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Author for correspondence:

Paulo Rodrigues, Faculty of Theology, Catholic University of Lille, 60 Boulevard Vauban, Lille 59000, France.
Email: paulusrod@gmail.com

Palliative care physicians' decision-making about palliative sedation for existential suffering: A Belgian nationwide qualitative study

Paulo Rodrigues, PH.D.¹ , Jozefien Ostyn, M.A.², Sarah Mroz, M.A., PH.D.³, Axelle Ronse, M.A.², Johan Menten, M.D., PH.D.⁴ and Chris Gastmans, PH.D.²

¹ETHICS EA 7446, Catholic University of Lille, Lille, France; ²Centre for Biomedical Ethics and Law, KU Leuven, Leuven, Belgium; ³End-of-Life Care Research Group, Free University of Brussels (VUB), Brussels, Belgium and ⁴Department of Oncology, Laboratory of Experimental Radiotherapy, KU Leuven, Leuven, Belgium

Abstract

Objectives. This study aims to provide an in-depth understanding of the content and process of decision-making about palliative sedation for existential suffering (PS-ES) as perceived by Belgian palliative care physicians.

Methods. This Belgian nationwide qualitative study follows a *grounded theory approach*. We conducted semistructured interviews with 25 palliative care physicians working in 19 Belgian hospital-based palliative care units and 4 stand-alone hospices. We analyzed the data using the *Qualitative Analysis Guide of Leuven*, and we followed the *Consolidated Criteria for Reporting Qualitative Research Guidelines* (COREQ).

Results. Analysis of the data identified several criteria that physicians apply in their decision-making about PS-ES, namely, the importance of the patient's demand, PS-ES as a last resort option after all alternatives have been applied, the condition of unbearable suffering combined with other kinds of suffering, and the condition of being in a terminal stage. Regarding the process of decision-making itself, physicians refer to the need for multidisciplinary perspectives supported by an interpretative dialogue with the patient and all other stakeholders. The decision-making process involves a specific temporality and physicians' inner conviction about the need of PS-ES.

Significance of results. Belgian palliative care physicians are not sure about the criteria regarding decision-making in PS-ES. To deal with complex existential suffering in end-of-life situations, they stress the importance of participation by all stakeholders (patient, relatives, palliative care team, other physicians, nurses, social workers, physiotherapists, occupational therapists, chaplains, etc.) in the decision-making process to prevent inadequate decisions being made.

Background

Palliative sedation (PS) is a clinical intervention of the last resort variety in end-of-life care, which is used to make tolerable the suffering caused by refractory physical, psychological, and/or existential symptoms. It can be 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 in a manner that is ethically acceptable to the patient, family, and health-care providers” (Cherny and Radbruch 2009, 581). A recent empirical study in 7 countries showed that PS was considered acceptable by physicians in cases of physical suffering (87–99%) and, to a lesser extent, in cases of psycho-existential suffering in the absence of physical symptoms in the last days of life (45–88%) (Heijltjes and Morita et al. 2022).

A recent French study involving 8,500 patients in palliative care units found that 0.5% of them requested PS; within this group, a psycho-existential distress item was present in 69% of the requests (Serey et al. 2019). PS for existential suffering (PS-ES) is far from a consensus among physicians and palliative care experts, specifically regarding its adequacy for treating this kind of suffering and the conditions of its application (Cassell and Rich 2010; Rainone 2015; Sulmasy and Jansen 2002). The objective and subjective assessment of existential suffering (ES) is a complex issue (Bozzaro and Schildmann 2018) as it has been described in a variety of ways, that is, as loss of dignity, demoralization, dependency, fear, panic, death anxiety, hopelessness, worthlessness, meaninglessness, loneliness, isolation, loss of control, lack of social support, a sense of burdening others, and being mentally exhausted or worn out. For our purposes, we assume that ES is pain, distress, or hardship due to a loss or interruption of meaning, purpose, or hope in one's life (Kirk and Mahon 2010).

A recent systematic literature review on physicians' perceptions of PS-ES (Rodrigues *et al.* 2020) establishes some evidence regarding the conditions that physicians consider essential for implementing PS-ES, for example, regarding prognosis and refractoriness, patient request, family, and team involvement. The review also reports the possible alternatives to deep continuous PS, for example, regular palliative care, mild and intermittent sedation, psychological and spiritual care, physician-assisted suicide, and euthanasia. However, physicians remain ambivalent regarding PS-ES (Anquinet *et al.* 2014; Cripe *et al.* 2017; Rodrigues *et al.* 2018; Smyre *et al.* 2015; Voek *et al.* 2017), and a recent systematic review on practices, ethical considerations, and guidelines concludes that it is still a very controversial practice (Ciancio *et al.* 2020).

The findings reported here come from a larger study concerning Belgian palliative care physicians' perceptions on PS-ES. In the first part of this study, which explores palliative care physicians' perceptions regarding the ethics of PS-ES, we found that physicians are unsure whether PS is an ethical appropriate answer to ES (Rodrigues *et al.* 2022).

Although extensive research has been done regarding decision-making in PS in general (Arantzamendi *et al.* 2021; Belar *et al.* 2022; Benitez-Rosario and Ascanio-Léon 2020; Schildmann and Schildmann 2014), to our knowledge, no empirical study has explicitly focused on what palliative care physicians take into account in their decision-making regarding PS-ES and how the decision-making actually takes place. To address this gap, we focused in the second part of our qualitative study on the content related to and the process of physicians' decision-making regarding PS-ES. Better insight into this topic can provide important elements to inform research, policy, and practice.

Method

Study design

We used a qualitative design for this study, along with a *grounded theory approach* (Singh and Estefan 2018) and the application of the *Consolidated Criteria for Reporting Qualitative Research* guidelines (COREQ) (Tong *et al.* 2007).

Recruitment and sampling

We used a nationwide sampling method to recruit palliative care physicians practising within hospital-based palliative care units or hospices in Flanders, Wallonia, and Brussels, who met the following inclusion criteria:

- (1) Palliative care doctors working within Belgian hospital-based palliative care units or stand-alone hospices;
- (2) Physicians with more than 1 year of clinical experience in palliative care, including experience with the practice of PS-ES; and
- (3) Individuals willing to be interviewed in English, Dutch, or French languages.

We compiled a list of potential participants ($n = 66$) from the membership rosters of the following organizations: the *Palliative Care Federation of Flanders* ($n = 37$), the *Walloon Federation of Palliative Care* ($n = 19$), and the *Palliative and Continuing Care Federation of Brussels* ($n = 10$). We sent an invitation letter to all potential participants by post, along with an information brochure about the study. Those willing to participate returned the informed

consent form and the demographic questionnaire by post or email. Nonrespondents were sent an email reminder after 3 weeks and again after 6 weeks.

Data collection

We carried out data collection and analysis with an interdisciplinary team of 2 senior researchers in bioethics (CG) and theology (PR) and 3 master's students in bioethics (JO, SM, and AR). We conducted semistructured interviews on campus between December 2018 and March 2019. Physicians from Brussels and Wallonia were interviewed in French (PR), and participants from Flanders could choose to be interviewed in English (SM) or Dutch (AR).

Prior to each interview, we asked the participants whether they had any questions, and they gave informed consent and permission to record their interviews. The interviews lasted from 28 to 96 minutes each (mean = 47 min), and most of these took place at the workplace of the participant. Other than the participant and the interviewer, no one else was present at the interview. We did not provide feedback or return the transcripts to the participants, and repeated interviews were not conducted.

The team developed and utilized an interview guide (Annex 1 in the Supplementary material) based on 2 literature reviews (Rodrigues *et al.* 2018, 2020) and a clinical vignette (Blondeau *et al.* 2005). The interview guide allowed researchers to explore participants' perceptions of the content and the process of decision-making regarding PS-ES. We took field notes during and after each interview and transcribed and anonymized the data from the audio recordings. We concluded the data collection process when the data saturation point was reached.

Ethical considerations

This study was approved by the Ethics Committee Research of KU Leuven (MP007690) in compliance with the *General Data Protection Regulation* 2016/679. We collected only relevant data for the research, which was coded and stored on a KU Leuven institutional server. Codes were stored in a separate password-protected file.

Data analysis

We (JO, PR, and CG) analyzed the data using the *Qualitative Analysis Guide of Leuven* (QUAGOL) (Dierckx de Casterlé *et al.* 2021, 2012), which involves a continual comparison of uncovered insights with the data. The QUAGOL consists of 2 stages, namely, the preparation of coding and the coding process. Examples of a "conceptual scheme" and an "overarching conceptual scheme" are provided in Annexes 2–3 in the Supplementary material. We used NVivo (1.5.1 (940)) by QSR International to code the data. The codes emerged from the data. Detailed methods are described elsewhere (Rodrigues *et al.* 2022).

Results

Participants' characteristics

We contacted sixty-six ($n = 66$) palliative care physicians, of whom 25 ($n = 25$; Return Rate = 38%) were willing to participate in the study and were subsequently interviewed. The participants were from Flanders ($n = 11$), Wallonia ($n = 11$), and Brussels ($n = 3$).

The sample had wide variability in regard to age (32–70 years), medical discipline, clinical experience (1–43 years), and experience in palliative care (1–30 years); in addition, the physicians worked in 23 different institutions (university hospitals, regional hospitals, and hospices) in Belgium (Flanders, Brussels, and Wallonia). The large majority had clinical experience within the last 12 months with receiving requests for and conducting PS-ES. Most participants were female ($n = 16$) and Roman Catholic ($n = 17$). Detailed characteristics of the participants are described elsewhere (Rodrigues et al. 2022).

The content of the decision-making regarding PS-ES

When pondering PS-ES, physicians consider certain criteria. They will not initiate PS-ES until their patients have asked and have given informed consent for it, and they will perform it only after they have explored all alternatives to reduce ES and found it to be refractory. In addition, they will perform PS-ES only when patients are suffering unbearably and, in most cases, when their ES is combined with physical suffering. Almost all physicians report that only patients with a maximum life expectancy of 2 weeks can undergo PS-ES (for quotations, see Table 1).

Patient's demand

All physicians consider the patient's demand for PS-ES a main requirement for initiating it, but they have different opinions about what a demand entails. Some physicians perceive patients' expression of suffering as an implicit demand for PS-ES, whereas others believe this expression is insufficient and wait for the patient to prompt them to take action. They explain that patients rarely request PS-ES but ask instead for someone to end their suffering or even ask for euthanasia. These physicians usually propose PS-ES and recognize the patient's consent as an essential requirement to start it.

When a demand is expressed, physicians discuss the demand with their patients to verify whether they truly want PS-ES or another kind of intervention. Some physicians believe it is necessary to explain PS-ES, including its drawbacks. Many physicians indicate that patients' demand for PS-ES has to be repeated over time, as their ES may fluctuate or even disappear. In addition, some physicians require that the patient's demand should not be driven by external factors, such as family members' demands or caregivers' desire to be relieved of their own suffering or fatigue. Nonetheless, physicians recall cases where the patient's consent for PS-ES was not obtained, for example, in case of extreme urgency, or when sedatives were gradually increased from mild sedation to a level of deep sedation.

Last resort option and alternatives to PS-ES

All physicians consider PS-ES as a last resort option and thus as a response to refractory symptoms. This requires that adequate care at the physical, psychological, social, and spiritual levels has already been provided but has not brought about any satisfactory relief of the patient's ES. One physician explained that PS-ES cannot be justified when the patient has been given non-up-to-date professional palliative care. Instead, PS-ES can be considered when optimal care has been provided but has not had a sufficient effect on the patient's ES and no other intervention seems sufficient to make the patient feel more comfortable.

Before initiating PS-ES, physicians first consider many alternatives. A large majority of physicians view ES as a state of global suffering and consider a wide range of options for its treatment. Some emphasize the importance of global support for the patient and his or her accompaniment by a palliative care team and relatives and perceive this as an alternative to PS-ES. Almost all physicians will involve a psychologist or psychiatrist to alleviate ES. However, some mention that psychotherapy comes too late for terminally ill patients, as this intervention takes time to produce a positive effect. A majority of physicians stress the importance of accompaniment by family members and the creation of a meaningful and supportive environment by the patient and caregivers, especially by social workers; some also recontact family members and try to organize a meeting. According to some physicians, ES can also be alleviated by regularly spending time with the patient.

A majority of physicians will offer religious, spiritual, or existential care to their patients, for example, anointment of the sick, meditation, and musicotherapy. In doing so, they take the patient's beliefs and values into account. Many physicians also try to give hope and meaning to their patients by talking with them and emphasize that this kind of care can be provided by many different health-care providers.

Some physicians point out that physical care – offered by physicians, nurses, physiotherapists, and ergotherapists – is key to reducing physical pain, which may in turn result in a reduction in ES. To a lesser extent, physicians also regard medication as a treatment for patients with ES. For instance, some physicians try to treat ES with anxiolytic drugs or antidepressants. However, some of them argue that ES cannot be treated by PS.

Some physicians perceive euthanasia as an alternative to PS-ES, but others believe that euthanasia and PS-ES are completely different from each other. Even if 2 physicians mentioned that they would allude to euthanasia during a conversation with their patient, most of them felt that such a request should come directly from the patient.

Some physicians view intermittent PS-ES as an alternative to deep continuous sedation. They will suggest or ask to try intermittent PS-ES first before allowing deep continuous PS-ES. Other physicians strongly disapprove of intermittent PS as an intervention for truly terminal patients with ES.

Unbearable suffering and the presence of other kinds of suffering

Physicians explain that PS is not performed on all patients with ES. Many physicians assert that PS-ES can only be performed when patients are in great discomfort, find their state unbearable, or are at the end of their tether. Some describe that the degree of suffering experienced by the patient is very subjective, as it differs from patient to patient. Nevertheless, physicians feel a need to determine how great the patient's ES is and whether it requires PS, despite the difficulty of assessing ES.

Nearly all interviewees report that they will only perform PS if ES is combined with physical suffering, which they claim is mostly the case with their patients. Some physicians express difficulty with patients asking for PS when they only have ES. In that case, physicians believe either they are not competent to deal with ES or that their patients are not in the end-of-life stage.

Terminal stage

Almost all physicians state that PS-ES can only be performed if the patient is in the terminal phase of life. Some argue that this

Table 1. Themes and illustrative quotations

	The content of the decision-making regarding PS-ES
Patient's demand	<p>But patients never ask me for sedation. The term "sedation," it is not a term used by patients, in fact. Patients, they say, "I want to end it." That is what they say. Or they say, "I don't want to live like this anymore," "It is insupportable," "I want to die," or "Give me the shot." There's a lot of terminology. But saying "I want a sedation," that doesn't happen. A10</p> <p>I noticed that sleep – for existential or nonexistential reasons – is very often something that is pushed, going against the opinion of the patient, who initially wanted something else, by the care team, or by the family, or even by the volunteer caregivers. I would say by the whole care team and the family; sometimes one, sometimes the other. And that is something I don't accept. A10</p> <p>So there must be prior consent of the patient, uh ... but we don't always have consent; we have experienced situations where uh ... the patient had not given her consent for sedation, and then she ended up in a situation of acute confusion with extreme agitation, with a hallucinatory delusional phenomenon. So uh ... it is something very noisy, very uh ... psychologically very ... uh ... very heavy ... to do a sedation without the consent of the patient. So there you have it. These are extreme emergency situations. B14</p> <p>I do something that they don't have the courage to decide; it's me who decides. Right, because we start out small, right, ... we put them to sleep, ... and then we increase the doses according to the state of the patient; if we see that he or she is tense or if he or she looks uh... bad at the time of the body care – and then at a given moment, well ... we increase, we increase, anyway ... And that, at times ... I have difficulties, with me! B2</p>
Last resort option	<p>I would really take a survey in a general sense of the team: did we really do everything to help him in his existential suffering? Have we tried to understand why his life no longer has any meaning, uh ... have we tried to see if, at the level of the entourage, in the family sense, the social network, are they aware of this loss of meaning? A1</p> <p>Well, when we have already tried many things, when we have already made several adequate periods of contact, the patient has already had several contact sessions with the psychologist, but she says that ... she doesn't get there ... [.] When we have already tried through several talks to try to see what else we could bring in, if there were things we could do, uh, to make life more meaningful, to propose activities, to propose certain things that could still remain in the realm of service, and when we don't get anywhere, and we say to ourselves, "Well, there you go. That's the worst solution of the good solutions, so to speak." B17</p> <p>Thirdly, you have a refractory symptom, a symptom that cannot be treated in a reasonable fashion, in a reasonable way, then palliative sedation comes up, eh. And it, ah, I think it's always a combination. We consider it in the guidelines, that is, we talk about one symptom, eh, but it's mostly a state, a refractory state of many problems, ah, combined, when a patient goes declines in health and he doesn't want to suffer anymore. C11</p> <p>I will always, like, do this as a series of suggestions as well, like, "Okay, shall we try to get your nights better?" Then, we ensure that we give the patient something for the night so that they sleep well; then tomorrow, we see how that's been and then rediscuss. So I think it's ... if after several talks with the patient and after you've tried getting other things to be better, if there isn't anything else. C29</p>
Alternatives	<p><i>Did you, uh ... consider other solutions before?</i> – Oh yes, used all possible imaginable solutions, it was a debate for over a week ... uh ... to see a bit, what could be done for a lady who could no longer get to sleep, who didn't dare to sleep anymore, who had anxiety; so an anxiolysis had just been done, she woke up anyway, every time it was awful, with nightmares, uh ... and so uh ... there you go. It was after a week that we decided to opt for deep and continuous sedation, knowing that the patient was really at the end of her tether and that there was no other alternative. We had really checked all the other alternatives, with the spouse, with the patient, and with the team, and with the psychologist who was following the patient. A1</p>
Psychological care	<p>There are several means that can be envisaged, yes, supportive accompaniment, uh ... psychotherapy? Well, there are few patients, if we look at the numbers, who can adhere to psychotherapy, because there are programmed disorders, attentional disorders, which make it just not possible as a means. B15</p>
Social and relational care	<p>Also, I think the link with the social support of the patient is very important. You can provide hope by supporting the family or by stimulating the family to be in touch with the patient, eh. That they can do; spiritual care is a spiritual issue that is very linked with the family and with support. So, for many patients in the last weeks of life, family is their hope, or is the meaning of living, ah, further, eh. Because it's the only thing they have; they lie in beds, and they are blocked. They cannot come out of their room, and the family comes over and that's ... I think it's, ah, seeing grandchildren and or their children, or the, yeah, it's very important, I think, to provide relief; that's what we can do. C11</p>
Religious, spiritual, and existential care	<p>If we see that they're struggling with some feelings of despair, we ask them if they would like to talk with someone; sometimes they talk with the nurses and sometimes they say it's not the right time to talk with me as a physician, but then they talk with someone who is a moral consultant, pastor, [...] yeah, so they can talk about their feelings of despair ... yeah. C9</p> <p>I think first of all, the main thing is don't leave the patient alone with his existential suffering; a lot can be dealt with, ah, with good palliative caregivers – informal, formal, ah, first-line palliative care, ah, specialized palliative care – who are ready to walk along with the patient in their existential and spiritual problems. Ah, sometimes with ah, more specialized palliative care, ah, sometimes people feel the need to talk to a priest or talk to a, ah, priest of another, a Catholic priest or another religion, or whatever; it can relieve them. C18</p>
Physical care	<p>But not only, not only. We must not psychologize everything either; sometimes interventions by ... an occupational therapist, or a physiotherapist, and uh ... of any caregiver ... can already uh ... can already build a little uh ... the beginning of an answer ... not to the suffering, but in any case ... it's an attempt to relieve this suffering. B14</p>

(Continued)

Table 1. (Continued.)

	The content of the decision-making regarding PS-ES
	Yes, but it's a lot of physical questions also, when there is pain; pain can provoke existential suffering also, and then when you cut the pain, the existential suffering diminishes also. It's all linked together, I think, eh, when you approach ... when you must do a general approach of a patient and your comfort and symptom control, eh, not only for existential suffering, but you must provide good physical care and you see, ah yes, the amelioration of existential suffering as well, I think. It's interconnected, eh. C11
Medication	I think that existential suffering should not be medicalized. It's not something that is part of the psychiatric illnesses, so it's not an illness for me. Uh ... so uh ... what we can relieve is the potential uncomfortable symptom that would result from this existential suffering. For example, anxiety ... disabling fear, insomnia, nightmares. So that we can alleviate via, possibly, uh ... drug therapy. B14
Euthanasia	I, in any case, I would find it to be a regression and an impoverishment of our society if we only had euthanasia to offer to people who are in this situation. Because for me, euthanasia is ... it's a kind of (<i>sic</i>) failure. We arrive at these situations when there is really nothing else to do. So, that would show well that, uh ... well, there is nothing else. And that's sad, I think. It's really, uh ... yes, it would really be the ... uh ... proof that our society, uh ... is becoming spiritually impoverished, since as soon as there are spiritual questions, the only answer society is able to give is death. B14
Intermittent PS-ES	Yes, when all the alternatives are exhausted and people are still suffering, and they say, "My life has no meaning," I'm going to tell them, "Well yes, uh I can understand ...". there you go. "Would you have wanted sedation?" But I'll start with an intermittent sedation first. And once they've experienced sedation, they say, "Oh, it feels good to sleep, I feel good when I sleep, I don't think about all this ... this pain," and I tell them, "Okay, well, we can go on like this." B18
Unbearable suffering and presence of other kind of suffering	<p>... her psychological distress, her lack of meaning and really her discomfort in living how she still had to live ... could justify that we do a sedation. Because there was still a major discomfort, so there was this psychological distress; but also symptoms more related to her asthenia and her inability to eat, which meant that she was really in great pain. B17</p> <p>When I have the feeling she is ... that she is at the border of what she can cope with, I would say, "I'll be there to give you that, I will sedate you, maybe not now, but know that I will be there." C9</p> <p><i>Would you say your attitude is open and positive to using palliative sedation for existential suffering or more negative?</i> I'm open to listening. I don't know if I ... if a patient ... if there is ... I don't know, if the question is whether there is no other symptom or problem, just existential, just...I will never say never, but it seems really difficult at this moment for me. C37</p> <p>Now, it's certain that when the psychological suffering is part of ... in the context of a mental illness alone, then personally ... it's beyond my capacity, so I would tell the patient to consult someone else. B5</p>
Terminal stage	<p>They are done according to strict criteria of palliative sedation; that is, they are done at the very end of life, when the life expectancy is counted in days or in a few weeks, that is, less than 15 days. So, in general, it is really a life expectancy that is counted in days. A4</p> <p>You must be very careful when it's only for existential suffering and the patient is not that terminal, it's not good, eh. It's not good; you must do other things. That's my opinion, eh. C11</p>

is an obvious condition because otherwise it would not be PS but rather a form of hastening death or a kind of disguised euthanasia. According to half of them, the life expectancy at this point should be less than 15 days or 1 week; however, one physician admits to having practised PS-ES outside the short-term prognosis.

The decision-making process regarding PS-ES

Based on our analysis of the interviews, we found that PS-ES decision-making is perceived by Belgian palliative care physicians as a process that is characterized by 4 aspects: 1) it appears to be a multiperspective process; 2) it takes place through interpretative dialogues; 3) it is followed by the physician's inner conviction of its necessity preceding the final decision; and 4) it takes place over time (for quotations, see Table 2).

Multiple perspectives

Physicians emphasize that they never make a decision about PS-ES without consulting the relevant stakeholders, namely, the patient, the patient's relatives, and the palliative care team, including other physicians, nurses, social workers, physiotherapists, occupational therapists, chaplains, etc.

Physicians indicate that they need input from multiple perspectives to make a decision about PS-ES, especially to assess

whether the ES is unbearable and whether there are any less invasive alternatives. Some physicians explain that the decision-making process would be too subjective without this multiperspective assessment of the patient's ES. A couple of physicians mention the danger of projecting their own feelings on their patients, while other physicians are aware they are not omniscient regarding ES and the adequacy of PS to treat it. By listening and talking to others, physicians can verify that their impression is being shared by others. Some point out that to make a decision about PS-ES, they should consider the physical, psychological, relational, and existential dimensions of the patient as a whole person. This holistic care approach calls for the active involvement and contribution of multiple stakeholders.

Interpretative dialogue

The PS-ES decision-making process, especially the evaluation of ES, is characterized by an active and iterative process of exchanging information and perceptions between the stakeholders and the understanding and interpretation thereof.

Almost all interviewees explain that they enter into dialogue with their patients multiple times and get to know them on a deeper level. Some physicians indicate that they try to follow their patients as closely as possible and emphasize the importance of a mutual trusting relationship to achieve this goal. By talking, listening to,

Table 2. Themes and illustrative quotations

The decision-making process regarding PS-ES	
Multiple perspectives	<i>How can you evaluate existential suffering?</i> ... I think it's through dialogue, and a dialogue that is ... uh ... made of multiple different views. Namely, I can feel a loss of meaning in relation to what the patient is saying, but I am unable ... well, I feel incapable ... to determine it, uh ... well to determine it all alone. Uh ... I think that you need, necessarily, a team, and a multidisciplinary team, with at least ... possibly a psychologist, a social worker as well, because the loss of meaning is sometimes just a social suffering that came at the end of the case; therefore, depending on ... the patient's condition, depending on ... the patient's ability to put words to, uh ... to his problem ... we broaden the team. I always try to have a look at the oncologist who followed the patient, the attending physician, and so on. B13
	In existential problems, you don't ... you cannot know in an hour's time that it is interactable, that's nonsense, that's not possible. I think the teamwork, multidisciplinary work is, ah, more important than physical problems. Well, in physical problems as a physician, well, you're the final decision-maker in fact and you're trained for that; in existential problems, well, ah, in a way, as a physician, you're an amateur. In the best world, you're a well-trained amateur, but you're not the final decision-maker, you're the performer of palliative sedation, but I don't see myself as the final decision-maker. The team can be the final decision-maker. When you have talked to your team in a proper way and everybody has come to the same point, well, that reassures me that okay, this is the right thing to do and we say, "Let's go on." C18
	It's already something well known, where clearly, the spiritual dimension, the psychological dimension, and the physical dimension are interconnected, and it's ... it's that what we have to deal with. So you have to ... you have to take everything into account, but that's also why we have these multidisciplinary discussions, right? There's the medical aspect, then there's the uh ... psychological aspect ... and the spiritual aspect, there's the sociofamilial aspect; all that comes into play. B5
Interpretative dialogue	<i>How would you evaluate it?</i> Ah, I don't evaluate it in a quantitative way. I assess it ... by listening to the patients, by asking them how they feel, and doing it in a repetitive way to see if there is an impact over time. A10
	But how, I think it can be small things, if the patient, yeah, does say, 'I'm afraid' or small things like, "I can't sleep" and you can say like, "Why can't you sleep? Are you thinking about ... are you worried about something?" And then see what comes out if they can talk about their fears or if they say, "I'm breathless" and then you can ask like, "Okay, what does that do to you? Does it make you scared? What are you afraid of? Are you afraid of what's going to happen in the next couple of weeks?" Then you try to get the psychological as well as the existential questions, I think. But I think I can only listen and try to, yeah, try to hear what is trying to be said underneath; that's what the nurses also do. I think that's a good thing that we come together very often and discuss everything because one will pick up something that others have not. C29
	So uh... uh... I don't go after the family, I don't ask for the family's opinion, but I try to feel what the family ... thinks, yes. And I take information from the family, but ... I'm careful that ... the family doesn't feel uh ... responsible in deciding, you know. Right, that's another thing. B10
	It's about the process and it's a lot of negotiation; I don't know if it's the right word, but yeah, it's always the relationship that's very important. It's always in palliative care there is a lot about the relationship between you, your team, the patient and the people around him, and then you get ... I always say the best solution can be found in the worst condition, the best of all the bad things, so yeah. C9
Inner conviction, common ground, and final decision	... I have to be convinced that there is no ... reasonable alternative to relieve the patient. In order for me to arrive at this firm conviction, it must be based on objective criteria and perhaps on much more subjective criteria. B15
	I think it has to do with autonomy in the relationship, for me as a caregiver, it's also important, not the feeling of the patient alone, but of his meaningful environment too, that you can ... that you can come to a point where no solutions are acceptable to everyone who's surrounding the bed but ah, is that an ethical principle? I think, ah, that the ethical principle could be to not harm the, ah, the meaningful relationships of the patient, in favour of the patient; you understand when, ah, I think that's for me quite important, of course, when they don't come to a shared point. Well, in some exceptional cases, you will have to choose, and that's always difficult, I think, because there is ... that can be a big problem afterwards for their partner, their children, so ah ... C18
	I should try to, ah, to see family, if it's possible and to make, ah, what we call a family meeting, eh. That's also when, ah, for me personally, it is a very important, ah, condition to be met before sedation, to meet the family, have a family meeting, eh. Sit the family down and talk with them and with the patient. Ah, I think in this case also, to get, not only to get the consent of the patient but from the whole system. C11
	No. Right... it's true that... we don't talk about it, but we always pay a lot of attention to the family and friends, in these decisions. So ... we don't ask for their authorization, but in any case we explain to them, and we always hold a meeting with the patient and the people closest to him ... before putting in place a sedation. <i>In order to explain what is going to happen?</i> To explain, and then to listen to them too, in relation to their suffering, or their experience in relation to this sedation, so that they can, in any case, express everything they feel. We don't ask them ... we don't ask for their agreement, but in any case we ... we try to take them into account and to ... to see how they see this situation, um ... in relation to their loved one. B17
Temporality	<i>Yes, how do you assess this suffering?</i> We give him sedation, for example. But, that is not done from one moment to the next. It's a whole ... it's a whole journey. We have ... the people here who come here, like in the other units I suppose, we don't have any time limits, right. B2
	Well ... we are further than that, yeah. And that gives us an ease of mind and of heart in our work ah, to say, 'Okay, we made the decision, and we carried it out in a proper way. We didn't do it overnight or too subjectively or something like that; we did it in a proper way. It takes time but it also takes experience, skills, yeah. C18

(Continued)

Table 2. (Continued.)

The decision-making process regarding PS-ES
Some things simply take time; you cannot decide to perform palliative sedation, euthanasia, at least for existential or psychological problems when you don't take the time to really work it out to see whether there are other possibilities, whether when you're a bit further along, ah, whether the suffering ah, persists in fact. So, time also means, not always means, ah minutes, but also means quality of, quality of your conversations, for instance. It's not always a question of a talking to a patient for hours and hours but in what way you talk to them. C18
But then also, it can still be that you say, "Okay, this is it ... we'll start with sedation but when do you want it? It can still be delayed a couple of days." It seems weird but sometimes they just need to know, like, "Okay, they've listened, and I can ask." It's the last bit of control that they can have. Like, "Okay, I can't do anything else, but this I can still ask for; I can have control over the way I die or so, yeah." C29

and asking questions, physicians are able to explore their patients' ES and actively look for ways to relieve it. One physician underlines the value of these conversations for the patients themselves because it allows patients to express what is happening to them.

Many physicians also ask their team members about their interpretation of patients' suffering. Some physicians mention that patients express their suffering in different ways to different team members or even hide it from certain members, thereby creating complex situations that require good team communication. A few physicians also remark that they talk to patients' relatives to gain insight into the latter's suffering. Based on the complementary information and perceptions gathered, physicians try to reach an interpretation of the patient's suffering, which to a certain level can be understood by the other stakeholders.

Inner conviction, common ground, and final decision

Physicians explain that at some point they arrive at the inner conviction that PS-ES can be the right course of action. Moreover, they aim to make a decision that is in accordance with their inner conviction. Some of them specify that their inner conviction is grounded in a deeper understanding of the patient's suffering. This contains a cognitive element, namely, understanding why the patient suffers, and an emotional element, which consists of a kind of "empathy" with the patient.

Physicians report that in most cases, their inner belief is supported by the patient's understanding of his or her suffering, as well as by the family members' and the team's interpretation of the situation. However, some physicians explain that relatives do not always understand the patient's suffering because patients can hide their ES from their family. In this case, physicians say it is essential that the relatives are at least aware of the patient's suffering in order to understand and accept the patient's request for PS-ES. However, only a few physicians share that they will explain the suffering of their patient to the relatives if he or she is unable to do so on their own.

Although most physicians indicate that a common ground can be found within the team, some mention that team members can have different opinions regarding PS-ES for a specific case. This is why physicians consider themselves to be the ultimate decision-maker: they make a decision about PS-ES when common ground within the team is lacking. Nevertheless, some other physicians require the consent of all team members and the patient's relatives to perform PS-ES.

A number of physicians mention the importance of clear prior communication with relatives when the final decision is made so that they know what to expect once sedation has been initiated. In addition, some physicians refer to a family gathering, that is, a time when the patient and their loved ones can say goodbye to each

another. One physician points out that team members also need a moment to say goodbye to the patient they have been caring for.

Temporality

Many physicians explain that due to the required multiperspective communication and interpretation process, final decisions about PS-ES are not made quickly but instead take some time. Two physicians explicitly add that when a decision is made quickly, it is not made properly. Most doctors do not specify the amount of time it takes to make such a decision, although some say it requires a minimum of 2 days. Furthermore, many physicians refer to a qualitative way of dealing with time in end-of-life care, such as taking time to gain a deeper understanding, processing relevant information, and allowing thoughts and points of view to mature. It is also pointed out that taking time does not imply that the decision-making process should be unnecessarily extended.

A couple of physicians explain that when a decision is made to perform PS-ES, they inform their patients and give them the freedom to determine the most appropriate moment to initiate such treatment. In this way, patients can maintain control of the situation. One physician also mentions that she prefers to perform PS-ES in the evening because it is a natural time to fall asleep.

Discussion

Content of decision-making

This study shows that physicians consider the following conditions under which PS might be used for ES: 1) the patient's demand for such treatment, 2) the presence of the condition of unbearable ES (preferably combined with physical suffering), 3) a less invasive alternative treatment cannot be found, and 4) a terminal stage condition. Even if, in general, physicians seem to agree with these conditions, the priority and interpretation given to each one is not equivalent when considering concrete complex cases of end-of-life ES.

A recent systematic review on physicians' perceptions of PS-ES (Rodrigues et al. 2020) provides evidence that these conditions do not have the same weight according to all physicians. Some consider the patient's explicit request for PS-ES to be determinant, while others consider the consultation and involvement of the family (Foley et al. 2015), the decision of the primary care team (Beauverd et al. 2014), or consultation with a multidisciplinary team (Papavasiliou et al. 2014) to be necessary in the final decision. Our study seems to confirm the latter process, as most of the interviewed physicians place a high level of importance on the involvement of all stakeholders in the decision-making process.

The refractory nature of ES is also a condition of consideration, as some physicians find it very difficult to objectively assess ES. For most participants in our study, ES must be combined with other types of suffering for PS to be considered, which is in line with the literature indicating that physicians have a higher level of comfort using PS for refractory physical symptoms and thus prefer to wait for the combination of physical suffering or physical deterioration to initiate PS-ES (Schur *et al.* 2015).

In our study, physicians also consider it important to verify the patient's terminal condition; however, a comparative study with French-speaking physicians from Quebec and Switzerland found that neither the prognosis nor the interaction between the prognosis and the type of suffering influenced physicians' attitudes toward PS-ES (Dumond *et al.* 2015). This difference in findings supports the need for further qualitative and quantitative research to confirm or refute it.

A recent scoping review (Amy *et al.* 2020) concludes that certain aspects complicate clinical decisions regarding PS-ES, namely, the lack of a precise definition of ES and clinical studies on PS-ES, difficulty assessing ES symptoms, monitoring the effectiveness of treatment, the degree of subjectivity in starting PS-ES due to the lack of guidelines, and the need for a clear understanding of the values and worldviews involved. In this review, 80% of the articles analyzed do not reach a clear consensus pertaining to whether PS-ES is acceptable or not; this finding supports our results, given that most of the physicians interviewed seem to hesitate regarding PS-ES interventions.

Process of decision-making

This study shows that PS-ES decision-making is an iterative multidisciplinary process of communication and interpretation that takes place over time. Physicians highlight the importance of consulting all relevant stakeholders to verify whether the conditions for PS-ES have been fulfilled and whether their interpretation is consensual. Belgian physicians try to reduce the risk of a subjective individual perspective by sharing their perceptions and opinions to come to some level of agreement and make shared decisions. In-depth communication between physicians, patients, relatives, and team members provides a profound understanding of the patient's global suffering, the ability to identify what is contributing to his or her ES, and the ability to assess it in a more comprehensive way. These results are consistent with recent systematic reviews (Amy *et al.* 2020; Reich *et al.* 2020), which show that diagnosing psycho-existential refractory symptoms requires a multidimensional perspective of a patient's condition and a collaboration between different professionals (physicians, nurses, psychologists, psychiatrists, spiritual/religious advisors, and ethics committee members) to add objectivity to the decision-making process.

Methodological discussion

To our knowledge, this is the first Belgian nationwide (Flanders, Brussels, and Wallonia) qualitative study to provide in-depth insight into palliative care physicians' decision-making regarding PS-ES. Even if theoretical sampling has not been applied, the sample reflects a wide range of gender, age, specialization, and experience in palliative care. The data were analyzed following the QUAGOL protocol, which integrated systematic team reviews and continuous dialogue. Conducting research in 3 different languages (Dutch, English, and French) was the main difficulty, but the team had the necessary skills to manage it. As our results are based on

data collected within hospital-based palliative care units and stand-alone hospices, they cannot be generalized to other care settings, such as home care and nursing homes.

Conclusion

This empirical study brings to light the content related to and the process of decision-making about PS for ES by Belgian palliative care physicians. Most physicians are not sure about the precise and objective criteria regarding decision-making in PS-ES and stress the importance of participation by all stakeholders to come to acceptable solutions in complex situations involving existential refractory suffering at the end of life.

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Data availability statement. The data for this study are kept by the first author and are available on request.

Author contributions. All authors were involved in the conception and design of this study. PR, SM, and AR carried out all the qualitative data collection. Data analysis and interpretation were performed by JO, PR, and CG, who also wrote the paper. All authors were involved in critically revising the article. All authors approved the final version of the manuscript. CG supervised the study.

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