# 'It is still intense and not unambiguous'. A grounded theory study of nurses' experiences in the euthanasia care process 15 years after legalisation

## **INTRODUCTION**

Euthanasia is legally defined as an act undertaken by a physician to intentionally end a person's life at his or her request. Currently, it can be legally carried out only by a physician in the Netherlands, Belgium, Luxembourg, Colombia and Canada under strict due care conditions (Emanuel et al., 2016). In Canada, registered nurses working under the authority of a physician or a nurse practitioner are allowed to conduct euthanasia (The Special Joint Committee on Physician-Assisted Dying, 2016). In other countries, euthanasia remains illegal, but it is the subject of societal debates (Emanuel et al., 2016). Prior research conducted in western countries has revealed that nurses, whether or not they live in countries where euthanasia is legal, are regularly confronted with patients requesting euthanasia (Elmore et al., 2016).

Nurses have an important role in the care process for patients requesting euthanasia (Lecock et al., 2015). They are often the first caregivers to receive a euthanasia request (De Bal, et al., 2008; De Beer et al., 2004). The care they provide is complex and dynamic, starting from the period before the request until the period after euthanasia when they provide care for the family (Dierckx de Casterlé et al., 2010). Communication is nurses' most important instrument in providing good-quality euthanasia care. Nurses are portrayed as advocates and mediators who facilitate open communication between the physician, the patient and the family (Denier et al., 2010a). Nurses feel personally and professionally responsible for assuring that patients who request euthanasia are provided with the very best of care (Elmore et al., 2016).

Nurses experience their involvement in this care process as very intense. In the qualitative study of Denier et al. (2010b), nurses described their involvement as carrying a twofold moral and emotional weight. They experienced a discrepancy because, on the one hand, they saw euthanasia as a peaceful and nice death, but on the other hand, they saw it as a planned and unnatural death (Denier et al., 2010b). In addition, nurses may experience diverse negative emotions, such as moral uncertainty and feelings of guilt, powerlessness, frustration, anxiety, and secrecy (Berghs et al., 2005; De Bal et al., 2008; Denier et al., 2010b).

Prior research has reported that nurses experience a gradual improvement over time in dealing with a euthanasia request on an organisational and practical level (Denier et al., 2010b). When they have more experience with euthanasia requests, nurses know better what they have to do to address a request and when and how to do it, and they feel less unsecure. However, this practical improvement does not mean that their involvement becomes easier on an emotional level (Denier et al., 2010b, Elmore, et al., 2016). The way nurses experience their involvement partially depends on contextual issues, for example, the length of time available to engage with patients (Elmore et al., 2016).

In Belgium, euthanasia was legalised in 2002 (Ministry of Justice, 2002). The reported cases of euthanasia have increased almost ten times, from only 259 at the beginning of the legalisation to 2309 in 2017 (Federal Commission for Euthanasia Control and Evaluation, 2004 & 2018). This increase implies that nurses are increasingly confronted with patients requesting euthanasia, although in the

Belgian law, the nurse's role is poorly described. According to article 2.4 of the Belgian Act on Euthanasia, the physician must discuss the patient's request with the nursing team or its members if there is a nursing team that has regular contact with the patient (Ministry of Justice, 2002). However, studies have reported that nurses' role in practice involves much more than described in the law (De Bal et al. 2008).

Despite prior research about the involvement of Flemish nurses in the euthanasia care process before and in the first few years after legalisation (Denier et al. 2009, 2010a, 2010b; Dierckx de Casterlé et al. 2010; De Bal et al. 2006), there have been few to no studies exploring how the involvement of nurses in the euthanasia care process has evolved 15 years after legalisation and the impact of the legislation on nurses' experiences. Hence, the aim of this study is to explore how Flemish nurses experience their involvement in the care of patients requesting euthanasia 15 years after the legalisation of euthanasia.

## **METHODS**

## Design

A qualitative design with a grounded theory approach (Corbin & Strauss, 2008) was used to explore and theoretically explain how nurses experience their involvement in the care process for patients requesting euthanasia and which factors and processes contribute to their experience. Theoretical insights were derived inductively from interviews with nurses.

## **Recruitment of participants**

We selected nurses with experience caring for patients requesting euthanasia. In Belgium, most euthanasia cases occur in oncology wards in hospitals and in home care (Federal Commission for Euthanasia Control and Evaluation, 2018). Nurses had to be Dutch speaking, have at least an associate degree in nursing, be employed in a hospital or in home care in Flanders (the Dutch speaking region of Belgium where 6 million people live) and be involved in the care of a patient requesting euthanasia (between January 2014 and April 2017). Nurses who were not personally involved in the care process for patients requesting euthanasia or who were involved in situations where euthanasia was not performed as well as nursing students were excluded.

Regarding nurses employed in hospitals, we focused on nurses working with cancer patients. We contacted an active member of the Flemish Association for Radiology and Oncology (VVRO) who released a call for nurses within the association. Nurses who saw the call contacted us, and some of them shared the call within their work environment. To recruit nurses working in home care, we contacted 'Wit-Gele Kruis', a non-profit organisation that provides person-centred, at-home nursing care in Flanders. A contact person from every province in Flanders recruited the respondents. Some of the nurses working in home care were recruited through the VVRO. We focused on nurses caring for oncology or palliative care patients.

# Sample

Participants were recruited by purposive sampling, followed by snowball sampling. Interested nurses were asked to complete a short questionnaire with sociodemographic questions as well as questions relevant to the subject of the study (e.g., their view on euthanasia, how often they had been involved in the care process). The questionnaire was used to obtain a heterogeneous sample capturing a wide

range of perspectives relevant to the phenomenon studied. We also used these data to understand the cases in their specific contexts and to describe the participants in detail.

#### **Data collection**

Individual semi-structured in-depth interviews were conducted with 26 nurses by three female researchers (first 3 authors) between December 2016 and April 2017; the interviews took place in the hospital where the participant was working or at the participant's home. The interviewers participated in this study as part of their master's thesis in nursing science and had no experience in euthanasia care. They received intensive guidance from two experts in qualitative research methods (author 4 & 5). The mean duration of the interviews was 80 minutes. All interviews were recorded. The topic and interview guide were developed based on previous studies (Francke et al., 2016; van Bruchem-van de Scheur et al., 2008a,b; Denier et al., 2009, 2010a, 2010b) and reviews (De Bal et al., 2008; Berghs et al., 2005). They were continuously adapted during the study in response to the emergent data. The participants were asked to describe a recent euthanasia case in which they were personally involved. By asking open-ended questions, the researchers invited the participants to tell more about their experiences in caring for patients requesting euthanasia.

#### **Data analysis**

Data analysis was performed by all research members and was guided by the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterlé et al., 2012). Data collection and data analysis were conducted simultaneously. All interviews were read multiple times to identify and understand the nurses' experiences and the underlying processes. Using the constant comparison method, we gradually developed and refined insights into nurses' involvement. The preliminary results and key concepts were discussed at regular intervals by the research team. This cyclical approach and the research team discussions enabled us to identify and understand the preliminary key themes across the nurses' experiences. To clarify and refine the themes, all data were entered into and coded with the NVivo11 software program by three researchers (first 3 authors). The codes were regularly adapted and restructured according to the insights developed through the analysis process. The researchers repeated this process on a regular basis, individually and as a team (all authors), increasing the level of abstraction of the codes. The concepts were described based on a cross-case analysis of the codes and then placed in a conceptual framework in response to the research question. Finally, a reconstruction of the story of the respondents took place on a conceptual, theoretical level.

# Methodological quality

To enhance the quality of the study, we used context and researcher triangulation. We included nurses working in hospitals (n=20) or in home care (n=8) geographically spread over Flanders. The three researchers collected and coded the data individually and as a group. At regular intervals, peer review was conducted with the supervisors.

Bracketing was used to minimise the impact of our own opinions about euthanasia and nurses' involvement on the analysis. Before the start of the interviews, we individually noted our personal thoughts about the subject. Regular critical self-reflection and discussion in team about our feelings and attitudes helped us foster an open attitude to listen to and interpret the experiences of the respondents.

The progress of the analysis process was systematically documented in the form of an audit trail. We justified every decision we made and used thick descriptions to ensure the transparency of the results.

#### **Ethical considerations**

Ethical approval was granted by the appropriate ethics committee (mp16497). Informed consent was obtained from all participants prior to data collection. All participants were provided with detailed information about the study and were informed that the interviews would be audio recorded, that their anonymity would be assured and that they could withdraw from the study at any time without further explanation. All data were treated confidentially. The care organisations in which the participants were employed did not have access to the interviews.

During the interviews, we were sensitive to the feelings that the nurses might be experiencing. If they felt the need for guidance after the interview, we were able to provide the contact information of a qualified person.

#### **RESULTS**

#### Sample

The final sample consisted of 26 nurses, employed in 11 hospitals and 8 home care settings geographically spread across the 5 provinces of Flanders (Table 1). Most of the participants were females (n=17) from 40 to 60 years old and were employed in a hospital (n=18). The majority of the nurses had at least a bachelor's degree (n=23), nearly half of whom had pursued additional education, such as a specialisation in oncology (n=7) or a master's in nursing science (n=5). Most nurses worked as bedside nurses (n=16) and worked full time (n=18). At the time of the interview, most nurses had been involved in the care process for a patient requesting euthanasia at least 5 times (n=17). Almost all nurses reported positive attitudes regarding euthanasia (n=21) and positive experiences with the euthanasia care process (n=21). One nurse did not rate her experiences with and attitude about euthanasia. This nurse had various experiences with euthanasia, which was why she found it difficult to give overall scores for her experiences and attitude. The majority of the nurses had recent experiences with the euthanasia care process, i.e., less than 6 months ago (n=16).

Table 1: Characteristics of the participants (n=26)

Demographic characteristics		
Gender	Male	9
	Female	17
Age	21 – 29	0
	30 – 39	5
	40 – 49	8
	50 – 59	12
	60 – 69	1
Education	Associate degree in nursing	3
	Bachelor's degree	23
	Specialisation in oncology	7
	Master's in nursing sciences	5
Professional characteristics		)
Setting	Hospital	18
	Oncology ward	11
	Palliative care ward	
	Palliative support team	8
	Home care	2
	Hospital and home care	6
		2
Employment	Part time	8
	Full time	18
Function	Bedside nurse	16
	Head nurse	5
	Advanced practice nurse	5
Experiences and attitudes		
Experiences of the euthanasia care process	Strongly negative	0
	Negative	1
	Neutral	3
	Positive	12
	Strongly positive	9
Attitude regarding euthanasia	Strongly negative	0
	Negative	
	Neutral	
	Positive	4
	Strongly positive	9
		12
Number of times involved in the euthanasia	1 time	1
care process	2 – 5 times	8
	>5 times	17
Last time involved in the euthanasia care	< 1 month ago	8
process	1-6 months ago	8
	6 months – 3 years ago	10

# Experiences of involvement in the euthanasia care process

The interviewees described their involvement in the euthanasia care process as very intense and not unambiguous. They experienced a mix of overwhelming, sometimes contradictory emotions that made the euthanasia care process emotionally demanding. In particular, the nature of euthanasia itself, ending someone's life based on his or her repeated request, contributed to the intensity of the euthanasia care process. The nurses described euthanasia as something unnatural and planned that made them, as caregivers, confront many questions and doubts.

However, most interviewees felt a great need to give the best possible care when involved in the euthanasia care process. Furthermore, being able to contribute to a patient's dignified end of life and truly make a difference gave them a profound feeling of professional fulfilment. They felt privileged to be allowed to share intimate life moments, which they described as unique and personally enriching experiences. In sum, being involved in euthanasia care was often experienced as an opportunity to contribute to 'a greater good', adding value to nurses' work.

However, when nurses were not able to contribute to good euthanasia care, they struggled with strong negative feelings and doubts about their involvement. Most frustrations were related to the patient's euthanasia request, in particular, to nurses' difficulties in truly understanding the request. This difficulty was especially strong when nurses observed that mental suffering was a major cause of the request for euthanasia. Some nurses described the patient's euthanasia request as an 'easy way out' or explained that they felt they were being pressured to act in a way that was not consistent with their views and values. Contextual limitations such as a lack of time or poor teamwork could also hinder nurses in providing good care and thus cause many frustrations.

We present these themes in detail below.

# Intense and not unambiguous

Most interviewees described their involvement in the euthanasia care process as very 'intense'. Caring for a patient asking for euthanasia resulted in a mix of overwhelming feelings, making the care process highly emotional and upsetting. Words such as 'stressful', 'confrontational', 'suffocating', 'awful', and 'speechless' were used to describe their experiences. In particular, the nature of euthanasia made involvement in the care process ambiguous. Euthanasia involves intentionally ending someone's life at his or her request. Most participants perceived euthanasia to be an abrupt way of saying farewell and described it as an unnatural and planned phenomenon, which made it surreal for them. This feeling was reinforced by the narrow time frame in which euthanasia is performed, often only five minutes. To use the words of one nurse, she literally 'saw the patient's life drain from his body'.

'Well, it's not just an ordinary medical act. With euthanasia, there is something very unreal, in the sense that someone, that a conscious person, goes in one or two minutes to death. So, from life to death. You see someone changing in his face; you see life that is pulling away. And that happens very quickly, and that is difficult to understand. This is something very unreal and difficult to get. How often that I've already seen that in the hospital, it remains difficult to get'. (Participant 15)

The interviewees clearly perceived death by euthanasia as completely different from a natural death. Hence, caring for a patient requesting euthanasia cannot be considered part of daily care. The

participants were confronted with many questions and doubts when caring for a patient requesting euthanasia. Their stories revealed questions about the underlying reasons for euthanasia requests, what to say or do at crucial moments, how patients and family will react, and, more generally, their own capacities and limitations to accompany the patients and their family through this process. These doubts resulted in nurses often feeling insecure, thereby adding to the complexity and intensity of being involved in euthanasia care.

'Afraid of the unknown. You know from the magazines and you know from the theory, from your books, from your education, how it goes. But then really being there, that is something else. (...). So, a bit worried, you know, is he really going to die? (laughs). Is he really going to die? What if the doctor doesn't succeed in getting an IV? What if I have to do it, and everyone is watching me? You don't know that. So, a bit worried, ill at ease, where do I have to stand? Because the family is standing around the bed, where is my place in here?' (Participant 9)

The specific nature of euthanasia care gave rise to a mix of sometimes contradictory emotions, as extensively illustrated by the participants. They described their feelings of disbelief, disappointment and anger but also of love, warmth and grief. They explained how they could feel the sadness, sorrow and fear of the patients and their families and simultaneously experience an atmosphere of peace, serenity and harmony. This discrepancy in feelings and experiences also contributed to the intensity of their involvement.

'It is exactly that; the emotions hit you so hard when you see all the sadness. And it lingers the rest of the day. In the evening, when you sit down on the sofa, you can still sit there and think, or like I told you, this one incident, the image of that patient with his girlfriend or wife laying down in his bed. I still find it a horrible image. On the one hand, it is a shame it is over, but at the same time, it was also beautiful to see how they stuck together, literally but also figuratively, the love between those two, and the fact that it is over, because of his illness, because of his death. That affects you very much'. (Participant 13)

In the context of contrasting and overwhelming feelings, the interviewees experienced a great need to provide the best possible care. They described how they wanted to make the last moments of the patients and their families as perfect as possible. Communication between the patient, the family and the nurses was considered an essential element of good care, although such communication was not experienced as self-evident. The sadness of patients' families was described as overwhelming, making these conversations very intense. The time to discuss and fulfil patients' last wishes was often limited. As told by the interviewees, care for a patient requesting euthanasia can be 'exhausting'.

'When someone has an actual euthanasia request, then everything suddenly comes closer. And to be totally honest, I have to admit that those conversations are very intense, because you feel that time is very limited. And those are interactions that 'drain' you. You really are exhausted when you get out of there; you really have to recover from it'. (Participant 23)

All the interviewees described their involvement in the euthanasia care process as intense, yet we noticed different levels of intensity between the nurses and within the experience of the same nurses. The level of intensity can change according to the specific context or the stage of the euthanasia care process. Most nurses, for example, described how they experienced the moment of the euthanasia itself as more intense than the days prior. Others experienced more difficulties in the previous days, as they were challenged with existential questions about the request and their role and attitudes towards this request. Some nurses explicitly described their first experience of involvement as the most intense. 'The first one you never forget', as one of the participants stated. In their first experiences being involved in the euthanasia care process, nurses did not know what to expect and

feel, how they would react, or how to behave, which clearly increased the intensity of the care process. However, even nurses with considerable experience in euthanasia care did not experience euthanasia care as routine nursing care.

# Professional fulfilment

Despite the intensity and difficulties of being involved in the euthanasia care process, almost every nurse described how these care experiences also often gave them a feeling of professional fulfilment. Analysis of the interviews revealed two sources of fulfilment.

First, nurses explained how they were able to effectively contribute to good care when involved in euthanasia care. They felt they were an ideal position to make a real difference for the patients and their families. Based on their professional competence, they tried to determine how to provide the best care for patients and their families in this stage of life and how to fulfil patients' last wishes. Their stories extensively illustrated how being involved in the euthanasia care process involved much more than just the technical aspects of care. 'Without our contribution, the euthanasia care process would be different', as one of the interviewees expressed.

'I find this a dignified death to which I have been able to make a positive contribution. As a nurse, a right, positive contribution, I mean, without my intervention, it would not have been the same. And I am not important, that is not what I want to say, but you, as a nurse, you don't have to minimise yourself. You can make a difference. And that is the position you want to take'. (Participant 11)

Second, most nurses felt privileged to be among the people allowed to share intimate moments in patients' lives, which also contributed to their professional fulfilment. They referred to the unique opportunity to accompany patients in the last stage of their lives and share extraordinary moments with everyone involved. Some participants considered it an honour to be part of a patient's intimate circle. Experiencing patients' confidence and willingness to share intimate feelings and thoughts was described as a unique and enriching, adding a special dimension to the nurses' work.

'Or like what they say to each other, at the last moment, then I think, 'Ooh' (grabs throat). Like, 'Daddy, you're the best dad in the world', or 'Mama, you're the best mother, you did great, and now we're going to take care of each other'. Oh, then you feel that love and that warmth, and I found it so beautiful that it all can be said. Those are beautiful moments, intimate moments that you as a nurse or as a doctor can experience. That also enriches you. Every euthanasia enriches you as a person. I think it has greatly enriched me'. (Participant 17)

Being able to respect and fulfil patients' wishes and to contribute to a dignified end of life gave nurses a profound feeling of professional satisfaction. This positive feeling was especially strengthened when everything in the euthanasia process went as planned by a patient and his or her family. The gratitude of the family and knowing that they truly could make a difference for the patient and the family gave nurses strength and energy and encouraged them to continue. As expressed by one of the participants, 'it is the fuel to the engine to make it run at a time that it is not going so well'. (Participant 22)

'When we know that day is the decisive day, what is my feeling about it? Uhm, I would have to invent a word for it. I can't say happy or unhappy, it just gives me a good feeling being able to help the people and especially when everything was well discussed; the picture needs to be right'. (Participant 22)

## **Frustration**

For some nurses or in some cases, although they represented the minority, experiences of involvement in the euthanasia care process were rather negative. Some participants described strong feelings of frustration, such as anger, irritation, indignation or exasperation. Not being able to contribute to good care for a patient requesting euthanasia seemed to contribute to these negative feelings.

Most frustrations were related to the euthanasia request and its underlying reasons. In some cases, it was difficult for the interviewees to understand why patients want to die, especially when psychological suffering incited the patient to request euthanasia. In some cases, the nurses felt that a patient's family did not truly understand what euthanasia was truly about, although they strongly supported the request. The nurses' difficulties in truly understanding some patients' wishes to die were often accompanied by the feeling that patients or patients' families could not accept the idea of a natural death. Requesting euthanasia mainly because 'one is afraid of what is coming' or because 'one wants to go through the last phase of life as quickly as possible to avoid suffering' was difficult for some interviewees to understand. The nurses observed many different ways of coping with suffering and existential questions. Caring for a patient with a perception of life and quality of life that was not in accordance with their own was, for some nurses, a challenge.

'I often think, of course, we have 15 patients over here, they are all severely ill people. And there are always people, well, not all are equally comfortable. And when you notice the difference in how people deal with that kind of suffering, then I think... And if a patient who suffers psychologically asks you, 'Come, give me a lethal injection, because it has been enough'. Well, I think, 'Come on, man, do you really think life is worth so little? It is not that you are suffering from pain or something. This is time you take away from your family, your relatives'. I think, maybe it is a little bit rude to say, but in some situations, I think it is a rather selfish decision. But yes, very often, those people are afraid of what is about to come. But I think, if you have to get a lethal injection preventively, that's just too much, I think that's too much'. (Participant 20)

In addition to the underlying reasons of the request, the emphasis on the self-evident and imperative nature of the request resulted in many frustrations. The interviewees described how in some cases, they felt pressured by a patient or his or her family insisting on the person's right to euthanasia. As one interviewee explained, 'Once the formalities have been rounded off, the performance of the act is expected'. The experience that euthanasia was used as an easy solution to resolve problems was confronting for some of the nurses and resulted in the feeling of being obliged to act in a way that was inconsistent with their values. The nurses suggested that the impact of performing euthanasia on nurses is often overlooked.

'And the increasing compulsion, the demands from patients and their family, in particular the family, 'This is not how his life should be, do something about it'. I do not mind doing it, really, especially when it is a well-founded request, but the compulsion behind it, the 'must' behind it. And in particular, 'Why do I have to solve this for you?'. You know, the legislator has foreseen this for me and the doctors, but really, why should I have to solve this? (...). Because it is not that easy. You are ending someone's life, you know, that is something I am always aware of'. (Participant 7)

The way the euthanasia care process was performed and/or organised could also evoke feelings of frustration. For example, when the doctor ignored the euthanasia request of the patient or acted rudely or dishonestly toward the patient and his or her family, nurses felt angry and powerless. All interviewees described good communication between the doctor and themselves in the euthanasia care process as an essential condition for good care. A lack of time or other essential care provisions

was another source of frustration. Not having the time or opportunity to get to know the patient and his or her family, to carefully listen to the euthanasia request or to meticulously plan and discuss the euthanasia care process resulted in a great deal of frustration.

'The man came to the hospital for his euthanasia, and you don't know him, and he only came for his euthanasia. (...) We weren't involved in any way, and I felt horrible about it, like, he comes over to die, and we haven't had any conversation with him, we didn't know him, was he married, did he have kids; the man just arrived for his injection, and that's it, that's his attitude. And especially afterwards, t o cope with that situation ...' (Participant 4)

#### Discussion

The aim of this study was to explore how Flemish nurses experience their involvement in the care of patients requesting euthanasia 15 years after the legalisation of euthanasia. As in previous research before and just after the legalisation of euthanasia in Belgium, the interviewees described caring for a patient who requests euthanasia as an intense experience characterized by ambivalence (De Bal et al., 2006; Denier et al., 2009, 2010b). The nurses experienced a mix of overwhelming, sometimes contradictory emotions, which made the euthanasia care process emotionally very demanding. Previous studies have described the same disparate feelings as a result of the contrast between the beauty of a death with dignity and respect and the unnatural and planned character of death by euthanasia (De Bal et al., 2006; Denier et al., 2009; Denier et al., 2010b; Georges et al., 2008; Beuthin et al., 2018).

The interviewees unanimously stated that they were able to significantly contribute to a good euthanasia care process, an experience that was also supported by previous research (Denier et al., 2010a; Dierckx de Casterlé et al., 2010). However, a comparison of the studies over time suggests a subtle shift in nurses' involvement, specifically, from a predominantly procedural role to more personal and emotional involvement as shown in the present study. Previous research included interviews of nurses in the period shortly after the law went into effect (2005-2006), and the timing of these interviews may have explained nurses' focus on procedures and the practical organisation of the euthanasia care process (Denier et al. 2009). Interviewing nurses 15 years after legalisation revealed stories that were less dominated by a procedural orientation. Nurses in the present study described how they took part in the full care process, communicating with patients and their families to try to understand their request and learning how best to guide and support them in this process. Euthanasia care was described as an interactive and relational process rather than a step-by-step procedural process.

Although negative experiences were discussed in our study, the majority of the interviewees reported mainly positive experiences related to euthanasia care. These positive feelings were also observed in previous studies conducted in the period just after the legalisation of euthanasia in Belgium and were explained at that time by the supportive role of the Belgian Act on Euthanasia (Denier et al., 2010b; Dierckx de Casterlé et al., 2010). It was argued that the new law enabled open discussion about patient requests for euthanasia and the ability to help patients within the limits of the legal framework. The Act on Euthanasia appeared to provide structure and support for the care of patients requesting euthanasia. The assumption about the supportive role of legalisation is consistent with the findings of a previous study about nurses' involvement in euthanasia before legalisation (De Bal et al., 2006). This

study revealed that nurses' primary feeling was powerlessness, which was predominantly caused by their inability to legally comply with the patients request to die. This finding was confirmed by Begley (2008), who discussed the guilt care providers experienced when confronted with euthanasia requests in a context where euthanasia was illegal. However, selection bias could also have contributed to a generally positive tone in nurses' interviews in our study. Nurses with negative attitudes towards euthanasia or those who found it difficult to cope with euthanasia requests in care may have been reluctant to share their experiences, which may have resulted in our findings suggesting a more positive view than is actually the case.

The findings raise some questions about the so-called 'normalisation' of euthanasia in Belgium. MacKellar (2017) warned about the consequences of the increasing acceptance of euthanasia whereby a form of desensitisation may occur. As Montero (2013, p94) described, 'euthanasia is no longer presented in Belgium as an exceptional and ultimate solution for extreme situations'. MacKellar (2017) suggested that euthanasia in Belgium is beginning to be considered a relatively normal and established practice. According to this author, the fact that there have been no attempts to repeal since legalisation has paved the way to increasing the acceptability of euthanasia. Additionally, the annual increase in the number of reported euthanasia cases in Belgium since its legalisation demonstrates, at least from a quantitative perspective, that the practice of euthanasia is increasingly accepted as a normal end-of-life practice in Belgium (MacKellar, 2017).

Although the results of the present study suggest some subtle shifts in nurses' experiences over time, they do not fully support the idea that euthanasia is seen as a normal procedure. The interviewees explicitly underlined the intense, not unambiguous and surreal nature of the euthanasia care practice, often resulting in a mix of overwhelming feelings and many doubts and questions. Most frustrations were related to euthanasia requests and nurses' difficulties in understanding the underlying reasons for the requests. Although surveys of the general public and health care providers may reveal a rather positive attitude towards euthanasia and its legalisation (Emanuel et al., 2016), the present study suggests that personal involvement in euthanasia care may affect attitudes and perceptions about what is normal.

This idea is in line with Sohar et al.'s (2015) finding that caregivers with euthanasia care experience show a significantly lower approval of euthanasia than caregivers without such experience.

However, the findings of our qualitative study cannot rebut MacKaller's concerns about the normalisation of euthanasia practice. The interviewees clearly described that in some cases, they felt pressured by a patient or a family, insisting that care providers provide a quick answer to the patient's or family's suffering. The nurses felt like they '[had] to solve' the problem as if it were their task. These experiences are in line with trends described in the literature (Vanden Berghe et al., 2013) referring to a perceived right to euthanasia among Belgian citizens (Montero, 2013).

The profound feeling of professional fulfilment, which was described by many interviewees, also requires particular attention. According to the nurses, being involved in euthanasia offered an opportunity to contribute 'to a greater good' and to make a real difference for patients and their families. They felt privileged to share these extraordinary moments with all involved. They described this care practice as added value from a professional and personal perspective. One can question whether this attitude or view may be seen as a strategy to cope with the intense and complex challenges of being involved in euthanasia care. Nurses' critical reflection on their roles and responsibilities in end-of-life care and their impacts on the evolution of euthanasia practice was less

evident in the interviews. More research is needed to understand the real meaning of this feeling of fulfilment and its underlying dynamics.

Another striking finding in line with previous reflections is that the interviewees used emotional and psychological rather than ethical terms to describe the intensity of the process. The results do not provide insights into how nurses deal with the euthanasia care process from an ethical point of view. The same observation was present in previous research (Denier et al., 2010b) and was explained by the medical emphasis in euthanasia care. It is indeed the physician who is responsible for evaluating a patient's request, applying the legal due care criteria, balancing the ethical values, and making a decision. This reasoning might indicate a preference for a utilitarian view of nurses' involvement, restricting their role to that of a patient advocate concerned with maximising the autonomous choices of the patient regardless of the content of that choice (McCabe, 2007). This finding raises questions about nurses' ethical responsibility in euthanasia care and their roles as moral agents. The results of the present study do not show any real changes with regard to nurses' roles in developing critical self-reflection on euthanasia care 15 years after legalisation. One factor might be that nurses who have ethically based objections to euthanasia are not involved in the euthanasia care process or were not included in the research sample; the presence of nurses who have conscientious objections may be an important factor in initiating ethical reflection within the nursing team.

# Strengths and limitations

The most important limitation of the study concerns the sampling strategy. Using a purposive and snowball method, we were not able to theoretically select the participants or sample participants with variation in their attitudes towards euthanasia. All of the nurses reported a positive or neutral attitude, and most of them had positive experiences in euthanasia care. Accordingly, the perspectives of nurses with strong negative experiences or conscientious objections to euthanasia were not included, which may have contributed to bias. Furthermore, the cases that were discussed more deeply during the interviews referred mostly to patients with an oncological diagnosis, limiting the transferability of the findings only to the oncological care setting. However, patients with cancer account for approximately 70% of the patients who request euthanasia in Belgium (Dierickx et al., 2016).

Despite the limitations in the sampling procedures, we found a large group of nurses who were willing to participate in our study, enabling us to achieve interesting heterogeneity in our sample and, thus, a wide range of perspectives. This willingness of nurses to share their experiences also had a positive effect on the quality of the interviews, which provided rich data allowing saturation for the core concepts reported in this paper.

The credibility of our results was enhanced by the use of researcher triangulation and peer review. The coding and interpretation of interview data were performed separately by at least two of the three researchers and intensively discussed and further analysed within the research team. Other built-in guarantees, such as bracketing, reflexivity and audit trail, ensured the trustworthiness of the data. The use of the QUAGOL, particularly the continuous and systematic stimulation of reflexivity and the method of constant comparison, was of great value in developing strong theoretical insights, grounded in the full potential of the rich interview data.

The major strength of our study lies in its nuanced description of nurses' perspectives on euthanasia care processes, which can help understand what involvement in the euthanasia care process means for nurses and how this involvement has evolved 15 years after legalisation. This study is the first large-

scale qualitative study exploring the impact of legislation on the experiences of nurses. Adding to existing research, the findings of this study provide us with a framework to critically reflect on nurses' roles and ethical responsibilities in the euthanasia care process.

# **Conclusions and implications**

Although the findings of our study offer a rather positive view of nurses' involvement in euthanasia care, they cannot support the hypothesis that euthanasia is considered a normal practice by the care providers who are involved. However, some interviewees' concerns about the underlying reasons for euthanasia requests and the self-evident and imperative nature of some requests underline the need to further examine whether a trend toward normalisation is taking place in Belgian health care. Further research on the involvement of nurses who have negative experiences or conscientious objections could be helpful to further clarify nurses' ethical positions on euthanasia care. The study also reveals the need for more clarification about the involvement of other care providers, particularly physicians, using qualitative methodology.

Nurses' descriptions of their involvement mostly in emotional and psychological terms should stimulate the nursing profession to further reflect on nurses' ethical positions on the euthanasia debate and their roles and impacts in dealing with euthanasia requests in practice. Finally, the findings underline the importance of nurses being supported in critically evaluating their involvement and ethical responsibilities in euthanasia practices.

#### **Conflict of interest**

The authors did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors to plan or conduct this research.

# References

- Begley A.M., 2008. Guilty but good. Defending voluntary active euthanasia from a virtue perspective. Nurs. Ethics 15, 434–445. https://doi.org/10.1177/0969733008090514
- Berghs, M., Dierckx de Casterlé, B., & Gastmans, C., 2005. The complexity of nurses' attitudes toward euthanasia: a review of the literature. J. Med. Ethics. (31), 441-446. http://dx.doi.org/10.1136/jme.2004.009092
- Beuthin, R., Bruce, A., Scaia, M., 2018. Medical assistance in dying (MAiD): Canadian nurses' experiences. Nurs forum, 1-10. https://doi.org/10.1111/nuf.12280
- Corbin, J. M., & Strauss, A. L., 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory.* Sage Publications, Los Angeles.
- De Bal, N., Dierckx de Casterlé, B., De Beer, T., & Gastmans, C., 2006. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. Int. J. Nurs. Stud. (43), 589 599. https://doi.org/10.1016/j.ijnurstu.2005.08.003

- De Bal, N., Gastmans, C., & Dierckx de Casterlé, B., 2008. Nurses' involvement in the care of patients requesting euthanasia: A review of the literature. Int. J. Nurs. Stud. (45), 626-644. https://doi.org/10.1016/j.ijnurstu.2007.06.009
- De Beer, T., Gastmans, C., & Dierckx de Casterlé, B., 2004. Involvement of nurses in euthanasia: a review of the literature. J. Med. Ethics. (30), 494-498. http://dx.doi.org/10.1136/jme.2003.004028
- Denier, Y., Dierckx de Casterlé, B., De Bal, N., & Gastmans, C., 2009. Involvement of nurses in the euthanasia care process in Flanders (Belgium): An exploration of two perspectives. J. Pal. Care. 25(4), 264 274. https://doi.org/10.1177/082585970902500404
- Denier, Y., Gastmans, C., De Bal, N., & Dierckx de Casterlé, B., 2010a. Communication in nursing care for patients requesting euthanasia: a qualitative study. J. Clin. Nurs. (19), 3372 3380. https://doi.org/10.1111/j.1365-2702.2010.03367.x
- Denier, Y., Dierckx de Casterlé, B., De Bal, N., & Gastmans, C., 2010b. "It's intense, you know."

  Nurses' experiences in caring for patients requesting euthanasia. Med. Health Care Philos.

  (13), 41 48. https://doi.org/10.1007/s11019-009-9203-1
- Dierckx de Casterlé, B., Denier, Y., De Bal, N. et al., 2010. Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium. J. Adv. Nurs., 66(11), 2410 2420. https://doi.org/10.1111/j.1365-2648.2010.05401.x
- Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y., 2012. QUAGOL: A guide for qualitative data analysis. Int. J Nurs. Stud. (49), 360 371. https://doi.org/10.1016/j.ijnurstu.2011.09.012
- Dierickx S., Deliens, L., Cohen, J. & Chambaere, K., 2016. Euthanasia in Belgium: trends in reported cases between 2003 and 2013. CMAJ., 188(16), E407-11. https://doi.org/10.1503/cmaj.160202
- Elmore, J., Wright, D. K. & Paradis, M., 2016. Nurses' moral experiences of assisted death: A metasynthesis of qualitative research. Nurs. Ethics., 1 18. https://doi.org/10.1177/0969733016679468
- Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W. & Cohen, J., 2016. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA*, 316(1), 79-90. https://doi.org/10.1001/jama.2016.8499
- Federal Commission for Euthanasia Control and Evaluation, 2004. First report to the Legislative Chambers (Years 2002-2003). [report in Dutch]. (Accessed 14 August 2018). http://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/federale\_control e\_en\_evaluatiecommissie\_euthanasie/14276508.pdf.
- Federal Commission for Euthanasia Control and Evaluation, 2018. Eighth report to the Legislative Chambers (Years 2016-2017). [report in Dutch]. (Accessed 14 August 2018). http://leif.be/data/press-articles/FCEEC\_-\_8\_euthanasie-verslag\_2016-2017-nl.pdf
- Francke, A. L., Albers, G., Bilsen, J., de Veer, A. J. E., & Onwuteaka-Philipsen, B. D., 2016. Nursing staff and euthanasia in the Netherlands. A nation-wide survey on attitudes and involvement in decision making and the performance of euthanasia. Patient Educ. Couns., 99(5), 783-9. https://doi.org/10.1016/j.pec.2015.11.008

- Georges, J.-J., A.M. The , B.D. Onwuteaka-Philipsen, and G. van der Wal. 2008. Dealing with requests for euthanasia: A qualitative study investigating the experience of general practitioners. J. Med. Ethics., (34), 150–155. http://dx.doi.org/10.1136/jme.2007.020909
- Lecock, D., Guerra, C., Schittekatte, V., Siddu, D., Di Pierdomenico, L., Mengal, Y. & Mayer, M., 2015. Le rôle de l'infirmière dans le cadre d'une euthanasie active volontaire dans les pays où elle est légalement autorisée, revue de la littérature. REFIRI, 1(2), 101-111. https://doi.org/10.1016/j.refiri.2015.04.004
- MacKellar, C., 2017. Some possible consequences arising from the normalisation of euthanasium in Belgium. In: Jones, D., Gastmans, C., MacKellar, C. (Eds.). Euthanasia and Assisted Suicide: Lessons from Belgium. Cambridge University Press. 2017, pp. 219-234. https://doi.org/10.1017/9781108182799.014
- McCabe, H., 2007. Nursing involvement in euthanasia: how sound is the philosophical support? Nurs. Philos., 8, 167-175. https://doi.org/10.1111/j.1466-769X.2007.00312.x
- Ministry of Justice., 2002. Wet betreffende de euthanasie. [The Belgian Act on Euthanasia of 28 May 2002]. Belgian Law Gazette of June 22, 2002. (Accessed 8 March 2016). http://www.ejustice.just.fgov.be/wet/wet.htm.
- Montero, E., 2013 Rendez-vous avec la mort. Dix ans d'euthanasie légale en Belgique [An appointment with death. Ten years of legal euthanasia in Belgium]. Limal: Anthemis.
- Sohar, B., Großschädl, F., Meier, I.M. & Stronegger, W.J., 2015. Effects of care experience to the attitude of active euthanasia among the Austrian populations a cross sectional study. Pflege, 28(6), 339-45. https://doi.org/10.1024/1012-5302/a000459
- The Special Joint Committee on Physician-Assisted Dying. Medical assistance in dying: a patient-centred approach. Report of the special joint committee on physician-assisted dying., 2016. (Accessed 12 May 2016). http://www.parl.gc.ca/content/hoc/Committee/421/PDAM/Reports/RP8120006/pdamrp01/pdamrp01-e.pdf.
- Van Bruchem-van de Scheur, C. G., van der Arend, A. J. G., Huijer Abu-Saad, H., van Wijmen, F. C. B., Spreeuwenberg, C., & ter Meulen, R. H. J., 2008a. Euthanasia and assisted suicide in Dutch hospitals: the role of nurses. J. Clin. Nurs. (17), 1618-1626. https://doi.org/10.1111/j.1365-2702.2007.02145.x
- Van Bruchem-van de Scheur, G., van der Arend, A. J. G., Huijer Abu-Saad, H., Spreeuwenberg, C., van Wijmen, F. C. B., & ter Meulen, R. H. J., 2008b. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J. Med. Ethics., (34), 254 258. http://dx.doi.org/10.1136/jme.2006.018507
- Vanden Berghe, P., Mullie, A., Desmet, M., Huysmans, G., 2013. Assisted dying the current situation in Flanders: Euthanasia embedded in palliative care. Eur. J. Pal. Care., 20(6), 266-272.