






Relatives' needs in terms of bereavement care throughout euthanasia processes: A qualitative study

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Abstract

Aim: To explore relatives' needs in terms of bereavement care during euthanasia processes, how healthcare providers respond to these needs, and the degree of commonality between relatives' and healthcare providers' reports.

Design: A phenomenological design was employed, utilising reflexive thematic analysis to examine interviews conducted with relatives ($N=19$) and healthcare providers ($N=47$).

Results: Relatives' needs throughout euthanasia processes are presented in five main themes and several subthemes, with similar findings between both sets of participants. Although relatives infrequently communicated their needs explicitly to healthcare providers, they appreciated it when staff proactively met their needs. Healthcare providers aimed to assist with the relatives' grief process by tending to their specific needs. However, aftercare was not consistently offered, but relatives did not have high expectations for professional follow-up care.

Conclusion: Our research offers important directions for healthcare professionals, empowering them to provide needs-based bereavement care during euthanasia processes. Moreover, it emphasises the importance of recognising the unique needs of relatives and proactively addressing them in the period before the loss to positively contribute to relatives' grief process.

Implications for the profession and/or patient care: Insights into relatives' needs in the context of euthanasia. Good practices on how healthcare providers can attend to relatives' needs before, during and after the loss

Impact: Current literature and guidelines on needs-based bereavement care in the context of euthanasia and, more generally, assisted dying, are limited. These findings provide concrete directions for practice in supporting (nearly) bereaved relatives in the context of euthanasia, potentially mitigating adverse health outcomes.

Reporting method: Standards for Reporting Qualitative Research (SRQR checklist).
Patient or Public contribution: Relatives of deceased cancer patients were involved in the conduct of the study.

KEYWORDS

bereavement care, euthanasia, family, grief, healthcare providers, qualitative research

1 | INTRODUCTION

A death-related loss is a profound experience that impacts an average of five to nine relatives and may affect their health (Beuthin et al., 2022; Verdery et al., 2020). Although most relatives are able to cope with the loss, a small minority may face abnormally persistent and debilitating challenges that significantly impair their daily functioning (Prigerson et al., 2009). Tailored bereavement care can mitigate the risk of developing grief-related complications (Aoun et al., 2012; Guldin et al., 2015; Harrop et al., 2020; Stroebe et al., 2007). However, it is insufficiently clear how to provide needs-based bereavement care to relatives in the context of assisted dying.

2 | BACKGROUND

Professional healthcare typically perceives patients as rational, autonomous and independent beings (Witkamp et al., 2016). This perspective is also evident in the practice of assisted dying, where pursuing aid in dying is considered an individual patient's right (Hamarat et al., 2022). Assisted dying, also known as Medical Assistance in Dying (MAiD) and Voluntary Assisted Dying (VAD), is an umbrella concept that encompasses euthanasia and physician assisted suicide (Mroz et al., 2021). Assisted suicide involves a healthcare provider supplying a lethal drug, which the patient then administers themselves, whereas euthanasia involves a professional, often a physician, directly administering the drug (Chambaere & Cohen, 2017; Yan et al., 2022). Currently, healthcare providers are permitted to administer lethal medication under strict conditions in nine countries: Belgium, the Netherlands, Canada, Colombia, Luxembourg, Portugal, Spain, Australia and New Zealand (Vissers, 2023).

In Belgium, the term commonly used to refer to assisted dying is euthanasia, which has been applicable to both physical and mental intolerable suffering since 2002 (Staatsblad, 2002). The Belgian Parliament passed laws decriminalising euthanasia alongside legislation on patients' rights and the right to palliative care for all. Notably, the framework for palliative care was already well-established before 2002 (Vanden Berghe et al., 2013). In Belgium, specialised palliative care is frequently involved in euthanasia processes (73.8%) (Palliatieve Zorg Vlaanderen, 2015) ensuring a tailored, collaborative and multidisciplinary approach with high standards of care (Andrew et al., 2013).

What does this paper contribute to the wider global clinical community?

Support healthcare providers in providing needs-based bereavement care, which can mitigate relatives' risk for developing grief-related complications.

Palliative care aims to enhance the well-being of patients and their families, and bereavement is an essential component (WHO, 2023). Recently, the European Association for Palliative Care (EAPC) recommended a needs-based approach to bereavement care. This approach aligns relatives' needs with the intensity of professional response, ranging from universal and basic support to more intensive professional care (Keegan et al., 2021). However, lacking guidelines, education and training (Kusano et al., 2012) complicate its provision in practice (Aoun et al., 2017; Bužgová et al., 2016; O'Sullivan et al., 2021). Healthcare providers often rely on their subjective opinions (Guldin et al., 2015; Kobel et al., 2019; Mather et al., 2008), which may not always be accurate.

There is a paucity of literature on needs-based bereavement care in assisted dying, and bereavement care itself is often vaguely described as 'giving support' (Inghelbrecht et al., 2010), 'providing the best possible care' (Bellens et al., 2020), 'guiding, counselling and supporting the family' (Denier et al., 2009), and 'having deeper conversations' (Beuthin et al., 2018).

3 | THE STUDY

The objectives of this study are: to (1) explore relatives' needs in terms of bereavement care before, during, and after euthanasia; (2) present the extent of common findings between the perspectives of relatives (direct reports) and healthcare providers (proxy reports); and (3) identify good practices for healthcare providers to address relatives' bereavement care needs. To answer the aforementioned objectives in depth, we conducted a qualitative study that will be reported using the Standards for Reporting Qualitative Research (O'Brien et al., 2014). The SRQR checklist can be found in File S1.

4 | METHODS

4.1 | Study design and recruiting

This study aims to explore the lived experiences of relatives and healthcare providers involved in euthanasia processes from a constructivist paradigm (Savin-Baden & Howell Major, 2013). The research objectives align with the phenomenological approach, which seeks to understand the essence of social phenomena from the perspective of those who have experienced them (Creswell, 1998).

Participants were recruited through various methods, including recruitment emails, flyers, newsletters, advocacy groups and professional associations, snowball sampling and a longitudinal survey study for the same research project. The recruitment material provided information on the study, including the inclusion and exclusion criteria, expectations for participation (either a one-time face-to-face or online interview) and contact information for the research team. Interested participants could contact the first author via telephone or email. The first author explained the study's aims and design, and answered any questions during this initial contact. Additionally, the first author explored whether these individuals met the inclusion criteria outlined in the recruitment materials.

The inclusion criteria were as follows: (1) being a Dutch-speaking relative (≥ 18 years old) of a person with cancer, who died at home or in a hospital due to euthanasia, not more than 24 months ago; or (2) being a Dutch-speaking physician/nurse/psychologist, employed in a hospital and/or homecare, who attended or performed a euthanasia less than 18 months ago. Most of the healthcare providers interviewed did not participate in the euthanasia processes of the included relatives in our study. A purposive sample was selected to ensure both homogeneity and heterogeneity (Holloway & Gavin, 2016) in terms of the relatives' age, gender, and relationship to the deceased, level of being at peace with the request, as well as the healthcare providers' gender, discipline, workplace, age and years of experience.

The sampling of healthcare providers ended after reaching sampling saturation, while this was not the case for relatives. We launched an additional call for participation to include relatives who were opposed to the euthanasia request and/or had negative experiences with euthanasia. Although we were able to include relatives with a variety of experiences, we only managed to include one relative who was against the euthanasia request of their deceased family member.

4.2 | Data collection

Data was collected between September 2020 and June 2022 by seven female interviewers (C.B., L.D., S.D., M.D.M., K.H., A.L. and H.V.K.), of which the latter four were master thesis' students. We ensured that all interviewers had no prior relationship with the participants. Prior to conducting the interviews, all interviewers wrote

a reflective framework on their individual belief systems, goals, and personal assumptions (Mortari, 2015). Based on the interviewers' individual perspectives, researchers (C.B. and S.D.) have a positive stance towards assisted dying, which may be influenced by their current or finished PhD studies in euthanasia. Additionally, their academic backgrounds in educational sciences and sociology could introduce a bias towards advocating for greater consideration of the patient's surrounding network. Regular meetings were held between all interviewers and with experts on palliative care, grief and bereavement care to facilitate reflection on potential biases and the research process.

Semi-structured interviews were conducted online or face-to-face in Dutch until data saturation was reached, meaning that no new data emerged during the interviews. Face-to-face interviews took place at the participant's workplace, home or Ghent University Hospital. The interview guides (Table S2 and Table S3) were based on the literature (Andriessen et al., 2020; Roest et al., 2019; Swarte et al., 2003) and the aforementioned experts. The interviewguides were iteratively adapted throughout the data collection process by deleting, adding or fine-tuning questions. Before the interviews began, participants were assured by the interviewers that they could pause or stop the interview at any time if necessary. Referral information to (specialised) organisations was provided if requested by relatives or if the interviewers felt that participants needed additional support.

All interviews were audio-recorded, pseudonymized and transcribed verbatim in Dutch by a professional transcriber and master thesis students, who were all bound by a confidentiality agreement. Participants were briefed on the pseudonymization process, in which their contact information was securely stored separately from the interview transcripts. The interviewers and L.V.H. and N.V.D.N (principal investigators) had access to the recordings and transcripts. Recordings were deleted after finishing data analysis.

4.3 | Data analysis

Transcripts were analysed between October 2020 and November 2022 using reflexive thematic analysis, with the purpose of inductively developing themes from codes. These codes are patterns of shared meaning underpinned by a central organising concept and require considerable analytical and interpretive work by the researcher (Braun & Clarke, 2022). Themes represent both the meaning constructed and communicated by the participants' (e.g. verbatims and words) and the researcher's interpretation of that meaning (Byrne, 2022). Themes were identified in a reflective, iterative and step-wise process that began with the authors (C.B., L.D., L.V.H. N.V.D.N.) reading the transcript in detail to familiarise themselves with the data. After reading the entire transcript, the authors began to code data patterns inductively, guided by the aims of the study. The resulting codes were then organised into five main themes and nine subthemes representing the reported needs of relatives and possible good practices throughout euthanasia processes.

The research team jointly discussed the data interpretations and final themes (C.B., L.D., R.P., L.V.H., L.V.D.B., and N.V.D.N.). Post-interview field notes and data analysis notes were used to enhance the reflective process. Interviews were initially coded on paper, and then transferred to NVivo12 (QSR International) to support analysis. Verbatims were used to illustrate the themes, and were translated from Dutch to English by the first author and then reviewed by the remaining authors.

4.4 | Ensuring quality of the research process and product

Several strategies were implemented to ensure the quality of products and processes, thereby contributing to the validity and trustworthiness of the research. These strategies included (1) triangulation of methods and investigators, (2) external audit, (3) valid data analysis methods, and (4) a detailed description of the methods and findings. Method triangulation was achieved by including observations and field notes in each interview, while investigator triangulation was achieved by involving experts (N.V.D.N., R.P., L.D., L.V.D.B., L.V.H., S.D., and C.B.), with multidisciplinary backgrounds in medicine, nursing, psychology, sociology and educational sciences throughout the research process. Meetings with the experts were also held to address potential interviewer bias, reflect on the interviews themselves and analyse the results. Two experts (R.P. and L.V.D.B.) provided further external review of the research products and process. A combination of two valid data analysis methods was used including traditional tools such as notes and coloured pens, as well as digital software (NVivo 12 QSR International). The software allows for data retrieval and management. Writing, organising notes, and visualising data leads to enhanced data interaction due to temporization (Maher et al., 2018). The researchers provided a detailed account of their methods and findings, including thick descriptions of themes and sufficient verbatims. This allows readers to assess the soundness of the decisions made and the generalizability of the findings (Savin-Baden & Howell Major, 2013).

4.5 | Ethical considerations

The research protocol was approved by Ethics Committee of Ghent University Hospital [registration number: B6702020000289]. All participants were adequately informed, and gave their oral and written consent to participate. All data and verbatims were pseudonymized.

5 | FINDINGS

A total of 66 participants were interviewed: 19 relatives of 17 deceased cancer patients, and 47 healthcare providers. Two relatives lost the same family member, one interview involved a couple. The

17 deceased patients were on average 70 years old (range: 32–88), mostly female ($n=10$), and diagnosed with digestive ($n=6$) or lung cancer ($n=5$). Euthanasia was often performed more than 1 month after the request ($n=10$) and at home ($n=10$). Relatives were mostly female ($n=10$), spouses ($n=10$), and had a mean age of 63 years old (range: 33–86). The interviews with relatives usually occurred face-to-face ($n=16$) and had a mean duration of 106 minutes (range: 57–183). The research team made an exception in the study by including one participant who was interviewed 27 months after the loss, exceeding the 24-month limit. This deviation from the inclusion criteria was necessary due to unforeseen circumstances related to the COVID-19 pandemic. The scheduled face-to-face interview with this participant was postponed due to tighter restrictions and public health guidelines prompted by the pandemic.

Interviews with healthcare providers were mostly conducted online ($n=31$), and included nurses ($n=17$), physicians ($n=15$), and psychologists ($n=15$). Participants were on average 47 years old (range: 26–69) and had an average work experience of 19 years (range: 1–44). The average length of the interviews was 68 min (range: 39–116). More information on the demographics of the participating healthcare providers and relatives can be found in Table 1.

Our findings revealed several relatives' needs in the context of euthanasia that could vary throughout the process. The needs are presented into five main themes with several subthemes (see Figure S4 in the Supplementary Files): (1) ensuring comfort of the patient with cancer, (2) experiencing compassionate care, (3) walking the walk to process the euthanasia request, (4) being supported in saying goodbye, and (5) receiving tailored bereavement care. Needs were often not explicitly communicated to healthcare providers because relatives prioritised their family member's needs over their own. However, relatives appreciated it when healthcare providers (proactively) addressed their needs.

These findings were echoed in the study with healthcare providers, who reported doing everything they could to help relatives cope with the loss and the circumstances of death. They aimed to prepare relatives for the imminent death to prevent a traumatic experience. However, providing bereavement care to relatives in the context of euthanasia was often time-consuming and intense, as reported by healthcare providers.

'I always think about the long-term consequences for the family. [...] I have often noticed that you have to invest a lot of time in supporting relatives.' (Interview 13, nurse, hospital).

5.1 | Ensuring comfort of the person with cancer

This theme was particularly present in the interviews with relatives. Many relatives emphasised that their family member should not experience any pain or discomfort in the period leading up to the euthanasia and on the day of the euthanasia itself. Healthcare providers attempted to provide effective pain management either

TABLE 1 Sociodemographic characteristics of relatives ($N=19$), their deceased family member ($N=17$), and healthcare providers ($N=47$).

Interviews with relatives	
Demographics of relatives ($N=19$)	
Gender, N (%)	
Female	10 (47.4%)
Male	9 (52.6%)
Age (in years), N (%)	
31–40	1 (5.3%)
41–50	1 (5.3%)
51–60	7 (36.8%)
61–70	5 (26.3%)
71–80	4 (21.1%)
81–90	1 (5.3%)
Religious, N (%)	
Yes	3 (15.8%)
No	16 (84.2%)
Education, N (%)	
(Higher) secondary education	8 (42.1%)
College/university education	11 (57.9%)
Relationship to the deceased, relative is a N (%)	
Spouse	10 (52.6%)
Child (in law)	6 (31.6%)
Parent (of a child >18 years old)	2 (10.5%)
Granddaughter	1 (5.3%)
Demographics of the deceased ($N=17$)	
Gender, N (%)	
Female	10 (58.8%)
Male	7 (41.2%)
Cancer type, N (%)	
Digestive cancer	6 (35.3%)
Lung cancer	5 (29.4%)
Hematologic cancer	2 (11.8%)
Urogenital cancer	2 (11.8%)
Breast cancer	1 (5.9%)
Brain tumour	1 (5.9%)
Period between cancer diagnosis and the euthanasia request (in months), N (%)	
0–6	10 (58.8%)
7–12	2 (11.8%)
13–18	1 (5.9%)
19–24	2 (11.8%)
>24	2 (11.8%)
Period between expressing the request and the performance of euthanasia (in months), N (%)	
<1	7 (41.2%)
>1	10 (58.8%)

(Continues)

TABLE 1 (Continued)

Interviews with relatives	
Demographics of relatives ($N=19$)	
Period between the date of death and the interview (in months), N (%)	
0–6	2 (10.5%)
7–12	5 (26.3%)
13–18	9 (47.4%)
19–24	2 (10.5%)
>24	1 (5.3%)
Interviews with healthcare providers	
Demographics of healthcare providers ($N=47$)	
Gender, N (%)	
Female	17 (36.2%)
Male	30 (63.8%)
Age (in years), N (%)	
20–30	1 (2.1%)
31–40	14 (29.8%)
41–50	15 (31.9%)
51–60	10 (21.3%)
61–70	7 (14.9%)
Years of work experience, N (%)	
0–5	4 (8.5%)
6–10	7 (14.9%)
11–20	15 (31.9%)
21–30	15 (31.9%)
31–45	6 (12.8%)
Discipline, N (%)	
Nurse	17 (36.16%)
Physician	15 (31.92%)
Psychologist	15 (31.2%)
Setting of employment, N (%)	
Home	11 (23.4%)
Hospital	32 (68.1%)
Both	4 (8.5%)

independently or with the assistance of specialised palliative care services.

'You anticipate this moment [the day of the euthanasia], but you suppress it. My only priority was to give him the best possible care and comfort. I put off that moment until the day came, and then I dealt with it.' (Interview 3, spouse died at home).

Relatives valued healthcare providers who were transparent about their expertise and provided their (personal) contact information. This allowed relatives of cancer patients, being cared for at home, to reach out to a familiar contact if their family member was

experiencing suffering; or if they felt distressed or anxious about the patient's condition. This spared them from having to repeatedly explain the situation to unfamiliar healthcare providers.

'I provide my phone number and encourage people to reach out whenever they need me. This fosters a sense of safety and reassurance, knowing that I am always available. I compare myself to a call button next to a hospital bed, emphasizing that they can press it at any time. This builds trust with patients and their families, assuring them that I am committed to providing good care.' (Interview 8, nurse, palliative homecare).

5.2 | Experiencing compassionate care

The interviews underscored the significance of compassionate care alongside medical care for patients. Relatives valued healthcare providers who dedicated time to building trust and trusting relationships with them, expressed empathy and provided emotional support throughout the euthanasia process, which was often experienced by relatives as an emotional rollercoaster.

5.2.1 | Building trust and trusting relationships with healthcare providers

Both groups of participants emphasised the significance of establishing trusting relationships between relatives and healthcare providers, preferably in a timely manner. Healthcare providers stated that such relationships helped them gain insight into family dynamics and ensure that nobody was overlooked. This trust also reassured relatives that healthcare providers would be available when needed. Moreover, it created a leeway for follow-up contact.

'If a strong, trusting relationship is established with relatives, they feel confident in reaching out at any time, knowing that you'll be there to support them unconditionally.' (Interview 12, nurse, hospital).

Relatives and healthcare providers observed that the level of trust in the relationship also influenced the professional distance that relatives expected from staff. More precisely, most relatives preferred healthcare providers to take 'a back seat position' during the euthanasia performance.

'They seemed almost invisible. I think they were trying not to intrude. It is difficult to put into words, but even though they were physically present, it did not feel like it. I appreciated their discretion because, in that moment, only we mattered.' (Interview 8, female, parent died in the hospital).

Healthcare providers attempted to maintain a professional distance and adjust their behaviour accordingly. However, this process often involved trial and error. If healthcare providers were unfamiliar to the patient's relatives, they were generally accepted as functional participants during the euthanasia process. However, relatives appreciated it if the healthcare providers remained in the background or left shortly after completing their tasks. Relatives preferred that healthcare providers briefly introduce themselves beforehand.

'I was grateful that she only called the second nurse when needed [for the post-mortem care]. We did not know her, and had never seen her before. She managed to come and go discreetly, without us even noticing. For me, euthanasia is very intimate, and I believe there should not be any unfamiliar faces involved.' (Interview 6, spouse died at home).

5.2.2 | Experiencing empathy from healthcare providers

Several relatives reported that healthcare providers made insensitive remarks or had conversations lacking empathy.

'[Before the euthanasia], I noticed her long nails and questioned a healthcare provider about it. Her response was: 'It is not important, you won't see it afterwards...(sighs)' (Interview 5, child died at the hospital).

However, many healthcare providers said being conscious of their (non-)verbal behaviour, and some even rehearsed conversations with relatives in advance.

'I sometimes feel like I'm walking on eggshells when communicating with families. I meticulously select my words and phrasing, considering how it will be received by relatives [...] Good communication is challenging. It is about conveying necessary information in a way that is ok for the person on the other side of the table.' (Interview 17, nurse, hospital).

5.2.3 | Receiving emotional support during the emotional rollercoaster

Trust facilitated relatives' expression of emotions, thoughts and concerns to healthcare providers. The euthanasia process proved to be an emotional rollercoaster for most relatives, characterised by uncertainty and conflicting feelings of relief and anxiety regarding the imminent death. Because of the intensity of the euthanasia process, relatives appreciated the sympathetic ear from

healthcare providers. The emotional support made them feel recognised and comforted.

'I wish someone had taken the time to inquire about how I was handling the situation and the challenges I was facing. It would have been comforting to have someone check on my well-being, alongside that of my loved one. While he remained the priority, I would have appreciated it if someone simply asked me: 'how are you holding up?' Just once. Unfortunately, I never received that type of support.' (Interview 13, spouse died in the hospital).

Emotional support was often offered by a nurse, psychologist or physician, who provided a sympathetic ear to all or some relatives (e.g. if they felt relatives were struggling with the euthanasia). This type of support was provided before, during, or after the euthanasia. If healthcare providers felt they could not adequately support the emotional needs of relatives before or after the loss, they referred them to a psychologist or bereavement counsellor within their team or in the primary care setting. If physicians believed that some relatives would find the euthanasia difficult, they proactively invited an extra colleague (often a nurse or psychologist) to provide emotional support.

'In case a relative becomes overwhelmed or starts crying uncontrollably during the euthanasia process, we have an experienced colleague stationed near the door. This colleague can then escort the relative out of the room to offer comfort.' (Interview 30, physician, hospital).

5.3 | Walking the walk together to process the euthanasia request

Although relatives were often not completely surprised by the euthanasia request, they valued the opportunity to 'walk the walk together' with their family member and healthcare providers. This involvement, referred to as 'walking the walk', allowed relatives to navigate through the euthanasia process together, gaining understanding of their family member's decision, and preparing for the imminent death. Timely inclusion in the euthanasia process was crucial for this shared journey, fostering transparent communication and information exchange among patients, relatives and healthcare providers.

5.3.1 | Getting involved in the euthanasia process in a timely manner

Healthcare providers made efforts to involve the patient's relatives in the euthanasia process by encouraging patients to notify their

relatives in a timely manner about the request. If patients opted to withhold information from their relatives, healthcare providers listened to their concerns and emphasised the importance of timely involvement to facilitate relatives' grief process.

'When a patient chooses not to disclose their request for euthanasia to their relatives, I make an effort to understand their motivation. Then, I explain to them that it may benefit their relatives' grief process if they are aware of the request and that they are given the opportunity to come to terms with it. I always strive to consider the family's perspective.' (Interview 37, psychologist, hospital).

Relatives stressed the significance of timely involvement, as it helped them come to terms with the request, prepare for the upcoming loss, and receive bereavement care. It is imperative for healthcare providers to acknowledge all relatives involved. In our study, some relatives expressed disappointment that certain family members, such as children or older adults, were overlooked by healthcare providers. These individuals received information indirectly through another relative, often the spouse, but were not directly contacted or engaged by the healthcare providers. Consequently, they found it challenging to access pre- or post-loss bereavement care.

'After the loss of a child, it feels like parents are left behind. We were constantly placed in the second row, not only during our child's passing, but also in terms of receiving support. [...] I've heard stories of others getting support from a palliative care nurse, something we didn't have. I believe if we had, the trauma wouldn't have been as intense. Having meaningful conversations both before and after would have been greatly appreciated. The lack of it is a shame, especially because those who had it, felt supported, while we had to find our own way. [...] Had we had the right people in the right place at the right time, the grief process might have been less traumatic.' (Interview 14, child died at home).

Nevertheless, healthcare providers should consult with the patient beforehand to determine whom they wish to involve in the euthanasia process, as some patients deliberately choose to withhold information from certain individuals.

5.3.2 | Communicating transparently with healthcare providers and the family member requesting euthanasia

Both participant groups reported that relatives appreciated transparent communication from healthcare providers about the patient's condition and request for euthanasia.

'When a patient communicates their wish for euthanasia, they have usually given it much thought before informing their relatives. Consequently, the family often finds themselves lagging behind in understanding. It is essential to recognize this dynamic throughout euthanasia processes to ensure that relatives receive adequate support and guidance, enabling them to come to terms with the patient's decision.' (Interview 8, nurse, hospital).

Transparent communication regarding the patient's motivations for pursuing euthanasia, as well as updates on the illness progression and the patient's condition, helped relatives in gaining understanding. These conversations could take place through informal means or more structured approaches like family meetings, involving healthcare providers, patients and/or relatives. Joint conversations proved beneficial, allowing both relatives and patients to openly articulate their thoughts, feelings, and concerns.

'A brief ten-minute meeting, where everyone has a chance to introduce themselves and share their perspectives. This way, my mom could have said: 'I don't want this', I could have expressed: 'It's my dad's choice', and my son could have stated: 'It's grandpa's decision'. Unfortunately, that didn't happen.' (Interview 9, parent died in the hospital).

However, some patients or their relatives faced challenges in initiating discussions about the imminent death. They aimed to spare each other's emotions and preferred healthcare providers taking the lead in starting these conversations.

5.3.3 | Being adequately informed of the euthanasia

Both healthcare providers and relatives indicated that the latter desired to maintain a sense of control by seeking information regarding the legislative framework, the euthanasia process, and alternative scenarios. These alternative scenarios encompassed various possibilities, such as patients vomiting or falling asleep with their eyes open after receiving the lethal medication. Providing this information helped align relatives' expectations with reality.

'You should find a balance between truthfully explaining potential outcomes and avoiding to unnecessarily provoke fear or agitation. Often, what you caution them about doesn't even happen or turns out being less significant than anticipated.' (Interview 23, physician, palliative homecare).

In the event of an unforeseen deviation, healthcare providers tried to normalise the situation. Interviews with healthcare

providers revealed that nurses played a crucial complementary role alongside physicians. They frequently reiterated information provided by physicians, and clarified medical terminology, ensuring that relatives understood everything correctly. Relatives favoured multiple conversations well in advance. Some professionals said they reiterated the information just before or during the euthanasia performance.

Some relatives felt ill-prepared for the physical signs of death, such as pallor, or the suddenness of their family member's death, which was experienced as unfortunate. This occasionally resulted in feelings of regret about being present during the performance of euthanasia or questioning actions, such as not giving a final kiss goodbye.

'The only thing that shocked me was when his heart began to race after the lethal medication was administered. I was lying on his chest and thought: 'What is happening?' I panicked, because I wasn't aware this could occur. They should have informed me beforehand. It was very unpleasant moment, and I kept replaying it in my mind. Perhaps if I had known beforehand, I wouldn't have rested my head on his chest. [...] I felt him die' (Interview 8, parent died in the hospital).

5.4 | Being supported in saying goodbye

Most relatives preferred healthcare providers to facilitate a conscious goodbye from a 'background position.' Relatives valued healthcare providers who helped them create a good final image of their family member and foster a serene atmosphere. Additionally, they appreciated being given the time and space to address any unfinished matters, with or without the support of healthcare providers.

5.4.1 | Realising a serene atmosphere

Both relatives and healthcare providers stressed the importance of maintaining a serene atmosphere throughout the euthanasia process, particularly on the day of the euthanasia performance. Healthcare providers attempted to foster a serene atmosphere by meticulously performing the (technical aspects of) euthanasia and by taking 'a backseat position', allowing relatives to say goodbye and be close to the patient.

'Serenity is an atmosphere that is not too challenging to create, it often unfolds naturally. You simply need to be open to embracing it, without making it your own show. I tend to remain quiet, as the appropriate responses are often non-verbal and relate to technical aspects.' (Interview 28, physician, primary healthcare).

Both relatives and healthcare providers stated that it was important to minimise medical or technical aspects, even though euthanasia is a medical intervention.

'Before the children went outside, he [GP] had already arranged all the syringes on a side table in the living room. [...] I found it traumatic to see them there... [...] In my opinion, they shouldn't be displayed like that, neither for the patient nor for the relatives. In my opinion, It could and should be handled with more discretion.' (Interview 15, parent died at home).

Nonetheless, relatives asserted that their overall euthanasia experience remained unaffected by technical issues or deviations from the plan, as long as the serene atmosphere was preserved. Mutual agreements contributed to enhancing both healthcare providers' and relatives' sense of control. Relatives expressed dissatisfaction or even annoyance when arrangements were not upheld.

'When everything was over, especially a while after the death, I found it annoying that everybody [healthcare providers] arrived too early. It felt like they took time away from us.' (Interview 3, spouse died at home).

For healthcare providers, mutual agreements with both relatives and other healthcare providers helped to create a more serene atmosphere throughout the dying process.

5.4.2 | Dealing with unfinished business

During the interviews, dealing with unfinished business was mentioned by both healthcare providers and relatives. A conscious good-bye allowed relatives and patients to address certain matters before the imminent death. However, some relatives struggled to initiate this conversation, prompting healthcare providers to gently encourage patients and their relatives to deal with any unfinished business.

'In situations where relatives are aware of the euthanasia request, that things can be said candidly, without beating around the bush [...]. I always ask people: 'Did you tell him/her what you wanted to say?' It is important to let that person know their significance to you, but also to resolve any lingering tensions before saying your final goodbye. (Interview 44, psychologist, palliative homecare and hospital).'

5.4.3 | Having a good last image

Healthcare providers stated they were very mindful of their (non-) verbal behaviour during the euthanasia performance, recognising its

profound impact on relatives' memories. However, some relatives struggled to recall the specifics of the euthanasia performance and expressed feeling numb that day. Many found the euthanasia performance strange and elusive due to its abruptness. The rapid transition from a living, conscious individual to a corpse following medication administration was jarring for some relatives. The sight of the euthanasia performance or their family member's corpse also kept lingering in the memories of some, interfering with good memories, and triggering panic attacks and/or episodes of hyperventilation.

'I asked the physician: 'Is she dead?' 'Yes'. It happened so quick. I saw her turning pale, and in that moment I thought: 'What is happening?' [...] Suddenly, I was holding a corpse, my wife had died. It felt very lurid and weird.' (Interview 12, spouse died at the hospital).

Following the administration of medication, nurses attended to the body, ensuring a peaceful, serene appearance by for example, closing the eyes and mouth. Some relatives expressed dissatisfaction with the post-mortem care provided by healthcare providers, leading to an unfavourable last image of the deceased.

'They could have handled it [post-mortem care] better... Perhaps they should have waited a bit longer before showing her to us, ensuring she looked serene. Instead, everything seemed to sag, and her mouth was open... I've seen deceased individuals who looked way better than she did in that moment. It breaks my heart. [...]. The recall of that moment is far from pleasant, and it lingers in my mind. (Interview 5, child died at the hospital).'

5.5 | Receiving tailored bereavement care

Relatives valued to be treated as individuals rather than mere statistics or a number, emphasising the importance of healthcare providers attentiveness to their unique needs. Transmural and multidisciplinary collaborations played a crucial role in delivering holistic care to patients and their families during euthanasia processes. Effective communication and mutual agreements among all healthcare providers involved were essential for success. Healthcare providers stated that they were able to identify and address unique needs when having sufficient time, professional expertise/work experience, and trusting relationships with the involved relatives.

'Through your professional experience, you develop a mental grid akin to a toolbox. Depending on the situation, you select the appropriate tool, much like reaching for a wrench or screwdriver based on what's needed.' (Interview 19, nurse, hospital).

Several healthcare providers mentioned using a protocol or checklist to ensure they did not forget anyone or anything. However,

certain relatives expressed a preference for a more tailored approach, especially if they felt that the standard method did not fully address their specific needs.

'Leading up to the euthanasia, our general practitioner made frequent visits to check on us. During one visit, my wife said: 'Why does she come so often? And what exactly does she do?' We felt her constant visits were unnecessary, as I, a retired general practitioner, was fully capable of managing everything myself.' (Interview 16, spouse died at home).

Both relatives and healthcare providers stressed the importance of easily accessible healthcare providers, as mentioned in paragraph 1.1. This accessibility enabled relatives to rely on healthcare providers when needed, whether it is before (e.g. sudden escalation of pain in the patient), during (e.g. challenges with the performance of euthanasia), or after the patient's death (e.g. concerns about their own or other's grief process). Establishing a clear point of contact and receiving timely contact information from healthcare providers could enhance accessibility.

Most relatives had limited expectations of aftercare. Contact between healthcare providers and relatives often ended close to or after the patient's death. Relatives said they valued aftercare, when: (1) they had an inadequate support network; (2) they questioned whether it was the right decision to support their family member's euthanasia request; (3) they were promised by healthcare providers that they would be contacted post-loss; and (4) they were concerned about another relative and/or their own grief process. When aftercare was offered, relatives preferred a familiar healthcare provider, who was involved throughout the euthanasia process.

'I no longer held any expectations because ultimately, when you lose someone, regardless of how it happens, you're the one who has to cope [...]. If you feel the need to talk about it [with a healthcare provider], you're the one who needs to take the first step.' (Interview 10, grandparent died in the hospital).

Aftercare was also limited and unsystematic for some or all relatives. Some professionals stated that they relied on their gut feeling to identify relatives at risk of developing grief-related complications, and contacted them after some time to refer them to appropriate support within or outside their work context.

'Given our close involvement in the euthanasia process, we're aware of who might struggle after the patient's death. We reassure them that they can reach out to us or our team's psychologist for support [...]. However, our post-loss services are limited.' (Interview 10, nurse, hospital).

6 | DISCUSSION

Our findings illustrate that relatives experienced several needs throughout a euthanasia process. Similar themes were derived from both relatives and healthcare providers, with the exception of patient comfort. These needs were often not explicitly communicated to healthcare providers. Nonetheless, relatives appreciated healthcare providers proactively attending to their needs, which was experienced by healthcare providers as time-consuming and intense.

Under Belgian law (Staatsblad, 2002), healthcare providers are not obliged to inform relatives, which may contribute to their invisibility and unmet needs for bereavement care. Participants emphasise timely involvement to prepare for the imminent death. Evidence-to-date suggests that a lack of preparedness for death increases the risk of grief-related complications, such as Prolonged Grief Disorder (Schulz et al., 2015), depression (Aoyama et al., 2018), and anxiety (Hauksdóttir et al., 2010). Death preparedness includes cognitive, emotional and behavioural dimensions (Hebert et al., 2009). In our study, healthcare providers aim to increase cognitive preparedness among relatives by providing adequate information and transparent communication about the patient's condition and euthanasia. Behavioural preparedness is facilitated through timely involvement and mutual agreements, while emotional preparedness is promoted by offering empathy and emotional support for the feelings, thoughts, and concerns of relatives. Emotional preparedness entails the process of letting go and accepting the patient's death (Hebert et al., 2006), which in our study is related to being able to walk the walk together. Bereavement care in the period prior to the loss seems crucial, as our findings show that most relatives do not expect to receive professional aftercare, which is consistent with previous research on both unassisted (Kentish-Barnes et al., 2017) and assisted deaths (Hales et al., 2019b).

Insufficient information about the prognosis and imminent death can hinder relatives from preparing for loss (Barry & Prigerson, 2002). The extent of information should be tailored, as not all relatives want full disclosure (Dahlstrand et al., 2008). End-of-life conversations between relatives and patients can facilitate disclosure and give relatives permission to move on post-loss (Keeley & Generous, 2017), and reduce post-loss regrets (Jung & Matthews, 2021). Healthcare providers can facilitate these conversations, as relatives and patients are not prone to initiate them (Xu et al., 2022). Physicians are often perceived as responsible for discussing prognosis, while nurses provide individualised care (Anderson et al., 2019). Numerous scholars have advocated for individualised, needs-based bereavement care (Aoun et al., 2012; Hudson et al., 2018; Keegan et al., 2021; Lichtenthal, 2018), as it can mitigate the risk of developing grief-related complications (Aoun et al., 2012; Guldin et al., 2012; Harrop et al., 2020; Stroebe et al., 2007). In this study, healthcare providers make significant efforts to provide needs-based bereavement care and prepare relatives for the euthanasia to prevent potential trauma. However, some relatives experience vivid recollections or dreams of the dying process, which may indicate posttraumatic stress disorder (PTSD) (Baddeley et al., 2015). The current evidence on the increased

risk of PTSD in relatives bereaved by assisted dying is inconsistent (Andriessen et al., 2020). To ensure needs-based bereavement care, future practice would benefit from multidisciplinary and transmutal collaborations that contribute to sustainable and holistic care (Aoun et al., 2012).

Our study also reveals that healthcare providers are able to identify relatives' needs, but there are some limitations. Despite purposive sampling efforts to include a range of work experience, our sample mainly consists of highly experienced healthcare providers, often from specialised palliative care settings. This is evident in the disparity between healthcare providers' descriptions of good practices and relatives' reports of inadequate support, as reflected during the interviews. In the context of assisted dying, the provision of bereavement care is often unsystematic (Roest et al., 2019) due to inadequate education and training (Ward et al., 2021) and inconsistent guidelines (Sandham et al., 2022). A recent study illustrates that healthcare providers often rely on trial-and-error and their intuition when providing bereavement care to relatives during euthanasia processes (Boven et al., 2023). Enhanced education and training for current and future healthcare providers is recommended. Moreover, current Belgian euthanasia guidelines provide minimal directions for practice on needs-based bereavement care but rather focus on medico-technical aspects (De Laat, 2021; LEIF, 2020; Solidaris, 2022). To supplement these guidelines, larger quantitative research, along with a Delphi study, can verify the needs reported in this study. Future research can also explore relatives' expectations regarding different healthcare providers (e.g. nurses, physicians, psychologists, etc.) and settings (e.g. hospital, community, home-care, etc.) during the euthanasia process.

7 | STRENGTHS AND LIMITATIONS OF THE STUDY

This study has some strengths, such as a large participant sample and the in-depth data. The quality of the research findings and process is ensured throughout the study (see section 'ensuring the quality of the research process and product').

However, the study also has several limitations. (1) Conscientious objectors and relatives with negative experiences are underrepresented in our study, despite our intention to include diverse experiences and perspectives and additional recruitment efforts. Selection bias may be present, as individuals with greater feelings of grief have higher non-response rates (M. S. Stroebe & Stroebe, 1990). (2) Our study only included relatives of deceased oncological patients, so it is unclear if our findings can be applied to other conditions (e.g. neurodegenerative diseases). (3) The cultural sensitivity of our research is limited as we only interviewed white Catholic individuals. (4) COVID-19 and the corresponding restrictions might have biased our findings, as contact between relatives and healthcare providers was often limited. (4) Finally, participant groups were not paired. To explore whether common findings are still reported, future research

should interview both relatives and professionals who were involved in the same euthanasia process of a deceased patient.

8 | CONCLUSION

Our research provides important directions for healthcare professionals, empowering them to provide needs-based bereavement care during euthanasia processes. Nonetheless, our findings show that both proxy and direct reports offer similar insights, suggesting that healthcare providers are capable of accurately assessing relatives' needs. Unlike previous studies that often focus on broader aspects of assisted dying processes, our study delves deeply into relatives' needs of bereavement care before, during, and after the euthanasia, filling an essential gap in existing literature. One of the key messages is the importance of recognising and addressing the needs of relatives alongside those of the patients in the period before the loss. Relatives often prioritise their family member's well-being over their own and may not explicitly communicate their needs. Additionally, the majority of relatives seems to have limited expectations for professional aftercare. By offering tailored and timely bereavement care, healthcare providers can support relatives' grief process and foster a more compassionate and supportive healthcare environment.

AUTHOR CONTRIBUTIONS

Charlotte Boven: conceptualization, methodology, project administration, writing-original draft, formal analysis; **Let Dillen:** Conceptualization, methodology, project administration, supervision, writing- review& editing, formal analysis, project administration; **Liesbeth Van Humbeeck:** Conceptualization, methodology, funding acquisition; supervision, project administration, writing- review& editing, formal analysis; **Lieve Van den Block:** methodology; writing- review& editing, supervision; **Ruth Piers:** methodology; writing- review& editing, supervision; **Nele Van Den Noortgate:** Conceptualization, methodology, funding acquisition; supervision, writing- review& editing, formal analysis, project administration.

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

Data utilised in the submitted manuscript have been lawfully acquired in accordance with The Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from Their Utilisation to the Convention on Biological Diversity. The research protocol was approved by the Ethics Committee of Ghent University Hospital [registration number: B6702020000289].

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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