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ORIGINAL ARTICLE

Current debates on end-of-life sedation: an international expert elicitation study

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Abstract
Purpose End-of-life sedation, though increasingly prevalent and widespread internationally, remains one of the most highly debated medical practices in the context of palliative medicine. This qualitative study aims to elicit and record the perspectives of leading international palliative care experts on current debates.
Methods Twenty-one professionals from diverse backgrounds, sharing field-specific knowledge/expertise defined by significant scholarly contribution on end-of-life sedation, were recruited. Open-ended, semi-structured interviews, following a topic-oriented structure reflecting on current debates, were conducted. Results were analysed using thematic content analysis.
Results Three main aspects of sedation were identified and discussed as potentially problematic: (a) continuous deep sedation as an extreme facet of end-of-life sedation, (b) psycho-existential suffering as an ambivalent indication for sedation and (c) withdrawal or withholding of artificial nutrition and hydration as potentially life-shortening. On these grounds, concerns were reported over end-of-life sedation being morally equivalent to euthanasia. Considerable emphasis was placed on intentions as the distinguishing factor between end-of-life acts, and protective safeguards were introduced to distance sedation from euthanasia.
Conclusions This study shows that, despite the safeguards introduced, certain aspects of sedation, including the intentions associated with the practice, are still under question, parallels being drawn between end-of-life sedation and euthanasia. This reaffirms the existence of a grey area surrounding the two practices, already evidenced in countries where euthanasia is legalized. More clarity over the issues that generate this grey area, with their causes being uncovered and eliminated, is imperative to resolve current debates and effectively inform research, policy and practice of end-of-life sedation.

Keywords End-of-life sedation · Palliative care experts · Artificial nutrition and hydration · Psycho-existential suffering · Grey area

Introduction

End-of-life sedation is a last resort treatment strategy introduced to alleviate unbearable suffering, which is unresponsive to conventional therapies, in terminally ill patients with limited life expectancy. This can be achieved via the monitored use of sedative medication, leading to an intentional decrease in consciousness, occasionally to the point of complete loss, with no intention of causing or hastening death [1].

This decrease in consciousness has been argued to be concomitant with minimizing or removing the ability to think, feel or interact during the last days of life [2]. As a result, the ethical appropriateness of the practice has been questioned, parallels being drawn between end-of-life sedation and other end-of-life acts, particularly euthanasia [3–5]. Beyond the ethical or moral dilemmas, controversy also seems to have reached clinical practice, with discussions being raised about the extent to which end-of-life sedation is medically indicated [6]. A series of clinical characteristics of the practice, mainly time of initiation, clinical indications, drug administration and artificial nutrition and hydration (ANH) have been frequently debated [7]. Even at a purely conceptual level, end-of-life

The members of EUROIMPACT are Van den Block Lieve,[a] De Groote Zeger,[a] Brearley Sarah,[e] Caraceni Augusto,[g, h] Cohen Joachim,[a] Francke Anneke,[b] Harding Richard,[c, d] Higginson Irene J,[c, d] Kaasa Stein,[f] Linden Karen,[k] Miccinesi Guido,[i] Onwuteaka-Philipsen Bregje,[b] Pardon Koen,[a] Pasman Roeline,[b] Pautex Sophie,[j] Payne Sheila,[e] and Deliens Luc.[a, b]

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sedation appears to be rather problematic since no standard term or definition seems to have gained wider acceptance [8].

Research on end-of-life sedation has aimed to address and explore these issues. Prospective and retrospective studies have been undertaken to elicit and record detailed accounts of experiences, attitudes and viewpoints of various individuals directly (physicians, nurses, patients) or indirectly (relatives, medical house officers, general population) involved in the practice of sedation [9–14]. Evidence indicates that confusion and inconsistency persist in almost every aspect of the practice [15] leading to an increase in current debates over end-of-life sedation.

This study aims to explore current debates and seek answers to a series of critical conceptual, medical and ethical issues underpinning the practice of end-of-life sedation. This is the first study to recruit experts, defined as professionals sharing field-specific knowledge established by significant scholarly contribution on end-of-life sedation. The primary aim of the study is to elicit and record the perspectives of experts on the issues under question, explore commonalities and differences in reported perspectives and provide a basis to potentially account for the difficulty in reaching consensus.

Methods

Study design and data generation

This qualitative study is part of a European Commission Seventh Framework Programme project aimed at optimizing the quality of palliative care in Europe (EUROIMPACT). On the basis of a bibliometric analysis (1945–2011) conducted to map the scientific output on end-of-life sedation [16], literature searches were repeated, and results were updated. Data sources were expanded to include two additional databases (AMED and CINAHL) and two high-impact-factor journals (BMJ and NEJM). The timeline was also extended to account for new entries up to June 2012. In total, 352 published outputs comprised the pool of available participants for sampling to be initiated.

Sampling and recruitment

To select our panel of experts, purposive (expert) sampling was employed. Expertise in this context was defined as scholarly expertise, i.e. extensive field-specific knowledge defined by substantial scientific output. This was assessed on the basis of authorship credits allocated by using the harmonic credit counting model [17]. Inclusion criteria comprised authors (a) holding a PhD and/or MD as a minimum qualification and (b) scoring more than three authorship credits. Participants who engaged in the development of procedural guidelines or have published influential papers (>100 Citations) shaping research on the field were also included, regardless of their score. A final sample of 33 eligible participants was identified.

Of the 33 eligible participants, five could not be recruited into the study due to lack of contact details. The remaining 28 participants were sent an invitation email, including a written informed consent form, which they were required to sign and return to confirm participation. Twenty-one people consented to participate in the research, a response rate of 75 %.

Ethical approval

The study protocol, participant information and consent procedures were approved by the Faculty of Health and Medicine Research Ethics Committee of Lancaster University, UK.

Data collection and preparation

Data were collected from October 2012 through February 2013. Open-ended, semi-structured interviews were conducted. A flexible, topic-oriented interview guide including open-ended questions was developed. Topics were informed by the literature comprising frequently debated issues underpinning the practice of end-of-life sedation: (a) conceptual (terms and definitions), (b) medical (end-of-life suffering and patient symptomatology) and (c) ethical (end-of-life sedation vs. physician-assisted death). Open-ended questions were designed to reflect on such issues. Interviews sought to elicit and record participants' perspectives on the topics under question. To facilitate response, prompts were formulated for each question. All interviews were conducted in English (via telephone or Skype), were audio-recorded with permission and lasted approximately 30 min.

Upon completion of the interviews, audio-recordings were transcribed verbatim by professional transcribers. Each transcript was reviewed for quality, and all identifiers were removed. These transcripts comprised the study data.

Data analysis and procedures

Transcripts were analysed using thematic content analysis, as described by Strauss and Corbin [18]. This inductive approach involves open coding, clustering and category formation. An initial coding framework was developed. Results were compared, and the initial coding framework was refined to its final version through discussion and consensus. This final coding framework comprising four main themes (description and classification of end-of-life sedation, end-of-life suffering and qualifying clinical characteristics, the use of ANH at the end of life, and the role of intentions in end-of-life acts) was submitted and approved by all the authors.

The final framework was applied to all data, and the contents of each transcript were coded under the appropriate themes. Data were inserted into a spreadsheet, providing a

visual summary of the dataset that allowed for explanations and patterns to be identified. This was a means of connecting the data with the primary research aim to elicit, record and explore commonalities and differences in reported perspectives on current debates over end-of-life sedation.

To ensure explicit and comprehensive reporting, the COREQ (consolidated criteria for reporting qualitative research) checklist was used [19]. Direct quotations were selected to represent a significant body of data or to illustrate views and perceptions which were contrary to the majority.

Results

The demographic characteristics of the 21 participants are shown in Table 1. Most participants were male. The ages ranged from 31 to 69 with a median of 53. They all had substantial research and/or practice experience in end-of-life sedation (a median of 16 years). Their professional backgrounds were diverse, and they originated from ten countries worldwide.

Table 1 Characteristics of study participants

Characteristics	Value[a]
Gender	
Male	17 (81.0)
Female	4 (19.0)
Age (years)	
Median (range)	53 (31–69)
Years in research and/or practice	
Median (range)	16 (4–30)
Professional background	
Physicians	13 (61.9)[b]
Ethicists	3 (14.3)
Medical sociologists	2 (9.5)
Nurses	2 (9.5)
Health scientist	1 (4.7)
Country of origin	
USA	5 (23.8)[b]
Belgium	5 (23.8)
Netherlands	2 (9.5)
Germany	2 (9.5)
Italy	2 (9.5)
Norway	1 (4.8)
UK	1 (4.8)
Israel	1 (4.8)
Japan	1 (4.8)
Canada	1 (4.8)

[a] Data are given as numbers (percentage) of study participants unless otherwise indicated

[b] Percentages may not amount to 100 % due to rounding

Reported perspectives revealed patterns of convergence and divergence illustrative of participants' perceptions on end-of-life sedation and of similarities and differences in sedation practices. Such patterns were seen to underlie the responses to all main four themes identified.

Description and classification of end-of-life sedation

Considerable variation was observed in the way the concept of end-of-life sedation was approached. Our participants employed several terms to describe the practice, a strong preference being indicated for palliative sedation (n=13). Arguments cited for and against certain terms were diverse, mostly attributed to the circumstances under which end-of-life sedation is to be initiated (Box 1, quotes 1 and 2). These circumstances involved when, how and why end-of-life sedation should be considered. Regardless of the variation in term choice, however, reported perspectives seemed to coincide in the classification of end-of-life sedation. Two main groups (facets) of the practice were largely acknowledged, with most participants (n=12) classifying end-of life sedation based on level of consciousness (Box 1, quote 3). The first group, end-of-life sedation leading to decreased consciousness, was widely recognized as part of normal medical practice. In contrast, the second group, end-of-life sedation leading to complete absence of consciousness (continuous deep sedation), was referred to as being a distinct and extreme facet of sedation that should be rarely used and restricted to certain conditions. Presupposed conditions included the following: timeframe (the patient being imminently dying), last resort (all other alternatives having been exhausted) and informed consent (having been obtained). No explicit reasoning was provided to account for its extreme nature apart from that it could potentially associate end-of-life sedation with euthanasia.

Box 1. Description and classification of end-of-life sedation

Description

In favor of 'palliative sedation' (13/21)

Quote 1: I saw several reasons why I would prefer the term 'palliative sedation'. First of all, it shows why you are offering this type of sedation—it's for palliation, it's for the control of symptoms—that's the first thing. It shows to whom you are offering this type of sedation—palliative care patients—so the terminally ill. It does not suggest that the idea of sedation is to terminate life or to be permanent,… and then a fourth reason is that, as the word, as we decided to talk about 'palliative care' instead of 'terminal care', I thought also in the case of sedation it was better to talk about 'palliative sedation' because it has a much more positive meaning. It's not abandoning the patient; it's trying to help even in very difficult circumstances, and this positive notion of palliation I wanted to add to the concept. So 'palliative sedation'. (P14)

Against 'palliative sedation' (8/21)

Quote 2: Because 'palliative sedation' is a term that is—how should I put it—overly positive: it conveys the impression that it's by definition something good, it sounds good, 'palliative sedation,' when in some cases it might not be good at all. So this is what ethicists would call sanitizing terminology, which I think we should avoid. And at the beginning of my work, I used to use the term 'terminal sedation', but after two papers, I also came to the conclusion that this is overly negative and that, if I was criticizing other people for using sanitizing terminology, then I should also criticize myself for putting it perhaps in too negative a light. So that's why from then on, I only used 'continuous sedation at the end of life' or 'continuous deep sedation at the end of life,' because that in my view is a purely descriptive term and doesn't convey that the practice is either necessarily good or necessarily bad. (P15)

Classification

Based on level of consciousness (12/21)

Quote 3: But of the two things that are relevant here, one would be… well, the term we used was 'proportionate palliative sedation' where you basically use the least amount of sedation needed to help the patient feel more comfortable. So it might be very mild sedation; it might be medium sedation; it might be heavy sedation, but you basically gradually increase the amount of sedation until you get the right level… But the other common sedation is, I think, more extreme and that would be 'palliative sedation to unconsciousness' and that would be for use in severe cases where people are near death and suffering is extreme and there is no other way to escape. That should be relatively rare, in my opinion, and should… you'd have second opinion, should have a lot of thought go into as much as possible what you're doing. (P12)

No reference to classification (9/21)

End-of-life suffering and qualifying clinical characteristics

Certain inconsistencies were observed in the way our participants perceived and described end-of-life suffering. While symptom nature (intractable) was cited by all (n=21) as a prerequisite for sedation to be considered, symptom intensity (unbearable) was highlighted by some (n=7) as subjective (Box 2, quote 1). Distinctions were drawn between intractable and difficult symptoms as well as between symptom nature and symptom intensity. Several participants (n=10) provided complementary aspects such as timeframe and the last resort option to facilitate understanding of intractable end-of-life suffering. However, the main inconsistency lay in symptom classification, more specifically, in the types of symptoms that could be considered sufficient for sedation to be initiated. Though most participants (n=15) acknowledged end-of-life suffering as multi-dimensional including physical and psycho-existential suffering (Box 2, quote 2), concerns were expressed over the appropriateness of using end-of-life sedation to relieve the latter. Despite physical suffering being widely perceived as a clear-cut indication for sedation to be initiated, psycho-existential suffering attracted a wide range of responses (Box 2, quotes 3 to 6). Some participants (n=4) made no reference to it, and others (n=4) clearly rejected it while one (n=1) would only agree to it being considered as a qualifying indication for end-of-life sedation if directly related to physical suffering. Several participants (n=8) recognized this type of suffering as a possible reason to initiate sedation, delineating the need for protective safeguards. These involved the presence of a multidisciplinary team and consultation with experts to ensure optimal clinical assessment of symptom severity and establish the nature of such suffering as intractable, before proceeding with end-of-life sedation. Few participants (n=2) responded indirectly by citing evidence from the literature, while there were also cases (n=2) where participants refused to provide a response by calling upon their non-clinical status.

Box 2. End-of-life suffering and qualifying clinical characteristics

End-of-life suffering

Subjectivity of end-of-life suffering (7/21)

Quote 1: Well, I think suffering is something which is subjectively experienced, isn't it? It's a bit like pain is what the patient says it is; suffering is what the patient says it is… to some extent suffering is going to be in the eye of the beholder, and particular places, particular practitioners and particular cultures may respond to different types of suffering in a variety of ways. And some people may see a sort of loss of dignity to be far more important than any physical suffering. (P20)

End-of-life suffering perceived multi-dimensionally (15/21)

Quote 2: Well, you have refractory symptoms of whatever type… [Investigator: So basically it's more of a combination of psychical and existential?] Of course, because it's so difficult when you want to be too much analytical, but when you suffer, you suffer with your mind and your body together. (P01)

Qualifying clinical characteristics

In favour of psycho-existential suffering (8/21)

Quote 3: In fact, every symptom can cause an intractable situation. It can be pain, it can be delirium, it can be nausea and vomiting, it can be itching, it can be tiredness, the fatigue… yeah, so all this kind of symptoms can be at a certain moment for a patient intractable and insupportable… so it depends a little bit on the case and, there are also situations where it's not only a somatic reason because you have to consider also psychological or existential problems. (P16)

Against psycho-existential suffering (4/21)

Quote 4: My bias is that it should be focused on physical symptoms, not psychosocial or existential intractable suffering. Well, in our experience, the most common reasons in order of frequency would be delirium, dyspnea… pain being very further down in the list and nausea very infrequently. So delirium and dyspnea would be relatively common; pain and nausea would be very rare reasons. (P09)

No reference to psycho-existential suffering (4/21)

Psycho-existential suffering accepted only if directly related to physical suffering (1/21)

Quote 5: … suffering is often a mix, as you know, physical and psychological, social and spiritual issues, and it's usually a mix, but as long as it's anchored in a severe, physical illness, again I think we're on solid ground. (P12)

No (or indirect) response to qualifying clinical characteristics (4/21)

Quote 6: [Investigator: in your opinion, what symptoms you would consider sufficient to justify the prescription of sedation at the end

of life?] Well, I've not been in clinical practice for a long time, so I think I'm probably not that well equipped to answer that question. I think that's something that you'd have to ask your medical respondents. (P20)

The use of artificial nutrition and hydration at the end of life

Special attention was drawn to the use of ANH at the end of life and the direct association between this and ethical concerns and dilemmas. Some of our participants (n=5) perceived the decision to withdraw or withhold ANH during end-of-life sedation as potentially life-shortening (Box 3, quote 1). These participants clearly stated that forgoing food and fluids, especially in patients to whom continuous deep sedation is prescribed, might result in a hastened death. There was concern that crossing the line of intentions between alleviating suffering and hastening death could bring end-of-life sedation one step closer to euthanasia (Box 3, quote 2). On this basis, in cases where ANH is withheld or withdrawn, these participants perceived end-of-life sedation as a covert form of euthanasia.

Box 3. The use of ANH at the end-of-life

Against withholding or withdrawing artificial support (5/21)

Quote 1: Of course, you can point to, if you remove hydration, nutrition and all that kind of stuff and then you expect the patient to die in let's say two or three weeks, then you may… will think well, this is probably causing the patient to die because without those… I mean without hydration, without nutrition and all those things, there are a lot of processes going on in the body that is likely to cause death or you may begin to expect death to happen from that removal of support treatments. (P06)

Quote 2: I'm always very surprised when I read for example in guidelines, in a lot of the guidelines it is claimed that, since they have this limit usually of, you know, one or two weeks' life expectancy, they then say, 'Oh, it's no problem to withdraw nutrition and hydration' or to withhold nutrition and hydration 'because, well, it's not going to be life-shortening anyway.' That may well be true for nutrition but that is certainly not true for hydration and I think that… what some people even label as 'palliative care philosophy'—namely that you withdraw hydration and nutrition because you don't want to extend life—well, that is the same as saying that by not continuing it, you're in fact shortening life. If by continuing it the person would have a life expectancy of x and you withdraw it and you say, 'Oh, so we're not extending life.' Okay, fine, but then you are shortening it. Just be open and honest about it. And there may be good reasons to do so, but I have a problem with this… again these desperate attempts to emphasize the difference between sedation and euthanasia, when I think sedation without nutrition and hydration, or in any case without hydration, morally speaking is very similar to shortening life. (P15)

No reference to the use of artificial support (16/21)

The role of intentions in end-of-life acts

End-of-life sedation was widely perceived as part of normal medical practice, comprising part of the medical armamentarium available at the end of life. However, whenever responses focused on continuous deep sedation, psycho-existential suffering and withdrawal or withholding of ANH, this perception noticeably changed, and associations were drawn between end-of-life sedation and euthanasia. In such cases, the vast majority of our participants (n=16) focused on intentions as the key distinguishing factor, with the intention of sedation being to relieve end-of-life suffering while, in contrast, the intention of euthanasia is to end suffering (Box 4, quote 1). To facilitate understanding of this distinction, some participants (n=5) called upon the principle of double effect. This entails that an act which may have a good or bad effect is ethical if the nature of the act is morally good or neutral. However, some participants (n=3) voiced concerns over end-of-life sedation being ethically problematic since intentions cannot be always objectified while others (n=2) pointed out that, in countries where euthanasia is legalized, this lack of clarity on intentions has resulted in a grey area between the two practices (Box 4, quotes 2 and 3).

Box 4. The role of intentions in end-of-life acts

Intentions: drawing the line between end-of-life sedation and euthanasia (16/21)

Quote 1: I think, first, the intention is very different: the intention is to relieve suffering or in a most extreme version of terminal sedation, to erase it, if you like, and so that… the intention in euthanasia is to kill the patient as fast as possible, and thus it is to hasten death in a matter of minutes. (P06)

Intentions: an impractical criterion to distinguish between end-of-life sedation and euthanasia (5/21)

Subjectivity of intentions (3/21)

Quote 2: One of the challenges is that some of the patients who get this are really prepared to die, they're ready to die, they would prefer to have euthanasia but that is illegal and not available, so they might choose this as an alternative or as the best available alternative, and I think then for some people that would make it too close to euthanasia, but again I think… you know, requiring that patient have pure intentions in this situation is a tall order, so I don't know that you can ever require that. (P12)

Ambiguity of intentions: the 'grey area' (2/21)

Quote 3: So I think, when you want to… when you want to compare sedation to euthanasia, we must see that on a conceptual level, there is quite a big difference between the two but in practical terms, when you look at practice, especially in Flanders in Belgium where I did my research, you could see a very, very dark grey zone between the two practices—something that many people choose to ignore but I think should be addressed. (P03)

Discussion

Summary of main findings

Current evidence indicates that debates over end-of-life sedation still persist on multiple grounds (conceptual, medical and ethical). However, concerns seem to be rather focused on

specific aspects of the practice (Fig. 1). Three main aspects were identified and discussed as potentially problematic: (a) continuous deep sedation as an extreme facet of end-of-life sedation, (b) psycho-existential suffering as an ambivalent indication for end-of-life sedation and (c) withdrawal or withholding of ANH as potentially life shortening. There was concern that these areas might compromise end-of-life sedation as part of normal medical practice and result in a grey area concerning what constitutes sedation or euthanasia. Intentions were cited as the basis to distinguish between end-of-life acts, and the use of certain criteria (protective safeguards) to distance end-of-life sedation from euthanasia was also described.

Interpretation of results

Conceptually, continuous deep sedation was widely perceived as being a distinct, relatively rare and particularly extreme type of sedation that should only be considered under specific circumstances. This finding conforms to what part of the literature suggests about continuous deep sedation. This type of end-of-life sedation, frequently referred to as far-reaching, has been heavily criticized for intentionally suppressing the notion of personhood leading patients to social death and predictably shortening their life by inducing a permanent coma [20, 21]. As a result, patients rendered deeply and irreversibly unconscious lack personhood and ought to be considered 'dead' [22]. However, counterarguments comprise three main elements. First, personhood is not solely dependent upon the presence of consciousness-related features [22]. Second, the loss of consciousness in CDS is neither permanent nor irreversible. Indeed, it is the ongoing administration of sedative drugs that results in the patient remaining unconscious, but the potential for reversibility exists as long as the patient is alive [23]. Third, losing consciousness is often an inherent part of the dying process. Hence, having a low or very low consciousness at the end of life should not be perceived as an extraordinary or unnatural situation [2]. This evidence denies concerns over an association between end-of-life acts and distances continuous deep sedation from euthanasia.

Medically, psycho-existential suffering was not considered to be a sufficient indication for end-of-life sedation to be initiated. This perspective seems to coincide with guideline recommendations for extreme caution when there is evidence of psycho-existential suffering [24–26]. Similarly, a wide range of literature suggests that physical suffering is probably the most apparent and recognizable type of suffering and is likely to be a domain with which physicians are most familiar

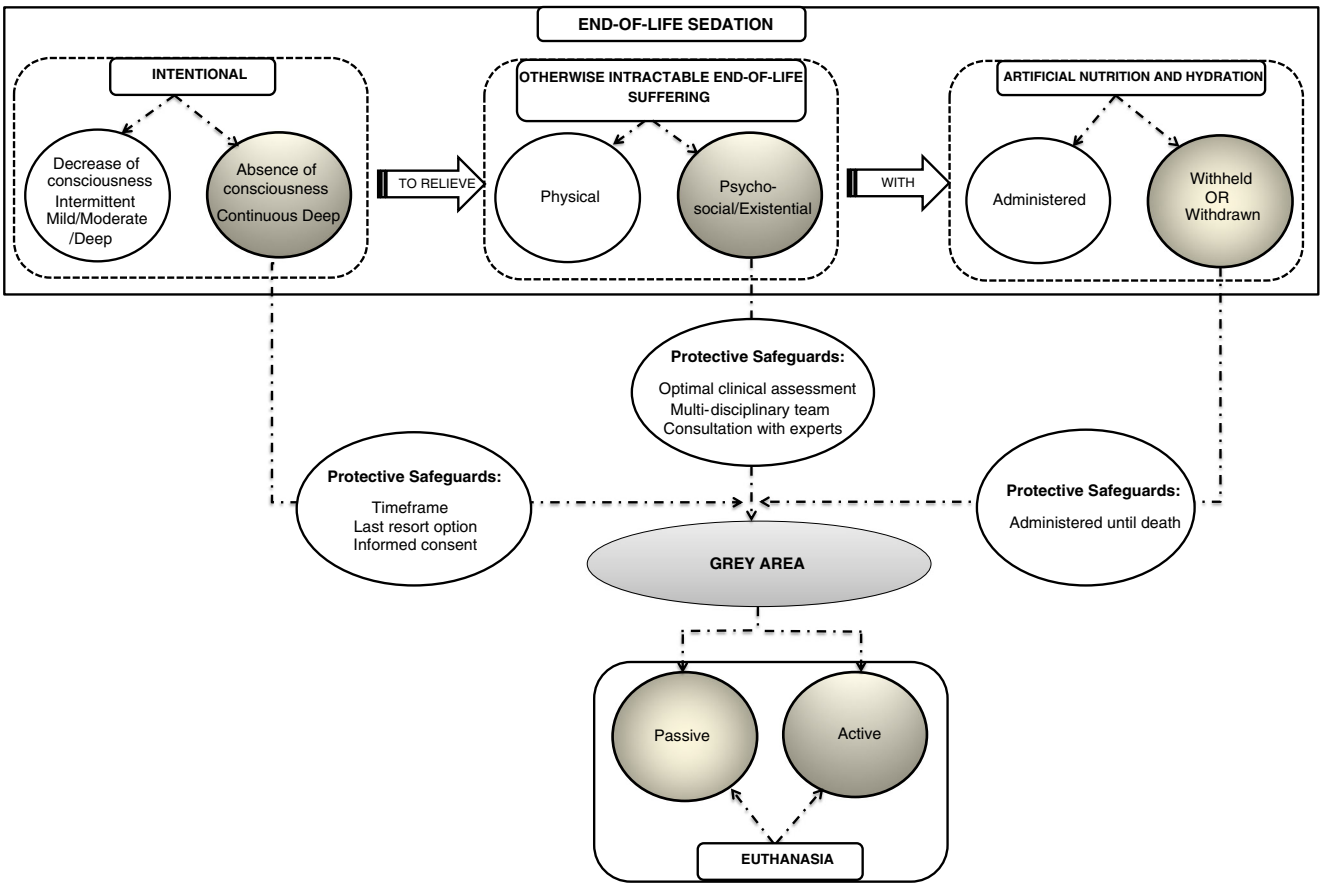

Fig. 1 Results framework

[27]. In contrast, psycho-existential suffering is considered subjective, hard to define and difficult to evaluate and manage given the lack of well-established tools or strategies [28–30]. However, making a medical distinction between the person and the body, relating suffering only to the latter, has been also criticized since the patient (person) is to be understood as a complex social and psychological entity whose suffering can include pain or other physical symptoms but is by no means limited to it [30]. This is probably why our participants acknowledged all facets of end-of-life suffering but, being mostly physicians, were hesitant to accept psycho-existential suffering as a clear indication for end-of-life sedation. However, in contrast to the concerns voiced over psychosocial/existential suffering being not a sufficient indication in itself for end-of-life sedation, literature reports that the practice is increasingly being administered to treat psycho-existential rather than physical symptoms [31, 32].

Withdrawing or withholding ANH at the end of life was perceived as life shortening. This finding seems to contradict guideline recommendations, whereby the continued administration of ANH is not encouraged unless the benefits outweigh the harm [33]. However, no strong evidence exists to support its use for the majority of terminally ill patients. Though retrospective studies on artificial nutrition in advanced illness have shown a consistent lack of benefit [34, 35], the role of artificial hydration still remains controversial. There have been arguments on both clinical and ethical grounds, for and against providing parenteral fluids in dying patients [36]. The impact of artificial hydration, however, on both quality and length of life cannot be determined due to the lack of sufficient good quality studies to allow for recommendations to be made [34]. Literature also suggests that discontinuation of ANH can occasionally result in distress for patients, family members and health-care providers [37]. Despite this, the decision to continue the administration of artificial support solely as a protective safeguard to avoid such distress or avert associations between end-of-life sedation and euthanasia might not always be the best choice.

Finally, intentions were widely used as the basis to distinguish between end-of-life acts. This evidence seems to comply with a wide part of the literature focusing on intentions and the principle of double effect to draw the line between end-of-life sedation and euthanasia. However, intentions have been widely argued to be an impractical criterion to distinguish end-of-life acts. Not only can they be highly personal, locked within the mind of the physician or the patient, and difficult to validate externally, but they may also be multi-layered, ambiguous and, in some cases, even contradictory [38, 39]. Similarly, the application of the double-effect principle to clinical situations has been criticized on the basis of preconceived ideas of what constitutes 'good' and 'bad' acts and the challenges posed by determining intentions [40]. Several studies examining end-of-life sedation confirm such criticisms by reporting subjectivity, confusion and considerable ambiguity of intentions [41–43]. This lack of clarity comprises the source of a grey area between alleviating symptoms and hastening death, where the intention stops being merely to palliate. In this context, end-of-life sedation begins to resemble euthanasia. Our findings indicate that this grey area, already evidenced in countries where euthanasia is officially legalized [44, 45], seems to exist internationally regardless of the legal framework on end-of-life acts.

Strengths and limitations

The major strengths of this study lie in its international scope and its sample of experts. This is the first study to recruit participants, from ten different countries, sharing expertise on end-of-life sedation stemming from diverse professional backgrounds, which allowed for a wider range and greater variation in reported perspectives. Still, this study suffers a number of limitations. First, our panel of experts was quite restrictive in terms of gender and age, most participants being male and over 50 years. This might have confounded a broader and potentially more diverse input of perspectives. Second, our participants' professional status might have influenced the validity of their responses, being overly firm or patronizing on the basis of their expertise. Third, the researcher's personal opinions and beliefs could have interfered with the interpretation of results. This, however, was counterbalanced by research team discussions.

Conclusion

This study adds new information about how current debates on end-of-life sedation should be approached and addressed. Our data show that, despite the protective safeguards introduced, certain aspects of the practice including the role of intentions associated with it are still open to criticism and questioning. As a result, space is allowed for parallels to be drawn between end-of-life sedation and euthanasia. This reaffirms the existence of a grey area surrounding the two practices, already evidenced in countries where euthanasia is legalized. This grey area might compromise end-of-life sedation as part of normal medical practice resulting in confusion, inconsistency and conflict concerning the extent to which end-of-life sedation is medically indicated and ethically permissible. More clarity over the issues that generate this grey area, with their causes being uncovered and eliminated, is imperative for current debates over end-of-life sedation to be brought to a close.

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Disclosures None

References

1. Cherny NI, Radbruch L (2009) European association for palliative care (EAPC) recommended framework for the use of sedation in palliative care. Pall Med 23:581–593
2. Claessens P, Menten J, Schotsmans P, Broeckaert B (2012) Level of consciousness in dying patients. The role of palliative sedation: a longitudinal prospective study. Am J Hosp Palliat Care 29:195–200
3. Fine PG (2001) Total sedation in the end-of-life care: clinical considerations. J Hosp Palliat Nurs 3:81–87
4. Baumrucker SJ (2002) Sedation, dehydration and ethical uncertainty. Am J Hosp Palliat Care 19:299–300
5. Sinclair CT, Stephenson RC (2006) Palliative sedation: assessment, management, and ethics. Hosp Physician 42:33–38
6. Rietjens JAC, Buiting HM, Pasman HRW, van der Maas PJ, van Delden JJM, van der Heide A (2009) Deciding about continuous deep sedation: physicians' perspectives. A focus group study. Pall Med 23:410–417
7. Cowan JD, Palmer TW (2002) Practice guide to palliative sedation. Cur Oncol Reports 4:242–249
8. Papavasiliou ES, Brearley SG, Seymour JE, Brown J, Payne SA (2013) From sedation to continuous sedation until death: how has the conceptual basis of sedation in end-of-life care changed over time? J Pain Symptom Manage 46:691–706
9. Blondeau D, Dumont S, Roy L, Martineau I (2009) Attitudes of Quebec doctors toward sedation at the end of life: an exploratory study. Palliat Support Care 7:331–337
10. Brinkkemper T, Klinkenberg M, Deliens L, Eliel M, Rietjens JAC et al (2011) Palliative sedation at home in the Netherlands: a nationwide survey among nurses. J Advan Nurs 67:1719–1728
11. Morita T, Ikenaga M, Adachi I, Narabayashi I, Kizawa Y et al (2004) Family experience with palliative sedation therapy for terminally ill cancer patients. J Pain Symptom Manage 28:557–564
12. Anquinet L, Raus K, Sterckx S, Smets T, Deliens L, Rietjens JAC (2012) Similarities and differences between continuous sedation until death and euthanasia—professional caregivers' attitudes and experiences: a focus group study. Pall Med 27:553–561
13. Kaldjian LC, Wu BJ, Kirkpatrick JN, Thomas-Geevarghese A, Vaughan-Sarrazin M (2004) Medical house officers' attitudes toward vigorous analgesia, terminal sedation and physician-assisted suicide. Am J Hosp Palliat Care 21:381–387
14. Morita T, Hirai K, Okazaki Y (2002) Preferences for palliative sedation therapy in Japanese general population. J Pall Med 5:375–385
15. Hauser K, Walsh D (2009) Palliative sedation: welcome guidance on a controversial issue. Pall Med 23:577–579
16. Papavasiliou E, Payne S, Brearley S, Brown J, Seymour J (2013) Continuous sedation (CS) until death: mapping the literature by bibliometric analysis. J Pain Symptom Manage 45:1073–1082
17. Hagen NT (2010) Harmonic publication and citation counting: sharing authorship credit equitably—not equally, geometrically or arithmetically. Scientometrics 84:785–793
18. Strauss A, Corbin J (1990) Basics of qualitative research. Sage Publications, London
19. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus-groups. Int J Quality Health Care 19:349–357
20. Juth N, Lindblad A, Lynoe N, Sjostrand M, Helgesson G (2013) Moral differences in deep continuous palliative sedation and euthanasia. BMJ Support Palliat Care 3:203–206
21. Rady MY, Verheijde JL (2010) Continuous deep sedation until death: palliation or physician-assisted death? Am J Hosp Palliat Med 27:205–214
22. Kumar L, Krishna R (2013) Personhood within the context of sedation at the end of life in Singapore. BMJ Case Reports. doi:10.1136/bcr-2013-009264
23. Materstvedt LJ (2012) Intention, procedure, outcome and personhood in palliative sedation and euthanasia. BMJ Support Palliat Care 2:9–11
24. Cherny NI, Portenoy RK (1994) Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care 10(2):31–38
25. Braun TC, Hagen NA, Clark T (2003) Development of a clinical practice guideline for palliative sedation. J Pall Med 6:345–350
26. De Graeff A, Dean M (2007) Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. J Pall Med 10:67–85
27. Pasman HRW, Rurup ML, Willems DL, Onwuteaka-Philipsen BD (2009) Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. BMJ 339:b4362
28. Thorns A (2004) The use of sedation at the end of life. In: Worthington R (ed) Ethics and palliative care: a case based manual. Radcliffe Publishing, Oxford, pp 63–83
29. Cherny N (1998) Commentary: sedation in response to refractory existential distress: walking the fine line. J Pain Symptom Manage 16:404–406
30. Cassell EJ (1982) The nature of suffering and the goals of medicine. N Engl J Med 306:639–645
31. Muller-Busch HC, Andres I, Jehser T (2003) Sedation in palliative care—a critical analysis of 7 years' experience. BMC Palliat Care 2:1–9
32. Menten J (2003) Cancer pain: interdiciplinary and comprehensive management. Dissertation, Acco: Catholic University Leuven
33. Chambaere K, Bilsen J, Cohen J, Rietjens JA, Onwuteaka-Philipsen BD et al (2010) Continuous deep sedation until death in Belgium: a nationwide survey. Arch Intern Med 170:490–494
34. Good P, Cavanagh J, Mather M, Ravenscroft P (2008) Medically assisted nutrition for palliative care in adult patients. Cochrane database systematic review CD006274
35. Borum ML, Lynn J, Zhong Z (2000) The effect of nutritional supplementation in seriously ill hospitalized adults: an evaluation of the SUPPORT data. J Am Geriatr Soc 48:S33
36. Lanuke K, Fainsinger R, de Mossaic D (2004) Hydration management at the end of life. J Palliat Manage 7:257–263

37. Dev R, Dalal S, Bruera E (2012) Is there a role for parenteral nutrition or hydration at the end of life? Curr Opin Support Palliat Care 6:365–370
38. Schildmann E, Vollmann J, Schildmann J (2012) Palliative sedation: further evidence needs to be accompanied by ethical guidance to ensure professional practice at the end of life. Am Soc Clin Oncol 4176
39. Quill T (1993) The ambiguity of clinical intentions. NJEM 329: 1039–1040
40. Billings AJ, Churchill LR (2012) Monolithic moral frameworks: how are the ethics of palliative sedation discussed in the clinical literature? J Pall Med 15:709–713
41. Douglas C, Kerridge I, Ankeny R (2008) Managing intentions: the end-of-life administration of analgesic and sedatives and the possibility of slow euthanasia. Bioethics 22:388–396
42. Putman MS, Yoon JD, Rasinski KA, Curlin FA (2012) Intentional sedation to unconsciousness at the end of life: findings from a national physician survey. J Pain Symptom Manage. doi:10.1016/j.jpainsymman.2012.09.007
43. Rietjens JAC, Voorhees JR, van der Heide A, Drickamer MA (2012) Approaches to suffering at the end of life: the use of sedation in the USA and the Netherlands. J Med Ethics. doi:10.1136/medethics-2012-100561
44. Anquinet L, Rietjens JAC, Van den Block L, Bossuyt N, Deliens L (2011) General practitioners' report of continuous deep sedation until death for patients dying at home: a descriptive study from Belgium. Eur J Gen Pract 17:5–13
45. Buiting HM, van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Rietjens JAC et al (2010) Physicians' labeling of end-of-life practices: a hypothetical case study. J Med Ethics 36:24–29