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Recognising and alleviating unbearable suffering in residents living in Swiss nursing homes: a grounded theory study on nursing staff's perspectives on sedating medications and palliative sedation

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Abstract

Background At the end of life, patients frequently experience distressing symptoms. When they become refractory, sedating medications and palliative sedation (PS) may be used to alleviate suffering. PS is mainly practised in specialist settings, as it requires defined procedures and guidelines. Little is known, however, about how registered nurses (RNs) and healthcare assistants (HCAs) manage refractory symptoms and unbearable suffering in nursing homes and how sedating medications are used in this non-specialist setting. This study explored how RNs and HCAs in Swiss nursing homes recognise, assess, and alleviate unbearable suffering, the challenges they face, and the strategies they employ to alleviate residents' suffering by using sedating medications and PS.

Methods This qualitative study involved 22 RNs and six HCAs from nursing homes in German-speaking Switzerland. Seven semi-structured focus group interviews were conducted between October 2023 and January 2024, transcribed verbatim, and analysed using a grounded theory approach.

Results The core category, 'Navigating palliative sedation in nursing homes – tension between alleviating suffering and over-sedating', was identified, with three subcategories: (1) recognising suffering, (2) assessing suffering, and (3) alleviating suffering. Challenges included distinguishing residents' suffering from that perceived by relatives or healthcare professionals, negotiating assessments with relatives and general practitioners (GPs), and uncertainties in the use of sedating medications – particularly morphine and midazolam. Strategies to address these challenges included 'double-checking' to validate symptom recognition, shared decision-making to 'get everyone on the same page' and align treatment goals, and the reliance on internal and external 'safety nets' (experienced colleagues and specialised palliative care services). Resource constraints such as personnel and financial resources, as well as

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beliefs and attitudes were reported to influence the management of unbearable suffering and the use of sedating medication.

Conclusions RNs and HCAs in nursing homes face complex challenges when recognising, assessing and alleviating suffering with sedating medications. Ensuring safe and ethical practice requires sufficient staffing, adequate training, clear protocols, and access to specialised palliative care support. Without sufficient expertise, interprofessional collaboration, and shared decision-making, residents risk either inadequate relief of suffering or inappropriate sedation.

Keywords Sedation at the end of life, Palliative sedation, Refractory symptoms, Unbearable suffering, Long-term care, Nursing homes, Grounded theory

Background

End-of-life care often involves distressing symptoms such as pain, breathlessness, delirium, and anxiety [1–3]. Although many symptoms can be managed with pharmacological and non-pharmacological interventions, some like delirium, respiratory distress, and severe pain [1, 4] become refractory, leaving patients with suffering that is perceived as unbearable [1, 2]. Unbearable suffering is not limited to physical symptoms; it may also arise from psychological, social, or existential distress, and is closely linked to the patient's subjective experience of their condition. Addressing such suffering is a central ethical and clinical challenge in palliative care. In these situations, palliative sedation (PS) may be considered a last-resort therapy [5–7] to alleviate otherwise intractable suffering.

Palliative sedation is a deliberate and monitored intervention, setting it apart from sedation as a treatment's side effect [5, 8]. It can vary in duration (continuous or intermittent) and depth (mild or deep) [7]. While intermittent and mild sedation is generally accepted, continuous deep sedation until death raises ethical concerns, particularly across diverse cultural contexts [5, 8–10]. Legal regulations and societal attitudes also influence sedation practices [11]. International studies have highlighted the complexity of palliative sedation in both acute and long-term care settings [10, 12], derived from a wide variation in practices and implementation guidelines, as well as the intricacies of shared decision-making, timing, and medications [12, 13]. This has led to PS remaining a contentious issue in palliative care [10, 14].

As PS is considered as a treatment option that requires specialised expertise, research on PS is often limited to specialised care settings, such as specialised clinics, hospitals or hospices, with general palliative care contexts, such as nursing homes, being sidelined [15]. While Grüne et al. [15] explored challenges and strategies related to end-of-life sedation in both nursing homes and hospitals in Germany, the inclusion of a mixed sample from acute and long-term care settings limits the understanding of the specific context in nursing homes. In Belgium, research focussed predominantly on the perspectives of general practitioners (GPs), with limited investigation into the views of nursing staff [16]. There remains a knowledge gap in understanding how unbearable suffering is alleviated and how palliative sedation is practiced in nursing homes, particularly from the perspective of nursing professionals, including healthcare assistants (HCA)[1] and registered nurses (RNs).

In Switzerland, the number of patients continuously deeply sedated until death has increased fourfold from 2001 to 2013 in hospitals as well as nursing homes [17]. Nursing homes in Switzerland are organised in a heterogeneous manner in terms of size, staffing and services they offer. Of the 1475 nursing homes in Switzerland, 52 have been listed as having competencies in palliative care, 44 of which have been certified by qualité palliative, a Swiss quality certificate in palliative care [18, 19]. Some nursing homes have access to specialised palliative care through cooperation with palliative care specialists, either through consulting physicians or mobile care teams. The accessibility of GPs, pivotal in the prescription of sedating medications, remains unstandardised and exhibits variations across regions and nursing homes [20, 21]. To address the shortage of GPs, a growing number of nursing homes are employing nurses in advanced roles, with a master's degree, known as advanced practice nurses[2] (APNs), to assume specific tasks that were formerly assigned to GPs and to engage with nursing home staff to improve resident's care [22].

Apart from GPs, APNs, RNs, and lesser-trained nursing aids, such as health and social care assistants, HCAs play a crucial role in Swiss nursing homes, making up approximately 45% of the nursing homes' workforce [23, 24]. Compared to acute care settings such as hospitals, nursing homes often have fewer GPs, palliative care specialists, RNs, and APNs available. This raises the question

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[1] Healthcare assistants (*Fachfrau/-mann Gesundheit EFZ*) undergo a three-year training and are comparable to licensed practical nurses (LPNs) in the U.S. or healthcare support worker/healthcare assistants (HCSW/HCA) in the U.K.

[2] In Switzerland, the role of APNs as a substitute for GPs is a relatively recent development, having emerged within the last eight to ten years. The employment of APNs within nursing homes remains limited, with most cantons lacking legal regulations that would clarify their responsibilities.

of whether a complex and highly specialised intervention such as PS – which depends on shared decision-making, communication, documentation and close monitoring – can be adequately managed and administered in long-term care settings. As approximately one-third of the Swiss population dies in nursing homes [11], it is essential to gain insights into how nurses recognise and alleviate unbearable suffering using sedating medications and PS in order to improve the quality of end-of-life care in this setting [4, 25].

This study aimed to explore how nurses and healthcare assistants in Swiss nursing homes understand PS and the use of sedating medications, how they recognise and respond to unbearable suffering at the end of life, and how their practices are shaped by challenges, strategies, and contextual factors.

Methods

Design

In this qualitative study seven semi-structured focus group interviews were conducted with RNs and HCAs from nursing homes in German-speaking Switzerland to generate data capturing shared meanings as well as collective sense-making processes and provided a rich dataset for analysis [26]. The grounded theory approach enabled inductive theory development through constant comparative analysis, allowing theoretical insights to emerge directly from the data [27, 28]. The approach was informed by a relativist ontology, which recognises multiple subjective realities shaped by individual experience and social contexts, and a constructivist epistemology, which views knowledge as emerging from interaction. Focus groups were selected as the primary data collection method to facilitate exploration of participants' subjective perspectives and to make use of the interactive dynamics that emerge when colleagues discuss their practice together. The report of the study followed the COREQ checklist to ensure methodological rigor [29].

Table 1 Characteristics of participating nursing homes ($N=7$)

Characteristic	Range/Frequency	Median/Notes
Residents per institution	60–180	Median: 130
Deceased residents in 2022	23–81	Median: 60
RNs in workforce	20–30%	-
Provision of GP care	6/7: weekly visits 1/7: biweekly visits	6/7: also available on request[a]
Access to a mobile specialised palliative care service[b]	3/7 palliative care physician 3/7 nursing service 1/7 no access	-
Institutional palliative care concept available	6/7	-
Institutional concept on PS available	2/7	1/7: assessment tool to evaluate depth of sedation

[a] In six of the seven participating nursing homes, GPs were available for additional visits on request

[b] Palliative care specialists (RNs, APNs or physicians with a specialisation in palliative care) who provide specialist expertise and care to residents in nursing homes upon request by the local nursing team. In Switzerland, some of the mobile specialised palliative care teams consist exclusively of RNs, with physicians only as backups

Participants and recruitment

The participants of the study comprised of RNs and HCAs. Lesser-trained nurse aides, who typically do not play a role in the management of medications, were not included in the study. To ensure a diverse sample, participants were recruited from various institutions across different cantons, thereby encompassing both urban, suburban, and rural settings. Convenience sampling was employed, with the first author MM (she/her) contacting head nurses of 13 nursing homes. MM had worked as a RN with long-term expertise in specialised palliative care and was a master's student in nursing at the time of the study. Head nurses were informed by email about the study, its objectives and the planned focus group interviews. Of the 13 head nurses who were contacted, seven confirmed their participation of their institution in the study and forwarded relevant information to potential focus group participants within their respective nursing teams. Reasons for non-participation were not collected. The study's eligibility criteria included working as a RN, or HCA in a German-speaking Swiss nursing home and fluency in German. Prior experience with PS was not a prerequisite for participation to reach more potential participants. Mixed focus groups including both RNs and HCAs were used to reflect the collaborative nature of end-of-life care in nursing homes. Sedating medications and decisions about PS often involve team-based communication, shared responsibilities, and interdependent roles. Bringing both groups together allowed for the exploration of interprofessional dynamics, differences in perspectives, and collective meaning-making around sedation practices. Mixed focus groups beyond the seven institutions were intended to increase transferability but not achieved due to organisational limitations. Participant were recruited between August and November 2023, with focus group interviews taking place from October 2023 to January 2024.

Data collection

Focus group interviews were conducted between October 2023 and January 2024 in seven nursing homes located in three German-speaking cantons in Switzerland (see Table 1). Socio-demographic, occupation-specific data, information about their training regarding palliative care and experience with PS or sedating medication were collected from the participants with a short questionnaire before the focus group interviews (see Table

2). Due to organisational challenges, one focus group interview had to be conducted online. A semi-structured interview guide, developed for this study by MM, focused on three themes: recognition of distressing symptoms and suffering at the end of life; understanding and use of sedating medications and palliative sedation; and challenges in dealing with suffering and sedating medications at the end of life. The interview guide was not pilot tested, (see supplementary material). MM conducted the interviews, supported by a fellow nursing master's student as co-moderator. The interviews were initiated with the German definition of PS [5] written on a flipchart to stimulate discussion on the participants' experience, and subsequently addressed the more widely recognised and frequently employed terminology 'use of sedating medications to alleviate distressing/refractory symptoms' as an alternative and addition to the concept of PS.

The interviews were voice-recorded in Swiss German, transcribed verbatim and translated into Standard German by MM. The transcripts were anonymised, and participants were given an identification number. The audio files and the coding key were stored in a safe institutional data repository. The average duration of the focus group interviews was approximately 1.5 h. After the focus group interviews, the head nurses of the participating institutions were asked by email for some key data about their institutions (see Table 1).

Data analysis

The transcripts were coded and analysed manually by MM between November 2023 and March 2024, following constructivist grounded theory principles and employing the constant comparison method [30, 31]. This entailed the use of open, axial, and selective coding to identify core and subcategories through an inductive process [30, 32, 33]. The method of constant comparison between the transcripts was applied by MM and JR throughout the entire process [30, 31].

Table 2 Characteristics of focus group participants ($N = 28$)

Characteristic	RN ($n = 22$)	HCA ($n = 6$)	Total ($N = 28$)
Training in general or specialist palliative care			
Yes	20	3	23
> 10 days	8	0	8
No	2	3	5
Experience with PS[a]			
Yes	18	6	24
> 10 cases	5	0	5
No	4	0	4
Years in nursing homes, mean	16.8	11.9	-

[a] Experience with PS was based on participants' self-report

Consistent with grounded theory methodology, the processes of recruitment, data collection and data analysis were conducted concurrently in an iterative and cyclical manner. To ensure the robustness and depth of the findings, regular memo-writing, discussions and consensus coding with the co-moderator and co-author, JR, were undertaken. The utilisation of mind maps (see supplementary material) facilitated the enhancement of the overview of the categories and subcategories, while concurrently serving as a tool to identify their connections and contexts, in addition to establishing the overarching category.

Ethical considerations

Ethical approval was sought from the responsible Cantonal ethics committee, which confirmed that no formal review was required for this study (BASEC-Nr.: Req-2023-00907). Throughout the research process, ethical principles of voluntary participation, informed consent, confidentiality, transparency, and participant well-being were strictly adhered to [34]. Participants provided written informed consent prior to participation, were assured of confidentiality and anonymity, and were informed of their right to withdraw at any time without consequence.

Results

The study involved seven focus groups with 28 healthcare professionals (RNs and HCAs) from seven nursing homes in three different German-speaking Swiss cantons[3]. Table 1 provides key data on the seven institutions: one in a rural area, two in smaller towns with populations of less than 18,000 inhabitants, two in larger cities with populations of more than 100,000 inhabitants, and two in the agglomeration of larger cities.

In total, seven focus group interviews were conducted. The age of the participants ranged between 23 and 65 years (median of 43 years), with 25 females. None of the 28 participants dropped out. Detailed participant characteristics are presented in Table 2.

Core category: Navigating palliative sedation in nursing homes – tension between alleviating suffering and over-sedating

PS is an intervention that requires specialist knowledge and experience, which are not generally available in nursing homes. Consequently, nursing teams are often unfamiliar with the concept and its specificities. This was also evident in the focus group interviews: in only two of the seven groups was the term 'palliative sedation' explicitly used. Instead, participants employed substitute

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[3] Switzerland consists of 26 cantons. As healthcare in Switzerland is regulated at the cantonal level, substantial differences exist in the organisation of services and in access to nursing home as well as specialist palliative care.

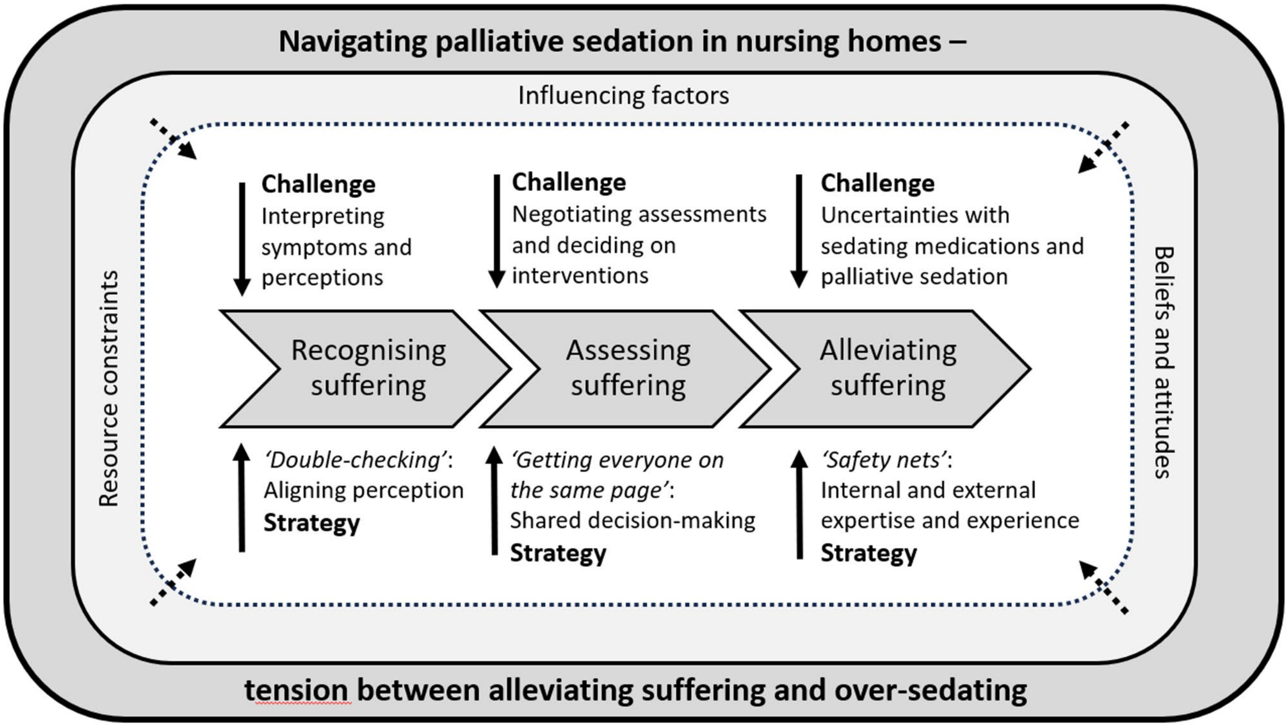

Fig. 1 Navigating palliative sedation in nursing homes – tension between alleviating suffering and over-sedating

expressions such as *'to calm down'*, *'being able to sleep'*, *'to be relaxed'*, as one nurse (P28) remarked. When asked to explain why the term 'sedation' was not used, one HCA responded as follows:

> *Palliative sedation is still a big taboo in long-term care. (…) That people are often sedated at night, (…) especially people with dementia, (…) it's a grey area. It [PS] often has a negative connotation. If you then try to sedate someone a little so that he or she can actually have a bit of a rest, (…) you don't want to be seen as an institution and have to say, hear or even read, 'This home, they sedate people'. It still has a negative connotation. (P5, HCA)*

This negative connotation is further reinforced by the common portrayal of nursing homes as institutions that tend to over-sedate their residents. '*It is often insinuated [unclear by whom] that we are sedating in long-term care*', a RN (P20) stated. While acknowledging the infrequency of deep, continuous sedation in such settings, participants indicated a preference for mild sedation, which is used more frequently and considered a standard approach, or '*a classic*', as asserted by a RN (P2).

The prevailing sentiment, encapsulated by the core category of 'Navigating palliative sedation in nursing homes – tension between alleviating suffering and over-sedating', signifies the predicament of balancing the alleviation of symptoms with apprehensions concerning the potential consequences of over-sedation. Figure 1 provides a schematic representation of the core category, the subcategories (1) recognising suffering; (2) assessing suffering, and (3) alleviating suffering, and the challenges, strategies and influencing factors.

RNs and HCAs often face challenges in using sedating medications to alleviate unbearable suffering associated with distressing and refractory symptoms. While their primary goal is to relieve their residents' suffering, they also risk that these efforts may be perceived as 'over-sedating'. This tension emerged clearly in the focus groups, where the intention to alleviate suffering was contrasted with unease about administering sedating medication or initiating PS. The data illustrate a distinct dichotomy: 'sedating' was perceived negatively, in the sense of 'over-sedating', whereas 'alleviating suffering' was perceived positively.

Subcategory 1: Recognising suffering

The first subcategory emphasises that recognising suffering in nursing homes can be a challenge, as staff members are frequently required to discern between residents' actual experiences and the perceptions of relatives or colleagues. These difficulties are compounded by residents' limited ability to communicate, especially in cases of advanced dementia, and by the varying levels of expertise among staff.

Challenge: Interpreting symptoms and perceptions

In nursing homes, many residents are unable to verbalise their symptoms due to cognitive impairments such as dementia. This places the responsibility on healthcare professionals to recognise and interpret signs of distress. As one RN explained:

> *Our clients can't say, 'Hey, I'm suffering from pain so much that I don't want to be conscious anymore'. They usually can't say it anymore due to the development of dementia. (…) So they show us that they are suffering from pain by being restless. (P9, RN)*

Another RN (P1) agreed that '*recognising these symptoms is a challenge, especially in dementia care.*' Professional competence is essential in identifying the underlying causes of distress, as one RN (P20) noted: *'I often think about the initial process of taking things apart: what exactly is it? Restlessness can also be caused by anxiety, or by pain. It takes a while to find out exactly what it is. And then it takes time to find something that works.'* RNs and HCAs also rely on the observations of less experienced and trained colleagues who spend more time with residents: *'Nursing students or nursing aids are closer to the residents than I am'*, (P13, RN).

Conflicting perceptions between relatives and healthcare professionals add further complexity. One HCA (P27) recalled: *'I remember a situation, where the relatives of a resident called me and asked for more morphine (…) And I just said: 'I don't see why at the moment [we should give her any morphine]', because she was calm. And they told me that she was so restless when she was actually asleep.'*

Others critically questioned whether interventions were always in the best interest of residents: *'And afterwards, I wondered who this solution [giving Lorazepam to a resident] was intended for: the employee or the resident?'* (P18, HCA).

These examples underline the difficulty of recognising suffering and identifying its causes, in residents with dementia.

Strategy: 'Double-checking' – aligning perception

To address these challenges, participants emphasised *'double-checking*: consulting colleagues, APNs, or team leaders to validate perceptions and ensure accuracy. This collaborative approach supports accurate interpretation, strengthens confidence and builds their skills. One RN (P20) explained: '*The double-checking together with the person in charge: to see what is needed now; where do we have to intervene?'* Another RN (P15) highlighted the reassurance it provides: *'Someone from the outside might notice something different. (…) Just in case you suddenly feel unsure [what to do]. That helps.'* Continuity and familiarity with residents further enhance accuracy, as one HCA (P18) noted: '*I often go through the double-checking with my colleagues. (…) It helps with identifying [symptoms], especially when you already know the residents.'*

In summary, recognising suffering in nursing homes requires professional expertise, teamwork, and continuity. The double-checking principle provides a practical strategy to navigate the complexity of symptom recognition, particularly when residents are unable to express themselves verbally.

Subcategory 2: Assessing suffering

The second subcategory addresses the challenge of determining whether a resident's suffering requires intervention. Assessment is a collaborative process involving the nursing team, relatives, and GPs. However, differences in perspectives can complicate decision-making and strain relationships.

Challenge: Negotiating assessments and deciding on interventions

Assessment tools that could support recognition of unbearable suffering were rarely mentioned. Several RNs (P1, P12, P13, P28) attributed this to staff shortage, lack of expertise and language barriers. As one RN explained: *'We have various assessment tools, but I notice that it really depends on who is doing the assessment. Actually, you need a common perception in order to do the assessment.'* (P1).

Conflicts with relatives also contribute to difficulties. One HCA described a situation in which family members insisted on more morphine, despite the resident appearing calm: *'Then I got together with my colleagues, and we didn't give it to her. But it was so difficult to say to the relatives, 'No, we're not giving anything now', even though they wanted to.'* (P27, HCA).

Limited access to GPs and specialists further complicates assessments. Their infrequent presence in nursing homes hinders timely evaluation and may undermine nurses' judgments. One RN (P10) highlighted the consequences: '*I've had a situation in which a resident needed something now, and not in an hour or two hours. (…) That is somewhat difficult in long-term care - that quick action with the doctors [is not always possible].'* In some cases, participants also perceived a lack of trust and competence from GPs toward nursing staff, as P20 (RN) mentioned: *'[The idea that] we could misuse it [morphine]'.* Several participants expressed the need for stronger support from GPs with training in palliative care and greater availability: '*It would help me a lot if GPs were actually available at all times, and were trained in palliative care*' (P10, RN).

Strategy: 'Getting everyone on the same page' – Shared decision-making

Shared decision-making was described as a key strategy to address these challenges. Aligning the perspectives of residents, relatives, GPs, and healthcare professionals can prevent conflict and clarify treatment goals. Several participants emphasised advance care planning (ACP) as a means of ensuring that residents' wishes and values are known and respected. One RN (P15) recalled a case in which a resident explicitly prioritised comfort over consciousness, which guided subsequent decisions. Another RN stressed the importance of discussing end-of-life preferences early and with the involvement of residents' relatives:

> *In my opinion, it would make sense to discuss the end of life with the relatives and the resident themselves in advance: 'How do I want to go, what do I need, what do I not need?' That you address this again and again (...) and you look at it (...) with foresight. (P10, RN)*

Overall, participants highlighted that clear, open, and repeated communication with relatives, together with ACP and collaborative reflection within the care team, helps to align treatment goals. However, they also acknowledged that this remains a *'challenge*' (P9, RN). This shared approach enables staff to better assess and respond to unbearable suffering in ways that reflect residents' best interests.

Subcategory 3: Alleviating suffering

The third subcategory addresses the challenges and strategies related to managing sedating medications for the alleviation of suffering in nursing homes.

Challenge: Uncertainties with sedating medication and palliative sedation

Participants described significant uncertainties in the use of sedating medications, particularly morphine[4] and midazolam, arising from fears of active euthanasia, lack of experience, and uncertainties about appropriate timing. One RN (P2) recounted a case in which a resident experienced refractory symptoms but was not yet in the terminal phase. Continuous deep sedation was considered ethically and medically inappropriate at that stage, leaving the team to manage the resident's suffering with limited options. Light sedation proved ineffective, and the situation persisted for several weeks until the resident entered the end-of-life phase, at which point continuous deep sedation became an option.

Morphine, though widely used, was often associated with death, leading to hesitation. As one RN (P26) explained: '*I sometimes try to explain to people that incorrect insulin dosing is far more dangerous than morphine. But I realise there is an intense fear surrounding it – whether among residents, relatives, or even nursing staff.*' Some participants admitted fearing that morphine might hasten death: '*Nobody wants to be the last person to administer it*' (P3, RN). Relatives and residents also voiced such concerns. One RN (P11) recalled a case, in which the daughter of a resident was worried that her mother was sedated with opioids and that this would lead to her death.

Midazolam presented different challenges, as it was rarely prescribed in nursing homes and staff lacked familiarity with its dosage and effects. One RN (P11) observed GPs' reluctance to prescribe it: *'I get the impression that some GPs are very hesitant to prescribe midazolam.'* Another RN (P1) expressed her own anxiety of killing residents with a subcutaneous injection of midazolam.

The management of sedating medications appears to be a notable challenge, particularly in relation to morphine and midazolam. Morphine is the most widely used, although its sedative effect is a side effect rather than the intended purpose. Morphine raised fears of active euthanasia, while midazolam raised concern about dosage and efficacy. Both highlight the need for expertise, training, and support systems to ensure safe and confident use, and avoid mismanagement.

Strategy 1: Experienced colleagues as internal 'safety net'

Participants emphasised the importance of an internal 'safety net', ensuring access to experienced colleagues for support. As one RN explained:

> *Official sedations [deep, continuous] are relatively rare. Then, in every shift handover, there is a need for head nurses who can provide explanations and support. They [the nursing team] need to know that they can always, always get someone [for support]. Especially with healthcare assistants, you can't just say: 'Here's the medication schedule – just do it.' That's doesn't work. Nursing homes need a safety net because the level of expertise (...) is lower than in a hospital. (P2, RN)*

This support by experienced colleagues, such as RNs with palliative care experience or APNs, reassured less experienced staff. One RN (P17) stressed the importance of professional support: *'If it's well supported with a strong network, it works well. (...) Fortunately, we have [name of a participant], who is highly experienced in palliative care.'* One HCA (P22) described feeling safer when an RN or APN approved the administration of morphine

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[4] Despite the fact that morphine is frequently used in a manner consistent with sedating medication, it is not a sedative.

or midazolam, even when a prescription was in place. Another RN stressed that such cases often exceeded the scope of general palliative care:

> *That went far beyond general palliative care. We were very much in the specialised area there. All these situations [involving deep continuous sedation] were actually beyond that limit, it has to be said. They were only possible due to the conditions in the [nursing] home, in terms of expertise, personnel, and the network [involving external expertise]. (P2, RN)*

Participants also called for more training, protocols, and guidelines to strengthen this safety net. As one RN reflected:

> *Even when it had been discussed beforehand, sometimes we still didn't dare to give (...) midazolam, even though it was prescribed. We could have tried it, but still, we didn't dare. I think there should be more education. (P20, RN)*

Another RN (P12) suggested formalising procedures, such as the implementation of a protocol and guidelines for PS, with information, standardised consent forms, and follow-up forms, as a supplementary 'safety net.'

Strategy 2: Specialised palliative care services as external 'safety net'

External specialised palliative care (SPC) services provided an additional external safety net, offering expert guidance, practical assistance, and ethical oversight. One RN (P12) described the positive impact of involving a palliative care physician in decision-making, which improved both resident care and the interaction with relatives. SPC services also provided practical support. An RN (P24) recalled: *'We called [name of palliative care home care service] at 09:00 AM, and by noon they were here to insert the [subcutaneous] access and told us how often we should inject [midazolam].'* Several participants confirmed that the involvement of SPC services was crucial for both medication management and shared decision-making.

Influencing factors

The challenges and strategies described in the preceding subcategories were shaped by broader contextual factors. Two key influences emerged: (1) resource constraints, and (2) beliefs and attitudes.

Resource constraints: personnel and finances

Staffing levels were consistently identified as a crucial factor. Participants emphasised that palliative sedation (PS) is a demanding intervention, and that staff shortages limit the capacity to provide safe and ethical care. As one RN explained:

> *Personnel resources are always a challenge because situations like this [PS] are very demanding, and when you have a second intense situation on the ward, we quickly reach our limits. (...) We need more human resources, which we can't just conjure up out of thin air. (P24, RN)*

Insufficient staffing was perceived as influencing the ability to recognise suffering, make collaborative decisions, and administer sedating medications. Ethical concerns were also raised about decisions being shaped by resource constraints rather than clinical need:

> *There have been situations that really scared me, where I thought that sometimes it depends on the employees, (...) depending on the staff shortage, a decision is made, yes or no. Do we give something now or do we give nothing? And leaving this to chance is something I often think about. (P19, RN)*

Financial limitations were seen as compounding these challenges. As one RN has pointed out:

> *For 10 years, there have been calls for the last days of life to be billed differently, considering the effort involved [...]. It is not financed. We get the standard rate*[5] *according to the [resident's] care level throughout. (P2, RN)*

Beliefs and attitudes: individual and societal

Attitudes towards death, dying, and the use of sedating medications also shaped the alleviation of unbearable suffering and the provision of PS. In four of the seven focus groups, participants highlighted the polarised views of residents, relatives, and society more broadly. Some viewed opioids such as morphine as indispensable for pain relief, while others associated them with addiction or the hastening of death, leading to reluctance in prescribing and administering them, even when clinically necessary. One RN (P26) summarised: *'I'm realising more and more that the dying process is not really part of the society. We have two camps: either people don't want any morphine at all, or they want you to inject and inject and inject.'*

Mistrust from relatives towards nursing home staff was also a recurring theme: *'What leaves a negative*

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[5] In Switzerland, most nursing homes are authorised to apply standardised rates, which exclude the provision of specialised care such as palliative sedation.

aftertaste for me is when [relatives] don't trust us; we are in long-term care and we have no idea and inject people to death with morphine' (P24, RN). Variations in training and cultural background further influenced professional practices: '*Doctors with a different cultural background sometimes have [...] a fear of prescribing morphine.*' (P20, RN).

Furthermore, personal experiences and individual beliefs shaped healthcare professionals' own attitudes towards sedation. One RN (P25) reflected: *'I don't want to feel sick; I don't want to feel pain. I'd rather sleep and not know any of it. (...) That's why I might be a bit hasty sometimes with giving reserves or reacting'.* Similarly, a HCA, linked her approach to her mother's death from cancer: *'My mum died young of cancer and was in a lot of pain. So, I have a completely different relationship to all of this. (...) I don't want anyone to suffer such pain. I want people to be free of pain'* (P8, HCA). By contrast, others stressed the importance of autonomy and the right to remain awake. As one HCA (P18) put it: *'Sometimes, I find it difficult to find the right time to help him, so that he would also have the right to be awake.'*

These examples illustrate how systemic constraints, societal attitudes, and personal beliefs intersect to influence the use of sedating medications and the practice of PS to alleviate suffering in nursing homes.

Discussion

This study highlights the central role of RNs and HCAs in recognising, assessing, and alleviating suffering in Swiss nursing homes, and the complex challenges they face in doing so. These challenges include limited expertise, and structural barriers such as staff shortages and limited GP availability. Our findings illustrate a subsequence from recognising to assessing to ultimately alleviating suffering, with each stage marked by uncertainties and tensions. RNs and HCAs often find themselves navigating between the imperative to alleviate residents' suffering and the risk of over-sedation, within a context of limited resources and expertise. Participants described a complex interplay of factors shaping their practice, including ethical and legal considerations, lack of experience, difficulties in communication with GPs and relatives, and structural barriers such as personnel shortages and financial constraints. These factors can lead to inadequate relief of suffering or, conversely, inappropriate sedation: for example, the frequent use of morphine as a sedative despite its indication primarily for pain and dyspnoea. This tension resonates with the concept of moral distress, defined as the psychological unease professionals experience when they are constrained from acting on what they believe is ethically appropriate [35, 36]. For RNs and HCAs in our study, moral distress may arise when structural constraints, lack of expertise, or the expectations of relatives limit their ability to alleviate suffering as they consider best.

Our findings are consistent with earlier research [15, 16, 37–40], identifying the challenges to the use of PS at individual, interpersonal, and organisational levels. As in Grüne et al. [15] participants in our study reported a lack of knowledge and experience, difficulties in timing sedation, concerns about hastening death, and barriers to communication and collaboration, in addition to structural, work environment and organisational obstacles. Guité-Verret et al. [37] similarly emphasised the complexity of assessing the suffering, including whether residents', relatives', or healthcare professionals' suffering should be prioritised – a challenge that also emerged in our data. Furthermore, Schildmann et al. [39] reported that the term palliative sedation is rarely used in German nursing homes, a finding echoed in our study, where only two of the participating nursing homes had an explicit PS concept and conducted official deep continuous sedation. The development of protocols and best practice recommendations [15, 38] corresponds with our participants' call for clear guidelines and standardised documentation.

What sets our study apart is its exclusive focus on nursing homes and, importantly, the inclusion of HCAs. To our knowledge, this is the first study to examine HCAs' perspectives on PS. Given their close proximity to residents, but limited decision-making authority, their insights offer a crucial addition to existing research.

Challenges in managing sedating medications and PS

A notable finding is the frequent reliance on morphine as a sedative, even though guidelines recommend its use primarily for symptom control of pain and dyspnoea and not for sedation. In our focus groups, morphine was consistently perceived as a sedative medication, reflecting limited knowledge of alternatives such as midazolam. Misconceptions about morphine, including its association with hastening death, reinforced fears among both professionals and relatives, sometimes leading to hesitation or avoidance. Midazolam, by contrast, was rarely prescribed, and staff expressed uncertainty about its use and dosage. Limited GP involvement further exacerbated these challenges: while GPs prescribe sedating and other medications, their infrequent presence in nursing homes means that nurses and HCAs often lack immediate medical support in decision-making and managing medications.

Strategies to manage suffering

Participants identified three main strategies to navigate these challenges:

1. Double-checking perception through collaborative assessment among colleagues, ensuring that signs of suffering are interpreted accurately.
2. Shared decision-making with residents, relatives, and professionals, supported by advance care planning, to align treatment goals and avoid conflict.
3. Establishing safety nets, both internal (access to experienced colleagues or APN) and external (specialised palliative care services), to provides expertise, reassurance, and ethical oversight.

Together, these strategies highlight the importance of teamwork, communication, and external support structures in ensuring that sedation is applied appropriately and ethically in nursing homes.

Strengths and limitations

A major strength of this study is its focus on the perspectives of both RNs and HCAs, based on a large and heterogeneous sample. This provides in-depth insight into how nursing staff experience the challenges of recognising, assessing, and alleviating suffering, and the strategies they employ in practice. To our knowledge, this is the first study to explicitly include HCAs' perspectives on PS in nursing homes.

Several limitations must also be acknowledged: Nursing aids and nursing students, who are the closest to residents, were not included, and their perspectives may have further insight. Selection bias may have occurred due to recruitment through gatekeepers, and the interview guide was not pilot tested. The lack of member checking and the absence of mixed focus groups beyond nursing homes may also limit credibility and transferability [41]. Furthermore, most participants had received palliative care training, which does not reflect the broader reality of Swiss nursing homes. The presence of superiors in some focus groups may have inhibited open discussion. Finally, inconsistent terminology between sedating medications and palliative sedation complicates interpretation and reflects the lack of conceptual clarity in practice.

Conclusions

This study demonstrates that safe and ethical use of sedating medications in nursing homes depends on sufficient staffing, adequate training, and effective support systems. RNs and HCAs need sufficient resources to recognise, assess, and alleviate suffering while avoiding inappropriate sedation.

Future research should investigate how healthcare professionals in general palliative care manage therapy-refractory symptoms, how residents and relatives are engaged in decision-making, and how collaboration with GPs can be strengthened. Including the perspectives of nursing aids, nursing students, GPs, and relatives would provide a more comprehensive understanding of the use of sedating medication and PS in nursing homes. Key areas for further study include the prerequisites for implementing PS in long-term care, the ethical use of sedating medication in line with guidelines, and the circumstances under which residents may need transfer to settings with greater expertise. Future research could also explore in more detail how the tensions identified here intersect with concepts such as moral distress, thereby linking nursing perspectives with broader sociological and ethical debates.

For policymakers, the findings underline the risks of staff shortages and limited expertise. In times of resource constraints, there is a danger that residents may be sedated inappropriately or that their suffering may not be recognised at all due to lack of knowledge, time, or interprofessional collaboration. Developing clear guidelines, investing in staff education, and ensuring access to specialised palliative care services are essential to safeguard the quality of end-of-life care in nursing homes.

Abbreviations

APN	Advanced practice nurse
ACP	Advance care planning
GP	General practitioner
HCA	Healthcare assistant
PC	Palliative care
PS	Palliative sedation
RN	Registered nurse
SPC	Specialised palliative care

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Authors' contributions

M.M. developed the proposal, conducted and transcribed focus group interviews, analysed the data, and wrote the main manuscript text. J.R. revised the proposal, assisted with data analysis, and reviewed the manuscript. M.F. assisted with data analysis and reviewed the manuscript. E.S., S.K., and C.N. contributed to manuscript revisions. All authors read and approved the final version.

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Data availability

The datasets generated and analysed during the current study are not publicly available due to participants' privacy and the sensitive nature of the collected data. However, these can be made available upon reasonable request to the corresponding author.

Declarations

Ethics approval and consent to participate
An application for a clarification of responsibility was submitted to the Swiss Association of Research Ethics Committees (swissethics). The Cantonal Ethics Committee of the Canton of Bern declared itself as not being responsible for the research project and waived the need for approval (BASEC no.: Req-2023-00907). The study was conducted in accordance with the principles of the Declaration of Helsinki. All focus group participants provided informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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