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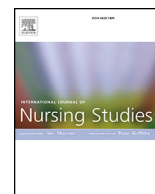
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## Bereavement care and the interaction with relatives in the context of euthanasia: A qualitative study with healthcare providers

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### ABSTRACT

**Background:** A recent review shows an interdependence between healthcare providers and relatives in the context of euthanasia. Belgian guidelines do focus on the role of certain healthcare providers (physicians, nurses, and psychologists), yet they hardly specify bereavement care services before, during and after the euthanasia.

**Purpose:** A conceptual model showing underlying mechanisms of healthcare providers' experiences regarding the interaction with and the provision of bereavement care to relatives of cancer patients throughout a euthanasia process.

**Methods:** 47 semi-structured interviews with Flemish physicians, nurses and psychologists working in hospitals and/or homecare, conducted from September 2020 to April 2022. Transcripts were analyzed using the Constructivist Grounded Theory Approach.

**Results:** Participants experienced the interaction with relatives as very diverse, which can be visualized as a continuum ranging from negative to positive, depending on each unique case. The achieved degree of serenity was the main contributor in determining their position on the aforementioned continuum. To create this serene atmosphere, healthcare providers undertook actions underpinned by two attitudes (wariness and meticulousness), which are guided by different considerations. These considerations can be categorized into three groups: 1) ideas about a good death and its importance, 2) having the situation well under control and 3) self-reassurance.

**Conclusions:** If relatives were not at peace, most participants said that they deny a request or formulate additional requirements. Moreover, they wanted to ensure relatives can cope with the loss, which was often experienced as intense and time-consuming. Our insights shape needs-based care from healthcare providers' perspective in the context of euthanasia. Future research should explore the relatives' perspective regarding this interaction and the provision of bereavement care.

**Tweetable abstract:** Professionals strive for a serene atmosphere throughout a euthanasia process to ensure relatives can cope with the loss, and the way in which the patient died.

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### What is already known

- Literature shows an interdependence between healthcare providers and relatives throughout a euthanasia trajectory.
- Current models and literature emphasize that bereavement care should be offered to (nearly) bereaved relatives.

### What this paper adds

- The achieved degree of serenity determined healthcare providers' experience of the interaction with relatives.

- Healthcare providers aim for a serene atmosphere to facilitate relatives' grief process.
- Healthcare providers "position themselves in the background", and make themselves as invisible as possible.

### 1. Background

Euthanasia, which is a mode of aid in dying, refers to a healthcare provider (often a physician) administering a legal drug to the patient, at the latter's request (Mroz et al., 2021). Aid in dying represents a socially regulated fulfillment of an ancient belief that one should be able to choose one's own death, reflecting principles of autonomy and self-

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determination that are subjected to time- and context-specific norms (Hamarat et al., 2021). The word 'euthanasia' is originally derived from Greek, and literally means 'a good death' (Van Hooff, 2004). People often see euthanasia as a means of dying in a controlled and/or painless way (Kelly et al., 2020). Over the years, assisted dying became increasingly legalized worldwide. Currently, the administration of medication is legal in Belgium, The Netherlands, Luxembourg, Canada, Colombia, New Zealand, Australia, and Spain (*Medical assistance in dying: the law in selected jurisdictions outside Canada* (HillStudies), 2022).

In Belgium, euthanasia is legal since 2002, and is eligible for physical as well as mental intolerable suffering (*Law of 28 May 2002 on Euthanasia*, 2002). Numbers have been steadily rising throughout the years. In 2020, euthanasia accounted for 2444 deaths in Belgium. The majority (64.2%) of these requests came from people suffering from cancer (*Tenth Report to the Legislative Chambers*, 2021). Although requesting euthanasia is an individual patient's right, it is still embedded in a broader (communal, familial, and societal) context (Attia et al., 2020). A death-related loss impacts the system surrounding a patient, and affects five to nine family members on average (Verdery et al., 2020; Beuthin et al., 2022). Loss is associated with relatives' psychological and physical morbidity, in which pre- and post-loss bereavement care "can help relatives prepare for their loved one's imminent death, and/or support them in coping with it afterwards" (p. 307) to mitigate for grief-related complications (Boven et al., 2022). According to the Belgian law, relatives do not need to be informed of the request and do not have a legal mandate throughout the decision-making process (*Law of 28 May 2002 on Euthanasia*, 2002). Nonetheless, a recent review states that in reality there is an interdependence between healthcare provider and relatives throughout a euthanasia process (Roest et al., 2019).

Belgian guidelines (*Leifdraad: leidraad voor artsen bij het zorgvuldig uitvoeren van euthanasie*, 2020; *Richtlijn Uitvoering Euthanasie*, 2018) do focus on the role of certain healthcare providers (physicians, nurses, and psychologists), yet they hardly specify bereavement care services before, during and after the euthanasia. This study aimed to acquire a deeper understanding of healthcare providers' experiences regarding the interaction with and provision of bereavement care to relatives throughout the euthanasia process of a cancer patient.

## 2. Methods

### 2.1. Study design

A qualitative study design was chosen, as this enables an in-depth exploration of how healthcare providers experience the interaction with and provision of bereavement care to relatives throughout a euthanasia process. In this study, the euthanasia process was defined as the period following the euthanasia request until several months after the patient's death.

In qualitative research, the interviewer does not simply reflect the phenomenon, but shapes it by his/her subjective gaze (Russell and Kelly, 2002). As such, it is important that researchers are mindful and reflective of their position (Savin-Baden and Major, 2013). Thus, all interviewers wrote a reflective framework beforehand. This reflective framework is a self-reflective stance on how the researcher's personal framework could have tacitly conditioned the research process, e.g. by clarifying personal assumptions, goals, and individual belief systems (Mortari, 2015).

### 2.2. Sampling strategy

Participants were recruited through newsletters, advocacy groups, and professional associations (see Appendix A, Supplementary material 1). The criteria for participation included: (1) being a physician, nurse or psychologist (as these healthcare providers have a direct contact with relatives and are mentioned in Belgian euthanasia guidelines),

(2) being able to comprehend and speak Dutch, (3) having performed or attended a euthanasia process of a person with cancer no longer than eighteen months ago, and (4) being employed in a hospital, homecare and/or primary healthcare. A purposive sample was derived to achieve maximum homogeneity and heterogeneity in terms of gender, function, place of employment, age, and years of experience (Holloway and Galvin, 2016). The sampling of participants ended after reaching sampling saturation.

### 2.3. Data collection and processing

Data collection occurred from October 2020 to April 2022, until data saturation was reached, using individual one-time semi-structured interviews done by six female interviewers (C.B., L.D., M.D.M., K.H., A.L., and H.V.K.). We made sure that all interviewers had no previous relationship with the participants. Interviews were conducted online or face-to-face, depending on participants' preferences and COVID restrictions. The face-to-face interviews were conducted individually without noise disturbances or other people being present. All interviews were audio-recorded, pseudonymized, and transcribed verbatim by master thesis students and a professional transcriber. They were all bound by a confidentiality agreement. Only the interviewers and the principal investigator of the study (L.V.H.) had access to the recordings and transcripts. Recordings were deleted after finishing data analysis. Data analysis was performed from October 2020 to May 2022.

The interview guide (see Appendix A, Supplementary material 2, Table 1) was based on literature, as well as on input from clinical and academic experts in palliative care, euthanasia, family-centered care, and grief. The interview guide was iteratively adapted by deleting, adding, or fine-tuning questions after every interview. All interviews started with a preliminary question about the healthcare provider's experience regarding the interaction with relatives throughout the euthanasia process. Subsequently, more in-depth questions were posed in order to further explore thoughts, feelings, and actions.

### 2.4. Data analysis

Transcripts were analyzed by C.B., L.D., L.V.H. and N.V.D.N. using the Constructivist Grounded Theory Approach. First, interviews were read entirely to obtain an overall picture of the interview before being coded. By comparing interviews and coded fragments, concepts were developed that guided the next wave of data collection. Subsequently, the emerging concepts, categories, and relationships between categories were clarified by carrying out new interviews, and reanalyzing previous interviews. The interpretative analytical process was underpinned by reflexivity, ensuring openness to the meaning of the data, and a general tenet to question, criticize and explicate understandings of the data (Malterud, 2001). Analysis was supported by NVivo12 (QSR International).

### 2.5. Rigor and trustworthiness

Several strategies were used to ensure trustworthiness of our results (Lincoln and Guba, 1985). We implemented investigator triangulation by using six different interviewers, and through involving professionals (C.B., L.D., L.V.D.B., L.V.H., N.V.D.N., R.P.) from different multidisciplinary backgrounds (educational sciences, nursing, medicine, and psychology). We used audit trails, memos, and exemplifying quotes to increase the dependability.

### 2.6. Ethical approval and informed consent

The research protocol was approved by the Ethics Committee of Ghent University Hospital [registration number B6702020000289]. All participants received verbal and written information about the study and gave their explicit and written consent to participate. All data and quotes were pseudonymized.

**Table 2**  
Sociodemographic characteristics of participants (N = 47).

Gender, N (%)	
Male	17 (36.2%)
Female	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%)
Setting, N (%)	
Home	11 (23.4%)
Hospital	32 (68.1%)
Both	4 (8.5%)
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%)

### 3. Results

In total, 47 interviews were conducted with nurses (N = 17, ten women), physicians (N = 15, five women), and psychologists (N = 15, all women) which took place face-to-face (N = 16) or online (N = 31). Participants were on average 47 years old (range: 26–69 years), and had an average work experience of 19 years (range: 1–44 years). Interviews had a mean duration of 68 min (range: 39–116 min), and were held at the place of preference of the participants. More information on the sociodemographic characteristics can be found in Table 2.

The results will be discussed by presenting key concepts that emerged from the accounts of the participants. The following four main categories appeared in the analysis: (1) a continuum of healthcare providers' experiences regarding their interaction with relatives (2) defined by the degree of serenity as the main objective (3) of their actions (ensuring that the relatives are at peace with the euthanasia and realizing a well-performed euthanasia) and attitudes (of wariness and meticulousness) towards relatives, (4) inspired by various considerations which were all affected by previous experiences and thus changed

over time as a result of trial-and-error (Fig. 1). These concepts will be discussed separately and in a linear fashion, but are in reality interwoven in various ways.

Participants found the interaction with relatives intense and time-consuming. They made every effort to provide tailored support and avoid a traumatic experience.

*“To the best of your ability, you try to make sure that relatives feel as comfortable as possible and, more importantly, that they are able to cope with the loss afterwards despite the very difficult circumstances. In the end, the patient is dead, but the relatives should be able to move on and accept the way in which their loved one died.”*

[(Interview 22, nurse, hospital)]

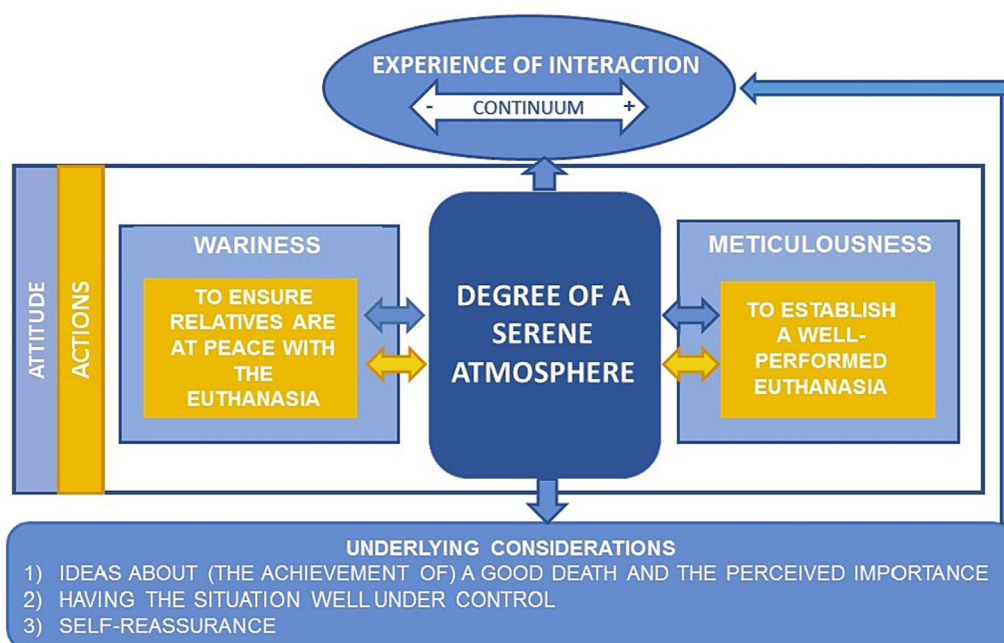
#### 3.1. Creating a serene atmosphere during the dying process

Participants stated that establishing a degree of serenity was the central driving force for their interactions with relatives. They wanted to make sure that relatives were able to cope with their loss, and accept the way in which their loved one died. Participants stated that a serene dying process could help relatives in constructing good memories, which according to them facilitated the relatives' grief process.

*“That moment [of dying] is so important that it should be fully experienced by the patient as well as by bystanders. It should take place in a serene and tranquil way. This is crucial for the grief process. Relatives should be able to look back on this moment positively and with warmth and not have their memory tainted with chaos and unrest.”*

[(Interview 9, nurse, hospital)]

Participants defined serenity as an atmosphere of connectedness, tranquility, and in which the dying process could happen as naturally as possible. Connectedness referred to relatives being more or less ready to let their loved one go, and having the opportunity to say goodbye to the patient without disturbances. In this way, relatives could focus on their loved one's dying process instead of the healthcare providers' actions. Staff tried to contribute to this atmosphere by “positioning themselves in the background, and making themselves as invisible as possible”. As a functional partner, they had to be present and



**Fig. 1.** An overview of central concepts and their underlying relationships.



perform certain actions, but they wanted to avoid disturbing the intimate moment between relatives and their loved one.

*“Serenity occurs when everyone is more or less ready to let the person go. The opportunities that are offered [by the conscious farewell] will help people to stay connected to their loved one. Grieving includes going back and forth, but actually it also includes maintaining a different kind of connection with the person that has died.”*

[(Interview 46, psychologist, hospital)]

Participants highlighted that the relatives' conceptualization of a serene atmosphere was sometimes different from their own (e.g. amount of bystanders, silence). Therefore, staff tried to explore this aspect beforehand, so they could accurately take into account relatives' wishes and needs regarding the dying process, and the last moments of saying goodbye.

*“Once, I was performing a euthanasia while the radio was on. Well, actually, I believed it was inappropriate, but that is none of my business if this was the patient's or relatives' choice.”*

[(Interview 15, physician, hospital)]

### 3.2. A continuum of healthcare providers' experiences

Participants had diverse experiences, that can be situated on a continuum ranging from highly negative to highly positive. These experiences varied according to each unique situation, and numerous contributing factors. Crucial in this aspect was the extent to which they realized a serene dying process.

An experience was labeled as more positive, when healthcare providers felt that they had achieved a good death, which according to them was comparable to a serene dying process. Participants found that in most cases, the first contributor to a more negative experience was located on the practical level. These issues were subdivided into two categories. Firstly, it involved failing to fulfill arrangements that were made between staff and relatives for the actual performance (e.g. staff arriving too early or late).

*“You should not arrive at half past two when you told relatives that you were going to be there at two o'clock. Otherwise, they will lose their trust in you. [...] [This trust] is important because it helps them accept what you are going to do and creates a serene atmosphere. Moreover, it helps to maintain a trusting relationship afterwards. I am convinced that all of this contributes to a good grief process.”*

[(Interview 32, physician, hospital)]

The second category contained problems regarding medical equipment (e.g. wrong dosage/order of medication or inadequate medical material). This caused professionals to panic (a bit), which they did not want relatives to notice. Otherwise, participants feared that relatives would start to panic, and doubt the healthcare providers' ability to fulfill their loved one's request.

*“Some time ago, I had a patient that kept talking [after the administration of sleeping medication]. The attending physician looked at me and I could see her thinking: ‘something is not right, is the intravenous drip working properly?’. At that point I panicked a bit. We both noticed it, but luckily the relatives never did.”*

[(Interview 1, nurse, hospital)]

The occurrence of unforeseen patients' reactions (e.g. snoring, falling over and/or vomiting) was a second contributor to a more negative experience. However, these reactions were only perceived as problematic, when participants felt uncertain or powerless. It was decisive whether staff could keep the situation under control (e.g. by communicating transparently or quickly finding a solution).

The final contributor to a more negative experience was situated on the relationship level, and existed of two categories. Firstly, participants

classified an interaction as more negative if relatives were strongly opposed or not at peace with the euthanasia (often because of poor or lacking preparation). It made healthcare providers cautious, and even unwilling to participate in future euthanasia processes taking place under similar circumstances.

*“The children were at peace with the performance of euthanasia, however, the sister was not. As I went outside the sister came to me and said: ‘you killed my sister.’ I was completely shocked and thought: ‘I will never do this again in such circumstances.’”*

[(Interview 5, physician, hospital)]

Secondly, healthcare providers had a more negative experience, when persons requesting euthanasia (relatives or other professionals) did not respect their boundaries. Staff wanted to guard their boundaries properly in order to be able to move on after the patient's death. For this reason, participants considered it essential that they always had the opportunity to reject or agree under additional conditions before accepting a euthanasia request.

*“I always tell the patient: ‘for you it is the end, but your relatives are the ones that will be left behind. This means that if the patient wants to have the euthanasia tomorrow but the relatives prefer to have it performed next week, we side with the relatives because it is important that they are able to move on afterwards.’”*

[(Interview 1, nurse, hospital)]

### 3.3. Healthcare providers' actions and attitudes towards relatives

Professionals performed several actions, which can be classified under two main targets (ensuring that relatives are at peace with the euthanasia and establishing a well-performed euthanasia), and contributed to a serene dying process. These actions, which were aided by a trusting relationship, were underpinned by an attitude of wariness and meticulousness.

Participants considered themselves merely a functional partner throughout the euthanasia process. As such, they tried to be as invisible as possible, especially at the performance of euthanasia, as this moment was etched in relatives' memory. They were mindful of relatives' experiences and provided an appropriate space for them to focus on their loved one, without too much interference.

*“I believe that we should just be present in the background, and let the dying process happen as naturally as possible. I already learned that you have to be cautious about what you say or do during the performance of the euthanasia because relatives have a tendency to put this under a magnifying glass, and it will be etched in their memory forever.”*

[(Interview 11, physician, primary healthcare)]

#### 3.3.1. To ensure that relatives are at peace with the euthanasia ~ an attitude of wariness

Participants wanted to ensure that relatives were more or less ready to let their loved one go. Informing relatives and stimulating connectedness before, during, and after the patient's death contributed to relatives being at peace with the request.

Wariness refers to finding the right way to be present (use of words, positioning, and emotions), based on the professionals' gut. This proved to be a process of trial-and-error, shaped by colleagues' and sometimes also relatives' feedback, in addition to staff's own experiences. This process was facilitated when professionals felt sufficiently acquainted with the relatives.

**3.3.1.1. Informing relatives.** Healthcare providers stated that they repeatedly informed relatives of the legal framework, course of the euthanasia, and possible scenarios (e.g. patient snoring, coughing). They also regularly checked if relatives understood everything correctly. According

to participants, being adequately informed prevented misunderstandings on behalf of the relatives (e.g. short duration of the dying process) and helped them to remain calm. Participants experienced that relatives were often not familiar with witnessing a euthanasia or a dying phase in general, thus, causing relatives to feel uncertain about what to expect or how to act. Professionals stated that feelings of uncertainty or unrealistic expectations made some relatives decide not to witness the dying process. Without insisting, professionals tried to explore relatives' reasons for doubt, and informed them accurately, so relatives could make an informed decision.

*"I believe it is important that relatives know what they are going to witness step-by-step, so they can decide for themselves: 'Do I want to see this? Do I want to experience this? What am I willing to endure?'"*

[(Interview 6, nurse, hospital)]

Healthcare providers tried to determine (by asking or sensing) the extent of and the timing when relatives wanted to receive information (e.g. whether or not during the performance of euthanasia). They tried to find a balance between, on one hand preventing relatives from panicking if something deviated from the plan, while on the other hand they wanted to avoid provoking fear or agitation in advance.

*"You should find a balance between truthfully explaining what could happen and avoiding to provoke fear or agitation at the same time. Most of the times the thing you warned them for does not even happen or turns out to be less significant than you told them it would be."*

[(Interview 23, physician, homecare)]

### 3.3.1.2. Stimulating connectedness between patient and relatives.

Healthcare providers mentioned that they stimulated connectedness between the patient and his/her relatives with the purpose to contribute to the creation, and preservation of good memories. Participants timely informed relatives of the patient's incurable condition to enhance relatives' comprehension of the request. According to participants, this meant that relatives respected the patient's wish, and gave him/her their permission to let go. Occasionally, the patient and relatives were immediately on the same page, while others needed more time and space to come to terms with the situation. Participants stated that it was helpful when the treating physician, potentially accompanied by a psychologist or nurse, organized family conversations. During these conversations, professionals aimed at creating a safe space, in which opinions could be shared (without disrespecting the patient's request).

*"As a psychologist, I find it really important to be as open-minded and unbiased as possible, so I can listen to everyone's story. I do not want to take sides but instead look at how we can reach a consensus. I always emphasize that it is the request of the patient that matters most and that his/her wish should be respected."*

[(Interview 38, psychologist, hospital)]

Physicians did not want to be perceived as an "advertiser of euthanasia", thus, they encouraged patients to clearly communicate their wish to their relatives themselves. If necessary, healthcare providers helped the patient to articulate his/her wish. Professionals also tried to ensure that relatives recognized the severity of the disease, and understood that there was no perspective of curing their loved one.

Some physicians turned down the patient's request, when relatives kept resisting, despite numerous efforts to reach a consensus. These physicians did not want to be held responsible for the patient's death, and feared risking emotional or legal consequences. Others did fulfill the euthanasia request, despite disagreement, but perceived it as a missed opportunity to involve relatives in the euthanasia process.

*"The husband told us that he was fed up and wanted euthanasia. I did understand him, because eventually he would have died within a week.*

*On the contrary, his wife did not understand his request at all. [...] I found myself caught between two fires. [...] These situations are very difficult for relatives and I am convinced that she did not receive the right support. [...] You are limited in things you can do, but I wanted things to go differently for her."*

[(Interview 1, nurse, hospital)]

Near to the performance of euthanasia, staff facilitated close contact, by offering a private room, double bed, flexible visiting hours, etc. Moreover, healthcare providers (mostly nurses or psychologists) explored in advance who would attend the euthanasia, and how they preferred to be present. On the day itself, healthcare providers made sure that, if they wished so, relatives could stand or sit close to the patient. When professionals sensed uneasiness, they told relatives that they could hold hands with or give a last hug to the patient.

*"In my opinion, the space immediately surrounding the patient during the performance of the euthanasia is reserved for relatives, for the people who will experience loss. [...] We may look important, because we have to make sure that everything goes well on a practical level, but we are not the people that make them feel loved or secure. [...] I believe that we should not take up too much space, but instead work from behind the scenes, and try to make sure that relatives are able to position themselves in a way that feels comfortable to them."*

[(Interview 39, psychologist, homecare)]

### 3.3.2. To establish a well-performed euthanasia ~ an attitude of meticulousness

By establishing a well-performed euthanasia, participants wanted to prevent relatives from panicking and doubting staff's ability to take good care of their loved one. Healthcare providers contributed to a well-performed euthanasia, by making specific operational plans with everyone involved beforehand, and by letting the dying process happen as naturally as possible.

An attitude of meticulousness reflects professionals' concerns that they might forget someone or something. Participants tried to avoid this through an (in)formal protocol, checklist, and/or conversations with persons involved in the euthanasia process.

#### 3.3.2.1. Making plans together.

In order to ensure that both sides were prepared, participants meticulously made operational plans with patients, relatives, as well as other healthcare providers.

Participants found that an operational plan helped relatives to anticipate, and remain calm, as it decreased levels of uncertainty. Healthcare providers explored how relatives envisioned the last moments with their loved one (e.g. whether or not having a goodbye-dinner or seeing the body after post-mortem care).

*"It is important that relatives are prepared for the course of those last days. We inform them about what their role could be, and assure them that they can openly talk to us about their preferences in this regard. It is essential for us to have an idea of what they can or cannot cope with, so we can discuss this with the patient, and thereby create awareness about this aspect on both sides. We want to make sure that, afterwards, relatives can look back, and feel that they finished the trajectory the way they wanted to."*

[(Interview 6, nurse, hospital)]

Participants explained that they also made arrangements with other staff members, that would (not) be present (e.g. avoid disturbance from the cleaning crew), so they could fully focus on carrying out their technical tasks.

*"The moment is always tense, even for us. Despite frequently having done this, we always discuss each step of the procedure time and time again. [...] However minor the affair, it remains important that everything had been discussed with other healthcare providers, as well as*

*with the family beforehand [...]. Actually, everything has always been discussed down to the last minute."*

[(Interview 8, nurse, homecare)]

**3.3.2.2. Letting the dying process happen as naturally as possible.** Physicians stated that they are responsible for guaranteeing the right material, dosage and administration order of the life-ending drugs. According to participants, medical material should be prepared in a timely manner and discreetly brought into the room on the day the euthanasia. In this manner, the dying process can happen as naturally as possible.

*"You should certainly not place all the medical material on the patient's nightstand and leave it there, or perform your preparatory work next to the patient's head. [...] Bystanders might perceive these actions as intrusive, which can easily be avoided by doing these things away from patients, and their relatives."*

[(Interview 32, physician, hospital)]

In the moments after the patient died, participants also tried to subtly take away medical equipment to avoid distorting relatives' memories.

#### 3.4. Healthcare providers' underlying considerations when interacting with relatives

Healthcare providers' interactions with relatives, and the provision of bereavement care were driven by three core considerations: (1) conceptualization of a good death and its perceived importance, (2) having the situation well under control, and (3) self-reassurance.

##### 3.4.1. Conceptualization of a good death and its perceived importance

Participants perceived a good death as a serene dying process that was warily and meticulously prepared, and which took place in an atmosphere of connectedness and tranquility.

*"To me, a euthanasia procedure went well if the patient accepted their end, insofar you can properly assess this. Where relatives can say goodbye in a tranquil and serene atmosphere, and where sadness is inevitably present. Nobody ever says: 'Yes! He is gone.', but there is always a soothing connectedness between those that are present. That is what I call a good ending."*

[(Interview 29, physician, primary healthcare)]

Some healthcare providers refused a euthanasia request or chose not to be part of one, when they felt that they would not be able to help achieve a good death. This was motivated by previous negative experiences (e.g. accusations of relatives).

##### 3.4.2. Having the situation well under control

Participants found maintaining control at all times very important, because they wanted to prevent relatives associating their loved one's death with feelings of chaos and unrest. Following a mutually agreed plan contributed to a tranquil environment for all those involved, whereas failing to stick to this plan could cause uncertainty and panic.

*"I had a patient whose dying process lasted unusually long. [...] You can always improvise and try to find another solution, but then it would no longer be consistent with the plan you worked out with the relatives beforehand. At a moment like that, you can feel time ticking and are very aware of everyone paying close attention to what you are doing."*

[(Interview 31, physician, hospital)]

If something did not go according to plan, healthcare providers tried to normalize the situation.

*"You should always make sure that you are the captain of the ship. If something unexpected happens, which is luckily rare, you should always try to reassure relatives."*

[(Interview 21, physician, hospital)]

Nonetheless, participants said euthanasia is inevitably associated with uncertainty, as it cannot be compared with machine work. Because of the intensity, professionals were relieved that accompanying a euthanasia process was not part of their routine work, and expressed their desire to keep it this way.

##### 3.4.3. Self-reassurance

A positive experience implied that relatives were able to move on after their loved one's death, which reassured healthcare providers that they "did the right thing". In this way, professionals could close this chapter for themselves. Most participants gave their contact information right before or after the loss, so relatives could contact them when needed. Professionals only scarcely initiated post-loss contact themselves. Only a few of them did this routinely, or in cases where they thought (certain) relatives were at risk of developing psychosocial difficulties.

*"It is not done very systematically, it depends on how long I've known the relatives and my estimation of their tendency to call for help themselves if needed."*

[(Interview 46, psychologist, hospital)]

By providing contact information or checking in on relatives, participants wanted to reassure themselves that relatives were able to cope with the loss, and the way in which their loved one died. They believed the euthanasia trajectory went well, if relatives did not initiate contact themselves, or if relatives were able to cope to a certain extent. Therefore, healthcare providers believed that they "did the right thing", and could move on. If relatives rejected these follow-up services, staff respected their decision without insisting.

*"I believe that you should not go too far. You should leave the door wide open, offer services and invite relatives to come inside, but if they refuse for any reason, that is just the way it is."*

[(Interview 28, physician, primary healthcare)]

Participants reacted differently to the feeling of relatives not being able to cope with their loss. Some healthcare providers placed this in perspective, while others blamed themselves for not having done enough, or felt that they should have handled things differently.

## 4. Discussion

Overall, our findings provide an insight into the perspective of healthcare providers on their interaction with relatives in the context of euthanasia, and the provision of bereavement care throughout. Participants said that they perceive themselves as a functional partner, and try to contribute by preparing themselves and relatives for the upcoming bereavement. A significant finding is that the central driving force behind the interaction between professionals and relatives is to ensure a good death. A good death is defined by participants as a serene dying process, in which relatives can construct good memories, and are able to cope with their loss afterwards. Professionals find that a lack of a serene atmosphere contributes to a more negative experience, which is often decisive for healthcare providers' future performances. Healthcare providers try to achieve a serene transition from life to death, by establishing a well-performed euthanasia, and ensuring relatives are at peace with the euthanasia request. Their actions are underpinned by two attitudes (wariness and meticulousness), and guided by different considerations, which in their turn, are subjected to a learning process (of trial-and-error).

Our results indicate that healthcare providers strive for a serene atmosphere throughout the euthanasia process, but especially during the



performance of euthanasia. Participants conceptualize a good death as a serene atmosphere, which contributed to good memories, thus, facilitating relatives' grief process. To achieve a serene atmosphere, healthcare providers perform several actions and attitudes on the background. They aim to fulfill relatives' needs regarding bereavement care to mitigate for grief-related morbidities. Future research should explore whether healthcare providers' conceptualization of a good death is in accordance with that of relatives, and which bereavement services contribute to this. Furthermore, longitudinal research with relatives can investigate the extent to which bereavement care before, during, and after the euthanasia decreases the risk for developing grief-related complications.

Participants described euthanasia as a time-consuming and intense process, which was also found in previous research (Ward et al., 2021; Georges et al., 2008). Participants voiced that they made every effort to provide tailored support and avoid a traumatic experience, which was aided by building trusting relationships with patients and families. Previous research (Ward et al., 2021; Sandham et al., 2022) indicated the importance of (in)formal emotional support (e.g. debriefings) for professionals in highly-demanding situations, such as euthanasia. Despite the intensity of the care process, professionals said that they found helping a patient and their relatives in itself worthwhile, which is described in literature as compassion satisfaction (Stamm, 2002). "Doing one's utmost" and ensuring the best possible end-of-life care were fundamental in supporting patients and relatives in their last days (Fridh et al., 2009). However, when participants felt that granting the request would cause problems (e.g. emotional or legal consequences), they were relieved that according to The Belgian Act on Euthanasia (*Law of 28 May 2002 on Euthanasia, 2002*), they could always refuse or formulate additional requirements.

Moreover, the Belgian Act on Euthanasia does not require relatives to be informed of the request or be involved throughout the decision-making process (*Law of 28 May 2002 on Euthanasia, 2002*). Nonetheless, participants preferred family involvement, and some even turned down a request when the family was not at peace. They did not want to risk legal consequences, or relatives not being able to cope with the loss and the way it happened. Belgian euthanasia guidelines (*Leifdraad: leidraad voor artsen bij het zorgvuldig uitvoeren van euthanasie, 2020; Richtlijn Uitvoering Euthanasie, 2018*) mention that physicians should try to consult relatives, but only with the patient's consent. The death of an individual is linked to and experienced by the whole community, so it cannot be reduced to the relationship between a doctor and patient (Sallnow et al., 2022). This generates a possible tension between the right of confidentiality of doctor and patient versus the social dimension (Devos, 2021). The Belgian law also prescribes that a euthanasia request should not be the result of external pressure. As such, other actors can be consulted without interfering with the doctor-patient relationship ('colloque singulier') (Hamarat et al., 2021). By adequately informing relatives of the legal framework (e.g. voluntary character of the request), healthcare providers tried to avoid relatives from putting pressure on them. Participants wanted relatives to respect their boundaries.

Belgian guidelines (*Leifdraad: leidraad voor artsen bij het zorgvuldig uitvoeren van euthanasie, 2020; Richtlijn Uitvoering Euthanasie, 2018*) only scarcely specify how healthcare providers can offer bereavement care to relatives pre- and post-loss. Previous literature showed that the lack of guidelines (Ward et al., 2021; Sandham et al., 2022; Fujioka et al., 2018), knowledge, and/or training (Sandham et al., 2022; Fujioka et al., 2018) in the context of euthanasia, caused healthcare providers to feel uncertain about what to say or do. Nursing students, whether or not recently graduated, and junior doctors lack skills and knowledge about death and dying. As such, they express an inability to deliver high quality end-of-life care (Jones et al., 2020; Bharmal et al., 2019). Our study also showed that healthcare providers often used their gut to guide their ((non-)verbal) actions and positions throughout the process, also called 'emotional knowing' in literature. They were especially mindful of their actions during the dying process, as this moment was etched in relatives' memory forever. Thus, clear

guidelines (including information on bereavement care pre- and post-loss), education, and training should be easily accessible and incorporated in curricula of (future) healthcare providers. Moreover, the use of (Belgian) consultation services, such as LEIF (End-of-life Information Forum), should be promoted, as healthcare providers can contact them to ask questions or support them throughout the euthanasia process.

Finally, participants stated that bereavement care is mainly taken up in the period before the loss, as they do not have a mandate or financial resources for post-loss support. These results are mirrored in a recent review of Hudson et al. (2018) in the context of palliative care, presenting that bereavement care is still insufficiently resourced, under-researched, and not implemented in a systematic way. It would be interesting for future research to explore relatives' expectations regarding aftercare, and their experiences in terms of coping with their loss. In most cases, participants only scarcely provided aftercare, but they did give their contact details, so relatives could contact them if needed. Research showed that groups-at-risk for developing grief-related disorders are less prone to seek support themselves (Lichtenthal et al., 2011). As such, it would be helpful to implement a tiered or stepped approach based on needs to early target and refer groups-at-risk, as they will benefit the most (Aoun et al., 2012). This approach aids healthcare providers in adequately targeting and referring relatives pre- and post-loss. Participants did contact relatives post-loss themselves, if they thought certain relatives were at risk of developing psycho-social difficulties.

To implement such a model, sustainable multidisciplinary and transmutal collaborations are required to match relatives' needs throughout the euthanasia process. A scoping review of Fujioka et al. (2018) found that the complexity of a euthanasia process (such as clinical and practical challenges) requires skills and expertise of multiple professionals. Participants of that study state that supporting family throughout a euthanasia process was a team effort, which required a collaboration between different healthcare providers. A recent survey study conducted with psychologists from Portugal and Luxembourg, showed that despite their lack of a legal mandate, the majority of participants agreed that they had a role in (emotionally) supporting patients and their relatives after a request (Marina et al., 2021). To enhance the success of collaborations, participants of our study said that they made operational plans with other healthcare providers involved, to clearly distribute roles and to ensure a smooth course of events.

#### 4.1. Strengths and limitations

Our study is characterized by strengths. A first strength, is the large sample of healthcare providers that participated in the study ( $N = 47$ ), and the variety of disciplines that participated. We were able to conduct in-depth interviews, and thereby reach data saturation of the key concepts, by using purposive sampling. Moreover, various strategies (see Section 2.4) ensured the rigor and trustworthiness of our results.

Our findings must also be considered in light of some limitations. Our findings mainly pertain to white, female healthcare providers, despite trying to ensure a balance in racial backgrounds and gender. Moreover, it is possible that healthcare providers who are not in favor of euthanasia did not respond to our call. Furthermore, the majority of participants had already attended or performed numerous euthanasia processes, while only a few indicated that they had only done it sporadically. As a result, we primarily received information from fairly confident healthcare providers with considerable experience. Next, we only included euthanasia procedures of persons with cancer, so it is unclear whether our findings are transferable to other conditions. Finally, COVID might have biased our results. During this time, interactions between healthcare providers and relatives were often limited, because of contact restrictions.

## 5. Conclusions

This study showed that participants had diverse experiences, in which the achieved degree of serenity was the determining factor for a more



positive or negative experience. Participants tried to create this serene atmosphere by performing certain actions from a position on the background, which were underpinned by an attitude of wariness and meticulousness. Moreover, their actions were guided by different considerations, which, in their turn, are subjected to a learning process (of trial-and-error). Our results substantiate the need to expand existing clinical guidelines, as the interaction between healthcare providers and relatives, and the provision of bereavement care are currently insufficiently described. Future research should explore relatives' experiences regarding the interaction with and bereavement care from healthcare providers, and assess relatives' needs before, during, and after the performance of euthanasia.

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## CRediT authorship contribution statement

**Charlotte Boven:** Conceptualization, Methodology, Project administration, Writing – original draft, Formal analysis. **Liesbeth Van Humbeek:** 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. **Let Dillen:** Conceptualization, Methodology, Project administration, Supervision, Writing – review & editing, Formal analysis.

## Data availability

Due to the sensitive nature of this study, participants were assured raw data would remain confidential and would not be shared. Data not available / The data that has been used is confidential.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Appendix A. Supplementary data

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## References

- Aoun, S.M., Breen, L.J., O'Connor, M., Rumbold, B., Nordstrom, C., 2012. A public health approach to bereavement support services in palliative care. *Aust. N. Z. J. Public Health* 36 (1), 14–16. <https://doi.org/10.1111/j.1753-6405.2012.00825.x>.
- Attia, J.R., Jorm, C., Kelly, B., 2020. Medical assistance in dying: the downside. *BMJ Support. Palliat. Care* 10 (3), 259–261. <https://doi.org/10.1136/bmjspcare-2020-002350>.
- Beuthin, R., Bruce, A., Thompson, M., Andersen, A.E.B., Lundy, S., 2022. Experiences of grief-bereavement after a medically assisted death in Canada: bringing death to life. *Death Stud.* 46 (8), 1982–1991. <https://doi.org/10.1080/07481187.2021.1876790> (in eng).

- Bharmal, A., Morgan, T., Kuhn, I., Wee, B., Barclay, S., 2019. Palliative and end-of-life care and junior doctors: a systematic review and narrative synthesis. *BMJ Support. Palliat. Care* <https://doi.org/10.1136/bmjspcare-2019-001954> pp. bmjspcare-2019-001954.
- Boven, C., Dillen, L., Van den Block, L., Piers, R., Van Den Noortgate, N., Van Humbeek, L., 2022. In-hospital bereavement services as an act of care and a challenge: an integrative review. *J. Pain Symptom Manag.* 63 (3), e295–e316. <https://doi.org/10.1016/j.jpainsymman.2021.10.008>.
- Devos, T., 2021. *Euthanasie: een ander verhaal*. Pelckmans, p. 263.
- Fridh, I., Forsberg, A., Bergbom, I., 2009. Doing one's utmost: nurses' descriptions of caring for dying patients in an intensive care environment. *Intensive Crit. Care Nurs.* 25 (5), 233–241. <https://doi.org/10.1016/j.iccn.2009.06.007>.
- Fujioka, J.K., Mirza, R.M., McDonald, P.L., Klinger, C.A., 2018. Implementation of medical assistance in dying: a scoping review of health care providers' perspectives. (in eng) *J. Pain Symptom Manag.* 55 (6), 1564–1576.e9. <https://doi.org/10.1016/j.jpainsymman.2018.02.011>.
- Georges, J.J., The, A.M., Onwuteaka-Philipsen, B.D., van der Wal, G., 2008. Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. *J. Med. Ethics* 34 (3), 150–155. <https://doi.org/10.1136/jme.2007.020909>.
- Hamarat, N., Pillonel, A., Berthod, M.A., Dransart, D.A.Castelli, Lebeer, G., 2021. Exploring contemporary forms of aid in dying: an ethnography of euthanasia in Belgium and assisted suicide in Switzerland. (in eng) *Death Stud.*, 1–15 <https://doi.org/10.1080/07481187.2021.1926635>.
- Holloway, I., Galvin, K., 2016. *Qualitative Research in Nursing And Healthcare, 4th edition* Wiley-Blackwell, Oxford, p. 376.
- Hudson, P., Hall, C., Boughey, A., Roulston, A., 2018. Bereavement support standards and bereavement care pathway for quality palliative care. *Palliat. Support. Care* 16 (4), 375–387. <https://doi.org/10.1017/s1478951517000451>.
- Jones, K., Draper, J., Davies, A., 2020. Nurses' early and ongoing encounters with the dying and the dead: a scoping review of the international literature. (in eng) *Int. J. Palliat. Nurs.* 26 (6), 310–324. <https://doi.org/10.12968/ijpn.2020.26.6.310>.
- Kelly, B., Handley, T., Kissane, D., Vamos, M., Attia, J., 2020. "An indelible mark" the response to participation in euthanasia and physician-assisted suicide among doctors: a review of research findings. *Palliat. Support. Care* 18 (1), 82–88. <https://doi.org/10.1017/s1478951519000518>.
- Law of 28 May 2002 on Euthanasia, 2002. Accessed on 25 November 2022. [Online] Available <http://www.const-court.be/public/e/2015/2015-153e.pdf>.
- Leifdraad: leidraad voor artsen bij het zorgvuldig uitvoeren van euthanasie, 2022. Accessed on 25 November 2022.
- Lichtenthal, W.G., et al., 2011. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatr. Serv.* 62 (10), 1225–1229. [https://doi.org/10.1176/ps.62.10.pss6210\\_1225](https://doi.org/10.1176/ps.62.10.pss6210_1225).
- Lincoln, Y.S., Guba, E.G., 1985. *Establishing trustworthiness*. *Naturalistic Inquiry*. Sage, London, p. 415.
- Malterud, K., 2001. Qualitative research: standards, challenges, and guidelines. *Lancet* 358 (9280), 483–488. [https://doi.org/10.1016/S0140-6736\(01\)05627-6](https://doi.org/10.1016/S0140-6736(01)05627-6) (London, England).
- Marina, S., Wainwright, T., Ricou, M., 2021. Views of psychologists about their role in hastened death. (Westport) *Omega*. <https://doi.org/10.1177/00302228211045166> p. 302228211045166.
- Medical assistance in dying: the law in selected jurisdictions outside Canada (HillStudies), 2022. Accessed on 25 November 2022. [Online] Available <https://lop.parl.ca/staticfiles/PublicWebsite/Home/ResearchPublications/HillStudies/PDF/2015-116-E.pdf>.
- Mortari, L., 2015. Reflectivity in research practice: an overview of different perspectives. p. 1609406915618045. *Int. J. Qual. Methods* 14 (5). <https://doi.org/10.1177/1609406915618045>.
- Mroz, S., Dierickx, S., Deliens, L., Cohen, J., Chambaere, K., 2021. Assisted dying around the world: a status question. *Ann. Palliat. Med.* 10 (3), 3540–3553. <https://doi.org/10.21037/apm-20-637>.
- Richtlijn Uitvoering Euthanasie, 2018. Accessed on 25 November 2022. [Online] Available [www.pallialine.be](http://www.pallialine.be).
- Roest, B., Trappenburg, M., Leget, C., 2019. The involvement of family in the dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. (in eng) *BMC Med. Ethics* 20 (1), 23. <https://doi.org/10.1186/s12910-019-0361-2>.
- Russell, G.M., Kelly, N.H., 2002. Research as interacting dialogic processes: implications for reflexivity. *Forum Qual. Soc. Res.* 3 (3). <https://doi.org/10.17169/fqs-3.3.831>.
- Sallnow, L., et al., 2022. Report of the Lancet commission on the value of death: bringing death back into life. *Lancet* 399 (10327), 837–884. [https://doi.org/10.1016/S0140-6736\(21\)02314-X](https://doi.org/10.1016/S0140-6736(21)02314-X).
- Sandham, M., Carey, M., Hedgecock, E., Jarden, R., 2022. Nurses' experiences of supporting patients requesting voluntary assisted dying: a qualitative meta-synthesis. (in eng) *J. Adv. Nurs.* 78 (10), 3101–3115. <https://doi.org/10.1111/jan.15324>.
- Savin-Baden, M., Major, C.H., 2013. *Qualitative Research: The Essential Guide to Theory And Practice*. Great Britain TJ International Ltd, p. 608.
- Stamm, B.H., 2002. *ch. Measuring compassion satisfaction as well as fatigue: developmental history of the compassion satisfaction and fatigue test*. In: Figley, C.R. (Ed.), *Treating Compassion Fatigue*. Routledge, New York, pp. 107–119.
- Van Hooff, A.J.L., 2004. Ancient euthanasia: 'good death' and the doctor in the graeco-Roman world. *Soc. Sci. Med.* 58 (5), 975–985. <https://doi.org/10.1016/j.socscimed.2003.10.036>.
- Verdery, A.M., Smith-Greenaway, E., Margolis, R., Daw, J., 2020. Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. *Proc. Natl. Acad. Sci.* 117 (30), 17695–17701. <https://doi.org/10.1073/pnas.2007476117>.
- Ward, V., Freeman, S., Callander, T., Xiong, B., 2021. Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): a scoping review. (in eng) *Palliat. Support. Care*, 1–15 <https://doi.org/10.1017/s1478951521000146>.
- Tenth Report to the Legislative Chambers, 2021.