

# Care about care for healthcare professionals providing palliative care

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Nursing assistants' perceptions and experiences with the emotional impact of providing palliative care: A qualitative interview study in nursing homes

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#### **ABSTRACT**

#### Aim

To gain insight into the perceived emotional impact of providing palliative care among nursing assistants in Dutch nursing homes, their strategies in coping with this impact and associated needs.

#### Design

Exploratory qualitative study.

#### Methods

In 2022, seventeen semi-structured interviews with nursing assistants working in Dutch nursing homes were conducted. Participants were recruited via personal networks and social media. Interviews were open coded by three independent researchers following thematic analysis approach.

#### Results

Three themes emerged regarding the elements that contribute to the emotional impact of providing palliative care in nursing homes: Impactful situations (e.g. witnessing suffering, sudden deaths), Interactions (e.g. close relationship, receiving gratitude), and Reflection on provided care (e.g. feeling fulfilment or feeling inadequate in caring). Nursing assistants used different strategies to cope, including emotional processing activities, their attitude towards death and work and gaining experience. Participants experienced a need for more education in palliative care and organised peer group meetings.

## Conclusion

Elements that play a role in how the emotional impact of providing palliative care is perceived by nursing assistants can have a positive or negative impact.

#### Implications for the profession and/or patient care

Nursing assistants should be better supported in coping with the emotional impact of providing palliative care.

#### **Impact**

In nursing homes, nursing assistants are most involved in providing daily care to residents and have a signalling role in recognizing deteriorating conditions of residents. Despite their prominent role, little is known about the emotional impact of

providing palliative care among these professionals. This study shows that although nursing assistants already undertake various activities to reduce the emotional impact, employers should be aware of the unmet needs in this area and the responsibility they have in this regard.

## Reporting method

The QOREQ checklist was used for reporting.

## Patient or public contribution

No Patient or Public Contribution

#### INTRODUCTION

In the U.S., 44% of decedents stayed in a nursing home in the last 90 days of life and approximately 25% of older adults are cared for in a nursing home until they die. 1 In the Netherlands in 2019, out of a total population of 18 million inhabitants, more than 115,000 people lived in a nursing home or care home and 27% of deaths in the Netherlands occurred in a nursing home. 2,3 A nursing home is 'a facility with a domestic-styled environment that provides 24-hour functional support and care for people who need assistance with activities of daily living and who often have complex health needs and increased vulnerability'. 4 Care in these nursing homes is provided by a wide range of healthcare professionals, including care assistants, nursing assistants, nurses and elderly care physicians. In the Netherlands, more than one-thirds of employees in nursing homes are certified nursing assistants of which the majority has completed a three-year practice-oriented training allowing them to support residents in daily living - such as bathing, dressing and preparing breakfast -, nursing care activities - such as giving injections, dressing wounds and administering medication and psychosocial care of residents.<sup>5-8</sup> In addition, certified nursing assistants have a signalling function for other healthcare professionals involved such as nurses and elderly care physicians. With this, Dutch certified nursing assistants (hereafter referred to as nursing assistants) are trained to a higher level than e.g. US nursing assistants, who typically receive a maximum of 75 hours of training.9 However, despite their important role in providing palliative care, palliative care education for nursing assistants varies between educational institutions in the Netherlands and often focuses only on the care in the terminal phase. 10

Worldwide, more and more people have complex chronic conditions and multimorbidity. It is estimated that by 2060 47% of all deaths will be people with serious health-related suffering.<sup>11</sup> This burden of health-related suffering is partially due to people getting older and is expected to lead to an increase in need for long-term care. Also the Dutch population is aging; the number of people older than 90 is expected to grow from 127,000 in 2019 to 318,000 in 2040.<sup>12</sup> Meanwhile, we are confronted with an aging labour force which will create a growing shortage of healthcare professionals delivering care. The shortage of professionals in long-term care facilities in the Netherlands is expected to rise to 90,000 employees by 2030.<sup>13</sup>

In many Western European countries the long-term care systems have changed in the last decades. <sup>14</sup> Most of these reforms focused on changing the access of care by focusing more on those most in need. Also in the Netherlands changes were made,

making nursing home care only accessible for clients with high-level care needs who need 24-hour care or supervision. <sup>15</sup> A cross-sectional study of deceased residents in six European countries showed that 33% of residents in Dutch long-term care facilities die within one year of admission and 73% of residents need assistance with eating or drinking. <sup>16</sup> As a result, care provided in nursing homes is often intensive and complex and includes to a large extent care for patients in their last phase of life, palliative care. <sup>16</sup> Palliative care aims to improve the quality of life of patients with a lifethreatening illness and their family by preventing and relieving of physical, psychological, social and spiritual suffering. <sup>17</sup> Because of the close personal contact that nursing assistants have with residents and the amount of time they spent with residents as a result of their work, they also have an important, signalling role in recognizing deteriorating conditions of residents. <sup>18</sup>

An international literature review showed that a substantial amount of healthcare professionals who provide palliative care experience symptoms of burnout, especially those working in non-specialized palliative care settings. Moreover, the emotional impact of providing palliative care is often experienced as rewarding and fulfilling, but also as demanding, as research among Dutch physicians and nurses showed. Although providing palliative care is a substantial part of their daily work, little is known about how nursing assistants experience the personal emotional impact of providing palliative care. The few studies present on this topic show that nursing assistants experience providing palliative care both as meaningful as well as emotionally distressing. A Swedish focus group study showed that nursing assistants experience providing palliative care as upsetting and have a need for support in encountering death. Purchase that direct care staff often experience grief symptoms similar to those experienced by family.

#### THE STUDY

The aim of this study was to gain insight into the perceived emotional impact of providing palliative care among nursing assistants in Dutch nursing homes. The specific aims were to get insight into: 1) what elements play a role in the perceived emotional impact of providing palliative care among nursing assistants 2) what are their strategies in coping with this emotional impact and 3) what are their associated needs?

#### **METHODS**

## Study Design

An exploratory qualitative research using semi-structured interviews was conducted. This study design allowed to investigate in a broad sense how nursing assistants perceive the emotional impact of providing palliative care, their coping strategies and needs. Using interviews allowed the researchers to get a close understanding of the perceptions of the nursing assistants.

## Recruitment and participants

Nursing assistants were eligible for inclusion when they (1) were working in a nursing home in the Netherlands, (2) had an IG3 educational level and (3) were older than 18 years. <sup>5,9</sup> An IG3 education is a European Qualification Framework (EQF) level 3 practice oriented training of three years for nursing assistants. This training addresses palliative care to a limited extent. <sup>10</sup> Participants were recruited between February and April 2022 by means of convenience sampling. Colleagues of the Netherlands Comprehensive Cancer Organisation and the Netherlands Association for Palliative Care were asked to send out a priorly constructed recruitment text to nursing homes in their network. Also, a recruitment text was posted on the Netherlands Association for Palliative Care social media accounts. Interested individuals could respond by sending an email to the researcher (YH), after which they received more information on the content and purpose of the study. When they decided to participate, an appointment for the interview by videocall was planned. Additionally, for further recruitment we asked participants at the end of the interview if they knew other potential participants.

A total of 17 nursing assistants were interviewed, with a mean age of 50, ranging from 23 to 67 years. The majority had more than 25 years of experience as a nursing assistant, ranging from 2 to 50 years working in the nursing profession. Most participants cared for an average of one to two residents in need of palliative care per month (Table 1).

#### Data collection

A semi-structured topic list was developed to guide the interviews, ensuring to cover all relevant topics (see Appendix A). The topic list was developed by YH based on previous research on the emotional impact of providing palliative care, and discussed with AD and LB.<sup>20, 23</sup> Prior to the interview, participants gave written consent and completed a questionnaire on socio-demographic characteristics (see Appendix B). All interviews were conducted via videocall by two researchers (YH and AD) and took

**Table 1** Certified nursing assistants' sociodemographic characteristics (n=17)

	N (%)*
Gender	
Female	16 (94)
Age (mean, range) (years)	50 (23-67)
< 35	3 (18)
35-55	8 (47)
> 55	6 (35)
Professional work experience as certified nursing assistant (years)	
<10	5 (29)
10-25	4 (24)
> 25	8 (47)
Working hours as certified nursing assistant (per week)	
< 20	1 (6)
20-24	5 (29)
25-28	5 (29)
29-32	5 (29)
>32	1(6)
Mean amount of nursed residents with palliative care needs (per month)**	
1-2	5 (29)
3-5	4 (24)
6-10	4 (24)
11-20	3 (18)

<sup>\*</sup>due to rounding the numbers do not always add up to 100%

place between March and May 2022. YH, a female master student in Health Science, held 16 interviews and one was held by AD, a female PhD student with a background in psychology. During the interviews, the participants were asked a) about their perceived emotional impact of providing palliative care, b) how they coped with this impact and c) their experienced needs related to dealing with the emotional impact of providing palliative care. Interviews were audio-recorded and transcribed verbatim by YH. Duration of the interviews ranged from 35 to 60 minutes. Analysis of the interviews started during the data collection to monitor what topics emerged from the interviews. This enabled the researchers to discuss both whether the topic list needed to be adjusted based on these initial analyses and whether data saturation had been reached. Data saturation was based on the description of Boeije: 'researchers may stop collecting data when analysis of the newly selected cases yields no further information with regard to the selected research topics'.<sup>24</sup> When no new topics emerged from the

<sup>\*\*</sup> missing data of 1 respondent

interviews, researchers concluded data saturation was approached and no new participants were recruited.

## Data analysis

Atlas.ti version 22 was used for analysing the data. The thematic analysis approach was used to identify, analyse and report patterns found in the data. The following steps as described by Braun and Clarke were carried out.25 First, each transcript was read to familiarize with the data. Meaningful information, such as key phrases, was then identified and initial codes were created. Based on a relationship between codes, themes and sub-themes were formulated. A check was done to compare if codes properly fit the themes and if all meaningful data were reflected in the themes, and themes and sub-themes were named. The last step was to writeup the findings and select quotes to support our findings. To increase confirmability, three researchers (YH, AD and LB) independently coded three randomly selected transcripts and generated initial codes. These initial codes were compared and discussed until consensus on the codes was reached. A constant comparative method was used to compare codes within and between interviews. This process was repeated with two more transcripts to confirm uniformity between researchers. All remaining transcripts were coded by YH after which the researchers YH, AD and LB through discussion jointly identified the main factors and themes. Member checking was not applied. Participants did receive a summary of the results, but were not asked to provide feedback on the findings. Weekly debriefing, the iterative process of examining the data several times and comparing our findings to earlier studies and the literature added to the dependability and confirmability. The Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used for reporting this study. 26

#### Ethical consideration

The study was conducted according to the declaration of Helsinki. The Medical Ethical Committee (METC) of Leiden Medical Center (LUMC, N22.017) in the Netherlands reviewed the study protocol and has decided to exempt this qualitative interview study from ethical review. This was done in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). Data analysis and collection were done in accordance with the Dutch Personal Data Protection Act. Prior to the scheduled interview, participants received an information letter and informed consent form. Before the start of the interview, participants were informed about the study aim, anonymity and the possibility to withdraw from the study at any time without any consequences. Written informed consent was obtained from all participants.

#### **FINDINGS**

In this study, the participants were asked about the elements that play a role in the perceived emotional impact of providing care, the strategies they use to cope with it, and what needs nursing assistants have regarding dealing with the emotional impact. Analysis of the results identified three broad themes for the elements and three themes related to coping strategies. Furthermore, two themes related to the needs of nursing assistants emerged.

## Elements that contribute to the emotional impact of providing palliative care

Three themes have been identified regarding how the emotional impact of providing palliative care was perceived: 1) impactful situations, 2) interaction with residents and relatives and 3) reflecting on personal contribution to the care provided. Table 2 shows the elements that were mentioned relating to how the emotional impact of providing palliative care was perceived and the identified themes and sub-themes.

Table 2 Factors affecting the perceived emotional impact of providing palliative care

Factors	Relates to	Examples of rewarding	Examples of demanding
		aspects	aspects
Impactful situations	Residents	-	Witnessing suffering of
			resident
		-	Witnessing family grief
		-	Young palliative care
			residents
	Process	-	Many deaths in a short
			time period
		-	Sudden deaths
Interactions with	Residents	Good understanding	Experiencing grief due to
residents and		through personal	having a personal relation
relatives		relationship	
	Relatives	Gratitude from families	Misunderstanding of
			families
		-	Incompatible family
			demands
Reflecting on	Feelings of	Contributing positively to	-
personal contribution to the care provided	fulfilment	wishes of family/residents	
to the care provided	Feelings of powerlessness	-	Lack of time/staff
		-	Disagreement with policy
			of doctors
	Feelings of inadequacy	-	Insecurity how to act
		-	Insecurity about quality of
			provided care

## Theme 1: Impactful situations

Some situations surrounding the care for residents in their last year of life were experienced as emotionally impactful. These situations concerned emotionally burdensome circumstances that nursing assistants were confronted with in their daily work and on which they personally had no influence. This theme consists of four subthemes: 1) dealing with suffering and grief, 2) unfairness of life, 3) accumulation of deaths, 4) unexpectedness of deaths.

Witnessing the suffering of residents and grief of relatives greatly affected nursing assistants. Participants indicated that being confronted with residents who are in pain or experience shortness of breath, but not being able to alleviate this suffering led to feelings of sadness for the resident that they have to go through this:

"Last week we had a woman who passed away. And that woman was really anxious. And then I notice..., then I find it..., then I would really like to help her and take that away from her, but that's not possible. So that's just..., yes, I find that very difficult; that you can't just take over something from someone. You know, you see it and you can do your best by talking about it or by getting a doctor, but still, that fear remains, and I find that difficult sometimes." (R20)

When nursing assistants had to care for a young resident in the palliative phase, they often experienced feelings of unfairness of life, feeling that such a young resident should not yet die. Accumulation of deaths occurred when many residents died in a short time period and was also experienced as an impactful situation relating to how the emotional impact of providing palliative care was perceived. Furthermore, several participants reported that it was emotionally burdensome when a resident died suddenly. Nursing assistants indicated that such unexpected deaths preoccupied them because they did not understand exactly what had happened:

"Well, those are usually situations [sudden death of a residence] where I can't really put my finger on it. Because when you can't put your finger on it, you're also not really sure of your own actions. And so that's for example when someone just dies or has a cardiac arrest and that is stressful for me, to not be able to do anything." (R15)

## Theme 2: Interactions with residents and relatives

The second theme that plays a role in the perceived emotional impact of providing palliative care related to the interactions nursing assistant had with residents and relatives. It involved the interaction both between the nursing assistant and the

resident and their relatives, but also witnessing the interactions between the resident and their family. Three sub-themes were identified: 1) closeness of the relation with residents, 2) receiving gratitude, and 3) struggles with relatives.

To develop a personal relationship with residents was viewed as a beautiful aspect of providing palliative care. Nursing assistants experienced that when there was a close personal relationship, residents felt safe and opened up to the nursing assistant, leading sometimes to in-depth conversations. It implies that nursing assistants really know the resident and their specific wishes and needs:

"And the moment that [a resident] enters the dying phase, then I try to give that person what he needs [...] With some, for example, you take into account that in the room, it's just as quiet as possible. And with someone else you make sure that voices are still present, because that person is more sensitive to that. And so with that other person the silence is necessary." (R17)

On the other hand, having a close personal relationship with a resident increased the emotional impact of providing palliative care compared to residents with whom nursing assistants felt less connected. The emotional impact of this personal relationship was especially felt when a resident dies:

"There was a resident who died last year, a woman with whom I had very good contact. So the last time I cried like that was when my own mother died. So ... off course that feeling can come very close. It doesn't always happen, but this was really an exception. It was really like I lost my eh... second mother, definitely, yes" (Ro6)

Receiving gratitude, both from residents and from their relatives meant a lot to nursing assistants. On the other hand, nursing assistants mentioned struggles with relatives of residents as being impactful for them. In these situations the wishes of the relatives did not match the care wishes of the resident or relatives made demands in the resident's last phase of life that were not in line with policy or were unrealistic in the view of the nursing assistants. Such contradictions in wishes can lead to an inner conflict among nursing assistants about how to act. When relatives did demand that such incompatible wishes be carried out, then nursing assistants experienced a sense of sadness or anger:

"And the children can also have quite an ... impact of, ... there's still this and there's still that, and then this has to be done and then that. While the father or the mother no longer wants all that. But that for the children, [...] well that the children are, well, annoying, and difficult about it. What we [healthcare professionals] think and what they [the children] think, [...] and that the one who lies in bed doesn't have much to say about it anymore. I find that a very difficult situation." (Ro6)

Theme 3: Reflecting on personal contribution to the care provided

This third theme included nursing assistants looking back at the palliative care provided and evaluating their own role in this process. It consists of three subthemes: 1) feelings of fulfilment 2) feelings of powerlessness, and 3) feelings of inadequacy.

Nursing assistants mentioned that providing palliative care often gives them a sense of fulfilment. Of knowing that they contribute to good care in such an important part of someone's life:

"Then we put an extra blanket over the bed, we went outside, and we stood by the Christmas tree and we sang a Christmas carol. That's a matter of fifteen, twenty minutes, but that was so precious. That lady absolutely loved it. And for me that gave a lot of satisfaction, that I can do that for someone. (R12)

On the other hand, nursing assistants also experienced feelings of powerlessness. This occurred for example when nursing assistants had a vision on how they wanted to provide palliative care, but were unable to do so due to situational factors or preconditions that were not met, such as not having enough time and staff to provide good palliative care.

'and sometimes, you sit hand in hand with [a resident] because you just have to, and then your alarm goes off. I find that very difficult, to split up then and to say: "I have to leave you for a moment, but I will be back soon" You know, sometimes you just can't. And I find that very difficult' (Ro7)

Participants also experienced powerlessness when nurses or physicians gave conflicting instructions. Moreover, also when nursing assistants felt they were dependent of the policy of the physician or nurse and they did not have a say in this feelings of powerlessness were experienced:

"I have experienced, once, that a doctor for example did not want to prescribe morphine. And yeah, then I can get very angry... and think; why does this woman have to suffer like this, while the morphine is available, you know, to give her that peace. Well, eventually I talk with that doctor, and then finally I do get the morphine. But yes, I have to fight for it very hard and sometimes I just don't understand that. Yes, that makes me angry" (Ro8)

A sense of inadequacy happened due to nursing assistants' insecurities regarding their personal competence on how to act in certain situations and whether the care provided by the team was qualitatively sufficient. Some participants mentioned feeling guilty due to a self-perceived shortcoming towards residents and questioned whether they had done the right thing:

"Uhm, yes it [caring for residents in their last year of life] can also make you sad sometimes or, uncertain.... That you... if you're doing it right..., if you're giving the right care." (Ro9)

## Coping strategies to deal with emotional impacts of providing palliative care

When asked about how they cope with the emotional impact of providing palliative care, nursing assistants mentioned several helpful strategies. Three themes arose from this 1) engaging in activities, 2) adopting a helpful attitude and 3) gaining experience. Table 3 shows the different strategies nursing assistants use regarding coping with the emotional impact of providing palliative care and the identified themes and subthemes.

## Theme 1: Engaging in activities

Nursing assistants mentioned a variety of activities for dealing with impactful experiences. This has been divided in two sub-themes: 1) releasing work-related stress and 2) consciously saying goodbye to a resident.

Activities that were aimed at processing and releasing of impactful situations and work-related stress were leisure activities (for example doing sports, walking or meeting with friends), talking with colleagues or a supervisor about what has happened, or seeking professional help. Sharing their experiences with colleagues helped nursing assistants in managing their emotions. A nursing assistant indicated that by crying, she was able to let go of the experienced emotions and therefore was better able to cope with these emotions. Nursing assistants also mentioned that this sharing of experiences led to mutual understanding among colleagues.

Table 3 Strategies regarding coping with the emotional impact of providing palliative care

Strategies	Themes	Examples
Engaging in	Releasing of work- related stress	Hobbies
activities		Collegial support
		Talking with supervisor
		Seeking professional help
	Consciously saying goodbye to a resident	Providing final care
		Funeral attendance
		Cleaning room of deceased
Adopting a helpful	Peace with death	Acceptance of death
attitude		End to suffering
	Professional vs	Expressing personal emotions in the
	personal attitude Work-life balance	presence of residents
	work-life balance	Not working outside working hours
Gaining	Experience with	Feeling more at peace in providing
experience	death	palliative care due to gained experience

Another important coping activity that was mentioned by participants was consciously saying goodbye to deceased residents. This was done by activities such as laying off the body, attending the funeral or cleaning the room of the deceased resident. This helped participants to figurately close the chapter of caring for this resident:

[when a resident died before the nursing assistant could say goodbye] "Well, that's kind of a weird, a strange thing I'm going to say now, but then I'm very happy that I get to clean up a room and leave it tidy for the family. That's just for the last time still being able to do something so to say. [...] But lately we are allowed to do that [washing & laying out] again, so then you are, so to speak, the last person who has cared for someone, and that embodies the closing of for me. Like okay, I make sure someone is neatly groomed for the family and things like that" (R15)

## Theme 2: Adopting a helpful attitude

This theme consists of thee sub-themes: 1) having peace with death, 2) balancing between having a professional or a personal approach towards residents, and 3) monitoring the balance of work versus private life. These attitudes served for many as a psychological coping mechanism through which they prevented becoming emotionally overwhelmed.

Having peace with death represents an attitude of acceptance that death is a natural part of life. Participants also mentioned it as a helpful attitude to realise that for many residents, dying means an end to pain and suffering. This yields a feeling of relieve among nursing assistants:

"Well, I think at some point, some people are obviously in a lot of pain or are expressing dissatisfaction. And then I think, well, of course you don't want to see someone in constant pain and things like that. So yes, sometimes I think, it's okay, you know. Like well, the body is drained, ...that resident is drained so to say. So yes, that way you can actually make peace with it" (R14)

Another helpful attitude many participants mentioned was to find a balance between being professional and being personal in relation to the residents. Most participants viewed personal emotional expression as unprofessional. They were very aware of their attitude towards residents and their relatives and the impact their personal expression of emotion may have on them. Many nursing assistants mentioned to try to allow some emotions whilst simultaneously suppressing them among residents and relatives. However, finding this balance remained difficult for most:

"With some people [residents] you always try to have a professional attitude; you try not to cry in front of the family because, well, that is not professional. Although I always say; you are not made of stone. You are not made of stone, but you should still try not to ... because well, it is not your mother, it is not your ..., but that is still difficult sometimes yes" (Ro5)

Many nursing assistants mentioned that monitoring their work-life balance was an important way of coping with the emotional impact of their work. Not working outside working hours, such as not reading their work e-mail or not being available for questions, was an often mentioned method to keep this balance.

#### Theme 3: Gaining experience

Gaining experience includes one sub-theme: exposure to dying and death. Participants mentioned how through practical experience with death and dying they had learned to cope both with their emotions and how to act in situations surrounding palliative care which also had an impact on the perceived impact. Some nursing assistants stated that through various palliative care experiences they became familiar with providing care to residents in their last phase of life, and therefore felt more at peace in these situations. More experience with providing palliative care led several participants to

develop anticipation skills, making them quicker in identifying approaching death. For instance, becoming more alert in identifying the right time for preparing the family for the transition towards the death of their loved-one:

"I think that throughout the years I have seen that it is good to mention what is happening. If family members are present, ..., that's what I've learned for myself, that you can give them a bit of guidance, to eh... well, to put it into words what is happening, and what the expectations are. And also, practical things like, if someone indeed seems to be dying, then it's better to already say on the first day: maybe it's a good idea to start thinking about what kind of clothes you want your mother to wear, and about a funeral undertaker or ... those really practical things. I've learned to just, well, mention that right away" (R19)

## Needs regarding dealing with the emotional impact of providing palliative care

Although participants named several coping strategies, they also mentioned unmet needs in dealing with the emotional impact of their work. These needs can be categorised into two themes: a need related to 1) obtaining knowledge and skills and 2) being supported in the emotional processing.

## Theme 1: Obtaining knowledge and skills

Nursing assistants felt they need more practical and/or social knowledge. Desired education in social skills consisted for instance of ways on how to emotionally support and cope with residents and relatives. More practical needs were expressed regarding learning for example the various ways the palliative phase can develop and how they can act in different scenarios:

[Regarding needs] "Well, I think mainly all you have to think of, in the care, so to speak. So just practical things too actually, like moistening the mouth, that sort of things. Like how you can do that even better or in different ways, that sort of things, because, I know the basics, but I know there are also more things I don't know yet.... And..., a bit of guidance with family, I sometimes miss that a bit too here. What is the best way to guide the family, because that is also a question." (R20)

Nursing assistants felt this learning does not always have to be in the form of a training, but also can occur through learning from experienced colleagues, by learning from their perspectives and exchanging advice among each other in for example team meetings. They reasoned that experiences of others could support them in coping with palliative care situations and accompanying emotions.

## Theme 2: Being supported in the emotional process

Participants expressed a need for organised collegial meetings to share experiences about palliative care situations and to vent their accompanying emotions to process them. They reasoned that it is important to feel safe to share your experiences and the related emotions whether it is anger, sadness or uncertainty with colleagues to help cope with the impact of their work:

"I think it might be good if there was some kind of training or meetings, so that people can, say, really pour their heart out if something bothers them, because there are of course plenty of colleagues who don't put it aside easily, but take it home with them. I think that's really something like, make it discussable, and it is not bad how you feel about it" (R15).

## **DISCUSSION**

To our knowledge, this is one of the first exploratory studies on the emotional impact of providing palliative care among nursing assistants in the Netherlands. The findings of this study show that nursing assistants perceive the provision of palliative care as a valuable part of their profession, but also find this part of their work as personally demanding and difficult. Elements that play a role in how the emotional impact is perceived are impactful situations (such as witnessing suffering or residents who die suddenly), the interactions with the resident and/or their relatives, and by how the nursing assistants reflect on their work. Nursing assistants have multiple coping strategies for dealing with the emotional impact of their work, such as engaging in activities to release work, adopting a helpful attitude towards death and work, and gaining experience. Despite these efforts many nursing assistants feel the need for more knowledge and skills and desire organised sessions to share experiences with colleagues in order to learn how to better deal with the emotional impact of providing palliative care.

Many participants felt that the **relationship they had with residents** was an important factor in how they experienced the emotional impact of their work. Having a personal connection with residents makes their work meaningful and helps nursing assistants to provide better care. Several nursing assistants mentioned that, especially in the last phase of a resident's life, knowing a resident well allows them to provide personalised care and often leads to in-depth conversations. A study of healthcare assistants in New Zealand found that many participants felt that they had a familial relationship with residents and that this supported them to provide good quality, individualised care.<sup>27</sup> The downside of this personal relationship is that nursing assistants mentioned that

the death of a resident they knew well affected them more than when there was less personal connection. This tension between building close relationship with residents and the associated feelings of loss and grief when a resident dies is also reflected in other studies. A US study showed nursing assistants working in nursing homes not only had a grief response after a patient's death, but that this response was similar to that of bereaved family caregivers, indicating a family-like feeling towards patients.<sup>28</sup> Therefore, it is important to recognize the impact of the relationship and possible subsequent grief, especially since grief over a patient's death play a role in the development of burnout symptoms in nursing assistants.<sup>29</sup> Although participants often mentioned that providing care to residents in their last year of life was fulfilling, many nursing assistants in this study mentioned that they regularly had feelings of inadequacy in caring for these residents. They expressed regular feelings of insecurity about the care they were able to provide to residents who were in need of palliative care. This insecurity and sense of falling short can have wider implications. Similar results were found in others studies, showing that nursing staff experience feelings of falling short and are hesitant to act in the care for residents who are in need of palliative care due to insufficient competence to for example have conversations with residents about death and dying.<sup>22,30,31</sup> Furthermore, studies show that such feelings threaten the staff's sense of self-respect and meaningfulness and lead to feelings of sadness, fear or shame. 21,31 This sense of falling short may be reflected in the need expressed by nursing assistants in this study for more knowledge and skills regarding palliative care. Another need frequently mentioned by nursing assistants in this study was being able to share experiences with colleagues. Although nursing assistants often engage in one-on-one informal collegial contact, they still expressed a need for organised collegial group meetings. Similar to our findings, a study of Danish nurses found that open collegial discussions to reflect on various emotions and situations were perceived as vital for coping with complex situations, but were still lacking at a formal organisational level.27,32

#### Limitations

There are several limitations to the present study. The participants in this study do not form a very heterogeneous group: all but one of the participants were women, with almost half of them having more than 25 years of working experience as a nursing assistant. Another limitation of this study is that data saturation was based on initial analysis of the interviews and the researchers' impression that no new issues came up in the interviews. This may have led to recruitment being stopped prematurely. Furthermore, by recruiting through convenience sampling and placing invitations to participate on social media of a palliative care organisation, we might have a bias in

nursing assistants who already have some affinity with palliative care and the personal impact this may have on them. Because of this self-selection bias and the homogenous group of women with many years of work experience, it may be that our participants have a different experience than if more men and nursing assistants with less work experience had been interviewed. However, across continents women constitute the large majority in the nursing profession and the aim of the study was not to generalize results, but to get a deeper understanding of the problem.<sup>33</sup> Although we chose to conduct this research in a single setting there is still much variation in the nursing home care setting. For example, within nursing homes there are often somatic, psychosomatic and rehabilitation units, all with their own characteristics and challenges. Further research on this may be interesting to gain insight into different aspects of providing palliative care in these units.

## Implications for clinical practice

This study reflects a need of nursing assistants in support to better cope with the emotional impact of providing palliative care. Nursing assistants in this study expressed a wish for education in palliative care, both in practical and social skills, and structural meetings to reflect with and learn from colleagues. In light of the expected increase in elderly people and the associate need for palliative care and the important role of nursing assistants in this respect, nursing home managers should be aware that an active role to address these needs is necessary. The desire for more knowledge and skills highlights the importance of structurally embedding palliative care education in the primary training of nursing assistants. However, until this is implemented, organisations should assess the palliative care knowledge of their current nursing assistant workforce and additionally train them in providing palliative care. This will not only possibly enhance the quality of care for the residents, but might also reduce feelings of sadness and fear among nursing assistants and the need for support. 31, 34 However, also with firm knowledge on providing palliative care, nursing assistants can encounter impactful situations and still have a need to share the impact of these situations. To enable reflection among colleagues, address the doubts regarding the provided care and encourage peer learning, the CURA intervention could be effective.<sup>35</sup> CURA is an instrument providing a structure for ethical reflection on palliative care related moral challenges. It guides in reflecting on challenges, express doubts and vent emotions related to palliative care. This tool can also be used in collegial group settings by jointly reflecting and asking questions, which stimulates joint learning via the sharing of different perspectives on palliative care challenges. A Dutch study among nurses and nursing assistants showed positive results regarding

feasibility of the instrument, but also that organisational preconditions need to be better addressed to help healthcare professionals use this intervention.<sup>35</sup>

#### Conclusion

When providing palliative care, nursing assistants experience both elements of providing palliative care that are emotionally demanding and elements that are rewarding. The emotional impact of providing palliative care on nursing assistants is underrecognized and deserves more attention. Although nursing assistants themselves already undertake several activities to cope with the emotional impact, employers must be aware of and take responsibility for unmet needs in this regard. Further research on how nursing assistants can be supported in dealing with this emotional impact is needed. In particular research on the duality of having a close personal relationship with residents while at the same time being able to cope with their personal feelings of loss may be interesting. In addition, it could be interesting to investigate whether educational interventions could be a valuable solution to diminish the emotional impact and foster emotional health among nursing assistants.

#### **DECLARATIONS**

## **Authorship**

YH, AD and LB participated in the design of the topic list. YH conducted all but one the interviews; AD conducted one interview. YH, AD and LB were involved in the analysis of the interviews. Interpretation of the data was discussed among YH, AD, LB and NR. AD drafted the manuscript. All authors were involved in the critical revision of the manuscript and approved the final version of the manuscript.

## Data availability statement

Data available on request due to privacy/ethical restrictions

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## APPENDIX A: Interview guide

## *Introduction of the interview*

Including introduction of interviewer, goal of the study, anonymity and confidentiality, the right to stop the interview at any time, and recording of the interview.

## General question

• Can you talk a little about how you are involved in caring for residents in their last year of life?

## Emotional impact of providing palliative care

- What does it do to you emotionally to care for residents in their last year of life?
- Do you remember any beautiful moments while providing care in the last year of life, can you tell something about them?
- Caring for residents in the last year of life is often perceived as a rewarding, beautiful experience from which you can personally also derive benefits. Do you recognize these positive effects or benefits in yourself? If yes: Which ones do you recognize?
- When providing care in the last year of life, difficult situations can arise such as sudden deaths, unenlightened suffering in the dying phase, many deaths in a short period of time. What do you personally find difficult of troublesome while providing this type of care?
- Does the care for residents in their last year of life sometimes preoccupy you outside working hours?
- Poor sleep, irritability, crying easily, and feeling agitated are examples of complaints that can be seen as precursors to emotional overload. Do you recognize such complaints as a result of providing care to residents in their last year of life? If yes: What kind complaints? Can you give an example of situations that may lead to such kind of complaints?
- There are several situations that can lead to stress in providing care during the last year of life of residents such as not having enough time to care for dying residents, not being able to cope well with your own emotions about a resident's death, dealing with the resident's emotions, feeling helpless or powerless in caring for residents who are about to die. Do you recognize these situations and feelings of stress? Can you explain a little more where exactly that (mentioned feeling) comes from? What makes a particular situation stressful for you?

## Dealing with the emotional impact

- How do you personally deal with the emotions you experience as a result of providing care to residents in their last year of life?
- You may feel overwhelmed by emotions whilst providing care in the last year of life or care around death of residents, how do you express these emotions?
- Is there a difference in how you dealt with emotions you experienced as a result of providing care in the last year of life of residents when you just started this work compared to now? If yes: What changed?
- The activities you undertake at the moment, do they help you cope well with the emotional strain?
- What would you still need in this regard?
- Suppose the organisation wants to pay attention to the impact of palliative care provision on healthcare professionals what would you like or recommend to them?

Finishing the interview

# APPENDIX B: Questionnaire socio-demographic characteristics of respondents

Age
Gender
Number of years of professional work experience in care:
On average, how many residents who are no longer getting better do you care for pemonth?
Number of residents dying per month:
How many hours in the week do you work as a nursing assistant: