participants signed a

consent form. In the second series, three years later, most participants had reached a more advanced stage of dementia. In consultation with their family members we decided not to interview them again, with the exception of Harry and Victor who were both competent at the time.

Data analysis

Every interview was audio recorded and transcribed verbatim. The interviews were read and re-read during the coding process by the first author (TSF). Open coding and inductive analysis were used to identify codes from the interviews. The second author (PS) read five interviews and independently coded them. The codes were compared and discussed within the group of authors and subsequently adjusted and refined until consensus was reached. This led to two series of codes: one for the interviews with the participants with dementia and one for the interviews with family members. The interviews were (re)coded using these two series of codes by the first author. A Reflexive Thematic Analysis approach was used to identify and analyze themes from the data; these were discussed and refined within the research group (Braun & Clarke, 2006, 2019). Atlas.ti 23 was used to organize and code the data.

Results

Four themes were identified in what people with dementia and their spouses or child(ren) said about the reasons for euthanasia, the changes in reasons, and the role of family and family's responsibilities regarding the euthanasia request.

1. *Protecting the relationship from the impact of dementia*

The people with dementia saw the disease as a process of deterioration toward an unworthy life. Moreover, it was perceived as having an enormous impact on family members due to intensive caregiving. In reply to the question how they perceived dementia, all respondents with dementia describe a negative experience with a family member or a friend who has dementia that left a deep impression on them and serves as an example of what they do not want. From the bystander perspective they sympathized more with the spouse and child(ren) than with the person with dementia.

They spoke only in negative terms about how dementia affected these relationships. It was important for the respondents with dementia to be remembered

as the person they were before the dementia manifested itself so strongly. Related to this was the fear of becoming someone with a different personality and the impact this would have on the relationship with the people that mean most to them. Ton described this explicitly in his advance directive. He wrote that he wants euthanasia when his *“dear wife thinks of him as ‘a troublesome person’ who meddles in everything.”* When asked to elaborate on this he said:

“Well, if you are at the start, my phase, then that is... then you are not a burden to them. But as you get a little older and you deteriorate, or you go downhill faster than expected. Well, then you may turn into a bastard.”

Some participants felt that people with dementia are treated differently by people around them. Victor describes this in his first interview when he talked about his brother who also has dementia:

“No longer (treated) as ... as a person. Like he was. He is treated differently. He is treated differently by his wife. His wife has to help him, support him, do everything for him. That’s treatment too! So, everyone is involved. Everyone reacts differently to the person he was.”

Most respondents feared losing their identity or control over who they are in the eyes of others. They described a fear of being or becoming a physical or mental burden to their spouse or child(ren) and the negative impact this will have on their well-being. When asked to elaborate on her reasons for wanting euthanasia, Toos says:

“And not so much for me but for the people around me. Because I can already see that it is very difficult for them as well.”

None of the respondents felt that they are a burden at the present time; they feared they will become so in the future when dementia progresses. As Harry explained in the first interview:

“And so if at some point you make the decision to say goodbye to life autonomously, so to speak. By... by not being there anymore. Because at some point you will become a burden to your environment, to your children, to your wife or to whatever. And... and in that way you can bring some relief to the people around you.”

For most respondents, not wanting to be a burden to loved ones is linked to self-determination, Victor describes this when he says:

“I don’t want others to have problems or suffer because of it. I want to carry it myself, carry myself to the grave, so to speak. I will do that on my own. And I hope that the people around me not so much support, but rather understand this.”

Dementia not only affects close relationships but all relationships. Several respondents indicated that they felt that meaningful contact with other people is obstructed or impossible for people with advanced dementia. Ton said:

“When you are young like me then it is all right. But when you are old and in a wheelchair, then you can’t make contact with anyone at all. There is no transmitter and no receiver. Something is blocking the connection.”

Not only being remembered in a positive way is important, but also being able to recognize loved ones. Three of the respondents included this in their written advance directive as a criterion for starting the euthanasia process. For example, Marion states:

“If I don’t recognize you anymore, then I don’t see the point, life will just have no meaning anymore.”

Mark also put this explicitly in his advance directive as one of the three criteria for wanting to end his life:

“When I lose control of my own body. When I don’t know my wife, children and grandchildren anymore. When I am no longer aware of myself.”

2. Private domain as primary setting to discuss euthanasia

At some point euthanasia becomes a medical affair and physicians are involved. However, talking about euthanasia and the further shaping of the wish starts as a private conversation in a familial setting. For all respondents, the diagnosis of dementia was the reason for writing or updating an advance directive or talking about euthanasia. A spouse and/or child(ren) are almost always involved from the beginning. Victor and Toos, the two people who received euthanasia, involved other family members and friends at a later stage, when the request for euthanasia was officially approved.

Two respondents talked about the family meeting they held to discuss their euthanasia wish. At the kitchen table Stien and her four sons discussed the advance directive and put it on paper together. Marion and her husband also called a family meeting and wrote an advance directive together with their daughters. The other respondents involved children at a later stage, spouses were engaged from the start.

Talking about dying and euthanasia was not common for all participants. During the interviews it became clear that Harry, who has dementia, and his wife Thea had talked about euthanasia only twice. Both times this interview series was the reason. During the interviews they spoke about it very openly,

but it was not a topic that they addressed between themselves. When asked about this Thea explains:

“We never talk about those kinds of things, always just about fun stuff. Other people and experts sometimes talk about the future. Such a future perspective could become reality, but we can’t and won’t think about it at all. I’m alive right now, today. This is how we live, it is what it is.”

Harry seemed to be using the interviews to inform his wife about how he feels about it, what his wishes are, and what he expects from her. At the end of the second interview he turns to his wife and says:

“So, now you are also completely up to date.”

3. *Implicit expectation to respect and agree with the euthanasia wish*

There is a mutual implicit expectation to respect and agree with and support the euthanasia wish. None of the family members questioned their loved one’s euthanasia request or opposed it firmly. They all state in different words that they have no say in it or that it is not their decision to make. On the other hand they indicate that, as far as they are concerned, euthanasia is not necessary. Nevertheless, understanding and respect for the wish comes first. Marie, Victor’s wife, explains this when she says:

“It’s how he felt about it. I have to let it go. This is about him. I have no say in the matter. It’s his life and it’s his death. If this is what he feels then I just have to accept it. I can tell him how I feel but I am not going to try to change his mind.”

Harm, Toos’ husband also stated that:

“I was at peace with it. I also said this to Toos: ‘Toos, it’s your life you must do what you want. People around you will be very sad, but you have to determine the moment. You decide when to say: ‘this is it, no more.’ I had no problem with it.”

When Thea was asked if there was ever a moment she felt she had to go against the euthanasia wish of her husband she replies:

“No never! I fully support it. He was really convinced from the start that he did not want to let it get to that point. Euthanasia was the first thing he said.”

Participants with dementia were also asked how they would respond if their spouse or child(ren) said they did not want euthanasia. Some respondents could not imagine this happening; Victor replies in his second interview:

“They’d never say that. (...) It wouldn’t occur to me that she would say that.”

The respondents with dementia were asked if they would proceed if their spouse or child(ren) did not agree with their euthanasia wish. In his second interview Harry responds:

“Then I wouldn’t do it. No, then there would be no point. It has to serve some purpose. (...) No, she has to agree with why I want it, or it would serve no purpose. If she doesn’t want it, then this desire to want it [euthanasia] is also gone. Then I would cause a problem for her and that is the opposite of what I intended.”

For him euthanasia was a mutual decision between him and his wife, the opinions of his children were less important. Most respondents indicated it was important that close family agree with the decision. For Stien it was almost like a negotiation to get everybody to explicitly agree on the right terms and conditions. Her son said that maintaining harmony in the family was important for his mother. In the end his mother agreed to a less firmly formulated advance directive to accommodate the more reluctant opinion of his oldest brother.

4. *Experienced responsibilities of family members regarding the euthanasia wish*

In the advance directive all respondents explicitly appoint a spouse or child(ren) as a representative who can make decisions if they are incapable to do so themselves. None of them appoints a physician or a medically trained professional. All but one respondent were unaware of the fact that this representative role of deciding on euthanasia for someone else is against Dutch law.

Respondents had great confidence in their spouse or child(ren) to make sure that their advance directive is executed if they are no longer able to do it themselves. When Stien is asked if she talked about her advance directive with her physician, her slightly agitated response is:

“I never thought about it. I always knew: the boys will take care of that! No, I have my boys! They know. No, no, no we’re not going to do that!”

Toos and Victor, the two respondents who received euthanasia, were very aware of the scope and limits of euthanasia and PAS law. They also appointed family members as their representative in their advance directive but felt strongly that they would never have to make use of them. Toos states:

“They know what I want and I can trust them to do what I want. I can rely on them 100%. But I will make sure that they don’t have to make that decision, that the arrangements are made before that time.”

Stien's son Ralph was struggling with feeling that he had failed in carrying out his mother's wish for euthanasia. Although the family had extensively discussed the advance directive and everything has been written down, time caught up with them. When his mother's dementia progressed, the moment for legal euthanasia had passed. Ralph discussed this with his mother's physician and tried to persuade him, but it was not possible, the rules of due care could no longer be met. When asked if his mother is now living in the situation she wanted to avoid when she wrote her advance directive he responds:

"I'm struggling whether the answer is yes or no. I think my other brothers do too, but it bothers me most, whether this was the right path. Who did we ultimately help? I don't have the answer."

Although euthanasia is no longer an option, they still use the advance directive as a guide to support other medical decisions.

"My role has been to continuously check whether we're doing the right thing for her. And I didn't know. Now if we are not sure what to do, we will always take her advance directive as the starting point. When she needs antibiotics, a corona vaccination, or some other treatment."

In the case of Marion, her husband and daughters decided in the three-year interval between the interview series that it was best not to bring up the euthanasia request again. Marion does not talk about it herself anymore and seems very happy and content with life at the moment. They fear that talking about euthanasia would be stressful and together decided that the current situation is in line with her wishes.

Some experienced responsibilities were implicit and not talked about. During our second interview Harry shared that he expects his wife to give the signal when it is time for euthanasia. His wife is unaware of this and responds:

"I'm taking a moment to reflect on what you just said, that I'm the one who should say when it's time. I think that would be very difficult for me. Would you accept it if someone else decided? The doctor or someone who knows a lot more about this than I do? About how you are doing and what lies ahead for you, and when that is, and what would possibly be a moment. Or do you just want to hear it from me?"

Harry: Hearing it from you, that's enough for me.

Thea: But maybe I'm not enough of an expert to say. Maybe I'll say it tomorrow.

Harry: I hope not."

In the individual interview with Thea this moment is reflected upon. Thea says:

"Shocked may be too big of a word, but I thought it was good that he said that. Now I know what is expected of me."

During a neurologist visit, Marie is the one who says that her husband wanted to start the euthanasia process. She felt a responsibility to bring it up even though her husband never asked her to do this. Although she feels she did the right thing, afterwards she also had a lot of doubts about this moment:

"Was I the one that set it all in motion? (...) I've never told anyone this. I don't feel the need to share it with anyone else. But I thought about it later. Suppose I hadn't said it and neither had he? But of course he could have said it eventually. Or the doctor could have gotten it out of him in some other way."

All family members reported that the situation of their loved one with dementia prompted them to think about their own death and consider euthanasia. Some of them have written an advance directive for themselves or are planning to. Ralph says:

"This process influenced me greatly. I wouldn't want it (dementia) for myself. Even if I still really enjoyed the food, the beautiful sky and the wine that is placed in front of me. No doubt I would enjoy it! But you're basically going down an open slide with your hands constantly searching for a way to slow down."

However, contemplating their own deaths did not lead all family members to the conclusion they would want euthanasia for themselves if they were in a similar situation. Jan, Marion's husband, says he would never choose euthanasia because he is afraid of death. He places decisions on this subject in the hands of his daughters:

"They should just look and see what happens. I feel they have enough sense to say: 'daddy wouldn't have wanted that'. I'll just go by their opinion."

Discussion

This study explored the reasons that people with dementia want euthanasia and whether these reasons changed over time, with a special focus on the role of family in the reasons and on families' experienced responsibilities regarding the euthanasia request. We found that for the people with dementia it is important to protect the relationship from the impact of the disease. They fear becoming a burden to their spouse and/or child(ren). They discuss their wish for euthanasia within the family setting first. Some expect their

family member to give the signal when it is time for euthanasia. Physicians or other medical professionals and family and friends in a wider circle are involved at a later stage. The family members in our research accept the wish to die from their loved one without questioning it explicitly. They also take on practical responsibilities such as writing an advance directive together or making doctors' appointments to discuss it. Some initiate the discussion on euthanasia with a physician.

Euthanasia is often seen as an act that only concerns one's own life, but this research shows a clear connection between the reasons for euthanasia and the responsibility that people with dementia feel for their relationships. The interviewed people with dementia fear for their loved one's happiness as the disease, with all its negative consequences, progresses. Relieving their family of this burden is a major reason for participants in this research to want to arrange their own death. The interviews reveal, however, how the advance directive and the wish to die create a new and different type of burden for the family members. The characteristics we found for this type of burden are in line with findings from other research on euthanasia and family (Dees et al., 2013; Srinivasan, 2019). First, the burden relates to the emotional impact of talking about euthanasia or a loved one wanting euthanasia (Andriessen et al., 2020; Srinivasan, 2019; Van Rickstal et al., 2023). The burden also has to do with feelings of moral responsibility to make the wish come true, which are made official if family is appointed as a representative in an advance directive (de Boer et al., 2011). Family members can also experience feelings of guilt or doubt when euthanasia is granted (Van Rickstal et al., 2023). Or, when euthanasia is no longer a legal option (as in one case in this study), they struggle with how to honor their loved one's wish (Anderson et al., 2019; Daskal et al., 1999). As a promise has been made or an expectation created, feelings of falling short arise. This is not referred to by the respondents with dementia. They feel that they are relieving their family members of a burden and may be unaware of the burden that their wish to die creates at the same time.

From the perspective of the person with dementia, the euthanasia wish and the period prior to euthanasia is a family affair. All participants discussed their wish to die with their family, in particular their spouse and/or child(ren). Advance directives are also written and discussed together with them and are only later discussed with physicians, which is also shown in research on family and euthanasia decision making (Kimsma & van Leeuwen, 2007; Van Rickstal et al.,

2023). A great deal of trust is put in the hands of family when it comes to deciding when it is time for euthanasia. The physician's objectivity and knowledge on dementia or euthanasia is deemed less relevant than the knowledge of a spouse or child(ren) concerning the life and values of the patient.

Research shows that relationships are an important aspect of euthanasia considerations (Van Rickstal et al., 2023). The analysis of the interviews shows that the people with dementia and their family mutually and implicitly expect that the euthanasia wish is not questioned. Questioning this wish seems inappropriate within the relationship, a finding which is also reported in research on family and euthanasia in general (Holmes et al., 2018; Variath et al., 2020). Perhaps family members fear damaging the relationship by going against such a personal and vulnerable wish. The interviewed people with dementia implicitly assume that the family member agrees, and this is also an important factor in pursuing the euthanasia wish. Our series of two interviews does not shed light on the potential consequences of a spouse or child(ren) raising questions or strongly opposing the wish for euthanasia, as such opposition did not occur. This may also be because of the inclusion criterion of having an active wish for euthanasia.

After three years, two of the seven people with dementia who participated in this study received euthanasia. Although this is a very small proportion, it is also noteworthy considering their active euthanasia wish. Their families were happy that the wishes of their loved ones had been fulfilled and that they no longer suffered. Reasons why not all respondents received euthanasia in the three-year interval are diverse. The dementia of Stien had progressed too far to meet the due care criteria. For Marion, Harry, Mark, and Ton life was still worth living, contrary to what they had previously feared. Harry's euthanasia wish still stands but the right time has not yet arrived. Mark and Ton had actively withdrawn their request for euthanasia. For Ton, the birth of grandchildren made the desire for euthanasia disappear, and for Mark living with dementia was manageable. Marion, contrary to what she and her family anticipated, seems happy and content and unaware of her preexisting euthanasia wish. Therefore, her family explained, they decided in a family meeting that euthanasia was no longer necessary or in line with her expectations. The anticipated future of living with dementia appeared to be different than reality, a finding reflected in other research (Gastmans & De Lepeleire, 2010; Hertogh & Ribbe, 1996; Lemos Dekker, 2020). A German study concluded that

patients who experienced suicidal ideations during early stages of dementia often stopped expressing them in advanced stages, which was explained as possibly resulting from a reduced awareness or decreased means to communicate (Ortner et al., 2021). However, other studies show that people can also cope with dementia; they find the ability to adapt and experience sufficient quality of life, which can lead to a fading euthanasia wish over time (de Boer et al., 2011; Lemos Dekker, 2021; Tomlinson & Stott, 2015). Most of these studies are based on observations of medical professionals. The findings from our study, although based on small numbers, confirm this diversity from the perspective of people with dementia.

Strengths and limitations

A strength of this research is that it includes the voices of people with dementia themselves, a perspective only a few studies present (Tomlinson et al., 2015). To our knowledge, there is no other longitudinal research on the sensitive topic of euthanasia or PAS based on interviews with people with dementia and their family. The first series of interviews with persons with dementia was, in most cases, in the presence of family as preferred by the persons with dementia. We focused on the persons with dementia, encouraging them to provide their perspective. The presence of family also provided the opportunity to observe how the person and family interacted. Data collection was not hindered by the pandemic. A limitation of this study is the small number of participants; saturation may not have been reached. More research is necessary, in particular research that includes people with dementia.

Recommendations

Based on how family relationships play a role in reasons for wanting euthanasia among people with dementia, euthanasia should not be seen as a purely medical and legal process between autonomous individuals and their physicians from which family members are excluded. Given that the desire not to damage meaningful relationships is an important reason for wanting euthanasia, this desire should be a basic concern in how physicians and other professional caregivers discuss the euthanasia wish with people with dementia. Professionals can address the new burden and implicit expectations or responsibilities of family members that come along with it.

This can alleviate feelings of guilt or falling short and support the grieving process. As ideas about family being able to arrange euthanasia if the person with dementia is no longer able to exercise his or her will are often incorrect, accurate information about what is possible and the limits of the legislation is essential as well, in particular as regards the role of representative.

In our study, family did not resist or question the wish for euthanasia of a loved one with dementia. This may be due to the inclusion criterion of having an active wish for euthanasia. The discovered link between euthanasia and family raises the question whether euthanasia wishes are not also questioned by family and if so, how family is involved in the fading of a euthanasia wish.

There is also an important ethical question beneath the surface that needs to be addressed more explicitly: how does the general public in countries where euthanasia is possible morally weigh the relational motivations for euthanasia of people with dementia and do they consider them legitimate, and if so to what extent. Moreover, ethical reflection on the relational nature of thinking about euthanasia calls into question current euthanasia policy which is based mainly on the value of autonomous end-of-life decisions.

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