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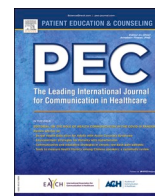
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# People with young-onset dementia and their family caregivers discussing euthanasia: A qualitative analysis of their considerations

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## ABSTRACT

**Objectives:** Research showed that people with young-onset dementia and their family caregivers raised the topic of euthanasia when talking about the broader topic of advance care planning. A better understanding of what people address and why may inform the evolving landscape of physician assisted dying. This study aimed to explore the considerations that people with young-onset dementia and their family caregivers expressed on euthanasia.

**Methods:** A secondary qualitative analysis on interviews with 10 Belgian people with young-onset dementia and 25 family caregivers, using constant comparative analysis.

**Results:** Respondents described similar contexts in which euthanasia had been discussed: the topic arose at 'key' moments, mostly with family caregivers, and was motivated by patients considering the impact of disease progression for themselves and their loved-ones. Caregivers shared opinions on the euthanasia law and discussed the emotional impact of discussing euthanasia.

**Conclusions:** Considerations of people with young-onset dementia towards euthanasia appear rooted in personal, as well as in anticipated interpersonal and societal suffering. The negative image associated with dementia and dementia care seemed to influence people's expectations for and thoughts on the future.

**Practice implications:** Patient-physician communication should include detangling motives for euthanasia requests, openly discussing fears and reflecting on prognosis.

## 1. Introduction

It is estimated that up to 4 million people globally develop dementia symptoms before the age of 65, captured by the term young-onset dementia (YOD) [1]. A recent systematic review and meta-analysis on population-based studies, points to an incidence rate of 370,000 new YOD cases annually worldwide [2]. Given that Alzheimer's disease and related neurodegenerative disorders are characterized by progressive cognitive decline, the significance of advance care planning (ACP) for this specific patient population is widely recognized [3–5]. ACP has been conceptualized as a communication process between patients, family and professionals to explore patients' preferences for future (medical) care, including at the end of life [6].

Despite the hypothesis that people with YOD and their caregivers want more involvement and autonomy in palliative care and specifically ACP [7], previous research showed [4,8] that they barely take part in

ACP and that they intuitively equate the term ACP with making medical decisions for the actual end of life [9]. Moreover, throughout interview studies, Belgian patients and caregivers spontaneously touched on the topic of euthanasia when discussing their views on ACP, as opposed to American family caregivers [8,9]. The interpretation of this discrepancy was that people with YOD and their caregivers think about end-of-life decisions within their countries' legal framework [8]. This valuable finding was not analyzed in depth in our previous main ACP analysis [4, 9] as these unsolicited statements did not address the aim of our previous research questions. Given that the specific topic of euthanasia in YOD as seen from the perspective of people with YOD and family caregivers themselves has never been addressed within existing literature, we conducted a secondary qualitative analysis on the actual content of what respondents expressed about euthanasia.

At present, more and more nations across the world establish legal grounds for physician-assisted dying, an umbrella term usually referring

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to euthanasia and physician assisted suicide [10]. Euthanasia is the act of where a health care practitioner intentionally ends a patient’s life by active drug administration at this patient’s explicit request [11]. Countries such as Belgium and the Netherlands currently have the most progressive physician assisted dying laws [12]. The euthanasia law [11] that was passed in Belgium in 2002, puts forward several central substantive criteria; one must suffer unbearably from an incurable condition, without any prospect of improvement and must express a well-considered, voluntary and repeated request for euthanasia. This request has to be ‘current’, entailing that an advance directive for euthanasia is relevant solely in the specific case of an irreversible persistent vegetative state. As such, in Belgium people with dementia are eligible for euthanasia only in those stages of their condition where they are still competent to voice a current request. At present, public debate focuses on the legal status of an advance euthanasia directive for patients in late-stage dementia, where it might be challenging to cognitively substantiate their euthanasia request [13].

As access to assisted dying may be legalized or expanded in varying jurisdictions, research has to follow to assess the effects and impact on patients and other stakeholders [10]. However, a systematic review on the attitudes of patients and caregivers, health professionals and the general public on assisted dying in dementia showed that the perspectives of people with dementia are depicted in only a very few studies, which are mostly of low quality [14]. Within the internationally evolving landscape, it is useful to shed light on the views of people with (young-onset) dementia and their caregivers regarding euthanasia. As such, we wish to increase the understanding of people’s thoughts on euthanasia in the context of YOD.

The research question for this study is: “what do people with YOD and their family caregivers who raise the topic of euthanasia, during an interview on the broader topic of ACP, express regarding euthanasia itself and regarding communication about euthanasia?”.

## 2. Method

### 2.1. Research design

This explorative qualitative study is based on data collected through semi-structured face-to-face interviews from two previous qualitative studies (see Table 1 for the studies’ characteristics). Qualitative study designs were chosen because of both the exploratory topic and the sensitive research questions. We performed secondary data-analysis, as the topic of euthanasia played a prominent role in remarks that respondents spontaneously added without any prompts by the interviewing researcher. Whenever respondents addressed the topic, further discussion was enabled through one or more follow-up questions (such as inquiring how communication about euthanasia had taken place, with who etc.) and through ‘silent probes’ by the interviewer, before associating respondents’ comments to a predetermined topic leading back to the interview guide.

### 2.2. Participants

This study is based on data generated during 2 previous qualitative studies [4,9] in which we included family caregivers of patients with YOD and persons living with YOD of the Alzheimer Type themselves. See Table 1 for inclusion criteria and Table 2 for respondents’ characteristics.

### 2.3. Recruitment

Respondents in both studies were recruited through four intermediate people: two neurologists, a coordinator of a day care centre for people with YOD, and the founder of a non-profit organization that organizes activities for people with YOD and their families. Coordinators at each site approached eligible respondents, briefly explained the study

**Table 1**  
Comparison of study characteristics.

Characteristics	Study 1	Study 2
<i>Respondents</i>	N = 15 Family caregivers of people with YOD	N = 20 Dyads of people with YOD (n = 10) and their respective family caregivers (n = 10)
<i>Data-collection</i>	Semi-structured in-depth interviews, face-to-face	Semi-structured in-depth interviews, face-to-face
<i>Data-analysis</i>	Constant comparative analysis	Constant comparative analysis
<i>Timeframe</i>	July - September 2017	August - December 2019
<i>Publication</i>	Reference [4]	Reference [9]
<i>Inclusion criteria</i>	No data from people with young-onset dementia	For <b>persons with dementia</b> (6):  1. Being formally diagnosed with young-onset probable Alzheimer’s disease (based on strictly applied standard diagnostic criteria; e.g. NIA-AA criteria) 2. Having a score of minimum 16 on the MMSE 3. Being diagnosed for at least 6 months (for reasons of sensitivity to grieving stage after diagnosis) 4. Being 18 years of age or older 5. Speaking Dutch 6. Signing written informed consent (themselves + caregivers’ consent as witnesses is required)  For <b>family caregivers</b> of persons with dementia (4):  1. The main family caregiver of a person formally diagnosed with young-onset dementia (regardless of dementia subtype), 2. Aged 18 or older, 3. Dutch-speaking and 4. Needed to have given written informed consent to participate.
<i>Ethics</i>	- Ethics Committee of Brussels University Hospital (B.U.N. 143201732034) - Institutional Review Board of Hospital Network Antwerp (ZNA, approval n° 4939) and of Hospital GasthuisZusters Antwerp (GZA, 170407ACADEM)	- Ethics Committee of Brussels University Hospital Brussels (B.U.N. 143201939497) - Institutional Review Board of Hospital Network Antwerp (ZNA, approval n° 5208) and Hospital GasthuisZusters Antwerp (GZA, 190304ACADEM)

and asked for permission to give their contact information to the researchers. Participants were contacted by phone or email by R.V.R. or A. D.V., addressing any questions and ascertaining willingness to take part in the study. After agreement, interviews were scheduled at a mutually convenient time, at a place of respondents’ choice (usually their home or the day care centre).

Further details on recruitment and ethical safeguards when recruiting participants can be found elsewhere [9].

### 2.4. Data-collection

Data were collected through face-to-face in-depth semi-structured interviews by two researchers (RVR and ADV). One researcher (RVR) obtained a master’s degree in clinical psychology and a PhD in social health sciences (this is the case now, so PEC can decide which

**Table 2**  
Respondents' characteristics.

	STUDY 1		STUDY 2	
	Caregivers N = 15		Patients N = 10	Caregivers N = 10
<b>Years of age</b>	Time of interview		Time of diagnosis Time of interview	Time of interview
35 – 39	1	/	/	/
40 – 44	/	/	/	/
45 – 49	1	/	/	/
50 – 54	1	2	1	1
55 – 59	4	4	1	3
60 – 64	2	4	4	3
65 – 69	4	/	4	3
70 – 74	2	/	/	/
<b>Mean</b>	61 yo	60 yo	63 yo	60 yo
<b>Gender</b>				
Female	9	2		8
Male	6	8		2
<b>Relationship of caregiver to person with YOD</b>				
Wife	7			8
Husband	5			2
Brother	1			/
Daughter	2			/

description is most accurate/ correct). The other researcher (ADV) is a professor with a background in sociology and was the daily supervisor of the former (RVR). For both studies two very similar interview guides were developed within the research team. In neither guide was a question about euthanasia. Data-collection of one included study dates from 5 years ago: we deemed that the time that has passed since these data were originally collected has not impacted the relevance of our findings, as our countries' legal framework for euthanasia has not changed during this time.

## 2.5. Data-analysis

All audio-recordings of the interviews were transcribed verbatim by the first author and subsequently analyzed through an approach to thematic analysis. As stated previously by Braun and Clarke [15,16], thematic analysis can be best thought of as a family of or an umbrella term for a set of approaches for the analysis of qualitative data that have a shared focus on developing themes (patterns of meaning) from qualitative data. More specifically, we opted for the strategy of the constant comparative method [15]. Transcripts were reviewed line-by-line and codes were assigned to discrete fragments of text, usually one or two sentences representing a certain idea or concept. For the secondary data-analysis, all text-fragments relating to the topic of euthanasia were assembled throughout the 35 interview transcripts. Of those 35 transcripts, 24 had explicit references/quotes regarding euthanasia. These were collected within a new dataset to subsequently be compared within and between interviews by two researchers (RVR and ADV), in order to identify broader themes. The goal of our analysis was to identify and describe patterns in data, and to interpret their relationships [15]. Based on the personal preference of the first author (RVR), no analytic software was used.

## 2.6. Ethics

This secondary analysis was in line with the aims of the original research studies and their initial ethics approvals obtained (see Table 1).

## 3. Results

Over two third of all respondents spontaneously raised the topic of euthanasia and their previous communication about euthanasia when discussing ACP.

When respondents raised euthanasia during interviews, they

addressed four major subtopics: (1) the context in which patients and family caregivers had already talked about euthanasia (when, with whom and why), (2) their views on the legality of euthanasia in dementia, (3) the ability to still experience joy after being diagnosed with YOD, and (4) the impact of euthanasia and euthanasia discussions as experienced by family caregivers.

### 3.1. The context in which patients and caregivers had already talked about euthanasia

#### 3.1.1. When: euthanasia brought up at several 'key moments'

Various key moments or events gave rise to euthanasia becoming a topic between people with YOD and their family caregiver. It emerged that the initial shock of receiving a YOD diagnosis could lead to patients, sometimes impulsively, discussing the option of euthanasia very early on in the disease trajectory. Other highly emotional moments, such as during arguments, were also identified as moments where euthanasia was explicitly brought into the conversation. Experiencing more difficulties in day-to-day activities and foreseeing or noticing deterioration could make the topic resurface later on.

*"If it worsens, then I will take the necessary decisions myself, huh, for euthanasia or such... No, at that point I am done with it." (man with YOD, 2codeE17-19)*

Being confronted with other patients who actually received euthanasia, was also said to be a moment when the topic of euthanasia arose. One caregiver explained that her husband had discussed his own request for euthanasia with another person with YOD whose euthanasia request was granted shortly after. This caregiver believed that being confronted with another patient's euthanasia, had strengthened her husband's idea at the time.

*"It reinforced him (patient) in the fact that it (euthanasia) was possible and that it was a good alternative".*

#### 3.1.2. With whom: euthanasia was discussed with family, rather than professional, caregivers

For the vast majority, conversations regarding euthanasia initially arose between the person with YOD and his/her family caregiver(s). More specifically, they were typically initiated by the patient, were directed towards family caregivers such as spouses or siblings, and sometimes simply 'faded away' over time.

*"But then I saw, the next day he (patient) was no longer occupied with that (euthanasia) at all." (caregiver, code D124)*

At other times, they were continued with medical or legal professional caregivers, mostly through the initiative of the patients' family caregiver.

#### 3.1.3. Why: personal as well as interpersonal considerations when discussing euthanasia

People with YOD's main motivation for thinking about or considering euthanasia, appeared to stem from their wish to spare themselves inevitable decline and suffering and to safeguard their sense of dignity.

*"It's going to have to happen one day, dying, right... I would prefer (to make) the best choice... Little pain and such..." (man with YOD, 2, Code 0122).*

*"To become incontinent for instance, I would have a lot of difficulties with that. And then it might be that I say that it needs to be over for me." (woman with YOD, 2, code E46)*

In this context, family caregivers discussed patients' attempt to avoid institutionalization and having the choice between living in a care facility (nursing home) or ending life through euthanasia.

*(Quote 1, code L142) A woman with YOD wanted euthanasia “from the moment she needed to be locked up”.*

*“In fact, you (caregiver) are always pushing him (patient) towards the exit... And then he has still got the choice ‘I am going to the institution’ or ‘I choose the other way’ (euthanasia).” (caregiver, 1, M70–71)*

Both people with YOD and caregivers elaborated on the meaning and importance of social relations in the context of (wanting) euthanasia. For example, patients wishing euthanasia when they no longer recognize their loved-ones.

*“I would not like to be... when the memory is completely gone, then it’s not necessary anymore...” (man with YOD, 2, codes O122–124)*

*“He (patient) says ‘if I am no longer able to speak, then it can stop for me’.” (caregiver, 2, code A34)*

Other considerations were not wanting to be a burden to their family and wishing to maintain the capability of having conversations with others.

*“But the phenomenon of euthanasia when you are doing really bad or right on the edge... then I don’t hesitate for a moment. And then of course that comes back to the story of X (wife) and X (daughter) who have to be all right.” (man with YOD, 2, code Q109)*

*“He (patient) has always said ‘I do not want you (caregiver) to suffer, and if it is not attainable any longer, then I choose to stop’.” (caregiver, 2, CodeP51)*

### 3.2. Opinions on the euthanasia law and the criterium for cognitive capacity

During the interviews several caregivers shared their, and according to them also their loved-ones’, viewpoints on the validity of euthanasia through an advance directive for people who have reached a stage of dementia in which they (might) lack the cognitive capacity to confirm their previous wish. The opinions expressed revolved around whether or not the current Belgian law should be expanded to allow people in advanced stages of dementia to receive euthanasia based on their previously stated request.

*“Everyone knows that you have it (dementia), that you do not want to continue life like a plant... yeah guys... then, why not?” (caregiver, 1, code G168)*

*“There are so many discussions about euthanasia for people with dementia, but actually the people who make the laws, should be in that situation themselves. They themselves should have a partner or a mother or a dear friend, and experience -for entire days- what that means. If X (patient) now, today, says ‘if I am no longer able to do this, and that and that, then I want euthanasia’, then I believe he has got the right to that.” (caregiver, 2, codes N67-68-68)*

Both persons with YOD and their caregivers discussed the legal requirement of having cognitive capacity at the time of formulating a current euthanasia request and/or being granted euthanasia.

*“One of her (patient who was granted euthanasia) statements was that ‘euthanasia is something you need to do with a sound mind’.” (caregiver, 1, code G157)*

*“At some point, if you wait too long you can no longer (request euthanasia). I know that’s an issue and I’m kind of aware of it but it’s not in the fore-figure for me now, because I figure I still have six months or a year where I still have the capability to make decisions.” (man with YOD, 2, code C28–29).*

In this sense, the need to address euthanasia recurrently, was discussed.

*“And you need to bring it (euthanasia request) up regularly and see if they... And clarify to them (patients) that it is now or never in their case.” (caregiver, 1, codes M, p.15)*

### 3.3. Dementia as condition that still allows room for joy

Caregivers also put forward that euthanasia for people with dementia was different from euthanasia in more somatically “aggressive” diseases.

*“I mean there are people here... many people... for whom that (euthanasia) probably isn’t the best solution because they are still... physically relatively okay. Because they can still enjoy many things. And... and that will continue to be the case until they are too far to make a decision.” (caregiver, 1, code165–166)*

This specificity was usually focused on the ability of people with dementia to still experience joy.

*“Should you perform euthanasia on someone who can still eat with a tasty appetite every day? Who can still enjoy?” (caregiver, 1, codeK87)*

*“Yes, but with a sound mind... Then you can also still enjoy life fully capable. Right. So the moment that you can still consciously enjoy all kinds of things with a sound mind, the beautiful weather, then you have to be able to say at the same time ‘I want to die, because tomorrow it might be that I’m gone’.” (caregiver, 1, Gp10,A3)*

Also, people living with YOD themselves talked about experiencing feelings of well-being despite their diagnosis.

*“There have been relatively many good days (since diagnosis).” (man with YOD, 2, codeO130)*

*“Today I feel well again and then I say to myself ‘yes, I don’t need anything else’.” (man with YOD, 2, codeQ49)*

### 3.4. Emotional impact of euthanasia and discussions about euthanasia for family caregivers

Caregivers elaborated on how emotionally challenging it felt to discuss euthanasia one-on-one with their loved-one.

*“I have to bring that (euthanasia) up and that is not pleasant for me because it seems like you’d wish she (patient) were dead.” (caregiver, 2E56)*

In this regard, several caregivers preferred to have a professional (an “outsider”) involved.

*“I find it difficult to do that, as a wife, to check how he feels towards euthanasia. I’m almost too involved. So I always find it very difficult to say something about that myself. I think it is best if he can talk to someone else about that (euthanasia).” (caregiver, 2, codes D79–82)*

One caregiver also explained the difficulty when her loved-one with YOD no longer remembered his own wish for euthanasia.

*“So, I thought, I don’t have to hold on to that (patient saying he wanted euthanasia). I might have someone else inform with him how he feels about that, if there’s a chance, but for the rest I’ve got to let that go. Because in the end he will get the impressions that I wish he were dead.” (caregiver, code D124–125)*

Family caregivers of persons with dementia who were actually granted euthanasia, elaborated on the sense of guilt they experienced afterwards.

*“Why have I not tried to convince her (patient) to not do it (euthanasia) after all.” (caregiver 1, code G122)*

*"You always feel guilty. The impression that you have not done enough." (caregiver 1, code M117 & M118)*

One caregiver explained feeling that his family regarded him as *"a bit of a murderer because he had encouraged it (sister's euthanasia)"*. (caregiver, 1codeG40).

## 4. Discussion and conclusion

### 4.1. Discussion

Over two third of our respondents spontaneously addressed the topic of euthanasia and how discussions in this regard took place. If euthanasia was discussed, four main results stood out: (1) People with YOD and their family caregivers described similar contexts in which these discussions about euthanasia arose. The topic was brought up at several key moments (such as the moment of diagnosis), usually with an informal caregiver, and was motivated by both personal patient considerations (the impact for the person with YOD), as well as by patients considering the impact of disease progression for their loved-ones. (2) Family caregivers paid a lot of attention to the criteria under which euthanasia is allowed in Belgium for people with YOD, specifically in the context of declining cognitive capacity. (3) Dementia is characterized as a condition that still allows room for enjoyment, making it different from other conditions in the context of euthanasia according to our participants. (4) Family caregivers elaborated on the emotional challenges they experienced when discussing euthanasia and, some, on the feelings of guilt after a loved-one with dementia was actually granted euthanasia.

The main strength of this study is its ability to shed light on an understudied topic through patients' and caregivers' own narratives. This is, to our knowledge, the first research to enter the new territory of euthanasia as discussed by people with YOD and their family caregivers. Since euthanasia was not included in the interview guides as a specific topic, these instances of communication were not consistently structured throughout interviews, and hence the topic was not discussed as 'in-depth' as it would have been in a study focused solely on euthanasia. As such, respondents' unsolicited remarks cover a broad range of ideas, for some of which we might not have reached data-saturation. However, given that the various viewpoints expressed are instances of unique experience-based perceptions on an undiscovered topic, they hold innovative value to both theory and practice. Nonetheless this study's findings form a steppingstone for further developing the international evidence base on this specific topic, it is necessary to put patients' and caregivers' experiences of and perspectives on euthanasia in YOD at the forefront of future research questions. As this study was homogeneous in terms of respondents' Belgian social and legal background, the way in which other legislative and social contexts possibly impact patients' and caregivers' considerations, should be subject of further qualitative research in various countries. Whilst some results seem to point to age-specific factors (for instance trying to avoid residential care), others appear rather dementia- than age-specific (for instance the issue of declining cognitive capacity). Future research should address this study's remaining question of to which extent our findings are cohort- or disease-specific, or both.

#### 4.1.1. Interpersonal relationships are an aspect of euthanasia considerations

Our study shows the emotional impact of receiving a diagnosis of dementia at a young age, with patients who at times rather impulsively express their 'interest' in euthanasia. A large-scale interview study with German family caregivers of people in advanced stages of dementia showed that over one out of four patients in early stages of YOD experience feelings of suicidal ideation that fade over time [17]. Similar to the euthanasia considerations found in the current study, these ideations are possibly caused by the wish to spare oneself from suffering, as well as

by the wish not to be a burden to family, rather than representing an actual wish to die [17]. Our respondents paid attention to social, and especially familial, relationships within their views on euthanasia. Not wanting to become a burden to loved-ones was an important consideration when thinking about the future. Yet again, this reiterates the previously reported protective role that people with YOD take on towards their family caregivers when contemplating their future care [9]. Our study further shows that people with YOD might wish to avoid not solely their personal, but also their families', suffering. Given the finding that the consequences of YOD for patients' loved-ones might be part of their euthanasia considerations, it seems important within practice to clarify and to the extent possible detangle this reason from the motive of unbearable personal suffering.

#### 4.1.2. Societal image of dementia and dementia care are present in euthanasia considerations

The finding that considerations on euthanasia entailed an attempt to avoid decline and maintain dignity can be linked to several previous findings on how society as a whole deals with dementia. Already a decade ago it was reported that popular media tend to focus on portraying the terminal stage of dementia which becomes representative of the entire trajectory [18]. More recently, it was reiterated that stigma and stereotypes shape our image of (young-onset) dementia [19]. Moreover, the strong relationship between the general public's views about the quality of life in advanced dementia and their views about legalizing euthanasia for these patients through advance directives has been established through an experimental survey [20]. In a Dutch qualitative study, physicians expressed that society tends to consider dementia as a condition with hardly any quality of life and regards euthanasia as a more dignified alternative [21]. Also Belgian physicians, as shown from a recent focus group study, felt that society's negative portrayal of dementia impacted patients and was associated to catastrophic reactions to being diagnosed [22]. Importantly, the societal image in which a life with dementia is at times reduced to 'a life not worth living' [19,23], which can be a driving force behind euthanasia requests [24], is contradicted by the majority of patients with both young- and late-onset dementia [17,25]. The current study corroborates the finding that caregivers and patients themselves also underscore the remaining capacity of enjoyment within a dementia trajectory [4] and that they might consider the burden of dementia differently than 'healthy' individuals do [17]. Through their own involvement in research, patients have been providing a more nuanced and at times brighter outlook on dementia [25]. So did the people living with YOD and their caregivers who took part in our studies, when explaining that there is still room for 'enjoying life' regardless of the diagnosis and the burden it causes. Topics regarding the 'negative' image of dementia might deserve a place within consultations since they appear to influence patients' and caregivers' expectations of the future.

Stigmatizing beliefs, particularly regarding inadequate residential care for people with YOD, have been described previously [26]. The current study found that euthanasia is at times regarded as a mean to avoid institutionalization. This highlights the urgency to address both the needs in and the misconceptions about residential care for people with YOD. Moreover, this result might shed further light on previous findings that contemplating decline in dementia is more threatening than thinking about death itself [27]. It seems evident that when the law on euthanasia states that all reasonable alternatives need to be tried before granting a euthanasia request, these alternatives ought to be deemed reasonable and adequate from the patient's perspective as well. Public and political debates about the legal criteria for euthanasia, such as capacity, should co-exist with initiatives on care-improvement (e.g. residential care).

#### 4.1.3. Legal context influences respondents' thought framework

Previous studies suggested that the framework people use to think about end-of-life decisions is likely to be influenced by the medicolegal

context in which people find themselves [8,28]. Former research with American caregivers of people with YOD showed that the actual life-ending decisions discussed mainly revolved around suicide. It seems plausible that due to Belgian law, the end-of-life decision of suicide is replaced -at least partly- by its legalized alternative with the same end-result, namely euthanasia [8]. In both our studies with Belgian participants, the majority of respondents elaborated on euthanasia when discussing ACP in YOD. Moreover, this study's finding that some caregivers, from their and their loved-one's perspective, specifically elaborated on the requirements of capacity and therefore the timing of a euthanasia request within Belgian euthanasia law, echoes the current public and political debate and, as such, its relevance. Our study reiterates that professionals being open to conversations about concerns and fears, possibly including those about ideas of (hastening) death, can be regarded as a service to people with YOD and their family caregivers [29]. Our study shows that patients and caregivers themselves are an indispensable voice to be heard at the table as their lived experience most likely leads to unique perspectives on the practice of euthanasia.

#### 4.2. Conclusion

Our findings suggest that the considerations of people with YOD towards euthanasia are not solely rooted in expected personal unbearable suffering, but also appear to stem from the anticipated impact of their condition on significant others. The negative manner in which (young-onset) dementia is socially framed and the embedding of euthanasia as a legal end-of-life option, might influence the considerations on euthanasia.

#### 4.3. Practice implications

It appears recommended for physicians to pay sufficient attention to familial relationships and interpersonal considerations when discussing euthanasia with people living with YOD and their caregivers. Also, our study suggests that patients and caregivers should be provided with the opportunity to openly discuss concerns and fears, including those about hastening death (euthanasia), and with the opportunity to reflect on their prognosis, in a timely and realistic manner. When outlining policy, it is important to reflect as a society on our portrayal of (young-onset) dementia and its ethical implications for people and families living with the condition. Moreover, it seems important for policy to re-evaluate the current care initiatives that are available in YOD and make improvements where necessary.

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#### CRediT authorship contribution statement

**Van Rickstal Romy:** Writing – original draft, Funding acquisition, Formal analysis, Data curation, Conceptualization, Writing – review & editing. **De Vleminck Aline:** Conceptualization, Formal analysis, Funding acquisition, Supervision, Writing – review & editing. **Chambaere Kenneth:** Writing – review & editing. **Van den Block Lieve:** Writing – review & editing, Supervision, Funding acquisition, Formal analysis, Conceptualization.

#### Declaration of Competing Interest

None.

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