

ORIGINAL ARTICLE

How should health care providers inform about palliative sedation? A qualitative study with palliative care professionals

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Abstract

Objective: In Switzerland, palliative sedation consists of using sedatives to relieve terminally ill patients. It is divided into several steps, with one of them consisting of informing patients and relatives about the procedure. In the current recommendations, there is a lack of orientation about how and when this discussion should take place. Hence, we aim to explore perceptions and experiences of palliative care professionals regarding these questions.

Methods: Qualitative semi-structured interviews with five physicians and five nurses working in specialised palliative care were conducted. They were then analysed with thematic analysis.

Results: Results showed a uniformity around definition, goals and indications of palliative sedation. However, there was a lack of consistency regarding the process of delivering this information to patients and relatives. Finally, some participants strongly opposed the idea of systematically informing patients in specialised palliative care, while others were more divided on this question.

Conclusion: Despite a common understanding of the concept of palliative sedation, there is no standard practice when informing patients on palliative sedation among palliative care professionals. Therefore, this study demonstrates the need for further guidelines on this question and calls for a better understanding and knowledge of palliative sedation among health professionals outside palliative care.

KEYWORDS

discussion, end-of-life care, guidelines, information, palliative care, palliative sedation

1 | INTRODUCTION

Palliative sedation (PS) is a treatment used in palliative care to relieve severe distress in terminally ill patients. It consists of the monitored use of medications intended to induce a state of decreased or absent awareness in order to relieve the burden of otherwise treatment-refractory suffering in a manner that is ethically acceptable to the patient, family and health care providers (Cherny & Radbruch, 2009).

Although PS and euthanasia may concern the same patient population, they are considered as fundamentally different by many palliative care professionals (Gurschick et al., 2015; Materstvedt, 2012; Radbruch et al., 2016). Indeed, PS intends to relieve the symptoms and not to hasten or cause death. It's choice of drug and dosage is proportionate to the severity of symptoms. Death of the patient is not considered a criterion of success of the treatment (Claessens et al., 2008; Materstvedt, 2012). Finally, studies have shown that

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correctly administered PS does not hasten death but can even delay it (Beller et al., 2015; Maltoni et al., 2012; Schildmann & Schildmann, 2014; Swart et al., 2012).

Depending on patients' needs, depth of PS can be mild or deep, and it can be temporary or continuous until death (SFAP, 2017; Swart et al., 2012). Population-wide studies in Europe have shown a significant variation regarding the overall prevalence of continuous deep sedation until death in the population, ranging between 2.5% and 18%, with one of the highest frequencies and steepest increases in Switzerland, from 4.7% in 2001 to 17.5% in 2013 (Ziegler et al., 2018a, 2019).

Professional guidelines can be very specific about the medical, ethical and decisional aspects of PS (Abarshi et al., 2017; Cherny & Radbruch, 2009; Gurschick et al., 2015). Yet there is a lack of orientation about how and when PS should be discussed with patients and their relatives. In Switzerland, the national guideline issued by the Swiss Association of Palliative Care does not offer any clear guidance on these questions (Groupe d'experts de la Société Suisse de Médecine et de Soins palliatifs, 2005). The question of communication about PS is all the more important as prior studies have suggested that PS is neither well known in the Swiss public nor among health professionals outside palliative care and that patients are inconsistently involved in the process regarding end-of-life decisions (Hurst et al., 2018; Ziegler et al., 2018b).

In order to improve these practices, however, it is necessary to gain more insights into the actual practice of patient-provider communication about PS as well as the experiences and perspectives of palliative care professionals with regard to communication about PS. Although it is an accepted practice when used in appropriate situations, PS is a topic of controversy with many ethical questions, which certainly influence the communication around it. Therefore, the aims of this study were to explore (1) how palliative care professionals, based on their concept of PS; proceed when discussing PS with patients and families; (2) which effects of PS-related information they have experienced; and (3) what they think about the idea of systematically informing all patients in specialised palliative care about PS.

2 | METHODS

This is a qualitative interview study with health care professionals specialised in palliative care. As the study did not fall under the Swiss Federal Act regarding research on human subjects, a formal review by the responsible research ethics committee of the respective state was not applicable (Fedlex, 2011). Nevertheless, careful attention was taken to be in line with the research ethics criteria as set out, for example, in the most recent version of the Declaration of Helsinki. Participants were given thorough information on the study, informed voluntary consent was obtained, and they were free to withdraw at any moment during the study.

2.1 | Study population

The sampling strategy was a combination of convenience sampling and cluster sampling: Among the palliative care professionals working at a tertiary care institution in Switzerland, we approached both women and men, nurses and physicians, professionals working within the hospital and those working in the outpatient and home care setting.

2.2 | Interview guide

An interview guide (Appendix A) was developed based on a literature review and the discussion in the study group, including a palliative care and ethics expert and an expert on qualitative methodology. It was designed to guide problem-focused interviews and consisted of four primary questions covering the main themes, supplemented by sub-questions to explore various aspects within each theme. Almost all questions were formulated as open questions, and participants were encouraged to develop their answers as far as they wished, with the speaker only intervening when he felt an answer needed specifying.

In the tertiary care institution where these health professionals worked, there are to date no written information documents on PS aimed at patients or their families. Therefore, the question on the value of a written document was designed as a closed question, as the first aim was to know broadly whether participants were in favour or against such a form of communication. Yet, if participants did not spontaneously motivate their opinion, the speaker asked them to explain their point of view.

2.3 | Data collection

Participants were contacted by the first author via e-mail asking them whether they would agree to be interviewed about PS. If this was the case they received in-depth information about the study, and a date was scheduled for a personal meeting. Here, participants were again informed orally about the aims, content, method and use of the interviews. It was also emphasised that the interviews would be audio-recorded, transcribed and anonymised and that they could withdraw their participation at any moment from the study. Finally, informed consent was obtained. The interviews were carried out by the first author, a last-year medical master student trained and supervised in conducting qualitative interviews by an expert on qualitative methodology. This training was done simultaneously to the research design. The interviewer did not know any of the participants. Each participant was interviewed individually in surroundings guaranteeing privacy and confidentiality; no third party was present. Interviews were conducted in French (except for one conducted in English) and lasted between 20–30 min, except for one lasting 60.

2.4 | Data analysis

Audio recordings were transcribed verbatim by the first author. All personal information (names, places and institutions) was anonymised. The transcripts were analysed in their original language using thematic analysis (Braun & Clarke, 2006, 2021; Willig & Rogers, 2017). This is a flexible approach that can provide a rich and detailed account of problem-focused interviews, highlight similarities and differences between interviews and enable the succinct identification of key features of a large body of data. In this case, the analysis was driven by the interview guide and hence a deductive approach was chosen to analyse the data. The common thread used for the analysis is the reflexive model according to Braun and Clarke, consisting of six phases: (1) Transcripts produced were repeatedly read in order to get familiar with the data. (2) The software TAGUETTE, an open-source qualitative data analysis tool, was used to identify and structure initial codes. The software was used to import interviews, highlight and tag quotes and then export the results. Thus, a list of codes for each question from the interview guide was obtained. (3) Codes and patterns were analysed and combined to form overarching themes. (4) The resulting codes were reviewed to make sure they formed a coherent pattern. Then, the entire transcripts were reread to make sure themes accurately reflect the meanings of the data. (5) Data extracts for each theme were organised in a consistent way, and themes were then named. (6) The fully worked-out themes obtained were illustrated with either a thematic map or a table. The thematic maps are not reported in this article but can be found in the Supporting Information. The analysis was initially performed by the first author and then reviewed and discussed with the co-author RJJ, based on second-rater coding of the material, before it was again discussed within the broader research team. The quotes used in this article were translated from French into English by the first author who is both a native English and French speaker. Quotes are presented in an anonymous way, with only the function (nurse or physician) of participants being displayed.

3 | RESULTS

A total of 10 palliative care professionals were invited and agreed to participate. Among these health professionals, seven identified as female and three as male. As qualitative studies do not aim to be representative but create hypotheses, a sample size of 10 rich interviews was deemed sufficient. The five nurses and five physicians all have been working in palliative care for at least 10 years and were familiar with the Swiss health care system, most of them having been trained in Switzerland. The participants worked in different contexts of specialised palliative care, some of them on an inpatient palliative care unit, others in an inpatient consultation team and again others in a home care team or in various of these contexts. The findings of the interviews are divided into four parts, corresponding to the four themes of the interview guide, with a focus on the most salient results, which concern the second and fourth themes.

3.1 | Personal understanding of PS

In the first section, where definition, indications and goals of PS were discussed, there was a concordance among participants' answers, with the same themes emerging throughout the interviews. PS is defined as a type of treatment used in the case of severe, refractory symptoms with the aim to provide relief. Yet the most prominent theme that emerged from the definition of PS, illustrated by Table 1, is that it is a treatment that is only considered once all other measures had been deemed insufficient. Thus, an interesting difference is made between 'standard' treatment approaches and PS as a non-standard treatment approach.

Regarding indications of PS, participants mentioned that PS is indicated in situations where health professionals find themselves helpless in front of patient complaints or symptoms such as distress, dyspnoea, pain or haemorrhage.

There was a strong agreement among interviewees that the goal of PS, from their point of view, was invariably to alleviate suffering. Some of the answers indicated a firm conviction that PS would be an effective solution when they feel helpless in front of severe, uncontrolled symptoms. Yet not all participants shared the belief that PS actually relieves suffering in an effective way. One participant mentioned that health care professionals cannot guarantee whether PS actually meets this goal of alleviating suffering. Hence, for example, if they manage to achieve a state without discernible evidence of discomfort, they assume that it means the patient is comfortable. Yet the latter being in a decreased state of awareness is neither able to confirm nor deny this assumption. Therefore, participants might be afraid that they could be accused of using PS to relieve their own distress when feeling helpless and powerless in front of an agonising patient. This explains why there was such a great insistence throughout the interviews that PS is only used once all other measures have failed and is considered a non-standard treatment. This concept of PS may also influence how these health care professionals communicate about PS towards patients and families.

3.2 | Information and communication on PS with patients and families

3.2.1 | Explaining PS to patients and families

There was a diversity of statements regarding how to explain PS to patients and families. Still, one of the major topics that surfaced,

TABLE 1 Personal understanding of palliative sedation

- 'It brings to mind patients who are really unwell, and we've not managed to be able to control their symptoms using standard methods'. (P4, nurse)
- 'For me, what is important, is that it is really a treatment of last resort. Once we've tried everything, we resort to sedation'. (P8, nurse)

TABLE 2 Explaining palliative sedation to patients and families

- ‘So, there are several scenarios (...) we can be caught in certain situations where we know the patient can have a respiratory decompensation (...) in this case we will inform rather early [about PS]’. (P7, nurse)
- ‘If, as a health professional, we can see the danger coming, well, we should think ahead and attempt to address the topic’. (P3, doctor)
- ‘We raise this topic when we are in a situation where we can see an upcoming distress’. (P6, doctor)

TABLE 3 Explaining palliative sedation to patients and families

- ‘You need to make a decision whether you have a meeting with the patient alone and afterwards with the family, or whether you have an entire family meeting’. (P4, nurse)
- ‘It either is a measure that is anticipated because we would like to offer it as a possibility if, suddenly, we were no longer able to comfort. (...) Now, if we are in an emergency situation, it happens that patients arrive in a state of total crisis (...) but for me, information remains important, it will simply be shorter in an emergency’. (P5, doctor)

which is demonstrated in Table 2, was about anticipation, with participants explaining that different scenarios must be distinguished, namely, emergency circumstances and situations where it is possible to anticipate an upcoming distress.

It is conspicuous how in these quotes very emotive words are used to justify PS and its anticipatory discussion: Health care professionals seem to unite with patients in the fear of imminent suffering, and this fear then provokes discussions on PS as a means to control the emotion and prepare the future management of such potential suffering. Thus, these quotes again reinforce the view of health care professionals that PS is a non-standard form of treatment that needs particular justification.

The other main theme that emerged, which is displayed in Table 3, concerned the importance of giving an explanation to relatives. Whether the situation allows anticipation or is already a medical emergency, explaining PS to family members is seen as a fundamental part of the process of PS.

3.2.2 | Timing of information

As stated previously, the national guideline issued by the Swiss Association of Palliative Care does not offer any clear guidance on when the discussion on PS should take place. Hence, the purpose of this question was to know whether participants could offer clear practice recommendations based on their experience. The main theme that surfaced here, presented in Table 4, is that there is not one ideal moment in time to address PS in communication. Nonetheless, several suggestions emerged from the interviews, for example, that it is important to address PS as soon as there is a request from the patient and that professionals disagree about whether the admission is the right setting to discuss PS or not.

TABLE 4 Timing of information

- ‘I don't think that we had any definite rules at the unit’. (P1, nurse)
- ‘It's very variable depending on requests (...) so either it is very shortly before death occurs and sometimes it is more in advance’. (P7, nurse)
- ‘I don't think that in the protocol there was a precise moment’. (P9, nurse)
- ‘I don't think there is a precise moment’. (P10, doctor)

As highlighted by the above quotes, participants used words such as ‘rules’ or ‘protocols’. This is certainly a way to reassure themselves that, in spite of not being able to give a precise answer to this question, they nonetheless follow the available guidelines when performing PS.

3.2.3 | Who should assume the role of delivering the information?

For this question, there was a consensus between nurses that it should be the physician who gives the explanation, whereas one physician declared that ‘a specialised nurse in palliative care is probably more suitable than the medical jargon’ (P5). Still, participants stressed the importance that this discussion should never be done by a single person alone but by a team of two. The most popular duo was doctor and nurse followed by a couple consisting of someone with whom the patient has developed a therapeutic alliance (e.g., his general practitioner, cardiologist or the responsible nurse) and a second person with experience and knowledge about PS. The second recurrent pattern was the need for precise knowledge and experience: At least one person should have good knowledge and experience of PS.

3.2.4 | Would a written document be useful?

Diametrically opposed opinions emerged on the question about the usefulness of a written document. Although this was a closed question, participants were quick to justify their opinion with some arguments. Those who were opposed to such a document indicated that it would not help them in their communication, that the quality of these documents and their retention by patients are usually poor and that they didn't believe ‘patients wish to hear or read it several times’ (P7, nurse). Those in favour of a written document argued that it can provide a concrete support to cling on to and that it could allow standardising of information that is delivered to patients. Nonetheless, participants agreed that a leaflet should in no case replace the discussion and some of those favourable for the written support insisted that it should not be given prior to a verbal explanation.

3.2.5 | Areas in need of improvement

With regard to PS-related information and communication with patients and families, the interviewees identified the following areas in need of improvement: written documentation, standardisation of

practice, knowledge on PS among health care professionals outside of palliative care and health literacy concerning PS in the general public, including the difference between PS and euthanasia.

3.3 | Effects of information about PS

Participants stated unanimously that information about PS could cause anxiety among patients, families and even professionals but that it could also act as a source of relief and comfort. Nonetheless, none of them was able to specify in which situations this information was comforting or when it could be anxiety provoking: 'Oh well, this is really patient dependant' (P9, nurse). Some interviewees acknowledged that this information increased patient autonomy, while others declared that it might restrict patient autonomy as 'in some situations there is no alternative choice' (P2, doctor). The fact that health care professionals could not agree on consistent effects of information about PS might indicate that they have disparate experiences, related maybe to the individual personalities and situations of patients, but maybe also to the specific communication practices of the professionals themselves.

According to the participants, the discussion of PS raises significant conflicts, exemplified by the following quote: 'If there is no conflict regarding a sedation that we suggest, for me it is not normal' (P10, doctor). In other words, information on PS almost invariably leads to conflicts, which can be between the patient and the family, between these and the care team, or even among health care professionals.

3.4 | Attitudes towards systematic information about PS

Initially, all of the participants were quick to disapprove the idea of consistently informing patients newly admitted to a palliative care institution about PS. Interestingly, while reflecting on this question, some of them changed their mind and recognised some situations where this practice could make sense. Still, some stuck firmly with their initial intuition and strongly opposed systematic information, as can be seen in Table 5. The main reason they brought forward is the ethical principle of non-maleficence.

The main thought that emerged among professionals whose opinion slightly changed over the course of their answer is that this might be an appropriate measure for some patients, or even a majority of patients, with a few exceptions. As illustrated by Table 5, they developed some arguments in favour of systematic information, for example, relieving proxies and families from having to make difficult decisions when a patient has lost his decision-making capacity. Yet the fact that despite their arguments, they were initially quick to disapprove this idea, underlines a certain apprehension to talk about PS. A sub-theme that emerged from this question is the courage required to talk about PS, which is highlighted by the quote of Participant 3 (see Table 5). This once again reflects that there is a real fear associated with talking about PS.

TABLE 5 Attitudes towards systematic information about palliative sedation

Against systematic information:	In favour of systematic information:
<ul style="list-style-type: none"> • 'My personal view would probably say no. I think it is a case-by-case basis because it's very specific and they have to be very clear clinical parameters for when you would use this. So, I don't think it's a general information thing'. (P4, nurse) • 'I am not favourable to this. I say it in a clear-cut way (...) I question myself on the balance benevolence-non-maleficence'. (P5, doctor) • 'I am against it! (...) systematic doesn't please me (...) here we kind of have the bullying of wanting to do everything well'. (P10, doctor) 	<ul style="list-style-type: none"> • 'For some patients it would be necessary and even essential to do it and for others you need to go slower and wait a little, follow their timing'. (P7, nurse) • 'It is true that when a patient loses his decision-making capacity it will be the family or a proxy who will have to validate this. And we could therefore put them in a delicate position'. (P1, nurse) • 'It is true that being able to anticipate would be worth it (...) but I am also a little bit concerned, I must admit, that it is an act that could become downplayed'. (P2, doctor) • 'I am not saying it shouldn't be done, I think indeed we should be a little more proactive (...) and braver to speak of this practice'. (P3, doctor)

4 | DISCUSSION

The results of this study show that, while palliative care professionals may share a common understanding of definition, indications and goals of PS, they are uncertain and even in disagreement about questions of information and communication with patients and families about PS. This was particularly striking with respect to how PS should be explained to patients and relatives, whether this information needs to be standardised, and whether written information would be useful. Additionally, although the participants globally agreed on the effects information about PS has on patients and families, none of them was able to clarify in which situations this information was a source of worry for patients. We can assume that this is probably dependent on patients' characters, beliefs and backgrounds as well as the stage of acceptance of their illness. Also, the sociocultural context probably plays a critical role.

The most salient results that will be discussed below are (1) how and when information on PS is delivered, (2) the utility of a written document, (3) opinions towards systematic information and finally, (4) how these questions are relevant in the current Covid-19 pandemic.

4.1 | How and when information on PS is delivered

The results concerning the discussion about PS with patients and its timing were consistent with the literature review (Abarshi et al., 2017; Cherny & Radbruch, 2009; Gurschick et al., 2015) as between the

different interviews there was a lack of consistency as to when these discussions take place. Moreover, participants were unable to mention any guidelines, only the lack of them, concerning communication about PS. Therefore, our results demonstrate the lack of standardisation when it comes to explaining PS to patients and families. So, for example, when a patient is admitted to a palliative ward, it varies in practice whether he or she will be informed about PS and when so. This is not only problematic from the perspective of fair and equal access to health care. It also seems to be in contradiction with the current trend of empowerment in health care (Bravo et al., 2015; Eskildsen et al., 2017; Jørgensen et al., 2018), as health and death literacy is becoming ever more important in advanced care planning and end-of-life discussions (Hayes et al., 2017). Furthermore, some health professionals highlighted the lack of standardisation when asked about areas of improvement, suggesting they would need guidelines or recommendations on the institutional or national level. This is in tune with prior studies that have shown that even in palliative care units the setting around PS remains ambiguous and that there is no consensus on important conditions for PS, such as unbearable suffering (Chazot & Henry, 2016; Tomczyk, 2018; Tomczyk et al., 2018).

4.2 | Utility of a written document

One way of achieving a more equally distributed, reliable information practice could be the use of written information material, as some participants suggested. However, interviewees were divided on this question, and some clearly opposed the idea of a written support in the form of a leaflet. Yet, according to the literature, when leaflets contain evidence-based information and are reviewed and updated on a regular basis, they can be a useful education aid for patients (Bapat et al., 2017; Piddennavar & Krishnappa, 2015). Maybe they could even be construed to serve as decision aids empowering patients, families and professionals to make better informed and more autonomous decisions on the use of PS (Cardona-Morrell et al., 2017). Also, such a document could improve end-of-life literacy or foster open discussion about the end of life, but this would need to be tested in a separate study. The concerns of some of our participants should, however, be taken seriously when designing and using such documents for the palliative care and hospice context: An easily comprehensible, cautious wording would be as important as its judicious application for those patients who have high information needs, who want to plan ahead and for whom PS could realistically become medically indicated.

4.3 | Opinions towards systematic information

None of the participants were favourable to a generalised information on PS for all patients admitted on the palliative ward. Some were strongly against it, while others were more divided. Our study revealed reasons in favour of such proactive information politics: It could allow patients to exert a better autonomy, be reassuring for caregivers, and some patients may resort to PS rather than forms of

hastening death. Still, the risk of in-advance information being harmful for some patients prevailed on all these reasons. Also, some were reluctant to systematically address PS with newly admitted patients, as it is still very much a taboo subject, a source of controversy and often confused with euthanasia and can therefore act as a source of distress for health professionals, which is in keeping with the literature (Anneser et al., 2016; Juth et al., 2013; Lokker et al., 2018; Toporski et al., 2017; Ziegler et al., 2018a).

Yet some health professionals mentioned the heavy burden carried by proxies and families when a patient loses his decision-making capacity. Previous studies observed a substantial negative emotional effect that lasts months or even years in one third of proxies that had to take treatment decisions for others (Wendler & Rid, 2011). Besides, one third of families acting as a proxy in such situations develop high levels of distress in relation to the burden of responsibility (Hamano et al., 2018; Wendler & Rid, 2011). In this way, early systematic information could help clarify patients' end-of-life treatment preferences and consequently reduce the weight on the shoulders of surrogates and families, which, however, needs to be carefully proven in naturalistic studies.

Additionally, one reason supporting systematic information that did not show up in the results is that it could be a way to standardise practice and thus increase equity in care. Moreover, articles in other settings have shown a strong correlation between standardisation of care processes and quality of care, reduced costs and patient satisfaction (Bozic et al., 2010; Thiele et al., 2015; Wolters Kluwer, 2017). Taken together, our results hint to various research questions and hypotheses that deserve a thorough investigation in larger empirical studies.

4.4 | Information on PS and Covid-19

The topic of PS is particularly relevant in the current SARS-CoV-2 pandemic. Indeed, Covid-19 frequently presents itself as a lower respiratory tract infection in at-risk patients, and dyspnoea is a common symptom and a risk factor for developing a severe disease (Kaeuffer et al., 2020; Krähenbühl et al., 2020; Nehme et al., 2020). Our study results also confirm a tenet in scientific literature that refractory dyspnoea is a frequent indication for PS (Arantzamendi et al., 2021; Cherny & Radbruch, 2009; Garetto et al., 2018). Given the fact that Covid-19 can progress rapidly and that end-of-life situations can develop abruptly and unforeseen in this context, an effective, proactive and empowering information about Covid-related end-of-life options, including PS, would merit consideration (Borasio et al., 2020; European Association for Palliative Care, 2020; Palliative Care, 2021). Such information could specifically be helpful for those patients who refuse intensive care treatment or for whom such treatment would be medically futile, for example, patients with highly advanced, severe illnesses who are near the end of their lives or patients in nursing homes who do not wish to be hospitalised and prefer a comfort-only approach. Informing them about palliative end-of-life options, including PS, should be integrated into a personal communication context, with competent palliative care nurses or physicians offering these discussions to patients and families.

4.5 | Limitations

Although we took care to maximise diversity with regard to gender, profession and work environment, all 10 participants came from one palliative institution in Switzerland. Our study results thus give insights into palliative care professionals in a particular institution, but we still hypothesise that the situation may not be completely different in other institutions. Furthermore, we decided to use a specific form of qualitative text analysis, namely, thematic analysis according to Braun and Clarke, which necessarily comes with a certain restriction in the interpretation of the data gained.

4.6 | Take home messages

- A better understanding and knowledge of PS among health professionals outside of palliative care and in the general public is needed.
- There is a lack of standardisation when it comes to discussing PS with patients and relatives.
- Larger empirical studies on the process of delivering information about PS, which include patients and families, are desirable, also with regard to the current Covid-19 pandemic.

AUTHORS' INSTITUTIONAL AFFILIATIONS

This work was conducted at the Centre Hospitalier Universitaire Vaudois (CHUV), 1011 Lausanne, Switzerland. At the time, the first author was completing his master's degree at Medical School at the University of Lausanne. However, he is currently working as a medical intern in the public regional hospital of Interlaken (Spitaler fmi AG, Weissenaustrasse 27, 3800 Unterseen, Switzerland). The second and third author's institutional affiliations remain the same.

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CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

The datasets generated and analysed during the current study are available from the corresponding author on reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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APPENDIX A: 'INTERVIEW GUIDE' USED DURING INTERVIEWS WITH PARTICIPANTS

Themes	Questions	Examples
1. Concept of palliative sedation	1.1 Definition 1.2 Indications 1.3 Goals	<ul style="list-style-type: none"> • What does the term 'palliative sedation' bring to mind? • In what situations is it justified to resort to palliative sedation? • For you, what is the goal/purpose of palliative sedation?
2. Information and communication	2.1 Personal experience 2.2 Timing of information 2.3 Who informs? 2.4 Written document 2.5 Improvements	<ul style="list-style-type: none"> • How do you proceed when you explain what palliative sedation is to a patient? • At what moment does this explanation take place? • Who is best equipped to inform patients/families? • Do you think a written document (leaflet) could help you in this process? • Which aspects concerning information on palliative sedation should be improved?
3. Effects of information	3.1 Anxiety or relief 3.2 Autonomy 3.3 Conflicts	<ul style="list-style-type: none"> • According to your clinical experience, what effects does this information have on patients and families? • How does this information contribute to patient's autonomy? • Could this information create conflicts or disputes?
4. Systematic information	4.1 Conclusion	<ul style="list-style-type: none"> • What do you think of systematic information for all patients in specialised palliative care as soon as they arrive on the ward/unit?