Assistant nurses' experiences of thirst and ethical dilemmas in dying patients in specialized palliative care—A qualitative study

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Abstract

Aims: To describe assistant nurses' experiences of thirst and ethical challenges in relation to thirst in terminally ill patients in specialized palliative care (PC) units.

Design: A qualitative, reflexive thematic design with an inductive analysis was used.

Methods: Data were collected during November 2021–January 2023. Twelve qualitative interviews with assistant nurses working in five different specialized PC units in different hospitals in Sweden were conducted. The interviews were transcribed verbatim and analysed with a reflexive thematic analysis. The study was guided by the Standards for Reporting Qualitative Research (SRQR).

Results: Two main themes were found in this study. (1) ‘A world of practice for thirst relief’ where assistant nurses present a task-oriented world where the knowledge of thirst is an experience-based unspoken knowledge where mainly routines rule. (2) Ethical challenges presents different ethical problems that they meet in their practice, such as when patients express thirst towards the end of their life but are too severely ill to drink or when they watch lack of knowledge in the area among other health professionals.

Conclusion: Thirst in dying patients is a neglected area that assistant nurses work with, without communicating it. Their knowledge of thirst and thirst relief are not expressed, seldom discussed, there are no policy documents nor is thirst documented in the patient's record. There is a need for nurses to take the lead in changing nursing practice regarding thirst.

Patient or Public Contribution: No patient or public contribution.

Impact: In palliative care, previous studies have shown that dying patients might be thirsty. Assistant nurses recognize thirst in dying patients, but thirst is not discussed in the team. Nurses must consider the patient's fundamental care needs and address thirst, for example in the nursing process to ensure patients quality of life in the last days of life.

Reporting Method: The study was guided by the SRQR.
1 | INTRODUCTION

The goal of palliative end-of-life care is to prevent and relieve suffering as much as possible (World Health Organization, 2015). Meeting the fundamental care needs of patients are essential in this care as patients lose their functions, for example the functions to independently eat and drink. One previously studied symptom in palliative care (PC) is thirst (Burge, 1993; Ellershaw et al., 1995). Thirst is the subjective sensation of a desire to drink water that cannot be ignored (Toto, 1994). According to Carroll (2020), ‘true thirst’ is osmolality regulated and ‘pharmacological thirst’ is the same as dry mouth (xerostomia) from pharmaceutical drugs that alter cholinergic activity. However, distinguishing between the two in clinical practice can be challenging, especially in PC units. However, healthcare practitioners question whether terminally ill patients suffer from thirst (Baillie et al., 2018). One often discussed issue arise when patients cannot drink anymore, i.e. whether artificial infusions would relieve thirst. A qualitative study among physicians found that they experienced fixed positive attitudes regarding the non-provision of assisted hydration to terminally ill patients among hospice practitioners (Kingdon et al., 2022). ESPEN guideline (Druml et al., 2016) clearly state (Statement 20) that: ‘dryness of the mouth and thirst should first be counteracted by nursing measures such as lip care (cleaning and moistening the lips) and mouth care with mouthwash, as well as repeated provision of small amounts of fluids. In the rare case that a patient is thirsty despite optimal care or when dehydration is associated with delirium, the effectiveness of artificial hydration could be reviewed but is doubtful in the dying phase. At this time, palliative sedation is another option and is increasingly applied’. However, thirst is still a challenging symptom, as it is dependent on healthcare professionals’ subjective interpretation of the dying patient’s behaviour and body language. In Sweden, nursing assistants are the occupation that often does the practical fundamental needs of the dying patient.

2 | BACKGROUND

The evidence regarding thirst in terminally ill patients is inconsistent. Most studies regarding thirst in PC are between 20 and 30 years old (Burge, 1993; Ellershaw et al., 1995; Morita et al., 2001). One study (Burge, 1993) reported that more than 50% of 52 terminally ill patients had a thirst intensity of 50mm on a visual analog scale (100mm) and pleasure from drinking of 61mm, which suggests that patients suffer from thirst. Another study (Ellershaw et al., 1995) (n = 23) showed that 83% of patients who were very close to death were thirsty and 87% had dry mouth. A Japanese study (Morita et al., 2001) (n = 88) showed that 44% of terminally ill patients had middle to severe thirst and 18% had severe thirst. In a Dutch study in a PC context, the median intake of fluids among dying patients was 250ml/24h, but the volume of fluids varied significantly (25-1650mL; Lokker et al., 2021). Today, thirst studies are rare, as symptom scales used in PC do not usually measure thirst; dryness of mouth is measured instead. The difference between thirst and dryness of mouth may be difficult to distinguish. However, in one study where thirst was added to the Memorial Symptom Assessment Scale, it was significantly correlated with existential distress in terminally ill patients (Oechsle et al., 2014).

In Sweden, the most common occupation in the healthcare field is that of an assistant nurse, with an estimated 200,000 individuals working in this role across the country (Strömqvist, 2021). Assistant nurses’ work in PC is about taking care of the terminally ill patient’s basic needs, such as personal hygiene, the prevention of decubitus, nutrition, elimination, skin care, oral care, optimizing the environment for the patient and providing comfort care (Mélin et al., 2020; Östergötland, 2019). They also monitor various symptoms (Value of the Nursing Assistant in Palliative Care, 2019). Since 2012, assistant nurses can be specialized in palliative nursing care through higher vocational educational courses running for 2 years (Strömqvist, 2021). During this period, studies are alternated with clinical work (50%/50%).

After this education, assistant nurses have obtained specialized knowledge regarding physical, psychological, social and existential needs among terminally ill patients and their next of kin. They have also gained additional knowledge about mouth care, but not thirst. However, nursing assistants involved in the care of terminally ill patients have expressed concerns about symptom management; when they cannot ease pain or other symptoms, they may experience powerlessness (Åhsberg & Carlsson, 2014). Still, nursing assistants’ role and contribution to PC remains under-researched (Fee et al., 2020).

In PC, the four bioethical principles of autonomy, beneficence, non-maleficence and justice as described by Beauchamp and Childress (2020) are of importance. However, a recent review (Schofield et al., 2021) highlighted a broad range of contextual ethical challenges, suggesting that these bioethical principles are not enough in PC, as the range of ethical challenges faced by specialist PC practitioners exceed the breadth of those detailed in PC textbooks and ethics resources (Regionala cancercentrum i samverkan, 2021a; Schofield et al., 2021). Other ethical topics may be dignity, fidelity,
equity of care (Schofield et al., 2021), vulnerability (Morberg Jämterud, 2022) and relational ethics (Wright et al., 2018). Ethical principles, sometimes described as belonging to ‘Western’ society, are challenged when caring for patients in minority groups in a multicultural society (Chater & Tsai, 2008), for example regarding the benefit of truth-telling or when PC ‘only’ offer oral care to dying patients instead of drips. Therefore, an adequate question is whether thirst in terminally ill patients creates ethical dilemmas and if so, what these ethical dilemmas are and how they are handled.

To the best of our knowledge, no studies have explored the experiences of assistant nurses regarding oral care and thirst in end-of-life care, despite their expertise in this area. As far as we know, there are no studies regarding thirst in end-of-life care from the occupation of assistant nurses, who might be those who have more knowledge about oral care and thirst, than other healthcare groups. The aim of this study was to describe assistant nurses’ experiences of thirst and ethical challenges in relation to thirst in terminally ill patients in specialized PC units.

3 | METHODS

3.1 | Design

A qualitative, reflexive thematic design with an inductive analysis according to Braun and Clarke (2020) was used where coding and theme development are directed by the content of the data by shared meaning. The design aims to identify, analyse, interpret patterns of meaning from the qualitative data and use the results to report concepts and assumptions underpinning the data, which are presented in themes. The study was guided by the Standard for Reporting Qualitative Research (O’Brien et al., 2014).

3.2 | Sampling and setting

Data were collected during November 2021–January 2023 in five cities in Sweden, with populations between 3000 and 1,000,000, all of which had specialized PC units. In Sweden, specialized PC is defined as care provided by multi-professional teams with specific knowledge and skills in PC (Regionala cancercentrum i samverkan, 2021b). These teams work with PC as their primary area of expertise, providing care directly to patients and their families and indirectly supporting other professionals in delivering such care. They address complex issues such as refractory symptom management and existential distress, between different involved parties. Specialized PC units provide both home-based care and inpatient care at a hospital ward. The number of patients admitted to home care ranged from 15 to 240 patients; the number of beds in hospital PC units ranged from 3 to 22. Each assistant nurse was responsible for 3 to 6 patients. Each unit has policies for oral health assessment. In addition, they assess oral health in the last week of life and record this in the Swedish PC register. However, thirst is not included in the assessment.

A purposive sampling was used to achieve a diverse mix of participants based on geographic location, gender, age and working experience in PC. The inclusion criteria were fluency in Swedish and employment as an assistant nurse in specialized PC. The head nurse of each department sent an invitation e-mail to eligible assistant nurses, asking them to participate.

3.3 | Data collection

Data were collected using individually recorded interviews (n=12) that lasted between 16 and 38 min. The place, date and time for the interviews were established in accordance with the participants’ wishes. Some of the interviews (n=6) were carried out in a secluded room at the hospital in each town. Due to the COVID-19 pandemic, six interviews were conducted by telephone. Of the 12 interviews, 2 research nurses with an MSc, as well as experience with PC and interviewing, conducted 7 interviews. A nurse lecturer with a PhD in pain nursing management conducted five interviews (A.S.S.). A professional transcriber transcribed all interviews verbatim and each interviewer listened through their recordings so that they matched the transcribed interviews. A semi-structured interview guide was developed by the research team based on the limited research available in the field; therefore, the interview guide was designed to capture the participants’ experience of thirst in patients at the end of life. It was used as a checklist to ensure that all questions had been discussed. One pilot interview was conducted to test the understanding of the questions and the flow of the questions. No changes were made after the pilot interview. The interviews addressed assistant nurses’ experiences of caring for terminally ill patients and their views on thirst (Table 1). Participants were asked to talk freely, and probing questions were occasionally asked in order to attain better clarity, for example, ‘Please, tell me more; Please, explain; and How? and Why/Why not?’ In this study, ethical challenges were referred to as ethical issues, moral challenges, moral dilemmas, values, good/bad and right/wrong. Ethical challenges could be labelled as such either by the authors or by the participants (Schofield et al., 2019). Data collection continued until no new information emerged.

3.4 | Data analysis

A reflexive thematic analysis according to Braun and Clarke (2020) was used. The analysis started with familiarization with the data, reading the whole dataset several times, generating initial codes of relevance to the research question, generating themes, reviewing, defining and naming themes (Table 1). One author (M.F.) who is an associate professor with a PhD in palliative medicine and extensive experience in PC research and thematic analysis read all 12 transcripts and conducted the coding and development of themes and sub-themes. Data were analysed both manually, on paper (theme mapping) and in a Microsoft Word® (interview transcripts, coding). No new data emerged after 12 interviews, as the same codes and themes reappeared, but no new ones.
TABLE 1 Interview guide.

| 1. Have you thought about whether end-of-life patients can be thirsty? If so, how? |
| 2. Do you think end-of-life patients suffer from thirst? Justify! |
| 3. Do you have a policy in your unit regarding thirst? Why/why not? |
| 4. What are your colleagues' views on thirst in patients at the end of life? |
| 5. Can there be any ethical problems with patients who are thirsty? |
| 6. Do you check whether a patient at the end of life is thirsty? How do you assess whether a patient is thirsty? If yes, what checks do you make? If not, why not? |
| 7. Do you do anything to quench the patient's thirst? What do you do? What do you think works best/worst? |
| 8. Have you ever discussed thirst with relatives of patients at the end of life? Tell me! |
| 9. How do you think one could work to quench thirst? |
| 10. Is there anything I have not asked about thirst that you think is important to share? |

Another author (A.S.S.), a nurse with a PhD in pain nursing management, scrutinized the analysis by comparing it with all excerpts from the interviews related to the purpose of the study. After this procedure, the preliminary analysis was modified, for example by adding certain content, descriptions and theme names, to better explain the participants’ narratives (Table 2). Additionally, the final analysis was examined and discussed in the research group until a consensus was reached. To further enhance the credibility of the results, the findings were clarified using quotations from the participants. The study adhered to ethical principles outlined in the Declaration of Helsinki and was approved by The Swedish Ethical Review Authority (Ref. 2019-04347). Prior to the study, the assistant nurses received oral and written information about the study. Written consent was obtained from all participants. No participants dropped out of the study. All collected materials in the study have been handled confidentially and the participants were given a number for anonymization.

4 | RESULTS

4.1 | Demographic data

Table 3 lists the demographic data of the 12 participating assistant nurses. Of the participants, 11 were women and 1 man. The median age was 51 years. Of the assistant nurses, five were specialized in palliative nursing care.

4.2 | The world of practice for thirst relief

Assistant nurses are practical when they narrate about thirst and oral care. They do not theorize about oral care, instead they interpret the patient’s behaviour and try to sense how patients feel in order to understand if a patient is thirsty or not. The sub-themes were: to interpret signs of thirst; experience-based unspoken knowledge about thirst; individual solutions for thirst relief and oral care as for routine or individual needs.

4.2.1 | To interpret signs of thirst

Assistant nurses describe that they need to be very responsive and observant to discover thirst in terminally ill patients. They believe they know how patients express thirst and how to be sure if a patient is thirsty. Signs of thirst might be that the patient is sucking on the oral swabs during oral care and express their desire for more liquids. They also describe that it is possible to see if a patient becomes satisfied, by watching their facial features before and after oral care. Patients who are conscious, express that they are thirsty, smack their lips and put hand to mouth. Assistant nurses do not assess thirst in terminally ill patients in other ways.

I do not know if a patient lying with his/her mouth open is thirsty, but I see if the patient is sucking on the swabs, then I realise that they are thirsty. Sometimes their mouths are just dry, but if they have their mouth moisturised and I see that they suck; then the patient is thirsty. That is different. I:8

But you can see that when they receive mouth care, how they bite down ... on these oral swabs that we use.// They hold on to them really tight, you can see how they sip the liquid. Then I usually say 'OK, let's fill them up again'.// I can see they want more water. I:9

Other assistant nurses were not certain whether patients were thirsty or just had a dry mouth, or both.

Well, you feel a dryness in your mouth and then you feel a bit thirsty. That was an interesting question//I have never heard anybody say, 'I feel dry in my mouth', I have only heard 'I feel thirsty'. That is how they express it, verbally. I:6

4.2.2 | Experience-based unspoken knowledge about thirst

According to the assistant nurses, you have to watch the patient to assess whether a patient is thirsty. Knowledge of thirst is implicit and generated through experience, not written down anywhere, neither as policy nor in practical guidelines. It also varies depending on each individual's experience. This knowledge is transferred from a practising assistant nurse to students, or to assistant nurses in training, but is not often discussed among colleagues. The level of interest about thirst and oral care also varies with some being more interested than others.
<table>
<thead>
<tr>
<th>Interview excerpts (interview number, side number and line number)</th>
<th>Generating initial codes of relevance to the research question</th>
<th>Generating themes</th>
<th>Defining and naming themes</th>
<th>Questioning and reflection process from co-authors</th>
<th>Themes of meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>It would be written down so that everyone knows that this is how we do this. When you have this oral tray, it becomes so evident that you do the oral care. You see it. 1:8;7–8</td>
<td>Documentation required regarding thirst</td>
<td>Thirst is not visual in policy documents</td>
<td>To assess the patients’ thirst is a silent knowledge</td>
<td>All symptoms such as pain, nausea, worries, anxiety and existential issues are on the agenda, but not thirst (see page 16)</td>
<td>Experience-based, unspoken knowledge about thirst</td>
</tr>
<tr>
<td>The oral tray is a visual reminder for oral care</td>
<td></td>
<td></td>
<td>Oral care is easily forgotten</td>
<td>This reads strange … thirst cannot be knowledge … Maybe it is more of a silent phenomenon, or is hidden … or undiscovered</td>
<td></td>
</tr>
<tr>
<td>It would be written down so that everyone knows that this is how we do this. When you have this oral tray, it becomes so evident that you do the oral care. You see it. 1:8;7–8</td>
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<td>Experience-based, unspoken knowledge about thirst</td>
</tr>
<tr>
<td>If they are thirsty, then I think water, cold water is probably the best. That is what I’ve heard. 6:11;27–28</td>
<td>Cold water is thirst relieving</td>
<td>Practice for thirst relief</td>
<td>Many solutions for thirst relief</td>
<td>This theme is about thirst and oral care. The name of the theme may instead be: The assistant nurses’ variation of solutions for individual thirst relief</td>
<td>Individual solutions for thirst relief</td>
</tr>
<tr>
<td>After all, there are soups, and powder that you can pour into thin liquids so that it becomes thicker. A viscous fluid is easier to swallow 8:11;5–6</td>
<td>Thick liquids are easier to swallow, which helps patients to drink</td>
<td>Practice for thirst relief</td>
<td>Many solutions for thirst relief</td>
<td>This theme is about thirst and oral care. The name of the theme may instead be: The assistant nurses’ variation of solutions for individual thirst relief</td>
<td>Individual solutions for thirst relief</td>
</tr>
<tr>
<td>We go to the patient, conduct oral care, just to relieve thirst. If you wet an oral swab, then you can see how it eases the patient’s thirst. 7:1;21–23</td>
<td>Oral care to relieve thirst</td>
<td>A moisturized oral swab to ease thirst</td>
<td>Assessing signs of thirst relieve</td>
<td>To interpret signs of thirst</td>
<td></td>
</tr>
<tr>
<td>So that’s very difficult because at the same time the patient can’t swallow when he’s in the final stages of life, he can’t do it, and then I don’t know how he would swallow, and it’s like I said … just putting drips in everyone, it can also do more harm than good. 5:34;10–12</td>
<td>Difficult when patients cannot swallow, but every patient cannot receive a drip as it may cause harm</td>
<td>The patient needs fluids but cannot drink and is not on a drip</td>
<td>Fluids that create suffering</td>
<td>Maybe we should add something about the assistant nurses wish to inform under ethical challenges?</td>
<td>Fluids that create multiple suffering</td>
</tr>
</tbody>
</table>
Table 3: Demographic data of the participating assistant nurses.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Female/male</th>
<th>11/1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td>51</td>
</tr>
<tr>
<td>Min–max</td>
<td>40–67</td>
<td></td>
</tr>
<tr>
<td>Working time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Part time</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Working experience in palliative care (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Min–max</td>
<td>5–27</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic level</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Specialized in palliative care</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

The assistant nurses describe oral care can easily be forgotten because of all the nursing care that needs to be carried out for all of the dying patients. Symptoms such as pain, anxiety and existential issues are assessed, and documented, but not thirst. When the patient deteriorates, an oral care tray is placed on the patient’s table as a reminder to the assistant nurses to provide oral care. The oral care tray contains everything needed to relieve dry mouth, thirst and soften the mouth cavity.

Err ... usually we document ... No, not dryness of mouth. Usually we document nutrition, and mouth care. No, not thirst//No, nothing about thirst, but in some way, it is included, when we make our assessments. Yes. I:7

The assistant nurses try to feel what it would be like if they themselves were in the patient’s situation. They describe how unpleasant it must be for the patient to feel thirsty or have a dry mouth while lying down, as it can lead to coatings in the mouth and a bad odour. In turn, this leads to consequences for all, patients, family members and healthcare staff. Patients who are unable to communicate and have bad breath may be unable to have intimate moments with their loved ones. Additionally, the patients’ vulnerability and lack of autonomy are highlighted, as they are unable to express themselves.

Above all, it is to go to yourself. I brush my teeth every night, I am very careful with my oral hygiene. In addition, if the patient cannot do it, or perhaps does not want to do it, then I think it is our responsibility to speak up about it. That it is important. That ‘even if you can’t take it, we’ll be happy to help you’. I:6

To let the patient lie hour after hour with no one looking in ... they cannot even call for our attention. I:7

4.2.3 | Individual solutions for thirst relief

The assistant nurses state that patients should be encouraged to drink on their own as long as they are able to, and then with assistance if needed, as this is the best way to relieve their thirst. Thereafter, they turn to oral care, which they claim relieves thirst. Some assistant nurses assess oral health themselves with Revised Oral Assessment Guide (ROAG); others meant that this is a task for nurses or physicians. They have many ideas on how to help patients drink and by this, relieve thirst. Some say that water is always the best for the patients’ thirst relief, but they also mention that they give patients carbonated water, fruit-berry creams as well as thick liquids. They believe that patients might also appreciate ice cubes and ice cream. However, not all of them have experience with other liquids besides water, and do not know why certain liquids might help or not.

Carbonated water and Vichy water quench the thirst best, I do not know if it is because of the bubbles or the salt. It is better than water. They may also be given a Popsicle if they can manage it themselves. I:5

Some patients that we cared for, who can still swallow, may like to suck on an ice cube. I:10

Some assistant nurses note that intravenous (IV) or subcutaneous drips may help alleviate thirst in patients, but they are also aware of the potential risk of pulmonary oedema.

Most of the time it gets a little better (with drips) but they still have that feeling of thirst. They will not be fully relieved, but they still get the liquid and so, even if it is not much, it will not give them total relief. I:5

If there are family members at the patient’s side, many assistant nurses ask them if they want to assist with oral care. They believe that involving family members in this task not only helps them feel involved, but also benefits the patient. They provide instructions and educate family members on how to perform oral care and evaluate the effectiveness of the care provided. However, some assistant nurses prefer to handle oral care themselves and do not involve family members in this task.

It is the first time they ask or when you ask them ‘Perhaps you would like to help a little?’. ‘Would you
4.2.4 | Oral care as for routine or individual needs

The assistant nurses describe that they usually do oral care when they carry out other caring tasks, such as turning the patient. They follow routine care schedules rather than addressing the patient’s specific thirst or oral care needs. For instance, they may provide oral care every 3h based on caring routines rather than on the patient’s individual needs.

We do it when we turn the patient, and we do that every two, to three hours, depending on ... how easily they become red in the skin and things like that. It tends to be quite individual there. We see how the patient reacts to redness on their buttocks, hips, elbows and ears and so on, where they get pressure sores. I:7

I: Do you usually check to see if a patient at the end-of-life is thirsty?
R: Er ... No ... well, mostly when we do other caring tasks. You do not go in to care for the patient specifically to do that. I:11

However, other assistant nurses mention that if they notice that patients suck on the oral care swab they go in more often, such as every 2h. Nevertheless, if the patient closes his or her mouth, then they do not perform oral care, trying not to disturb the patient. Some of the assistant nurses perform oral care every 20min.

I usually say every 30minutes anyway, that you should moisten the mouth or something like that, to make sure the patient is not very dry. Some patients do not tolerate it very often. Then you have to think differently, it is based on what the patient tolerates as well. I:6

Regardless of the patient’s level of consciousness, mouth care is given routinely, as many assistant nurses believe that patients feel stimuli, such as touch and sound.

Some assistant nurses question their own routines when patients are uncomfortable, as they only consider ‘ordinary symptoms’ such as pain and anxiety as reasons for discomfort. They wonder if patients could be thirsty instead of experiencing pain.

It is not easy to know. I am thinking about those we meet, if they cannot speak for themselves, but do not feel comfortable, then we guess. We think that we only pay attention to anxiety and pain. What I mean is that it can be very unpleasant to feel thirsty, and they cannot even tell us. I:12

4.3 | Ethical challenges when quenching thirst

When assistant nurses describe ethical challenges, they draw on their own personal experiences and what they find difficult or awkward. Some of them imagine themselves in the patient’s situation or show empathy for the suffering patient. The analysis revealed three themes: fluids that create multiple suffering, performing oral care in the face of resistance creates division and conflict and unmet educational needs.

4.3.1 | Fluid that creates multiple suffering

The assistant nurses describe that an ethical challenge that arises when providing oral care leads to discomfort for the patient. For example, when the patient shows signs of thirst and the assistant nurse tries to provide water orally, but instead of relieving thirst, the patient’s swallowing reflex may be too weak and the liquid instead creates an intense cough in an already weak patient. Being unable to fulfill a basic need such as providing fluids in this situation can create feelings of guilt.

When they cannot drink, then it makes me feel bad. They want to drink, although we cannot provide this, then it creates guilt problems. My conscience tells me I should have given them more, but if they cannot take it (due to swallowing problems)...? I:2

I really want to help, and I really want to give them some water, but at the same time, I know they cannot swallow. It is very difficult, maybe it will get stuck in the throat, but oral care can be given ... It does not make me feel good inside. It hurts, and you want to do your best for the patient. I:3

Another ethical dilemma is experienced when the patient or the relatives ask for a drip, to prevent thirst, but the assistant nurse does not believe it would benefit the patient. The assistant nurse knows that the drip could cause the patient discomfort in the form of oedema or rattles and are afraid that it may result in additional suffering during the patient’s last few hours/days etc. It could also
be in conflict with their own inner conviction that drips are of no benefit to the patient.

The healthcare system ‘has to act’ and ‘bring about change’. Then that ... you die without food and liquid ... they (the relatives) want to feed ... their relatives. Feeds the dying person into the last. Instead, to ... even if they receive information that they should avoid it. Then sometimes we give the patient a drip, and then they stop feeding. Then it all calms down. I:4

Other assistant nurses describe that it is a difficult task to make the right decision when patients express thirst towards the end of their life but are too severely ill to drink and nearing death to receive a drip. They feel insecure about their observations and decision making in such situations, as they want patients to have a ‘good’ death, without a drip.

What is ethically right in the end, if they cannot absorb fluids anymore? If the patient expresses thirst [pause] but is in such poor condition that the body is unable to absorb the fluid. I am not sure, do you feel thirsty then? I know, I do not know. Thirst is difficult. I:12

4.3.2 | Performing oral care in the face of resistance creates division and conflict

Another ethical challenge appears when the patient closes his or her mouth while receiving oral care, which the assistant nurses interpret as a refusal to receive any oral care at all. The assistant nurses then feel torn between giving oral care, as it is something expected of them, while at the same time they do not want to force the patient to do something that he or she clearly rejects.

Yes, they close their mouths. But then I have to take a step back, I can only try and I talk to them in the meantime, but if they close their mouths like that, I can’t do anything else. I:5

On one particular unit, assistant nurses used bite blocks to enable oral care even if the patient resisted. This caused conflicts among the assistant nurses, with some feeling that it was patient abuse, while others believed that it was necessary to carry out proper oral care.

We have the blue ones, which you put in their mouth so they cannot bite. You insert the oral care swab in between. Therefore, it is sort of a coercive intervention. I do not like it. If you do not want to open your mouth and receive oral care, even if you are unconscious, you have to respect that. I:7

4.3.3 | Watching unmet educational needs

Another ethical dilemma is when other professionals are in charge of carrying out the care of a dying patient at home, for example municipal home care. Some assistant nurses believe that the lack of time available during a home care visit indicates that they do not take the patient’s thirst and need for oral care seriously. The assistant nurses believe that there is a great need for training and education in this area.

Then you get there for a visit in the evening and they have not had their position changed nor has any oral care been carried out. Then you ask ‘why?’ and you get the reply that ‘but she or he was sleeping so soundly’. But the patient can’t communicate, so even if the patient looks like he/she is sleeping ... you just have to do it. If you have been sick for half a day and have been lying in bed, the body will experience pain. In addition, you can get terribly thirsty. I:6

5 | DISCUSSION

The main finding of this study is that assistant nurses’ work alone when it comes to thirst, as they do not communicate that patient has needs or communicate their knowledge to the rest of the team, neither verbally nor through documentation. In addition, their interventions to quench thirst vary. When there is variation in practice and a lack of communication and documentation, it can also create uncertainty about whether and how oral care is provided and how thirst is quenched, which in the worst case can lead to patients not having their thirst quenched and a range of other oral complications. In the sub-theme, ‘To interpret signs of thirst’, all assistant nurses describe how they believe that patients are thirsty through observing if the patient is sucking on the oral care swab and noting the satisfaction expressed through facial features during and after oral care. To discover thirst, assistant nurses need to regularly check on patients, see if the patient is sucking on the swab and if mouth care seems to comfort him or her. This is a topic not usually discussed by the team, as it is implicit knowledge not transferred to other colleagues. PC is team based, and not letting other professionals know that the patient is thirsty may result in patients who are thirsty and in need of IV infusions not receiving them. In addition, one can question nurses’ responsibility for the guiding and lead in palliative nursing care. Still, assistant nurses manage to quench patients’ thirst, but without explicitly mentioning it. This type of knowledge was also found in another study (Wallin et al., 2022), it was referred to in the study as ‘tacit knowledge’. This is knowledge that is gained solely through experience and is difficult to communicate. A review study (Moran et al., 2021) reported that in many studies palliative nursing values were seen but not heard, as the concepts of compassion, caring and commitment were unspoken. The authors meant that the contribution of nursing was at risk of being vague...
and only task oriented. Similarly, in this study, the implicit knowledge surrounding thirst and thirst quenching seem to be imprecise and task oriented. Nurses in specialized PC have to focus more on each patient’s need, setting goals, intervene and evaluate.

When examining guidelines on oral care, some recommend that dying patients’ level of thirst should be checked and that they should be given frequent sips of fluids (NICE Guidelines, 2015), mouth care as often as a patient tolerates it (Royal College of Nursing, 2021) or offered liquids at least every 30 min (Scottish Palliative Care Guidelines, 2020). However, a study on thirsty healthy individuals found that gargling water resulted in sustained thirst reduction for 15 min and longing for 30 min, raising the question of how long thirst reduction persists in dying patients. Unfortunately, not much is known about how long the thirst of dying patients’ remains quenched.

In this study, some assistant nurses had problems distinguishing between dryness of the mouth and thirst, while others were more certain, claiming that thirsty patients suck on the swab and need more water. In a previous study (Friedrichsen et al., 2023), PC physicians identified dry mouth as a bigger problem than thirst, which is consistent with the ESPEN guideline (Druml et al., 2016), which suggest that fluids may not always be necessary at the end of life, as patients ‘frequently experience dryness of the mouth … but rarely hunger and thirst’. This hypothesis is based on the idea that thirst results from unpleasant dryness of the oral cavity. A recent review showed that the two main physiological signals for stimulation of thirst are plasma hyper-osmolality, via cellular dehydration, and hypovolemia due to low blood volume and low arterial pressure. Also oropharyngeal and gastric distension causes activation of neural inputs in the hypothalamus, immediately suppressing the thirst sensation (Adams et al., 2020). However, whether or not this physiological mechanism is the same in dying humans is unknown.

Ethical challenges regarding thirst arose when fluids created multiple suffering, for example when patients could not drink due to a cough reflex. Assistant nurses felt they were not able to satisfy that basic need, and this created feelings of guilt. A review study on the moral distress experienced by professionals in PC found that managing own emotions and other people’s, witnessing suffering and disability, and failing to provide adequate end-of-life care for patients’ generated guilt (De Brasi et al., 2021; Maffoni et al., 2019).

A Swedish study among nurses and assistant nurses highlighted that they could not always uphold the values and norms of PC. The definition of PC places the patient and their family at the centre, and it provides a clear standard for healthcare staff to adhere to (Sandman et al., 2017). In this study, the management of thirst symptoms was difficult for the assistant nurses to describe, as some had not thought of thirst in detail, even though all of them had met thirsty patients. Instead, they tended to rely on practical, ‘hands-on’ oral care rather than addressing the underlying issue of thirst. How often oral care should be provided was more related to their routines than to relieve thirst. This suggests that thirst may be an overlooked symptom in PC.

However, in certain areas, such as thirst, it is unclear how to optimize care for the dying patient due to the absence of specific evidence and reliance on implicit knowledge. Therefore, more research in this area is needed, for example which caring interventions work best to quench thirst, observational studies and interviews with registered nurses, patients and family members. Patients and family members, in particular, have a clear picture of what thirst feels like and ideally, how to quench it.

### 5.1 Implications for policy and practice

It is important to determine whether patients are experiencing a dry mouth or are thirsty, as this can affect the appropriate treatment. Moisturizing the mouth with oil can alleviate a dry mouth, but it does not address thirst. There are a number of suggestions to improve oral care and patient thirst at the end of life. The first suggestion is to make oral care more team based, so that all team members are involved in what the assistant nurse is observing and what interventions he or she is doing. If assistant nurses recognize that information is requested from the other team members, they will also communicate more to them. The second proposal is the requirement of a proper documentation of the patient’s thirst; so that each team member can read how often oral care has had to be done. Third, assistant nurses need continuous training in oral care and how to assess whether the patient is thirsty. Therefore, more research is needed in this area to guide training. The fourth proposal is about strengthening the team's knowledge so that oral care and thirst are included in their theoretical and practical training. Then oral care and thirst will be visible to all professional groups. The ROAG is used in most PC units in Sweden, but the assessment of thirst is not included. The fifth proposal involves a development of oral health assessment where thirst is added to ensure patient care and comfort at the end of life. Similarly, international guidelines and policies need to be developed in PC so that thirst is included as a possible symptom. Today, only dry mouth is measured. There is a need for nurses to take the lead in changing nursing practice regarding thirst. Nurses must consider the patient’s fundamental care needs and address thirst, for example in the nursing process to ensure that dying patients suffering from thirst will have their needs satisfied.

### 5.2 Strengths and limitations

In reflexive thematic analysis, it is important to conceptualize themes as patterns of shared meaning instead of a domain summary themes, which are only organized around a shared topic, like content analysis. A theme of shared meaning should be seen as analytical output, developed through and from the creative reflecting analytical work, and is actively created by the researchers at the point of intersection of data, the analytical process and subjectivity (Braun & Clarke, 2019). To achieve this and a reliable coding we used two different coders not only to test for consistency of judgement but also to sense-check ideas and to explore multiple assumptions or interpretations of the data aiming.
to achieve richer interpretations of meaning. This is a strength. Transparency is achieved by providing the number of interviewees, positions of interviewees, length of interviews, how they were conducted and citations linking specific interviews to the empirical evidence presented in the text. Analytical transparency is accomplished by showing how the authors interpret and analyse data (Table 3). To enrich confirmability, we present quotations to support study findings and we have tried to present the study context as precisely as possible for readers to decide on transferability of findings to their context. This study was conducted in Sweden and it is not obvious that it can be transferred and compared to other countries. The interviews were rather short and their quality is therefore questionable. However, deeper answers cannot be expected as the area is not topical or unreflected. In addition, telephone interviews may have affected the study, as this interview technique will affect the quality of the interview as the body language is lacking, that may otherwise give additional information.

6 | CONCLUSION

Assistant nurses work close to terminally ill patients and are familiar with their thirst. However, their knowledge regarding thirst is unspoken and seldom discussed. There are no policy documents about thirst, nor is thirst documented in the patient’s record. Thirst is professionally and ethically challenging and needs to be more emphasized in specialized PC.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE: http://www.icmje.org/recommendations/): (1) substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

PEER REVIEW

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DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions.

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