

ORIGINAL ARTICLE

Caring for patients with eating deficiencies in palliative care—Registered nurses' experiences: A qualitative study

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Abstract

Aims and Objectives: The aim was to explore RNs' experiences of caring for patients with eating deficiencies in palliative care.

Background: Food and mealtimes are fundamental aspects for wellbeing and social interactions. The worldwide trajectory of ageing populations may result in increased need for palliative care. Everyday life with chronic life limiting illness and eating deficiencies is challenging for patients and families. RNs are key care providers at end-of-life.

Design: A qualitative study with an inductive approach was used.

Methods: Nineteen experienced RNs in palliative care were interviewed through telephone; interviews were audio recorded and transcribed verbatim. Inductive qualitative content analysis was performed, and the COREQ checklist was used to guide proceedings.

Results: The overarching theme, Supporting persons with eating deficiencies in-between palliative care and end-of-life care, is represented by three sub-themes: Easy to stick with doing, Just being, without doing, is hard and Letting go. Near end-of-life, eating symbolized social belonging and quality of life for RNs, whereas for patients and families, eating symbolized life. RNs tried practical solutions, however, not always according to patients' and families' preferences.

Conclusions: RNs were well prepared to tackle physical inconveniences and provide support, however, less prepared to encounter existential, psychological and social issues in relation to eating deficiencies. Although RNs stated that human beings stop eating when they are about to die, letting nature run its' course and facilitating patients' transition to end-of-life care was challenging.

Relevance to clinical practice: Food and mealtimes represent fundamental aspects of human life and denote central parts in RNs clinical practice in palliative care. The findings can inspire development of a comprehensive palliative care approach to support patients and families. Structured reflection in relation to clinical practice may support and encourage RNs, caring for patients with eating deficiencies, in mastering both doing and being.

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KEYWORDS

caring, eating problems, end-of-life, families, mealtime, nursing, nutrition, palliative care, patients

1 | BACKGROUND

Food and mealtimes are fundamental aspects for human well-being, both considering physiological aspects of human life and social interactions. Eating is an important family practice (Morgan, 2013), offering both routines and chances to socialise (Castelo et al., 2021). When people eat together, they typically communicate with each other and experience social bonding (Baumeister & Leary, 2007), and food and eating often comprise daily rituals in the sociocultural family context and other social groups (Ares et al., 2016). Well known is that people are likely to eat more when eating together than when eating alone. In social contexts, people influence each other as they provide a guide or norm for appropriate behaviour (Higgs, 2015), social norms are set by peers, thereby influencing both food choices and intake. Common perceptions are that healthy eating habits align with healthy lives (McCarthy et al., 2017). In addition, food choices and eating habits are linked to identity, both how people want to appear and how people look at each other (Morgan, 2013).

Food as nutrients are often stressed in relation to illness and cancer, in terms of cancer cachexia causing metabolic changes and reduced appetite (Arends et al., 2017). However, other diagnoses result in cachexia (von Haehling et al., 2016), and various conditions themselves cause eating deficiencies, for example when suffering from chronic obstructive pulmonary disease or heart failure. The various illness-related symptoms and signs of hampered eating in the present article are referred to as eating deficiencies (Wallin et al., 2015).

For patients during their illness trajectory, mealtimes and eating deficiencies are more than nutrients and encompass daily life with food preparation, social gatherings and interactions around mealtimes (Hilário & Augusto, 2021). Eating deficiencies add to consequences and stressors for patients with diminishing appetite and deteriorating conditions. Mealtimes change from something well known and taken for granted, to being more unpredictable (Lize et al., 2020). Less pleasure is experienced around mealtimes as patients' eating deficiencies have social consequences. Challenges and struggles with food and mealtime can be experienced during the whole illness trajectory, and not only in the late phase when death is closing in. Forced eating aiming to improve health and to resist death is described (Wallin et al., 2021), and conflicts between patient and family around food are recurrently described (Wheelwright et al., 2016). The situation around mealtimes is demanding for families as the illness entails weight loss, changed eating habits and suffering for a family member (Hopkinson, 2016). Often families struggle to provide support through food (Wheelwright et al., 2016). The nature of the experienced eating deficiencies is multidimensional and needs to be recognised and adequately managed by healthcare professionals (Wallin et al., 2021).

What does this paper contribute to the wider global community?

- Food and mealtimes represent fundamental aspects of human life and denote central parts in clinical practice for RNs in palliative care. RNs struggle with existential aspects of care, focusing of medical interventions.
- RNs caring for patients near death need to be aware of the conflicting dualities of doing and being. Focusing on compassionate care alongside medical interventions may help experienced RNs mastering both doing nursing and being caring.

According to the World Health Organization (WHO, 2021), palliative care is an approach that aims to improve the well-being of patients and families encountering potential difficulties associated with chronic life-limiting illness, regardless of diagnosis. This requires an integration of physical, psychological, social and existential care interventions. Furthermore, expectations are that a palliative approach is implemented by healthcare professionals early in the disease trajectory of chronic life-limiting illnesses, as well as near the end of life, irrespective of care setting. Palliative care continually has close connotations to end-of-life care (Ryan et al., 2020), often leading to fear and uncertainty for patients and families (Gardiner et al., 2015). However, contemporary palliative care philosophies embrace concepts such as health-promoting palliative care (Rumbold & Grindrod, 2015), life-prolonging palliative care (Sercu et al., 2018) and life-enhancing care (MacArtney et al., 2017), to describe different stages in the disease trajectory. Information and support to families are vital dimensions of palliative care (IAHPC, 2018; WHO, 2021) and registered nurses (RNs) meet patients and families with palliative care needs, often independently providing palliative care aligned with the nursing process (Sekse et al., 2018).

Everyday ethical nursing practice is guided by core responsibilities to alleviate suffering and to provide care that respects human rights (ICN, 2012). Globally, palliative care is not available to everyone; hence, palliative care provision and coverage need improvement (Centeno et al., 2016), and sensitivity to values, customs and beliefs of people is crucial (ICN, 2012). A vital aspect of nursing is supporting food intake, and findings indicate that RNs experience ethical dilemmas and challenging situations regarding food and nutrition intake in palliative care; in particular artificial nutrition (Jones, 2007), and in situations when worried families are pushing a dying person to eat (Hopkinson, 2016). Eating-related concerns present RNs with challenges of supporting differing patient preferences for

managing and living with symptoms, which can include expectations of support for self-governance (Hopkinson & Corner, 2006). Today, many with chronic life-limiting illness live longer, and with the worldwide trajectory of ageing populations (Cristea et al., 2020), conditions with multimorbidity and frailty are more common (Vetrano et al., 2018). Therefore, increased need for palliative care, incorporating sensitivity and attention to aspects regarding food and meals, is expected.

Everyday life with chronic life-limiting illness and eating deficiencies is challenging, both for patients and families. RNs are key care providers at the end of life, therefore, exploring professional, experience-based knowledge is warranted. Thus, the aim of this study was to explore RNs' experiences of caring for patients with eating deficiencies in palliative care.

2 | METHOD

This was a qualitative study employing an inductive approach suitable for exploration of phenomena (Lindgren et al., 2020). RNs were interviewed about their experiences pertaining to food and meal-times in palliative care. An inductive qualitative content analysis, as described by Graneheim and Lundman (2004), was used.

2.1 | Rigour

The Consolidated Criteria for Qualitative Research (COREQ) (Tong et al., 2007) guided proceedings, see Appendix S1. The COREQ was

used in combination with rigour criteria, that is credibility, transferability, dependability and confirmability, adopted from Lincoln and Guba (1985), see Table 1.

Researchers' backgrounds, reflexivity and qualifications are important aspects to consider when interpreting results from qualitative studies (Lincoln & Guba, 1985). All authors are RNs, and the first and last authors have extensive clinical experience from palliative care and thus, from meeting patients with eating deficiencies. In addition, the first author is an RN specialised in nutrition and a PhD student in palliative care. The second author is a RN and a registered midwife, whereas the third author is a specialist psychiatric nurse. All authors, except the first, are senior researchers with experiences of qualitative analyses, including qualitative content analysis. The first author, who was responsible for the primary analysis together with the last author, has formal training and previous experience of conducting qualitative analyses.

2.2 | Setting

This study was conducted in Sweden, where most of palliative care is provided outside hospitals, in primary care or specialist home care (Håkanson et al., 2015). The organisation of palliative care can be divided into general and specialised palliative care. Specialised palliative care is provided by multi-professional teams with expertise regarding complex palliative care needs. The care can be provided in hospital settings, long-term care or in the patients' homes, and also by regular care providers receiving support from palliative care consults (Radbruch & Payne, 2009). Potential inequalities in Sweden

TABLE 1 Rigour criteria adopted from Lincoln and Guba (1985) in establishing trustworthiness

Rigour criteria	Strategies applied to achieve rigour
Credibility, that is confidence in the <i>truth</i> of the findings	<ul style="list-style-type: none"> We ensured that we had the required knowledge and research skills to perform the study The interview guide was tested and discussed with two clinically active RNs and subsequently discussed with two senior researchers within palliative care and nutrition outside the research team. Interview guide was pilot tested with RNs During the analysis proceedings, to explore aspects from interviews that otherwise might have been remained implicit, the second author acted as a debriefer. This process aimed to awareness about postures towards data (e.g. pre-understanding, preconceptions)
Transferability, that is showing to what extent the findings have applicability in other contexts	<ul style="list-style-type: none"> We adhered to the Consolidated Criteria for Qualitative Research (COREQ) guided proceedings to make thick methodological descriptions, allowing readers to evaluate the extent to which our conclusions drawn are transferable to other context, settings, situations and times
Dependability, that is showing to what extent the findings are consistent and could be repeated	<ul style="list-style-type: none"> We adhered to the Consolidated Criteria for Qualitative Research (COREQ) to provide as many details as possible regarding the methodology used. To ensure information for replication we also paid specific attention to the description of the study context and setting.
Confirmability, that is showing to what extent the findings are shaped by the respondents and not the researchers' bias or interest	<ul style="list-style-type: none"> An audit trail was kept on Microsoft Teams available for all authors. It included methodological notes, raw data (audio-recorded interviews and verbatim transcripts) including fields notes from the first author, data analysis products and memos from research meetings The first author kept a reflexive journal throughout the research process, weekly meetings with last author and bi-monthly meetings with the entire research group

regarding the availability and/or utilisation of healthcare services at the end of life have been highlighted (Håkanson et al., 2015).

In Sweden, nursing science was introduced as an academic discipline in 1993 (The Swedish Code of Statutes [SFS] 1993:100, 1992:1434). The education was also adjusted to conform to the rules laid down by the European Union. Thus, from 1993, the Swedish university educations comprise a Bachelor of Science in Nursing degree after completing course requirements of 180 ECTS credits (SFS 1992:1434). Today there are 48 407 active RNs in the country. Palliative care is included within Swedish undergraduate nursing education, but there is variation between universities in how much palliative care is taught (Martins Pereira et al., 2020). Regarding continuing nursing education, there are 11 post-graduate degree programmes in Specialist Nursing, 60 ECTS credits, on a national level in Sweden (The Swedish Code of Statutes [SFS] 1993:100). Palliative care is not included; however, the Swedish Government introduced the possibility for universities/university colleges to start new specialist programmes in 2013 (The Swedish Government Official Report [SOU], 2018:77). Between 2013 and 2017, 97 RNs had started post-graduate programs comprising Master of Science in Nursing—palliative care.

2.3 | Data collection

An interview guide was constructed by the authors, based on a previous systematic review about patients' experiences of food and mealtime in palliative care (Wallin et al., 2021). Open-ended questions were posed, and the interview guide was tested and discussed with two clinically active RNs (one specialised in palliative care). Thereafter, the interview guide was pilot tested and discussed with two senior researchers within palliative care and nutrition in another university. As a result, minor revisions regarding wording and order of questions were made.

Participants were recruited by convenience sampling. RNs who took part in an online quantitative survey (19 items) about their perceptions of food and mealtimes in palliative care (in manuscript) were invited to participate further in interviews. The survey was advertised via a post on a closed Facebook group for RNs in palliative care, and in an internal newsletter within an association for RNs in palliative care (approximately 80 and 400 members, respectively). The administrator of the Facebook group and the chairperson of the association were contacted by the first author with an invitation to publish information and a link to the survey. Oral and written information about the study were provided, and subsequently, the administrator and the chairperson of the association consented to publish the invitation to the survey. At the end of the survey, to further explore perspectives on food and mealtimes, RNs were asked if they were interested in participating in a telephone interview; that is the data that this study is based on. Between November and December 2020, 100 RNs (94 females and 6 males) answered the survey and 33 (32 females and 1 male) expressed interest to participate in this interview study.

Via telephone, the first author consecutively contacted the first 10 RNs who had expressed interest in interview participation. Nine of them were reached and still wanted to participate, whereas one was unreachable. Verbal information was provided, and interview appointments were scheduled. An e-mail was sent with information about the study, that is aim, procedure for interview, confidentiality, possibility to withdraw at any time and contact details to the researchers conducting the study. All nine agreed to participate and were interviewed. Thereafter, purposive sampling was made from the remaining RNs ($n = 24$), aiming for variation in age, education, years in nursing and work location in Sweden. Eleven RNs were contacted according to the procedure described above. However, one was unavailable, and thus, 10 more interviews were conducted. In total, between December 2020 and January 2021, 19 individual telephone interviews were conducted, and audio recorded, after verbal informed consent procedures.

The first author, a female nutrition nurse specialist and a PhD student with training and experiences of qualitative methods, conducted all interviews. The interviews started with an open-ended question: 'Can you tell me about a challenging situation concerning food and mealtimes in palliative care? Other questions asked were: 'How do you ask and talk about food and eating?' 'What would you like to teach a new college about food and meal?' Probes were used for elaboration (Price, 2002), for example 'Can you tell me more about...?' 'Can you give an example?' 'How did you experience that?' At the end of the interview, the RNs were asked if there was anything more they wanted to share regarding food and mealtimes in end-of-life care. RNs were also given possibilities to ask questions about the research project. The interviewer and participants had no relationships prior to the study. The RNs were sent a gift certificate equivalent to 47 Euro, as a token of appreciation.

No new information of interest for our aim was obtained after 16 interviews. Nevertheless, another three interviews were conducted and when no new meaning units were added, the data collection was closed at 19 completed interviews, by joint decision of the first, second and last authors. Field notes were used to summarise and gather thoughts at the end of interviews. The interviews were read, listened to and judged to generate sufficient data regarding breadth and depth to capture a variety of experiences related to the aim. An audit trail was kept on Microsoft Teams available for all authors. In addition, the first author kept a reflective journal.

The interviews lasted from 28 to 59 min (median 46). The RNs had various work locations in Sweden, divided into the north of Sweden ($n = 3$), the middle ($n = 8$) and the south ($n = 8$). Demographic data, that is age, graduation year, years in caring profession, years in palliative care and workplace, were collected via the survey (Table 2).

The youngest interviewed was 31 years old, whereas the oldest was 71, and the majority were women. Years since graduation varied between 5 and 50 years. All, except three, of the participants had post-graduate degrees in palliative care or other post-graduate education. Two of the RNs had two post-graduate degrees. Three quarters worked in a palliative care context, and most of the participants

TABLE 2 Demographic characteristics of the interviewed RNs (n = 19)

Characteristics	
Age, years: median (range)	41 (50)
Gender: n	
Female	18
Male	1
Years since graduation as RN: median (range)	12 (46)
Post-graduate degree: n	
Yes/No	16/3
If yes ¹ :	
Palliative care	10
Primary care	3
Intensive care	2
Oncology care	2
Dementia care	1
Workplace: n	
Specialist palliative homecare	7
Palliative care/Hospice	6
Acute care	2
Elderly care	2
Primary care	1
Palliative consultation team	1
Years in caring profession: n	
1–5 years	1
6–10 years	6
>10 years	12
Years in palliative care: n	
1–5 years	5
6–10 years	8
>10 years	6

^aTwo RNs had double post-graduate degrees

had ample work experience as RNs (>5 years). Three quarters had worked more than 5 years in palliative care.

2.4 | Analysis

An inductive qualitative content analysis as described by Graneheim and Lundman (2004), and further elaborated by Lindgren et al. (2020), was elected, since the method was found suitable to the aim and data. Interviews were transcribed verbatim by a professional transcriber, and transcripts were read multiple times to get a sense of the whole. Thereafter, first and last authors independently extracted meaning units, condensed and coded them, for example *physical obstacles*, *challenges*, *doing*, *communication* and *a good death* (Table 3). During this process, initial de-contextualisation was made as data from individual interviews, illuminating the studied phenomenon, were condensed

and separated from context (Lindgren et al., 2020), representing manifest content. These were descriptively coded, close to the text, with low levels of abstraction and interpretation. Further, to explore aspects from interviews that otherwise might have been remained implicit, the second author acted as a debriefer, that is checked and validated the initial analysis, questioning pre-understanding, preconceptions and prompting further analysis. This process aimed to awareness about the first and last authors posture towards data as they both have extensive clinical experiences from supporting patients with eating deficiencies in palliative care.

In later analysis phases, the de-contextualised units were re-contextualised, that is separate units were combined and returned to context and formulated in sub-themes and an overarching theme, illustrating interpretation of latent content. Differences and similarities found in the data-guided analysis proceedings and alternating closeness to distance when data were compared and grouped resulted in increasing abstraction levels (Lindgren et al., 2020). The findings were read, reflected on, and discussed recurrently with all authors until consensus was reached. Selected quotations were used to substantiate the findings. Square brackets indicate a clarification made by the authors and the number after each quotation indicates the participants.

2.5 | Ethical considerations

Ethical approval was granted by The Swedish Ethical Review Authority [2020-04618]. The study adhered to ethical principles as per World Medical Association (2018). Before the interviews, informed consent procedures were observed. Participants were given verbal and written information about the study, including their rights, how confidentiality was guaranteed, including data management and presentation of findings.

3 | FINDINGS

The analysis resulted in an overarching theme: *Supporting persons with eating deficiencies in-between palliative care and end-of-life care*, represented by three sub-themes: *Easy to stick with doing*, *Just being, without doing, is hard* and *Letting go*, see Table 4.

When patients were on the threshold to end-of-life care, eating symbolised social belonging and quality of life for RNs, whereas for patients and their families, eating symbolised life. To ease stressors around food and mealtimes, RNs were busy trying practical solutions, however, not always in accordance with patients' and families' preferences. RNs struggled with moving away from a nursing care model of 'fixing' to one that was more empowering and embraced shared responsibilities with patients and families. Although RNs stated that human beings stop eating when they are about to die, letting nature run its' course and facilitating patients' transition to end-of-life care was problematic.

TABLE 3 Example of the analysis process

Meaning unit	Condensation	Interpretation	Code	Sub-theme	Theme
You are a bit eager to help in this profession. (—)	There is an eagerness to help, RNs want to do things, finding solutions and the well-intended efforts may not always be what is best for the patient.	Eagerness and focusing on doing	Doing	Easy to stick with doing	Supporting persons with eating deficiencies in-between palliative care and end-of-life care
That's how I feel sometimes anyways, that there's a lot you'd like to do and you get busy doing this and that and then it ends up... and it may not always be what's best for the patient even if we (RNs) mean well. (RN 19)					
Yes, and it's challenging to talk (about death and dying), but I try to encourage talking even if you do not have all the answers, and unfortunately the how comes with experience. And... then possibly one also thinks about it, that perhaps I'm making it more complicated in my head and think that it is so hard to talk about instead of just talking about it. (RN 10)	It is challenging to initiate conversations (about death/dying), but I try to encourage talking, even if there are no answers, you learn with clinical experience. Thinking about difficulties makes it harder, instead of just seeing it as a conversation	Being open to communicate about death and dying is challenging	Being (open to communicate)	Just being, without doing, is hard	
Firstly it's about not forcing food, nagging about food, and trying to help families to, because I think it is mainly families who nag when patients have no appetite, to get them to understand that where we are now, eating is not important and that this late in the disease trajectory, the body shuts down, it becomes a burden for the body to take care of food, it's more stress for the body. (RN8)	Helping families to understand that food is not important at the end of life when there's no appetite, that it may even be a burden, it's adds stress for the body; patients can do without the forced eating	Natural to stop eating at the end of life	A good death	Letting go	

TABLE 4 Overview of theme, sub-themes and sub-theme content

Supporting persons with eating deficiencies in-between palliative care and end-of-life care	
Sub-theme	Sub-theme content
Easy to stick with doing	Patients' eating deficiencies were met with multiple caring interventions. The eagerness of doing something, vs. the individual patient's will and preferences, was a challenge for experienced RNs in palliative care
Just being, without doing, is hard	Stressors related to patients' eating deficiencies were part of RNs everyday work. RNs struggled with moving away from a nursing care model of 'fixing' to one that is empowering and embraces shared responsibilities with patients and families
Letting go	Although the RNs stated that human beings stop eating when they are about to die, it was complicated to let nature run its' course in palliative care

3.1 | Easy to stick with doing

Worries and difficulties related to food and mealtimes, experienced by patients in palliative care and their families, were met with multiple caring strategies by the RNs. Although the RNs were well aware that eating habits and nutritional needs change during end of life, they were busy trying practical solutions to counter patients' eating deficiencies.

Analysing physical signs and symptoms which influenced eating and could be solved or eased was emphasised by the RNs. This included recurrent evaluation of where patients were in the illness trajectory and the dying process. RNs emphasised not overlooking vital clues. Expressions as '*the food tastes like nothing, I don't want any*' could be a sign of death closing in, that is the process of moving closer to end-of-life care but could also be linked to oral thrush or ill-fitting dentures. Sometimes RNs were concerned that they would miss something that could have been solved, and inadvertently cause harm. But mostly the RNs were confident in their analyses. Practical problems, as difficulties in eating with ordinary utensils or providing suitable food alternatives, were examples of solvable issues to alleviate obstacles. As a means towards this end, RNs were supported by other members of the palliative care team, that is dieticians, occupational therapists, physicians and physiotherapists. RNs described that through education, both general and specialist level, they were well prepared to tackle physical inconveniences and provide support related to practical assistance or solutions.

Well, ... if it's problems with pain or nausea, one needs to alleviate all symptoms so that patients can have some kind of appetite that gives pleasure in food, or desire to eat. And if you've alleviated symptoms in the ways that you can, and..., then it's down to advice and help and explaining options, what may work or not. Warm foods or cold foods or nutritional drinks or whatever they can... to get the nutritional status as good as possible in the time that's left.

(RN12).

RNs described their passion for their work and found they felt good solving challenges around food. Doing something extra around meals

was described as providing care with extra consideration and was exemplified as setting the table nicely and adding flowers or arranging utensils for oral care on a beautifully coloured tray with a napkin.

Extra consideration in some way. Yes, it feels good both for me doing it and the person I go to.

(RN8)

This was described as work satisfaction; being experienced and confident that patients and families felt that they were cared for with warmth and flexibility. Nursing interventions were meant to be supportive, aiming to reach mutual understanding that fulfilling energy requirements might not be possible nor prudent, when death was closing in. Eating a little and finding enjoyment around food and mealtimes could be a more constructive goal. However, RNs described that it was easy to get caught in 'just doing' in caring situations around food and mealtimes in palliative care. '*And it's easy to get stuck in just doing*'. (RN5).

Some of the RNs reflected on the possibility that patient perspectives were lost in the pursuit of finding practical solutions to eating deficiencies.

One is very eager to help in this profession... that's how I feel sometimes anyways, that there is a lot one wants to do, and one is very active in finding solutions, and bending over backwards to help... and the result may not always be what is best for the patient, even if we mean well, we staff.

(RN19).

Taken together, eating deficiencies were met with multiple caring interventions. The focus for the RNs was to support patients' eating, not to maintain life but to enhance quality of life. The eagerness of doing something, vs. the individual patient's will and preferences, was a challenge for experienced RNs in palliative care.

3.2 | Just being, without doing, is hard

Registered nurses stressed that loss of appetite is normal when death is approaching. This was, on the other hand, difficult to understand and accept for family members. RNs experienced being

less prepared to meet stress around mealtimes in families and participating in challenging conversations about food, as this was not taught in their educations. Finding what to say could be difficult, and RNs were afraid to frighten and upset patients and their families.

Tacit knowledge, that is abilities, knowledge and skills that RNs gain through years of clinical practice, was described in the interviews. One example was physiological processes in the human body related to nutrition when death was approaching. However, knowledge gained solely through clinical experience was difficult to communicate.

... I believe there's a lack of knowledge in general about all this, how food and nutrition affect the dying body... It eventually becomes a burden, we know that. But how? ... I mean, I don't feel like I've gotten any knowledge about that conversation from my education, it's knowledge that I've gotten from [clinical] experience and from looking for it myself'.

(RN15).

Registered nurses described that they also had a supportive, informative role, providing patients and families with needed and sought-after knowledge. Being in a palliative care context might be new to both patients and families; keeping that in mind was imperative. Information given could reduce stress for patients and families and in relation to supportive communication, RNs reflected, that healthcare professionals wanted to share perspectives for support. *'We want them to understand our way of looking at it'* (RN15). The knowledge RNs aimed to provide, was the healthcare professional view on food, dying and death. However, dying persons and families may have other preferences based on their life philosophies. *'It is our truths, what we think are truths [about food and meals]'*. (RN5).

Knowing when to inform about changed eating habits and nutritional needs during the illness trajectory was difficult according to the RNs. Considerable energy was spent on how to share bad news without upsetting or frightening patients and families. Thus, individual counselling with family members, without patients' presence was performed, and this could result in important information being withheld.

...a booklet about the last days of life, and what may be expected, with very good information about food and nutrition and drink, but that is something we give to families very, very late [in the illness trajectory] and families often express that 'Oh, why didn't we get this sooner?'. It is described in a nice way, about food and drink, but we are a bit, well..., we don't want to scare anyone by coming with the folder months ahead of time.

(RN7).

Identifying symptoms and providing symptom management were in focus for the RNs. Thus, symptom checklists were often used in clinical practice. In a time-constrained working environment, for some of the RNs, the checklists represented increased administration and a risk of undermining natural and engaging conversations. Adhering strictly to checklists caused communication breakdowns. Asking questions about obvious symptoms related to eating deficiencies, such as weight loss, was perceived as tactless by the patient. Bridging such mistakes was difficult or even impossible according to the RNs.

One can be offended by questions about food and... that... I know he [patient] said specifically to me, that I could see that with my own eyes, just looking at him, that he didn't eat anything. And that he'd lost weight, and it was 19 kilos in just six months, and that he didn't have energy. He used to go running 11k each day and now he couldn't even make it up the stairs. And still he kept losing weight and stuff. ... he was really upset [with me].

(RN18).

Constructive dialogue in assessing individual needs and concerns about food and mealtimes in end-of-life care often occurred during 'doing', that is when the RNs were giving intravenous therapy, blood transfusions etc. RNs realised the importance of capturing these moments by showing openness, interest and focus, being truly present with patients. In addition, challenging conversations were described; information that did not reach the recipients and issues with approaching existential queries. Existentially loaded questions were often met by silence from RNs.

And after her death, he [her father] carried it with him and felt guilty because he had pushed her to eat even though she didn't have energy for it, because he'd..., when he thought back on her last days he sort of saw that... she didn't want to eat the food that was pushed on her. But we tried to provide information, but they couldn't receive it. And I think that this... it has to be that we didn't reach him where he was at. We forgot to talk about food and how do you feel about food. I remember, because I was involved with that patient, and I remember never asking him that question.

(RN2).

Instead, RNs relied on physicians to handle what they regarded as tricky conversations about eating deficiencies. Often, these conversations were done with both physician and RN; however, RNs took a more passive role as they regarded the physicians to be more influential in their interactions with the patients and families. *'...even if we may say the same things, it weighs more sometimes, if a physician says it'*. (RN1).

Taken together, stressors related to patients' eating deficiencies, that is not eating enough or needing to eat more to stay alive were part of RNs everyday work. RNs struggled with moving away from a nursing care model of 'fixing' to one that is empowering and embraces shared responsibilities with patients and families.

3.3 | Letting go

For RNs in palliative care, eating symbolised social belonging and quality of life, whereas for patients and families eating symbolised life. RNs interpreted families' concern for starvation as lack of knowledge about the dying process. Yet thoughts about starvation also existed among team members, and RNs had ambivalent feelings regarding when, how and to what extent eating deficiencies should be addressed.

Registered nurses described daily discussions about eating deficiencies and concerns for starvation with family members. But for RNs, it was clear that human beings stop eating when they are about to die.

...you don't die because you stop eating, you stop eating because you are dying.

(RN15).

Some RNs argued that the best thing to do was letting nature take its course that loss of appetite and eating deficiencies were natural parts of the dying process and should be left without interference or interventions.

You stop eating well ahead of time, I even say this, well, not to families, but to staff, that it may be a good thing to be a little dehydrated when one is about to die, it often becomes calmer, so it's not a bad thing really.

(RN9).

In contrast, families were often not willing to give up. To postpone death, favourite foods and snacks were brought to patients, and family members were described to go as far as nagging and pushing patients to eat. Patients, on the other hand, felt compelled to eat or felt guilty for failing to eat. In these situations, when repeated information about the dying process had failed, RNs described that they had to take on the role as a 'bad cop.' They asserted that family members were relieved from responsibilities of food preparation and patients' food intake. This could be hard for families to accept and often parenteral nutrition was used in end-of-life care. RNs talked about 'family IVs' as an easy way out to alleviate distress regarding hunger and thirst when death was near. Nevertheless, parenteral nutrition for dying patients was met with ambiguity by RNs. Some regarded it as a strategy to ease concerns of starvation, whereas others thought it was wrong as it could cause further complications, such as pulmonary oedema.

...but when it's become IVs all the way, for families' benefit, it's been awful when we've been unable to discontinue, and you feel like it is not a good ending, when you know it is wrong, but that's how it goes anyway.

(RN14).

Issues of enteral- and parenteral nutrition were subject to numerous discussions among palliative care team members. Considerations regarding if and when to start, as well as when to withdraw or diminish enteral- and parenteral nutrition caused ethical dilemmas among RNs. For patients in an early phase of palliative care, when death was not expected in the near future, healthcare professionals actively persuaded unconvinced patients to accept enteral nutrition. This was done aiming to avoid complications and suffering later in life. Nevertheless, there were also examples of patients feeling compelled to accept healthcare professionals' suggestions of invasive procedures to decrease eating deficiencies, that is a percutaneous endoscopic gastrostomy (PEG).

And then we had conversations about food and stuff, and then that turned out the same way, that it became a chronic obstruction, and then... then we went in and talked about a PEG. This patient was adamant, no, I do not want a PEG and stuff. But he finally accepted, after discussions. And he was very disappointed, I remember coming there the first night to administer... he hardly looked at me, because he really didn't want the PEG once it was in place'.

(RN2).

Once in place, PEGs were described by RNs as causing dilemmas when it was time to phase out nutritional support.

'The ones who have... if you say PEG, I mean food through their PEG, we find it quite difficult when you need to... phase it out, because that person has not chosen for themselves, how little they want to eat'.

(RN16).

Taken together, the RNs, though educated and experienced in clinical practice, found that even though human beings stop eating when they are about to die, it was complicated to let nature run its' course in palliative care.

4 | DISCUSSION

Supporting patients with eating deficiencies and their families were part of RNs daily work in palliative care. RNs were well prepared to tackle physical inconveniences and provide support related to practical assistance or solutions. Eating symbolised social belonging and quality of life for RNs, whereas for patients and their families eating also symbolised life. Thus, stressors related to not eating enough,

or needing to eat more to stay alive, were prominent, especially when patients were on the threshold to end-of-life care. Although RNs stated that human beings stop eating when they are about to die, letting nature run its course and facilitating patients' transition to end-of-life care was challenging. When interpreting these findings, it is important to bear in mind that most of the interviewed RNs had extensive clinical experience in palliative care as well as a post-graduate degree in nursing. In the forthcoming discussion, we will reflect upon our findings through the lens of dying and death in our Western society and the concept of liminality.

4.1 | Nursing in-between palliative care and end-of-life care

According to the RNs in this study, an obvious sign of death approaching was when a patient stopped eating. Although this was a natural part of the dying process for the RNs, they had difficulties with conferring this to patients and families. The transition to end-of-life care was challenging, and our interpretation is that patients were left in a liminal space, that is in-between palliative care and end-of-life care. Liminality is defined as a state of transition between one stage and the next and includes three phases, namely separation, liminality/transition and incorporation (Turner, 2011). The liminal space refers to an in-between state characterised by uncertainty. A non-place, where people are separated from their social structure and/or identity, and thus, left in limbo. Liminal experiences when living with a life-threatening illness include ambiguous pervasive perceptions, such as being alive but not living (Bruce et al., 2014). Based on our findings, liminality also seems to affect nursing care, causing uncertainty and ethical dilemmas regarding how and to what extent eating deficiencies should be supported in-between palliative care and end-of-life care. Additionally, it may also hinder patient-nurse communication as these experienced RNs described that they were afraid to frighten and/or upset the patient by breaking bad news too early. Recent research, however, suggests that entering a liminal space with a patient raises opportunities for strengthening holistic nursing care (Bruce et al., 2014), in other words, responding to physical, psychological, social and existential needs. As a means towards this end, RNs need to more consciously listen to patients' narratives without striving to resolve ambiguous liminal experiences. It has been put forward that experiences somewhere between living and dying may be understood as concurrently living and dying (MacArtney et al., 2017). Thus, patients are able to recognise both realities, in a way that acknowledges the benefits of being multiple (MacArtney et al., 2017), indicating possibilities of new perspectives within the liminal space (Turner, 2011). We need to keep in mind that communication is not always about what or how things are said. Offering silent presence can provide the space to 'hear' what patients and families cannot articulate (Dettmore & Gabriele, 2011). Taken together, to better understand the breadth of experiences related to eating deficiencies among patients on the threshold to end-of-life care, we urge RNs to practice 'being without doing'.

4.2 | Medicalised death and contemporary nursing

In this study, RNs described that it was easy to 'stick with doing' when confronted with distress related to eating deficiencies among patients and their families. RNs were well prepared to tackle physical inconveniences, however, less prepared to encounter existential, psychological and social challenges in relation to eating deficiencies. These findings relate to how death is regarded in our Western society. The idea of a 'good death' is vital in palliative care (Saunders & Clarks, 2006; IAHP, 2018; WHO, 2021); however, the concept of 'good death' has evolved over time (Walters, 2004). In the pre-modern period, that is prior to advances in modern medicine, death was mirrored through religion, and being free of physical pain was of secondary importance. During the modern period, from the latter part of the 19th century and onwards, the way death was regarded was transformed due to advances in medical science (Gellie et al., 2014; Walters, 2004). Our ability to treat diseases has increased our life span (Cristea et al., 2020; Vetrano et al., 2018) and thus, we have started to perceive death as something to be prevented or indeed avoided, as well as repressed from everyday life (Walters, 2004). Although these perceptions still exist, a gradual change regarding how we perceive death started in the beginning of the 21st century. Nowadays, death is no longer taboo or invisible, instead, it is embedded in our social lives. Not generally through personal experiences, but dramatised and presented to us via movies, social media and television with the aim to entertain or provoke (Gellie et al., 2014). These perceptions of death and our continued thrust for treatments may leave us ill-prepared for the 'real' death. RNs are socialised with the pervading perceptions about death in general society which naturally influences our caring practices. Consequently, we need to identify our prejudices to develop compassionate caring practice and presence when caring for dying patients. In addition, we need to acknowledge that the key difference between the concepts of good death in the pre- and postmodern periods is the sense of control over death that was achieved through medical science (Gellie et al., 2014; Walters, 2004). This, in turn, may explain why RNs in this study focused on solving physical problems when caring for patients with eating deficiencies. We are trained to treat, and the literature does emphasise that medical care should be considered along with compassionate nursing care (Wiechula et al., 2016). As a result, both aspects of care can and should be provided in parallel, that is RNs need to practice doing *and* being when caring for patients with eating deficiencies.

4.3 | Controlling death, dignity and letting go

Exercising medical control of eating deficiencies was highlighted in our study. The possibilities of offering enteral- and parenteral nutrition seemed to block existential encounters with patients and families. Even though RNs had extensive clinical experience and post-graduate diplomas, it appears as if it never was the right time to sit down to express 'there is nothing more we can do to postpone

death', with empathy and honesty. Perhaps we need a gentle reminder that the hospice and subsequent palliative care movements grew out of the refusal to accept death as a failure (Saunders & Clark, 2006). Dame Cicely Saunders (1918–2005), attributed to have established the discipline and philosophy of palliative care, emphasised that dying people need compassion, dignity and respect. Perhaps less known is that she also advocated rigorous scientific methodology in the testing of treatments. Nonetheless, we are a far cry from high-quality evidence to guide clinical practice with regards to the use of enteral- and parenteral nutrition in palliative care (Good et al., 2014). In fact, it is uncertain whether medically assisted nutrition helps patients to feel better or live longer. Thus, we need to pay attention to individual wishes of patients at the end of their lives. This can only be achieved through open, humble and frank discussions in which we respect patients' perspectives.

Suffering can be endured and even explored for meaning (Cassel, 1982). Bearing that in mind, we need to reaffirm the existential aspects of dying to uphold dignity and respect when caring for patients and their families (Sand & Strang, 2006). 'Letting go' is part of the dying process and international policy documents or guidelines stress that palliative care should pay special attention to the specific needs and preferences of individuals (IAHPC, 2018; WHO, 2021). Thus, involving and empowering patients in the decision-making process regarding food, mealtimes and medically assisted nutrition is imperative.

4.4 | Methodological considerations

As in every study, there are limitations to consider. Thirty-three of those who participated in the initial survey ($n = 100$) volunteered for interviews, indicating that RNs with experiences and interest in the area were reached. The data collection was performed during the COVID-19 pandemic 2020, with heavily increased workloads among healthcare professionals, which in turn may have skewed our sample.

Due to the pandemic, all interviews were performed via telephone. Our impression is that RNs appreciated the data collection method and shared their experiences freely. It is possible that face-to-face interviews would have generated other findings, and we encourage future research employing other qualitative data collection methods to explore RNs experiences of eating deficiencies in palliative care.

The first author performed all interviews, this may present a risk for bias by one researchers' pre-understanding and premature interpretations. The researchers were aware that a challenge with inductive analyses is to truly embrace an inductive approach, and avoiding results based on researchers' pre-understanding. Open, critical reflection and discussion in the research group were aimed at avoiding shallow descriptions and general summaries, both during interviewing and analysis phases. Even though choosing meaning units comprises initial interpretation, the parallel working process initially between two researchers, and later the research group was a chosen strategy to reduce the risk of bias. This approach, and also

providing readers with representative quotations, were strategies to achieve credibility. The researchers had no former relation to the participants. Careful accounting of the research process and adhering to COREQ guidelines (Tong et al., 2007), in combination with highlighted rigour criteria adopted from Lincoln and Guba (1985), were measures to ascertain a systematic research process and transparent reporting. It is our hope that this allows readers to form an assessment of the trustworthiness of findings.

There is a limitation concerning variation of healthcare context, for example elderly care settings are underrepresented; areas where knowledge of palliative care may be more limited (Voumard et al., 2018), which challenges transferability of findings. Furthermore, the vast majority of the interviewed RNs were women with extensive clinical experience, and they were highly educated, that is all except three had post-graduate degrees in nursing. These circumstances also imply limited transferability of our findings to clinical settings where RNs provide general palliative care.

5 | CONCLUSION

Experienced RNs in palliative care were well prepared to tackle physical inconveniences and provide support related to practical assistance or solutions, however, less prepared to encounter existential, psychological and social issues experienced in relation to eating deficiencies. Eating symbolised social belonging and quality of life for RNs, whereas for patients and their families eating also symbolised life. Thus, stressors related to not eating enough, were prominent, especially when patients were on the threshold to end-of-life care. Although RNs stated that human beings stop eating when they are about to die, letting nature run its' course and facilitating patients' transition to end-of-life care was challenging.

We need to pay attention to individual wishes of patients at the end of their lives. Thus, involving and empowering patients in the decision-making process regarding food, mealtimes and medically assisted nutrition is imperative. Working in palliative care is knowing that nothing is more certain than death. It seems, however, time to reconsider that despite all our efforts to control death, nothing is more uncertain than the time of dying. This is truly something to remember and convey when supporting patients with eating deficiencies, and families, on the threshold to end-of-life care.

6 | RELEVANCE TO CLINICAL PRACTICE

Food and mealtimes represent fundamental aspects of human life and denote central parts in clinical practice for RNs in palliative care. Eating deficiencies are closely related to impending death, thus causing distress among patients and families. This study's findings can inspire discussions in clinical settings regarding core holistic values in palliative care, highlighting the balancing act of not solely focusing on medical aspects of care, and further developing a holistic palliative care approach to support patients and families.

Our results further underscore the importance for clinically experienced and well-educated RNs to be aware of the somewhat conflicting dualities of doing and being. Structured reflection in relation to clinical practice may support and encourage RNs, caring for patients with eating deficiencies, in mastering both doing and being. Further research should consider aged care settings and evidence regarding enteral-parenteral nutrition at the end of life. Also, research specifically exploring the liminal experiences perceived by RNs would be helpful in identifying foci for future interventions studies regarding RNs' practice in relation to food and meals at the end of life.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

Performance of the interviews: VW; Performance of the analysis: VW, AK and EM; Draft manuscript: VW, EM and AK; with critical revision AK; Study design and the guide interview, read, contribute and approval of the final manuscript: All authors.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

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