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Opinions of the Dutch public on palliative sedation:

a mixed-methods approach

Abstract

Background

Palliative sedation is defined as deliberately lowering a patient's consciousness, to relieve intolerable suffering from refractory symptoms at the end of life. Palliative sedation is considered a last resort intervention in end-of-life care that should not be confused with euthanasia.

Aim

To inform healthcare professionals about attitudes of the general public regarding palliative sedation.

Design and setting

A cross-sectional survey among members of the Dutch general public followed by qualitative interviews.

Method

One thousand nine hundred and sixty members of the general public completed the questionnaire, which included a vignette describing palliative sedation (response rate 78%); 16 participants were interviewed.

Results

In total, 22% of the responders indicated knowing the term 'palliative sedation'. Qualitative data showed a variety of interpretations of the term. Eighty-one per cent of the responders agreed with the provision of sedatives as described in a vignette of a patient with untreatable pain and a life expectancy of <1 week who received sedatives to alleviate his suffering. This percentage was somewhat lower for a patient with a life expectancy of <1 month (74%, $P = 0.007$) and comparable in the case where the physician gave sedatives with the aim of ending the patient's life (79%, $P = 0.54$).

Conclusion

Most of the general public accept the use of palliative sedation at the end of life, regardless of a potential life-shortening effect. However, confusion exists about what palliative sedation represents. This should be taken into account by healthcare professionals when communicating with patients and their relatives on end-of-life care options.

Keywords

continuous deep sedation; general practice; palliative care; palliative sedation; public opinion.

INTRODUCTION

Providing good end-of-life care is one of the five main processes in health care.¹ Many patients with incurable cancer consider quality of life to be more important than prolonging life when death is approaching.² However, in practice many patients suffer from multiple symptoms at the end of life, including physical symptoms such as pain, fatigue, and nausea, and psychosocial and existential issues.^{3,4} Sometimes these symptoms are refractory, that is they cannot be sufficiently controlled with medication and/or other treatment modalities.⁵ Therefore end-of-life care sometimes involves intensive forms of symptom alleviation, such as palliative sedation.

Palliative sedation is a medical treatment for refractory symptoms at the end of life.⁶ In the Netherlands, a guideline for palliative sedation is available. This guideline defines palliative sedation as deliberately lowering a patient's consciousness, by using sedatives, to relieve intolerable suffering from refractory symptoms at the end of life. The guideline states that the life expectancy of a patient may not exceed 2 weeks at the moment palliative sedation is started.⁷ Other terms used for this practice are continuous (deep) sedation or terminal sedation. The prevalence of palliative sedation differs considerably between countries, depending on the definition, the setting, and research methodology used

(3–51%).⁸ In the Netherlands, continuous deep sedation until death was found to be used in 12% of all deaths in 2010.⁹

International research regarding palliative sedation is increasing rapidly and has been mainly focused on practices,^{10,11} experiences,^{12,13} and attitudes of professionals.^{14,15} There is concern about the potential of palliative sedation to hasten death. Whereas these issues tend to evoke rather fierce debate, also in the lay press, physicians taking care of patients at the end of life may be confronted with varying expectations, attitudes, and possibly misunderstandings. This study aims to provide insight into the attitudes of the general public towards palliative sedation, to inform healthcare professionals about how to adequately communicate and make end-of-life decisions with patients and relatives.

METHOD

Study design and population

A cross-sectional survey was conducted with an online questionnaire, followed by a qualitative interview study among a selection of the responders. The study population was a random sample of the Dutch general population. An established panel was used, the CentERpanel¹⁶ (University of Tilburg, the Netherlands). This panel comprises a random sample of postal codes and reflects the composition of Dutch population with

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Submitted: 15 April 2013; **Editor's response:** 5 June 2013; **final acceptance:** 15 July 2013.

©British Journal of General Practice

This is the full-length article (published online 30 Sep 2013) of an abridged version published

in print. Cite this article as: **Br J Gen Pract 2013;**

DOI: 10.3399/bjgp13X673685

How this fits in

The attitudes of the general public towards a controversial intervention at the end of life, such as palliative sedation, are largely unknown. This study reveals that most of the Dutch general public accept the use of palliative sedation. Some confusion exists about what palliative sedation represents, which should be taken into account by healthcare professionals when communicating with patients and their relatives on end-of-life care options.

respect to income, type of housing, region, and urbanity. During the survey period (December 2009–February 2010), 2503 individuals were active members of the panel. All responders were aged ≥ 18 years.

Questionnaire

The structured online questionnaire assessed personal experiences with knowledge of, and opinions about palliative care and palliative sedation. The questionnaire included statements, closed questions, and a vignette (Box 1). This vignette consisted of a hypothetical case description of a patient with incurable cancer with metastases who is in severe pain, which cannot be sufficiently alleviated.

Responders were randomly divided into two groups: one group was presented a vignette of palliative sedation in which the patient had a life expectancy of 1 week and the other group was presented a vignette of a patient with a life expectancy of 1 month. In the vignette where the patient's life expectancy was 1 week, the physician's goal was described as relieving the patient's suffering. This vignette is the 'standard vignette', because the act of the physician

is in agreement with the Dutch guideline for palliative sedation.⁷ The group that was presented a vignette of a patient with a life expectancy of 1 month was subsequently divided into two subgroups: for one group the vignette stated that the physician's goal was to relieve the patient's suffering and for the other group the vignette stated that the physician's act was to hasten the patient's death. Responders were asked to give their opinion of the physician's act, that is providing palliative sedation, and to indicate if they thought that this act was legal in the Netherlands.

Sociodemographic data for the panel (age, sex, urbanisation, education level, religious beliefs) were obtained through self-reported data. For comparison, similar characteristics of the whole Dutch population were obtained from Statistics Netherlands.¹⁷

Interviews

At the end of the questionnaire, responders were invited to participate in an interview. It was indicated that anonymity would be lost in this case. Responders were selected who were willing to participate, for an indepth interview based on their responses to the questionnaire. The method of purposive sampling¹⁸ was used to obtain a broad range of opinions, as described earlier.¹⁹ Furthermore, the aim was for a balanced distribution of age, education, and sex. Interviews were conducted by different researchers. There was an interview guideline which was piloted for length and comprehensibility. This led to minor adjustments. During the interview, responders' associations were first assessed with the term 'palliative sedation'. Secondly, it was assessed whether they had ever experienced a situation where palliative sedation was used. Finally, the interviewees were asked to reflect on the vignette describing palliative sedation. Responders were asked if their opinion on this vignette changed when the life expectancy of the patient of <1 month was changed into <1 week or 6 months. All interviews were audiotaped, transcribed, and read by two researchers and then discussed with the other researchers. A content analysis, by categorising the different opinions of the interviewees, was performed by one author and results were discussed with the other researchers.

Statistical analyses

Descriptive statistics of responders' experiences with, knowledge and opinions of palliative sedation are presented.

Box 1. Vignette Mr Avezaath

Mr Avezaath is a 70-year-old male with incurable intestinal cancer with metastasis. He is in severe pain. The physician thinks he has a life expectancy of <1 week/1 month. Pain medication cannot sufficiently alleviate his pain. After talking to Mr Avezaath, the physician decides to sedate him until the moment of death to relieve him from suffering/to hasten his death. In this situation Mr Avezaath cannot eat or drink anymore and fluid and food will not be given. The physician gives sedative medication, whereupon Mr Avezaath soon falls into a deep sleep. He passes away a week later.

Table 1. Background characteristics of responders and Dutch population

	Responders, % (n=1960)	Dutch population, % ^a
Sex		
Male	54	50
Female	46	50
Age, years		
<50	39	56
50–70	48	32
>70	13	12
Urbanisation living area		
Low	39	39
Middle	21	18
High	39	43
Education^b		
Low	32	32
Middle	29	40
High	39	29
Religious beliefs		
Yes	58	59
No	42	41
Experience with palliative sedation		
Yes	16	Unknown
No/ don't know	84	Unknown
Experience with euthanasia		
Yes	8	Unknown
No/ don't know	92	Unknown

^aData based on statistics from 2009 of Statistics Netherlands. ^bAccording to the International Standard Classification of Education (ISCED).²⁷ Low = level 1–3 primary school, lower secondary general education, lower vocational education. Middle = level 4 intermediate vocational higher secondary general education. High = level 5–7 higher vocational education or university.

Multivariate logistic regression analyses were used to calculate odds ratios (OR) with 95% confidence intervals (CI) for the relationship between agreeing with the provision of palliative sedation as described in the vignettes and the responder's background characteristics, having experienced palliative sedation as a relative and being against euthanasia in all cases. All analyses were carried out using SPSS (version 20 for Windows). Missing data did not exceed 5%, unless stated differently.

RESULTS

Sample characteristics

In total, 1960 responders completed the questionnaire, resulting in a response rate of 78%. Background characteristics of the responders are shown in Table 1 and are compared with the Dutch population. The responders were more often male, older, and more highly educated compared with the Dutch population. Of the 1960 responders, 16% reported an experience in the past 5 years of a situation in which

a relative was put into a deep sleep until death by a physician (Table 1). Additionally, 16 responders were interviewed. Their characteristics are shown in Table 2.

Knowledge of, and opinion on palliative sedation

Of the 1960 responders, 40% reported never having heard of the term palliative sedation, and 17% claimed not to know the term, but had heard of it. Twenty-two per cent of the responders indicated knowing the term palliative sedation and 21% indicated that they were somewhat familiar with the term (Table 3). The interviews showed a variety of views on what palliative sedation entails, such as 'stopping eating and drinking', 'starvation' or 'slow euthanasia' (Box 2). In total, 974 responders were presented the standard version of the vignette, in which palliative sedation was provided to a patient with a life expectancy of <1 week who had severe pain that could not sufficiently be alleviated, and where the goal of sedation was relieving the patient's suffering. Seventy-six per cent of these responders correctly reported that the act as described in this vignette is allowed in the Netherlands.

Table 2. Background characteristics of interviewees

	Responders, n (%) (N=16)
Sex	
Male	50 (8)
Female	50 (8)
Age, years	
<50	38 (6)
50–70	56 (9)
≥70	6 (1)
Education^a	
Low	31 (5)
Middle	38 (6)
High	31 (5)
Experience with palliative sedation	
Yes	38 (6)
No/don't know	63 (10)
Experience with euthanasia request	
Yes	25 (4)
No/don't know	75 (12)

^aAccording to the International Standard Classification of Education (ISCED).²⁷ Low = level 1–3 primary school, lower secondary general education, lower vocational education. Middle = level 4 intermediate vocational higher secondary general education. High = level 5–7 higher vocational education or university.

Of the 471 responders who were presented with the second version of the vignette, in which the life expectancy of the patient was changed into <1 month, 74% agreed with providing palliative sedation. This was a lower percentage compared with the standard vignette ($P = 0.007$). Of the 515

responders who were presented with the third version of the vignette in which the life expectancy was <1 month and the goal of the sedation was changed, from alleviation of suffering into hastening of the patient's death, 79% agreed with the physician's act ($P = 0.540$). Seventy-three per cent of the responders who indicated knowing the term palliative sedation, labelled the physician's act in the standard vignette correctly as 'palliative sedation'. For all three versions of the vignette, the physician's act was labelled as 'euthanasia' by one-fifth of the responders (18–21%) (Table 4). The demographics of the three groups were similar in their characteristics, no significant differences (>5%) were found.

The interviews suggested that interviewees' opinions on the acceptability of palliative sedation were related to their values regarding end-of-life issues. Responders who agreed with palliative sedation emphasised the patient's gentle and natural way of dying while using sedation, whereas responders disagreeing with palliative sedation underscored the uselessness of prolonging life (Box 3). Both the life expectancy of the patient (Box 4) and the goal of the palliative sedation did not influence the opinions of interviewees. Interviewees considered the patient's suffering and wishes to be more important than the life expectancy of the patient.

Factors associated with positive attitudes towards palliative sedation

The probability of agreeing with palliative sedation in the standard vignette was higher for persons who were against euthanasia in all cases (OR 5.7; 95% CI = 3.0 to 10.8). Responders aged 50–70 years were less likely to agree with palliative sedation compared with responders aged <50 years (OR 0.6; 95% CI = 0.4 to 0.9). Sex, urbanisation grade of the living area, level of education, being religious, and having an earlier experience with palliative sedation were not associated with responders' attitude towards palliative sedation.

DISCUSSION

Summary

This study shows that most of the general public accepts the use of palliative sedation at the end of life to alleviate refractory symptoms. However, there is some indistinctness about the term palliative sedation. When judging the acceptability of palliative sedation, the suffering and wishes of the patient seem to be of greater importance than life expectancy and the goal of palliative sedation.

Table 3. Familiar with the term 'palliative care' and 'palliative sedation' ($n = 1960$)

	Do you know what the term 'palliative sedation' includes?, %	Do you know what the term 'palliative care' includes?, %
Yes	22	28
Yes, somewhat	21	26
No, but I've heard of	17	18
No, I've never heard of	40	28

Box 2. Variety in ideas what palliative sedation entails

Stopping eating and drinking, starvation

Interviewee 7 *'Bringing an end to life by stopping eating and drinking (...) a sort of dehydration I think.'*

Interviewee 10 *'Starvation (...) stopping with eating and drinking.'*

Interviewee 12 *'Sedation is simply stopping with the administration of fluids and food.'*

Giving medication (with different purposes)

Interviewee 1 *'Yes, I think that it is to let someone sleep (...) actually (...) keeping him asleep and not, eh, bringing him back alive.'*

Interviewee 6 *'They slowly take the life through medication, I think.'*

Interviewee 11 *'The sedation is probably a treatment with medication (...) and (...) it is used to reduce the pain.'*

Different form of euthanasia

Interviewee 12 *'It is in fact a fairly long means of euthanasia.'*

Table 4. Opinions on palliative sedation in different circumstances

	To relieve the patient from suffering, %	To relieve the patient from suffering, %	To hasten death, %
Life expectancy	1 week ($n = 974$)	1 month ($n = 471$)	1 month ($n = 515$)
Personally agreeing with the physician's act	81	74 ^a	79
The physician's act is legal in the Netherlands	76	69	67
How would you label the physician's act?			
Pain and/or symptom management	17	13	12
Palliative sedation	41	38	40
Stopping with treatment	14	19	17
Euthanasia	18	19	21
Euthanasia without request from a patient	2	4	3
Different	1	1	1
Don't know	8	7	6

^aSignificantly different with respect to 1 week, $P < 0.05$, based on χ^2 test.

Box 3. Arguments for agreeing and disagreeing on palliative sedation

Agreeing

Interviewee 3	<i>'The life slowly ebbed away (...) It was a peaceful end.'</i> (after personal experience with palliative sedation therapy as a relative)
Interviewee 13	<i>'I found it humane, once he received the medication. (...) You have time to say goodbye (...) he is only put to sleep and died naturally.'</i> (after personal experience with palliative sedation therapy as a relative)
Interviewee 18	<i>'Why should you, whatever the cost (...) want to get food in using drips, tubes and equipment?'</i>
Interviewee 20	<i>'I think it's good (...) if someone has so much pain and he cannot recover, why should you not help them by reducing the pain? When you know for sure that he will die.'</i>

Disagreeing

Interviewee 6	<i>'I don't agree with it at all (...) the delay; you could just as well stop directly.'</i>
Interviewee 7	<i>'I see the person's life slowly ebbing away. It takes longer and I feel it is a degrading thing to do.'</i>
Interviewee 10	<i>'I believe it is degrading actually (...) I see it as suffering (...) really terrible. Also for everyone involved.'</i>
Interviewee 12	Interviewer: <i>'In your view, is this prolonging things?'</i> Interviewee: <i>'Yes, then the family also hasn't anything to gain from the relative just lying on bed. Yes, I wonder what we are doing.'</i>

Box 4. Does life expectancy matter?

No

Interviewee 3	<i>'Oh, that doesn't matter.'</i>
Interviewee 7	<i>'It doesn't change anything for me, if the diagnosis stays the same.'</i>
Interviewee 12	<i>'The story would be exactly the same (...) He has the certainty that he will not reach 100 years old (...) He knows that the end is here (...) I wonder what we are doing to force him to live for an extra month in the most awful pain.'</i>
Interviewee 21	<i>'No, the most important factor for me is the severe pains to be endured which how do you say it, cannot be controlled. And the life expectancy, no.'</i>

Yes

No response received

Strengths and limitations

This study is one of the first studies on attitudes of the general public towards palliative sedation. The high response rate (78%) of this high-quality nationwide sample of the general public is worth mentioning. Furthermore, the mixed-methods approach gives a better understanding of the reasoning behind the quantitative results, which enables a more thorough understanding of these results. Different types of questions and presentations including statements and vignettes were used in the questionnaire. Vignettes have proven their value in

previous decision-making research.^{20,21} Some methodological limitations need to be taken into account. Firstly, despite a good response rate, the responders were not fully representative of the Dutch population: the responders were older, more often male, more highly educated, and more often sharing a household. Moreover, most of the responders who claimed to be religious were Christian; other beliefs were underrepresented in this sample. People with non-Christian religions may have other opinions on end-of-life care and palliative sedation.²² Secondly, an internet panel may involve selection bias. To minimise this bias, an existing panel consisting of a randomised sample of people (thus not self-selected) was used, which enabled all selected members to participate (no restriction to internet users only). Thirdly, a newly developed questionnaire was used, because no validated tool was available.

Comparison with existing literature

Several findings deserve particular attention. At first, the term palliative sedation is comparatively unknown among the general public, although 16% indicated having experienced palliative sedation on a relative. Moreover, there seems to be some confusion about the meaning of the term palliative sedation. It is sometimes confused with euthanasia or described as starvation. In communication with patients and relatives about end-of-life care, it is important for healthcare professionals to take this potential confusion into account.

Secondly, the opinions on palliative sedation of the general public seem to be largely in line with those of healthcare professionals. In a linked study, it was found that, using a similar vignette, 95% of physicians and 80% of nurses agreed with continuous deep sedation.¹⁹ The practice of continuous deep sedation was considered morally justified in 73% of the opinion pieces of physicians and nurses, according to an international content analysis.¹⁵

Thirdly, the level of agreement with palliative sedation in this study is comparable with the level among bereaved relatives of patients who died after palliative sedation. Most of these relatives have been found to be comfortable with the use of palliative sedation, although some had experienced substantial distress.²³

Furthermore, changing the life expectancy of the patient from <1 week into <1 month resulted in a small but significant decrease in the level of agreement with the physician's act of providing sedation. The interviews revealed that the patient's

wishes and suffering are more important aspects when considering the acceptability of palliative sedation than the patient's life expectancy and whether or not palliative sedation was provided with the goal of hastening death. This is in contrast with the Dutch guideline for palliative sedation,⁷ in which a limited life expectancy (<2 weeks) is stated to be an important prerequisite. Many healthcare professionals have also been found to consider life expectancy to be of limited importance.¹⁹ This discrepancy between the opinions of the general public and healthcare professionals and the guideline for palliative sedation may raise questions. Should the wishes of the patient and relief of suffering have a more important place in the moral evaluation than the possible life-shortening effect of palliative sedation? Should the guideline for palliative sedation in the Netherlands be revised accordingly? When considering such a change, the effects of abandoning a limited life expectancy as a prerequisite should be taken into account. A potential consequence is that for patients with a more extended life expectancy the duration of sedation may increase, which could create stress for relatives, and possibly also for the patient when they know that upfront. Another unwanted consequence may be that the confusion between palliative sedation and euthanasia increases, also

for healthcare professionals who currently feel supported by guidelines and the law clearly distinguishing both practices.^{24,25}

Finally, according to the interviewed responders, relieving patients from suffering and the wishes of the patient for palliative sedation were important arguments to support the use of palliative sedation. Dying pain-free with dignity and having a sense of control have been found to be important aspects of a 'good death' elsewhere, too.²⁶

Implications for practice and research

The vast majority of the general public accepts the use of palliative sedation at the end of life, although the term palliative sedation is not well known among the general public.

The finding that many people do not know the term palliative sedation emphasises the importance to clearly inform patients and relatives about palliative sedation, and to verify their beliefs on and expectations of palliative sedation.

The suffering and wishes of the patient seem to be more important in judging the acceptability of palliative sedation than the patient's life expectancy and potential hastening of death. Healthcare professionals should take these results into account when communicating with patients and their relatives about treatment modalities at the end of life.

Funding

This study was supported provided via ZonMw, an organisation which stimulates health research and health innovation commissioned by the Ministry of Health, Welfare and Sports. The sponsors approved the study design, but were not involved in the collection, analysis and interpretation of data.

Ethical approval

The Dutch Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO) does not apply to this study. Therefore, no ethical approval of the Medical Ethical Committee had to be obtained.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors would like to thank all responders who participated in this study of the KOPPEL consortium. KOPPEL is a study on Knowledge, attitudes and Opinions of Public and Professionals on End-of-Life decisions.

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