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Original Article

Challenges and Strategies Regarding Sedation at the End of Life in Hospitals and Nursing Homes

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Abstract

Context. Sedation is an accepted, but controversially discussed and challenging measure to treat suffering at the end of life. Although most people die in hospitals or nursing homes, little is known how professionals in these settings deal with sedatives and sedation at the end of life.

Objectives. To explore 1) challenges regarding use of sedatives and sedation at the end of life in hospitals and nursing homes, and 2) strategies, and supportive measures to meet these challenges, as perceived by nurses and physicians.

Methods. Multicenter qualitative interview study. Forty-nine participants: 12 general practitioners and 12 nurses from five nursing homes, 12 physicians, and 13 nurses from five hospital departments (hematology/oncology (n = 2), neurology, geriatrics, gynecology). Semi-structured qualitative interviews. Data analysis guided by framework approach.

Results. Perceived challenges relate to three levels of the care situation: individual, interaction with others, and work environment. The main challenge was defining the adequate timing and/or dose. Other challenges, e.g., disagreements regarding indication or legal uncertainties, were highly interrelated, and strongly associated with this major challenge. Reported strategies and supportive measures to address challenges also corresponded to the three interrelated levels. Major named strategies were education and training, joint decision-making within the team and regular discussion with the patient and family. On the level work environment, no implemented strategies, but wishes for change were identified.

Conclusion. To meet the identified challenges in a sustainable way and enable continuous improvement of quality of care, best practice recommendations, and other supportive measures have to address all identified levels of challenges. J Pain Symptom Manage 2022;63:530−538. *© 2021 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).*

Key Words

Sedation, sedatives, end of life, hospital, nursing home, qualitative research

Key Message

Challenges and strategies regarding sedation at the end of life in general palliative care relate to three interrelated levels: individual, interaction with others, work environment. Defining the adequate timing and/or dose was the main challenge, and education and training the major strategy. Results indicate a need for complex supportive measures.

Introduction

The end of life and dying can be accompanied by symptoms such as pain, dyspnea, or anxiety, and some people suffer severely.[1,2] Sedation is one potential measure to relieve suffering at the end of life. "Sedation in palliative care" is defined as "the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering [. . .]".[3] Patients can be sedated intermittently or continuously

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until death with varying depth. Sedation is used in specialist palliative care settings, e.g., palliative care units or hospices, but also in general palliative care, provided by professionals not specialized in palliative care, e.g., nursing homes and general hospital wards.[4]

Healthcare professionals in all settings face various challenges regarding sedation at the end of life. Ethical uncertainties concerning the differentiation between sedation and euthanasia or physician-assisted suicide are predominant and are partly accompanied by concerns to hasten death.[5−11] Other reported challenges include difficulties in the decision about indication and timing of sedation,[5,8,11−13] insufficient education, and experience,[8] problems regarding the interaction within the team and with the family[8,14] and organizational barriers such as the unavailability of medication.[8] Reported strategies and measures to meet challenges regarding sedation at the end of life include multidisciplinary team-meetings and discussions,[6,10,12,15] the involvement of the family in decision-making and the procedure[15,16] as well as education for healthcare professionals, e.g., concerning communication with people involved.[17,18]

Most of these data on challenges as well as strategies originate from specialist palliative care. However, the majority of people dies in hospitals outside palliative care units or in nursing homes.[19−21] Moreover, studies mostly focused on broader themes such as sedation practice, presented data on challenges and strategies as by-products, or addressed a specific theme such as ethical dilemmas only. Overall, little is known about sedation-related challenges that professionals face in the hospital or nursing home setting, and how they deal with them. A better understanding of these challenges and respective strategies and supportive measures is essential to promote best practice of sedation at the end of life and avoid harm to patients. Therefore, this study aims to explore (1) challenges regarding use of sedatives and sedation at the end of life and (2) strategies and supportive measures to meet these challenges, as perceived by nurses and physicians in hospital wards and nursing homes.

Methods

Design

Multicenter qualitative interview study with physicians and nurses in hospitals and nursing homes, as part of a mixed methods study on use of sedatives at the end of life.[22−26] We followed the COREQ checklist to ensure methodological rigor (see Appendix I).[27]

Setting and Participants

Nursing homes differing with regard to number of residents, funding affiliations (municipal, Protestant, and Catholic) and location (urban and suburban) participated. There were strong variations in general practitioners' on-site presence; none of the nursing homes had a physician permanently available on-site. Some nursing homes cooperated with a particular specialist palliative home care team, others involved one of the home care teams in their region, if required. Participating hospital departments were hematology/oncology (n = 2), geriatrics, gynecology and neurology of two hospitals (university and teaching hospital). All hospital wards had established cooperations with in-house palliative care advisory teams.

In each participating center, a contact person was involved for recruitment. Inclusion criteria were experience in caring for dying patients/residents and sufficient German language skills. Purposive sampling regarding care setting, profession, gender, age, work experience, and palliative care experience was intended. However, this was not fully achieved due to difficult recruitment. All participants gave their written informed consent.

Data collection and Analysis

Face-to-face, semi-structured interviews were conducted from May to October 2019. Two trained researchers conducted the interviews. An interview guide (Appendix II) was developed to ensure consistency. It was designed using the existing literature and the preceding quantitative part of this mixed-methods project.[22,24,25] The guide covered four main themes: understanding of palliative care and end of life, indications for the prescription of sedatives, experience with different forms of sedation, and perceived need for change and/or supportive measures in handling sedatives. To cover experiences with all types of sedation within the interviews, we used a figure illustrating the range from use of sedatives "as needed" via intermittent and/or light to continuous and/or deep sedation. We did not further define the concept of sedation at the end of life. Furthermore, we did not define sedatives but asked the interviewees to name drugs they perceived as sedating. The interview guide was pilot tested in five interviews. Due to only minor changes in the guide, these were also included in the analysis. Participants completed a short questionnaire on sociodemographic data. Parallel to the interviews, the research team constantly discussed whether new and important themes emerged. Interviews were conducted until this was no longer the case, and data saturation was confirmed at the end of the indexing process.

All interviews were audio-recorded and transcribed verbatim. We analyzed the data applying the Framework Approach.[28] After familiarization with the data, two researchers (B. G., S. M.) identified themes as well as subordinate categories and developed a thematic framework in a deductive/inductive approach. The framework was continuously refined during indexing. Key messages of indexed data that were relevant to the research question were summarized. Summaries were transferred to thematic charts with themes in columns and interviewees in rows. To ensure consistency, two researchers (B. G., S. M.) independently indexed 16% of transcripts (n = 8 interviews) and summarized a subset of indexed data, respectively. Disagreements were discussed until consensus was reached, involving a third researcher (E. S.), if necessary. Data interpretation was based on commonalities and differences as well as relations within and between themes. Quotations are presented to illustrate the findings.

Challenges were defined as situations, which interviewees associated with uncertainties and concerns, regarded as problematic, perceived as inadequate treatment or related to interpersonal disagreements. Interviewees' statements that described their own behavior or measures to address the reported challenges - either already used or wished for - were defined as strategies and supportive measures.

Constant joint discussions within the project team (B. G., S. M., E. S.) and with two qualitative research groups at the University and the University Hospital ensured rigor and integrity of data collection and analysis. For data management and analysis, we used MAXQDA (2018.2).

The study was approved by the relevant Research Ethics Committee.

Results

In total, 49 interviews were conducted, with 12 general practitioners and 12 nurses in nursing homes as well as 12 physicians and 13 nurses in hospital. Interview duration ranged between 30 and 81 minutes. About two-third of interviewees were female, the majority was 40 years old or older with median professional experience of 22 years, and about half had training or work experience in specialist palliative care (see Appendix III).

Challenges

The predominant challenge regarding use of sedatives at the end of life was the definition of the appropriate timing and/or dose. It was described as finding a balance on the continuums 'too early - too late' and 'too much - too little'. All extremes were perceived to potentially cause harm for patients/residents. Struggling for adequate timing and/or dose was mainly motivated by the aim to control symptoms and concurrently sustain the patient's/resident's ability to communicate. Interviewees viewed the timing and/or dose rather as 'too late or too low' than as 'too early or too high'.

Other topics were closely related to the major challenge as they intensify uncertainties regarding timing and/or dose. These can be categorized into three interrelated levels: (1) individual, (2) interaction with others, and (3) work environment (for detailed information see Fig. 1, for quotes Table 1).

Individual. On the individual level, we found legal and ethical uncertainties, lack of experience and knowledge, difficulties in evaluating the patient's/resident's wish and anticipating effects of the medication as well as dilemmas regarding indication (Table 1).

Interaction with Others. On the level interaction with others, challenging interactions with the patient/resident, with the family and/or within the team were described. Problematic interactions with the patient/resident were situations in which the wishes of the patient/resident were unknown or contradictory. Moreover, it was perceived as burdensome, when patients/residents rejected the use of sedatives although it was indicated (Table 1).

Challenges in the interaction with the patient/resident were less prominent than with the family. Interviewees perceived the rejection or request of sedatives or of dose increases by the families as challenging when this conflicted with the clinical necessities. Challenges regarding the team were difficult communication between nurses and physicians as well as disagreements regarding the indication for use of sedatives (Table 1).

Work Environment. Concerning the work environment in hospital, interviewees reported staff shortage on some hospital wards and generally at weekends as demanding. In nursing homes, environmental challenges were more prominent. The major factor was a substantial shortage of (qualified) staff. Moreover, legal regulations, as well as self-imposed restrictions by chief nursing officers regarding sedatives and opioids as PRN medication and syringe drivers with bolus function were perceived as barriers to adequate practice. Another challenge on environmental level mentioned by general practitioners was the unavailability of specific drugs (Table 1).

Substantial relations between the three levels of challenges were mentioned. For example, little experience in end of life care and sedation increases uncertainties concerning the use of sedatives. These uncertainties on the individual level can either be intensified by or produce challenges on the interaction level, e.g., disagreements regarding the indication of sedation. Challenges on the environmental level intensify challenges on the individual as well as the interaction level.

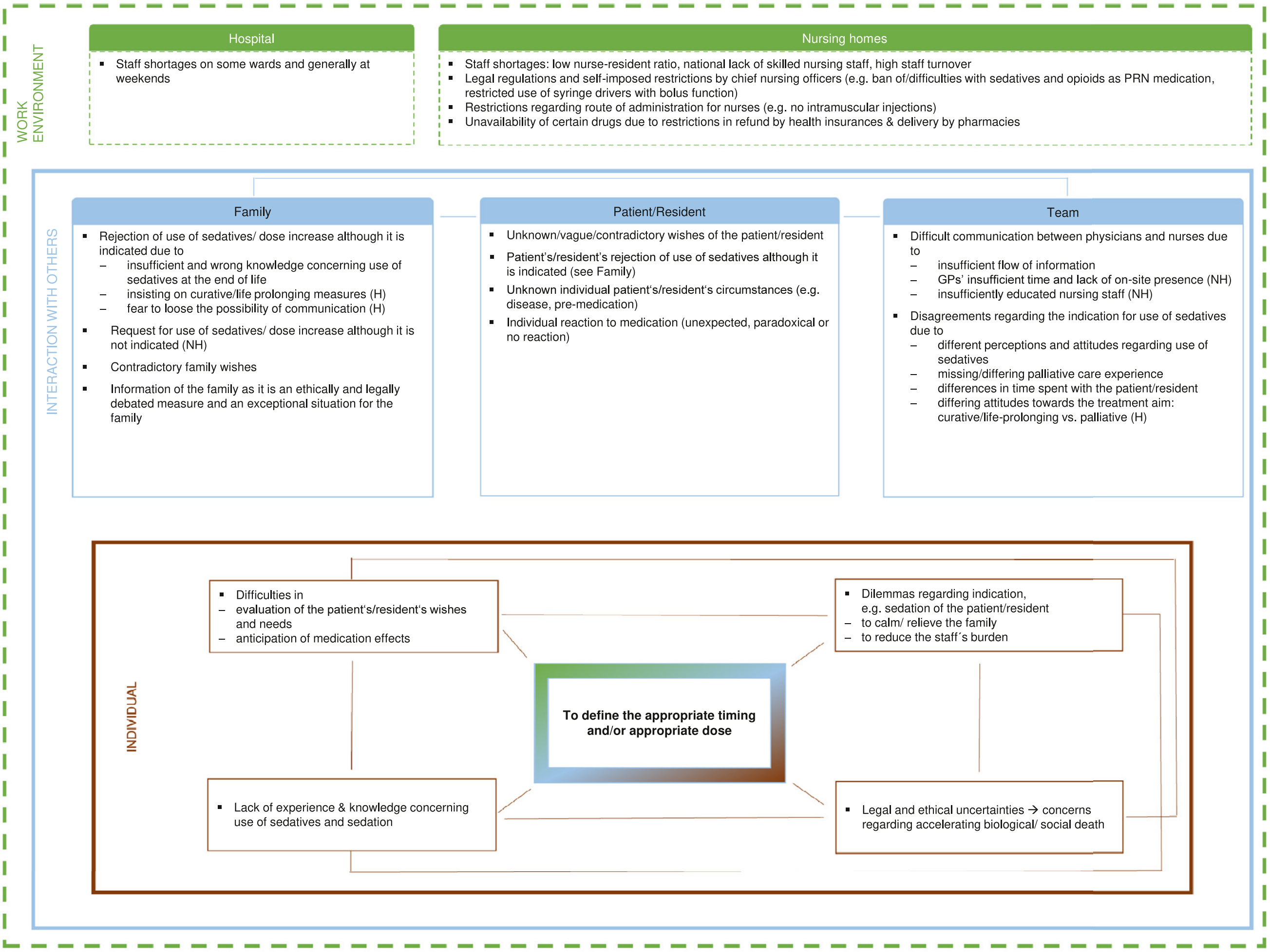


Fig. 1. Challenges regarding use of sedatives at the end of life as perceived by nurses and physicians in nursing homes and hospitals. For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.

Strategies and Supportive Measures to Meet the Identified Challenges

The reported strategies and supportive measures to address challenges regarding use of sedatives at the end of life can also be categorized into the same interrelated levels: (1) individual, (2) interaction with others, and (3) work environment. The degree of implementation of the named strategies and supportive measures varied considerably. Whereas some interviewees already used strategies and recommended them, others solely made respective suggestions for changes or wishes for necessary supportive measures (for detailed information see Fig. 2, for quotes Table 2).

Individual. On the individual level, two major strategies were reported by interviewees. First, the enhancement of certainty and confidence, e.g., by training and education. Second, the adaptation of procedures, e.g., by a comprehensive evaluation of the patient's/resident's situation or the continuous reflection of the indication for sedatives (Table 2).

Interaction with Others. Concerning the interaction with the patient/resident and the family, a major strategy was constant information and discussion to meet concerns and demands or rejections of use of sedatives perceived as inappropriate by the team (Table 2).

As an important strategy to overcome challenges related to the patient/resident, interviewees emphasized the need to comprehensively evaluate the patient's/resident's wishes by e.g., private conversations with the patient in absence of the family. Many interviewees stressed that the patient's/resident's wishes are superior to the family's or the professionals' expectations.

General practitioners reported the resident's admission to hospital or the general practitioner's withdrawal from the resident's care as strategies of last resort in conflicts with the family.

Table 1
Quotes of the Healthcare Professionals in Hospitals and Nursing Homes Concerning Challenges Regarding Use of Sedatives at the End of Life

1	*Individual level:* "[...] Well, I think that for young colleagues in particular it is, I think, sometimes a bit difficult, when you talk to them, they say: "Oh yes, so am I giving them too much now?" Or they are worried that they will somehow euthanize him or contribute to speeding up the dying process or something like that? [. . .]." (Jens, Hospital Physician)
2	*Interaction level:* "Well, we noticed that he was afraid, he was suffering, but he didn't want to take any medication. And for me the difficulty was to give him a little bit of symptom relief against his will at a stage where he was seeing ghosts sitting at his bedside, because he just didn't want medication. [...] It's always stupid when you can't talk to the patient the way you want to." (Antonia, General Practitioner)
3	*Interaction level:* "In general, I find it difficult that you have these tensions. The relatives tend to want less sedation, the nurses more. That's, of course, you have to mediate. And sometimes that's not easy at all." (Konrad, General Practitioner)
4	*Environmental level:"* The ["Tavor] Expidet" [brand name of a sublingual lorazepam preparation], [. . .] actually you're not legally allowed to do [prescribe] it at all, because the patient could also swallow the cheaper lorazepam tablet. But if it's hard to swallow for someone who [...] can't drink much more and so on, it's just easier. But it is so that you're not actually allowed to prescribe it." (Theo, General Practitioner)

Each quotation is identified by a name unrelated to participants' real names.

To meet challenges within the team, interviewees' major strategies comprised the improvement of communication by enhancing regular exchange of information and multi-professional case conferences. Interviewees of both settings agreed on the important role of experienced team members and of joint decision-making (Table 2).

To meet the challenges in cooperation with understaffed and/or unqualified nursing teams in nursing homes, general practitioners underlined the necessity to individually adapt and precisely explain the procedures and associated nursing tasks according to the nurses' competencies and capacities.

The core strategy regarding interaction with others, therefore, was to jointly define and agree on a procedure with all involved parties.

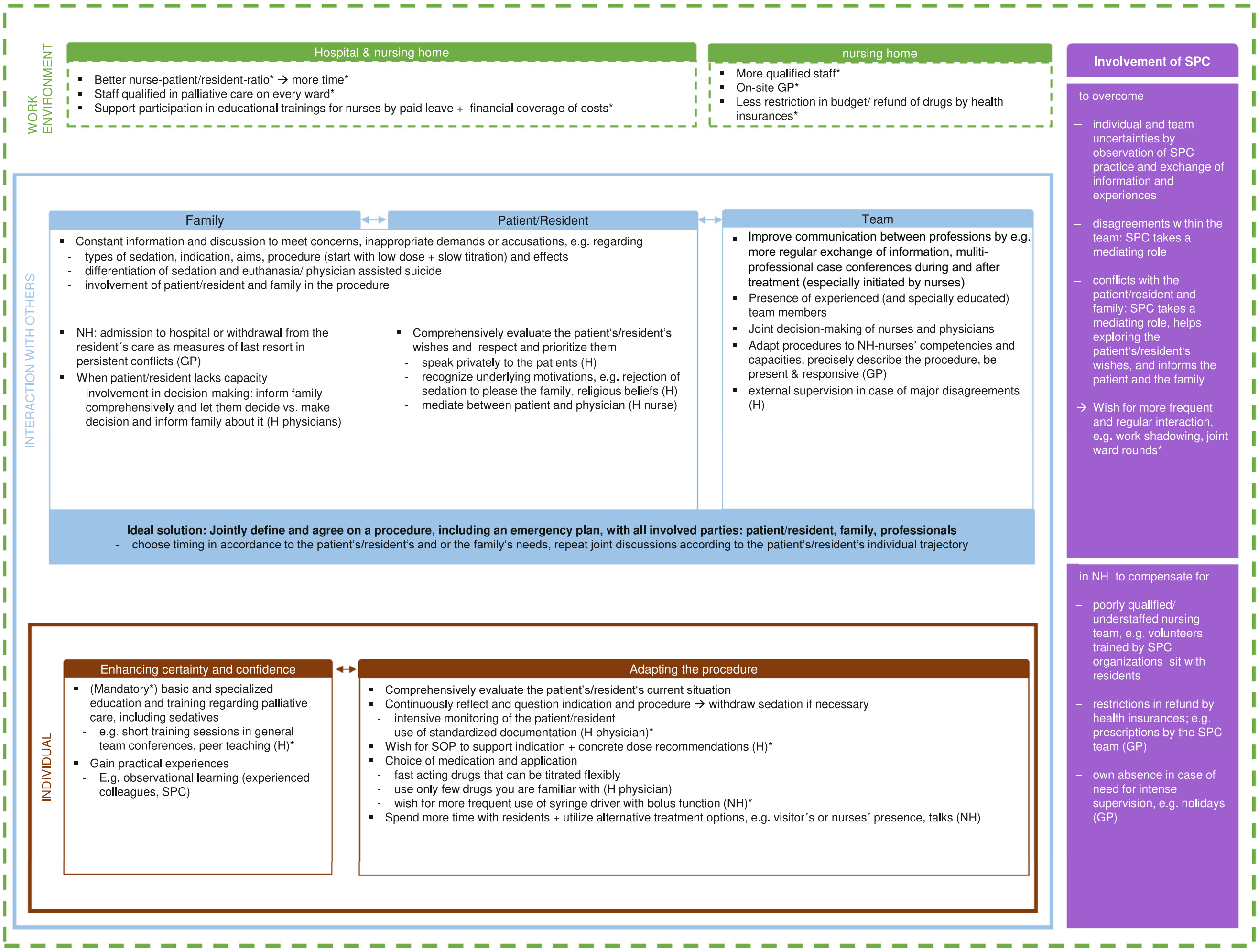
Work Environment. On the level work environment, wishes for changes and supportive measures were expressed. These mainly included more (qualified) staff and time for the care of patients/residents.

Involvement of Specialist Palliative Care Services. Involving specialist palliative care services was a strategy to overcome challenges with sedation at the end of life on all three levels. Interviewees regarded the observation of specialist palliative care practice and the exchange of experiences as very helpful to address individual as well as team uncertainties regarding the use of sedatives. Moreover, specialist palliative care consultation was used as a strategy to overcome disagreements within the team and conflicts with patients/residents and/or families. The involvement of specialist palliative care services to address challenges on the environmental level was exclusively mentioned by nursing home nurses and general practitioners. Some interviewees in both settings wished for more and regular interaction with specialist palliative care services, e.g., work shadowing and joint ward rounds (Table 2).

Discussion

Our data indicate that nurses and physicians perceived challenges regarding sedation at the end of life on three levels of the care situation: individual, interaction with others and work environment. The main challenge was defining the adequate timing and/or dose. Further challenges at the identified levels were strongly associated with this major challenge and highly interrelated. The reported strategies and supportive measures to address challenges also corresponded to the three interrelated levels. They differed substantially in their degree of implementation between interviewees. On the level work environment, strategies only consisted of wishes and suggestions for change.

Despite differences in work environment, expertise and experience as well as patient populations, reported challenges in our study were comparable to those reported mainly for specialist palliative care. This especially applies to the challenges perceived at the individual level, namely insecurities in decision-making concerning timing and/or dose[5,11–13] as well as ethical uncertainties.[5–7,9–12] This consistency of perceived challenges underlines that sedation at the end of life is a complex, much debated issue that is likely to be associated with uncertainties regardless of professional competencies. A lack of knowledge and experience in specialist palliative care is known to be associated with the perception of ethical uncertainties.[11,29,30] In our study as well as in a previous study in nursing homes,[8] knowledge and experience were emphasized as crucial to safely handle sedation. Therefore, the described challenges at the individual level may be more pronounced in general than in specialist settings. Challenges in specialist palliative care were mostly described in relation to continuous deep sedation.[5,7,9,12–14] In our sample, the challenges were perceived regarding the whole range of use of sedatives - even the use of relatively small doses and without the explicit intention to sedate the patient. The latter was the most common practice in our participating centers.[22,24–26] The perception of sedation as a "side effect" rather than an intentional act when using



Hospital & nursing home

- Better nurse-patient/resident-ratio* → more time*
- Staff qualified in palliative care on every ward*
- Support participation in educational trainings for nurses by paid leave + financial coverage of costs*

nursing home

- More qualified staff*
- On-site GP*
- Less restriction in budget/ refund of drugs by health insurances*

Family ↔ **Patient/Resident** ↔ **Team**

- Constant information and discussion to meet concerns, inappropriate demands or accusations, e.g. regarding
  - types of sedation, indication, aims, procedure (start with low dose + slow titration) and effects
  - differentiation of sedation and euthanasia/ physician assisted suicide
  - involvement of patient/resident and family in the procedure

- NH: admission to hospital or withdrawal from the resident´s care as measures of last resort in persistent conflicts (GP)
- When patient/resident lacks capacity
  - involvement in decision-making: inform family comprehensively and let them decide vs. make decision and inform family about it (H physicians)

- Comprehensively evaluate the patient's/resident's wishes and respect and prioritize them
  - speak privately to the patients (H)
  - recognize underlying motivations, e.g. rejection of sedation to please the family, religious beliefs (H)
  - mediate between patient and physician (H nurse)

- Improve communication between professions by e.g. more regular exchange of information, muliti-professional case conferences during and after treatment (especially initiated by nurses)
- Presence of experienced (and specially educated) team members
- Joint decision-making of nurses and physicians
- Adapt procedures to NH-nurses' competencies and capacities, precisely describe the procedure, be present & responsive (GP)
- external supervision in case of major disagreements (H)

Ideal solution: Jointly define and agree on a procedure, including an emergency plan, with all involved parties: patient/resident, family, professionals

- choose timing in accordance to the patient's/resident's and or the family's needs, repeat joint discussions according to the patient's/resident's individual trajectory

Enhancing certainty and confidence ↔ **Adapting the procedure**

- (Mandatory*) basic and specialized education and training regarding palliative care, including sedatives
  - e.g. short training sessions in general team conferences, peer teaching (H)*
- Gain practical experiences
  - E.g. observational learning (experienced colleagues, SPC)

- Comprehensively evaluate the patient's/resident's current situation
- Continuously reflect and question indication and procedure → withdraw sedation if necessary
  - intensive monitoring of the patient/resident
  - use of standardized documentation (H physician)*
- Wish for SOP to support indication + concrete dose recommendations (H)*
- Choice of medication and application
  - fast acting drugs that can be titrated flexibly
  - use only few drugs you are familiar with (H physician)
  - wish for more frequent use of syringe driver with bolus function (NH)*
- Spend more time with residents + utilize alternative treatment options, e.g. visitor´s or nurses´ presence, talks (NH)

Involvement of SPC

to overcome

- individual and team uncertainties by observation of SPC practice and exchange of information and experiences
- disagreements within the team: SPC takes a mediating role
- conflicts with the patient/resident and family: SPC takes a mediating role, helps exploring the patient's/resident's wishes, and informs the patient and the family

→ Wish for more frequent and regular interaction, e.g. work shadowing, joint ward rounds*

in NH to compensate for

- poorly qualified/ understaffed nursing team, e.g. volunteers trained by SPC organizations sit with residents
- restrictions in refund by health insurances; e.g. prescriptions by the SPC team (GP)
- own absence in case of need for intense supervision, e.g. holidays (GP)

Fig. 2. Strategies and supportive measures to meet challenges regarding use of sedatives at the end of life as perceived by nurses and physicians in nursing homes and hospitals. For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.

Notes: The nested boxes illustrate the interrelations between the three levels; NH = nursing home(s), H= hospital(s), SPC = Specialist Palliative Care, GP = general practitioner, SOP = standard operating procedure; Strategies and supportive measures only mentioned by interviewees from one setting or one group of professionals are followed by the respective abbreviation in brackets.

* Solely wished for/seen a need for, not implemented by any interviewee/institution.

sedatives[26] might also explain why our interviewees did not mention acknowledged challenges of sedation at the end of life, e.g., the evaluation of refractoriness of symptoms or survival.[5] Another aspect associated with the concept of sedation and sedatives was the reporting of restrictions regarding opioids in nursing homes as a sedation-related challenge. The perception and use of opioids as a means for sedation by some of our interviewees - despite contrary recommendations[3] - raises the question of inadequate treatment.[26]

In line with previous studies,[8,14] described challenges in the interaction with the family and within the team mostly consisted of disagreements regarding the indication of sedation and communication problems. Challenges in the interaction with the family were more prominent than challenges with the patient/resident. Decisions regarding use of sedatives were associated with fewer doubts when communication with the patient/resident about her/his wishes was possible. This is supported by a study reporting that nurses rated palliative sedation-related critical issues as less difficult when the patient was involved.[31]

As reported for end of life care in general,[32–34] staff shortage and lack of time were substantial challenges regarding sedation at the end of life on the work environment level, and much more prominent in nursing homes. Moreover, additional challenges on the environmental level were relevant only in nursing homes, e.g., legal regulations and self-imposed restrictions by chief nursing officers and the availability of medication. Only the latter has previously been reported by a Belgian study.[8]

Table 2

Quotes of the Healthcare Professionals in Hospitals and Nursing Homes Concerning Strategies and Supportive Measures to Meet Challenges Regarding Use of Sedatives at the End of Life

1	*Individual level:* "What needs to be changed is [. . .], I think, the awareness [. . .] of the nursing staff, to look closely at what the person needs. Also in relation to sedation. When is it a relief for the person? But when do I want it just as a relief for myself? [. . .] Because it can also have something to do with me. Because I am so overwhelmed, because I have so much to do, so many people to look after, that I prefer to resort to a sedative for one person. But even that should be made consciously." (Emma, Nursing Home Nurse)
2	*Interaction level:"* It is important, I think, to communicate to the relatives that you do not provide euthanasia, and to say so actively, otherwise there is always fear or predominantly fear. But if you say: We are helping here to make something bearable, to alleviate fears and pain, then very few relatives have good arguments either subjectively, so to speak, or emotionally to say: "No, please keep the medicine in the drawer. I would rather that, my loved one suffer pain and be afraid." So I think it's a question of how we / how one communicates with the relatives, then it's okay." (Heinz, Hospital Physician)
3	*Interaction level:* "So, you have to say that things are going super well here on the ward. That every opinion is important. And every concern. No matter by whom, whether from the nursing or medical side. Yes, of course, nursing is often the impetus because they see the patients more often and know them better. Doctors often go in to make rounds. And then they don't see the patient again for half a day. Until something happens again. So, I think the nurses always give the impetus [. . .] or often. But about which medication, that is then such a team decision. So, the doctor then makes a suggestion of what we could give them now. And then the nurse says, "Don't you think that's better?" And that is actually such a collaboration, yes." (Janine, Hospital Nurse)
4	*Involvement of specialist palliative care services:* "I think it's up to the general practitioners. I think they need much more palliative care training, yes. Because many general practitioners don't want that either and wouldn't come if we didn't always push: "How about "Tavor" [brand name of lorazepam]? How about morphine? Because no one needs to be in pain." Don't we want the palliative care team, so that we also have a proper contact person. Because we don't know everything either. We are only skilled workers. If I have a general practitioner who doesn't really want it that way, then a palliative care team is one hundred percent great to work with." (Anna, Nursing Home Nurse)

Each quotation is identified by a name unrelated to participants' real names.

Consistent with previous studies,[6,10,12,15,17,18] multi-professional case conferences or repeated discussions with the patient/resident and the family were identified as supportive measures to meet challenges on the individual and interaction levels. In addition, our data revealed some more specific strategies such as nurses initiating multi-professional discussions or general practitioners individually adapting the procedure to nursing home nurses' competencies (see Fig. 2). Despite existing recommendations regarding "care for the medical professionals" in guidelines,[3] our interviewees rarely mentioned specific strategies to cope with distress, such as supervision, and these were not regularly applied in clinical practice. Environmental barriers might prevent implementation.

The reported strategies on the individual level "enhancing certainty and confidence" and "adapting the procedure", but also the strategies on the interaction level "improving communication" and "constant information and discussion" as well as "jointly define and agree on a procedure with all involved parties" are to some extent included in guidelines on sedation in palliative care.[3] However, recommendations focusing on the interaction of the involved parties are sparse. Additionally, recommendations on sedation differ between guidelines.[3,35] More consensus and target group-specific recommendations adapted to the needs of professionals in hospitals and nursing homes are essential, e.g., guidance on communication issues. Nevertheless, guidelines alone cannot address all identified challenges and their complex interrelations.

Our results indicate that challenges as well as strategies and supportive measures regarding the use of sedatives at the end of life occur on three interrelated levels of healthcare. Thus, use of sedatives at the end of life represents a complex adaptive system in which factors could be allocated to the patient system, the family system, the team system and environmental factors. This is in line with the findings of barriers regarding continuous sedation until death in Belgian nursing homes,[8] and with the description of palliative care situations in general as complex adaptive systems.[36] Single measures which neglect the complex structure of the system cannot adequately address the identified challenges. Instead, the complex system of interrelated challenges requires a complex system of interrelated strategies and supportive measures. For example, education and training measures must complement recommendations in guidelines. However, training measures can only enhance certainty and confidence if staff is given the opportunity to participate despite staff shortages. Considering the high staff turnover, especially in nursing homes, the effects of education and training sessions are only sustainable, if they are offered repeatedly. The involvement of specialist palliative care services as a measure to meet challenges on all three levels illustrates interviewees' needs for complex supportive measures. The specialist palliative care services were perceived to convey knowledge and certainty to individual professionals and the team, to mediate in conflicts, and to compensate for environmental challenges. Interviewees wished for more regular interaction with specialist palliative care professionals.

Strengths & Limitations

The major strength of this study is the inclusion of perspectives of nurses and physicians of different settings outside specialist palliative care. This is the first study embedding challenges as well as strategies and supportive measures for the use of sedatives at the end of life. In the interpretation of this study's results, some limitations need to be considered. As sedation at the end of life is a controversial issue, social desirability might have influenced the interviewees' answers. Commonly known challenges, such as legal and ethical uncertainties, were very prominent. Interviewees might have been cautious in describing other challenges or deviations from good practice. Furthermore, many of our interviewees had numerous years of professional experience, and about half had palliative care training or work experience in specialist palliative care. We had anticipated that contact persons might pre-select more experienced and/or less critical interviewees, and that young professionals may be reluctant to participate due to the complexity and controversy of the topic. We had, therefore, encouraged contact persons to particularly include young professionals. However, despite these measures, purposeful sampling regarding the professional experience was not fully achieved. We might have missed some challenges and strategies or supportive measures from the perspective of more unexperienced professionals.

Conclusion

The use of sedatives and sedation at the end of life can be described as a difficult balancing act between "too early - too late" and "too deep - too light". It is associated with complex challenges and respective strategies or supportive measures, which correspond to the health care system's levels individual, interaction with others and work environment. Challenges and strategies or supportive measures heavily depend on the work environment. Due to the complexity and interrelations of challenges, single supportive measures focusing on a single challenge will not result in a major, sustainable change. Changes in work environment are essential. This mainly includes more staff and time resources as well as sustainable measures for better and setting-specific qualification - regarding end of life care in general and use of sedatives specifically. To develop and implement needs-adapted and sustainable measures, more research jointly evaluating setting-specific challenges, needs, strategies and necessary supportive measures is required.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2021.12.012.

References

1. Imai K, Morita T, Yokomichi N, et al. Efficacy of two types of palliative sedation therapy defined using intervention protocols: proportional vs. deep sedation. Support Care Cancer 2018;26:1763–1771.

2. Beller EM, van Driel ML, McGregor L, Truong S, Mitchell G. Palliative pharmacological sedation for terminally ill adults. Cochrane Database Syst Rev 2015;1::Cd010206. Cd010206.

3. Cherny NI, Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med 2009;23:581–593.

4. Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. Eur J Palliat Care 2009;16:278–289.

5. Abarshi EA, Papavasiliou ES, Preston N, Brown J, Payne S. The complexity of nurses' attitudes and practice of sedation at the end of life: a systematic literature review. J Pain Symptom Manage 2014;47:915–925. e911.

6. De Vries K, Plaskota M. Ethical dilemmas faced by hospice nurses when administering palliative sedation to patients with terminal cancer. Palliat Support Care 2017;15:148–157.

7. Raus K, Brown J, Seale C, et al. Continuous sedation until death: the everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium. BMC Med Ethics 2014;15:14.

8. Robijn L, Deliens L, Rietjens J, Pype P, Chambaere K. Barriers in the decision making about and performance of continuous sedation until death in nursing homes. Gerontologist 2019;60:916–925.

9. Seymour J, Rietjens J, Bruinsma S, et al. Using continuous sedation until death for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. Palliat Med 2015;29:48–59.

10. Vivat B, Bemand-Qureshi L, Harrington J, Davis S, Stone P. Palliative care specialists in hospice and hospital/community teams predominantly use low doses of sedative medication at the end of life for patient comfort rather than sedation: Findings from focus groups and patient records for I-CAN-CARE. Palliat Med 2019;33:578–588.

11. Ziegler S, Merker H, Schmid M, Puhan MA. The impact of the inpatient practice of continuous deep sedation until death on healthcare professionals' emotional well-being: a systematic review. BMC Palliat Care 2017;16:30.

12. Leboul D, Aubry R, Peter JM, et al. Palliative sedation challenging the professional competency of health care providers and staff: a qualitative focus group and personal written narrative study. BMC Palliat Care 2017;16:25.

13. Maeda S, Morita T, Ikenaga M, et al. Changes in opinions on palliative sedation of palliative care specialists over 16 years and their effects on clinical practice. Support Care Cancer 2019;27:2211–2219.

14. Lokker ME, Swart SJ, Rietjens JAC, et al. Palliative sedation and moral distress: a qualitative study of nurses. Appl Nurs Res 2018;40:157–161.

15. Ziegler S, Schmid M, Bopp M, Bosshard G, Puhan MA. Continuous deep sedation until death in patients admitted to palliative care specialists and internists: a focus group study on conceptual understanding and administration in German-speaking Switzerland. Swiss Med Wkly 2018;148:w14657.

16. Bruinsma SM, Rietjens JA, Seymour JE, Anquinet L, van der Heide A. The experiences of relatives with the practice of palliative sedation: a systematic review. J Pain Symptom Manage 2012;44:431–445.

17. Patel B, Gorawara-Bhat R, Levine S, Shega JW. Nurses' attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals. J Palliat Med 2012;15:432–437.

18. Zuleta-Benjumea A, Muñoz SM, Vélez MC, Krikorian A. Level of knowledge, emotional impact and perception about the role of nursing professionals concerning palliative sedation. J Clin Nurs 2018;27:3968–3978.

19. Dasch B, Blum K, Gude P, Bausewein C. Sterbeorte. Veränderung im Verlauf eines Jahrzehnts. Eine populationsbasierte Studie anhand von Totenscheinen der Jahre 2001 und 2011. Deutsches Ärzteblatt 2015;112:496–504.

20. Bekelman JE, Halpern SD, Blankart CR, et al. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. JAMA 2016;315:272–283.

21. Broad JB, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health 2013;58:257–267.

22. Schildmann E, Meesters S, Grüne B, et al. Sedatives and sedation at the end of life in nursing homes: a retrospective multicenter cohort study. J Am Med Dir Assoc 2021;22:109–116.e101.

23. Meesters S, Grüne B, Bausewein C, Schildmann E. Palliative syringe driver'? A mixed-methods study in different hospital departments on continuous infusions of sedatives and/or opioids in end-of-life care. J Patient Saf 2021. Published Online.

24. Schildmann E, Bolzani A, Meesters S, et al. Sedatives and sedation at the end of life: a nursing home retrospective cohort study. BMJ Support Palliat Care 2019. Published Online.

25. Schildmann E, Meesters S, Grüne B, et al. Sedation at the end of life in hospital – a multicenter retrospective cohort study [Sedierung am Lebensende im Krankenhaus – eine multizentrische retrospektive Kohortenstudie]. Deutsches Ärzteblatt 2021. Submitted for publication.

26. Meesters S, Grüne B, Bausewein C, Schildmann E. We don't want to sedate him" - a qualitative interview study on intentions when administering sedative drugs at the end of life in nursing homes and hospitals. BMC Palliat Care 2021;20:141.

27. Tong A, Sainbury P, Graig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care 2007;19:349–357.

28. Ritchie J, Spencer L, O'Connor W. Carrying out aualitative analysis. In: Ritchie J, Lewis J, eds. Qualitative Research Practice: A Guide for Social Science Students and Researchers, London: SAGE Publications; 2003.

29. Foley RA, Johnston WS, Bernard M, et al. Attitudes regarding palliative sedation and death hastening among Swiss physicians: a contextually sensitive approach. Death Stud 2015;39:473–482.

30. Rietjens JA, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. Palliat Med 2007;21:643–649.

31. Venke Gran S, Miller J. Norwegian nurses' thoughts and feelings regarding the ethics of palliative sedation. Int J Palliat Nurs 2008;14:532–538.

32. Bloomer MJ, Endacott R, O'Connor M, Cross W. The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. Palliat Med 2013;27:757–764.

33. Donnelly S, Prizeman G, Coimín D, Korn B, Hynes G. Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives. BMC Palliat Care 2018;17:117.

34. Reyniers T, Houttekier D, Cohen J, Pasman HR, Deliens L. The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers. Health Place 2014;27:77–83.

35. Schildmann E, Schildmann J. Palliative sedation therapy: a systematic literature review and critical appraisal of available guidance on indication and decision making. J Palliat Med 2014;17:601–611.

36. Hodiamont F, Junger S, Leidl R, et al. Understanding complexity - the palliative care situation as a complex adaptive system. BMC Health Serv Res 2019;19:157.