

Review Article

The Experiences of Relatives With the Practice of Palliative Sedation: A Systematic Review

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Abstract

Context. Guidelines about palliative sedation typically include recommendations to protect the well-being of relatives.

Objectives. The aim of this study was to systematically review evidence on the experiences of relatives with the practice of palliative sedation.

Methods. PubMed, Embase, Web of Science, PsycINFO, and CINAHL were searched for empirical studies on relatives' experiences with palliative sedation. We investigated relatives' involvement in the decision-making and sedation processes, whether they received adequate information and support, and relatives' emotions.

Results. Of the 564 studies identified, 39 were included. The studies (30 quantitative, six qualitative, and three mixed methods) were conducted in 16 countries; three studies were based on relatives' reports, 26 on physicians' and nurses' proxy reports, seven on medical records, and three combined different sources. The 39 studies yielded a combined total of 8791 respondents or studied cases. Caregivers involved relatives in the decision making in 69%–100% of all cases (19 quantitative studies), and in 60%–100% of all cases, relatives were reported to have received adequate information (five quantitative studies). Only two quantitative studies reported on relatives' involvement in the provision of sedation. Despite the fact that the majority of relatives were reported to be comfortable with the use of palliative sedation (seven quantitative studies, four qualitative studies), several studies found that relatives were distressed by the use of sedation (five quantitative studies, five qualitative studies). No studies reported specifically about the support provided to the relatives.

Conclusion. Relatives' experiences with palliative sedation are mainly studied from the perspective of proxies, mostly professional caregivers. The majority of

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relatives seems to be comfortable with the use of palliative sedation; however, they may experience substantial distress by the use of sedation. *J Pain Symptom Manage* 2012;44:431–445. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative sedation, relatives, experiences, systematic review

Introduction

During the last decades, death as the result of acute diseases largely has been replaced by death from chronic diseases,¹ resulting in an increased need for end-of-life care. In some cases, patients who are approaching death experience refractory symptoms that are difficult to alleviate despite intensive medical treatment.^{2,3} This sometimes requires a treatment of last resort: palliative sedation.³ Palliative sedation entails the use of sedating drugs to induce a state of decreased consciousness until death.⁴

It is known that palliative sedation is frequently used in end-of-life care. A study in six European countries reported that it was used in 2.5%–8.5% of all deaths.⁵ Dutch nationwide studies showed that palliative sedation is increasingly used in The Netherlands, up to 8.2% of all deaths in 2005.^{6,7} Palliative sedation is used in all settings where patients die, but most often in hospitals and for patients with cancer.^{5,8–11} Within palliative care settings, incidence estimates of the use of sedatives prior to death range from 15% up to more than 60% of patients.^{12–16} It is usually recommended that for the use of palliative sedation, the patient's disease should be irreversible and advanced, with a life expectancy of, at most, two weeks; benzodiazepines should be the drug of first choice; artificial hydration should only be offered to sedated patients when the benefit will outweigh the harm; the sedation should not be intended to hasten death; and advice from palliative care specialists should be sought before initiating the use of sedation.^{4,17}

To guide caregivers, several international, national, and local guidelines for the use of palliative sedation have been published.¹⁸ These guidelines typically also include recommendations to protect the well-being of relatives of

patients who receive palliative sedation. In 2009, the European Association for Palliative Care introduced a 10-item framework for the development of institutional guidelines for the use of palliative sedation.¹⁷ In 2005, the Royal Dutch Medical Association published a national guideline for palliative sedation in The Netherlands, which was revised in 2009.⁴ Guidelines have been published in other countries also, for example, in 2005, a clinical guideline for palliative sedation was constructed in Japan.¹⁹ According to these guidelines, relatives should be involved in the decision making, for example, by discussing the decision to sedate. Furthermore, relatives can be involved in the provision of the sedation, for example, by spending time with and observing the patient and providing physicians and nurses with information about the patient. Relatives should be kept informed, at various points in the course of palliative sedation, of the patient's well-being and what to expect; and the care team should communicate with the relatives in a language they can understand. The care team also must provide supportive care to the relatives by comforting them and lending a sympathetic ear to help them cope with the experience.

How these recommendations relate to the actual experiences of relatives has never been systematically investigated. The aim of this study was to systematically review evidence on the experiences of relatives with the practice of palliative sedation.

Methods

Search Strategy

A search strategy was developed for finding relevant publications in electronic literature databases. In November 2010, five electronic databases were searched (PubMed, Embase, Web of Science, PsycINFO, and CINAHL) using the

following search string (“palliative sedation” OR “terminal sedation” OR “continuous deep sedation” OR “continuous sedation”) AND (“end of life” OR palliat* OR terminal* OR death OR dying*). The search string was initially developed in PubMed and later adapted for the other databases. Because “experiences of relatives” with palliative sedation was not always the primary objective of the studies found, and information about this topic was sometimes only provided in tables or text, these and other related key words were not included in the search string. To retrieve all the relevant literature, the search string was not restricted by language or date of publication. The search covered the literature published between 1991 and 2010. In addition, reference lists of the eventually selected studies were manually screened.

Selection Criteria

Studies were included when they met the following inclusion criteria: the study concerned empirical research (quantitative or qualitative); the study was about palliative sedation, not sedation in the context of surgical procedures; the study included information about the experiences of relatives with palliative sedation; the experiences of relatives were either directly measured or found through medical records or via a proxy (e.g., physicians, nurses); and the study was about the provision of palliative sedation in adults (older than 18 years). Studies were excluded when they did not meet these inclusion criteria. Reviews, studies reporting duplicate data, comments, case studies, ethical analyses, and conference abstracts also were excluded.

Relatives were not necessarily restricted to family members, but could also include others (friends, etc.).

Inclusion and Evaluation Process

The studies identified were entered into End-Note and duplicates were removed. Ten percent of the publications were independently assessed by SMB (first author) and JACR (second author) using the inclusion criteria. Cohen’s kappa was calculated to determine the degree of agreement: $\kappa = 0.78$, indicating a substantial agreement. The remaining titles were assessed by SMB. This procedure was repeated for the assessment of the abstracts ($\kappa = 0.78$). Of all the studies that did not pass the selection

process, the reasons for noninclusion were listed.

Data Extraction

Data were extracted using a standard form that included as themes: general information, decision-making process, information/communication, involvement in the sedation therapy, feelings/emotions toward sedation, and support. SMB extracted the data from the studies and discussed the results with JACR.

Quality Assessment

Because the review included qualitative, quantitative, and mixed-methods studies, a multi-methods assessment tool, devised by Hawker et al.²⁰ was used to evaluate the quality of individual studies. An assessment form was used, which covered nine areas; each area was rated on a four-point scale, from 1 (very poor) to 4 (good). The areas covered were abstract and title; introduction and aims; method and data; sampling; data analysis; ethics and bias; results; transferability or generalizability; and implications and usefulness. For each paper, it was possible to calculate a total score (9 = very poor to 36 = good) that indicated its methodological rigor. As the studies used different methods, outcome measures, and samples, it was not appropriate to combine data across studies for meta-analysis.²¹ The methodological quality of the selected publications was assessed by SMB; JACR assessed a 10% random sample of studies. Both authors agreed on the quality assessment of all the studies.

Results

Characteristics of the Studies

Searching the electronic databases, 564 studies were identified (excluding duplicates). After scanning the titles, abstracts, and full texts, 36 studies were included (6%) (Fig. 1). After manually screening the reference lists of the selected studies, three studies were added, resulting in 39 studies. The 39 studies included 30 quantitative studies, six qualitative studies, and three mixed-methods studies. The studies used different methods to gather data: questionnaires (23 studies), medical records (seven studies), interviews (five studies), and focus groups (one study). Three studies used

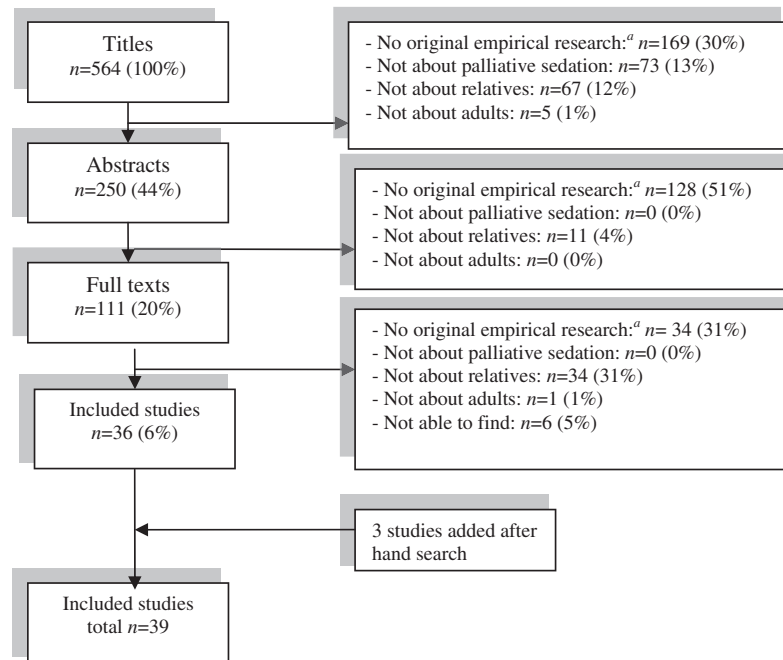


Fig. 1. Inclusion and evaluation process. ^aIncluding reviews, case studies, ethical analyses, studies reporting duplicate data, comments, and conference abstracts.

several methods. The studies were conducted in different care settings: palliative care unit (eight studies), hospital (four studies), home (two studies), hospice (two studies), and a nursing home (one study). Most studies were conducted in multiple settings (21 studies); and in one study, the setting was not restricted. Three studies concerned relatives' reports about their experiences and 26 studies concerned proxy reports, mainly from physicians and/or nurses (23 studies) (in three studies, researchers and pharmacists were included as respondents). Seven studies concerned reports from content analysis of medical records. Three studies combined several sources. Because the data gathered from relatives, proxies, and medical records did not show substantial differences, the results will not be broken down for these groups. The studies originated from 16 different countries, most often from The Netherlands (10 studies) and Japan (eight studies). Thirteen studies were published between 1999 and 2005 and 26 studies between 2005 and 2010. The 39 studies yielded a combined total of 8791 respondents or studied cases (see Table 1 for a full description of the included studies).

In this study, the concept of relatives was not necessarily restricted to family members. Because the included studies did not always provide a clear definition of "relatives," it remains unclear to whom the concept of relatives exactly relates.

Decision-Making Process

Of the 39 studies included, 30 provided information about relatives' involvement in the decision-making process. Of these, 25 were quantitative,^{11,16,22–44} two were qualitative,^{18,45} and three used mixed methods.^{46–48} The 30 studies yielded a combined total of 8060 respondents or studied cases (quantitative, $n = 7775$; qualitative, $n = 35$; mixed methods, $n = 250$).

The involvement of relatives in the decision-making process was variously described in the studies. Some studies reported about involving the relatives in the decision-making process in general terms, whereas other studies reported specific types of involvement, such as discussing the decision, obtaining consent, or informing the relatives about the decision. Quantitative studies found that relatives were involved in the decision-making process in 81%–100% of all cases of palliative sedation.^{22,28,32,36,44,47}

Table 1
 Characteristics of the Included Studies

First Author (Reference)	Year of Publication	Country	Study Design	Data Collection Method	Setting	Respondents	Number of Respondents/ Studied Cases	Methodological Appraisal: Total Score ^a
Seale ¹¹	2010	U.K.	Quantitative study, retrospective	Questionnaire	Home, elder care, hospital	Physicians	519 respondents	32
Chiu ¹⁶	2001	Taiwan	Quantitative study, prospective	Medical records ^b	Hospice and palliative care unit hospital	—	70 cases	26
Rietjens ¹⁸	2007	United States	Qualitative study, retrospective	Interviews	Palliative care unit, medical intensive care unit hospital	Nurses	16 respondents	33
Alonso-Babarro ²²	2010	Spain	Quantitative study, retrospective	Medical records	Home	—	29 cases	25
Chambaere ²³	2010	Belgium	Quantitative study, retrospective	Questionnaire	Home, hospital, care home	Physicians	561 cases	31
Claessens ²⁴	2010	Belgium	Quantitative study, prospective	Questionnaire	Palliative care units in hospitals and hospice	Nurses, researchers	20 cases	28
de Graeff ²⁵	2008	The Netherlands	Quantitative study, retrospective	Medical records ^b	E.g., hospital, nursing home, hospice, home	—	138 cases	20
Eckerdal ²⁶	2008	Sweden	Quantitative study, retrospective	Questionnaire ^c	Hospital	Physicians, nurses	22 cases	19
Forde ²⁷	2001	Norway	Quantitative study, retrospective	Questionnaire	Hospital	Physicians	47 respondents	27
Hasselaar ²⁸	2008	The Netherlands	Quantitative study, retrospective	Questionnaire	Hospitals, home, nursing homes	Physicians	304 cases	29
Marin ²⁹	2003	Spain	Quantitative study, prospective	Medical records ^b	Hospital	—	36 cases	24
Morita ³⁰	2004	Japan	Quantitative study, retrospective	Questionnaire	Palliative care units	Physicians	29 respondents	25
Morita ³¹	2004	Japan	Quantitative study, retrospective	Questionnaire	Palliative care units	Physicians	29 respondents	27
Morita ³²	2005	Japan	Quantitative study, prospective	Questionnaire ^c	Palliative care units	Physicians	102 cases	28
Parker ³³	2008	Australia	Quantitative study, cross-sectional	Questionnaire ^c	Hospital, home	Physicians	1478 respondents	28
Pomerantz ³⁴	2004	United States	Quantitative study, cross-sectional	Questionnaire	Not restricted	Physicians	135 respondents	29
Porzio ³⁵	2009	Italy	Quantitative study, retrospective	Medical records ^b	Home	—	16 cases	19

(Continued)

Table 1
Continued

First Author (Reference)	Year of Publication	Country	Study Design	Data Collection Method	Setting	Respondents	Number of Respondents/ Studied Cases	Methodological Appraisal: Total Score ^a
Rietjens ³⁶	2006	The Netherlands	Quantitative study, retrospective	Interviews	Home, nursing home, and hospital	Physicians	211 respondents	31
Rietjens ³⁷	2004	The Netherlands	Quantitative study, retrospective	Interviews	Home, nursing home, and hospital	Physicians	211 respondents	31
Rietjens ³⁸	2008	The Netherlands	Quantitative study, retrospective	Medical records	Palliative care unit hospital	—	68 cases	29
Van Dooren ³⁹	2009	The Netherlands	Quantitative study, retrospective	Medical records ^b	Palliative care unit hospital	—	45 cases	28
Van Deijck ⁴⁰	2010	The Netherlands	Quantitative study, retrospective	Questionnaire	Nursing homes	Physicians	316 cases	30
Mercadante ⁴¹	2009	Italy	Quantitative study, prospective	Medical records, interviews	Palliative care unit	Relatives	42 cases/ respondents	23
Morita ⁴²	2004	Japan	Quantitative study, retrospective	Questionnaire	Palliative care units	Relatives	185 respondents	30
Morita ⁴³	2004	Japan	Quantitative study, cross-sectional	Questionnaire	Cancer centers, hospitals palliative care units	Nurses	2607 respondents	28
Swart ⁴⁴	2010	The Netherlands	Quantitative study, retrospective	Questionnaire	Home, nursing homes, hospices, and hospitals	Physicians, nurses	555 respondents	26
Blondeau ⁴⁵	2009	Canada	Qualitative study, retrospective	Interviews	Hospitals, hospices, long-term care facilities, home	Physicians	19 respondents	28
Blondeau ⁴⁶	2005	Canada	Mixed-methods study, cross-sectional	Questionnaire ^c	Hospitals, hospices, home	Physicians, pharmacists	124 respondents	29
Chater ⁴⁷	1998	Canada, U.K., Ireland, Italy, United States, Australia, New Zealand, South Africa	Mixed-methods study, retrospective	Questionnaire	Inpatient palliative care facility, hospital, home, outpatient care	Physicians, nurses	53 respondents	32
Venke Gran ⁴⁸	2008	Norway	Mixed-methods study, cross-sectional	Questionnaire	Hospitals and palliative unit nursing home	Nurses	73 respondents	30
Morita ⁴⁹	1999	Japan	Quantitative study, prospective	Questionnaire ^c	Hospice	Physicians	87 cases	26

Brajtman ⁵⁰	2003	Israel	Qualitative study, retrospective	Interviews, focus groups	Hospice	Relatives, clinical staff (nurses, physicians, social worker)	32 respondents	17
Morita ⁵¹	2004	Japan	Qualitative study, retrospective	Questionnaire	Palliative care units	Relatives	185 respondents	32
Forde ⁵²	2006	Norway	Quantitative study, retrospective	Questionnaire	Hospital	Physicians	12 respondents first questionnaire, 116 respondents second questionnaire	26
Van den Block ⁵³	2009	Belgium	Quantitative study, retrospective	Questionnaire ^c	Home, care home (elderly or nursing home), hospital, inpatient palliative care unit	Physicians	177 cases	33
Maessen ⁵⁴	2009	The Netherlands	Quantitative study, retrospective	Questionnaire	Hospital, outpatient care	Physicians, informal caregivers	31 cases	29
Miyashita ⁵⁵	2008	Japan	Quantitative study, retrospective	Questionnaire, medical records	Cancer center, palliative care unit	Relatives	32 cases	28
Rietjens ⁵⁶	2009	The Netherlands	Qualitative study, cross-sectional	Focus groups	Home, nursing home, and hospital	Physicians	24 respondents	31
Seymour ⁵⁷	2007	U.K., The Netherlands, Belgium	Qualitative study, cross-sectional	Interviews	Hospices, hospitals, palliative care unit, community setting	Physicians, nurses, researchers	35 respondents	31

^aScoring system: 9 = very poor, 18 = poor, 27 = fair, 36 = good.

^bMedical records also refer to assessment forms, recording forms, consult records, clinical investigation records, charts, and notations in multidisciplinary records.

^cQuestionnaires also refer to surveys, clinical vignettes, data collection sheets, and registration forms.

Specific aspects of the use of palliative sedation (e.g., the indication, goal, or the expected course of the sedation) were discussed with the relatives in 90%–93%.^{27,32,37,38} Relatives gave their consent to use palliative sedation in 69%–100%.^{16,23,29–31,35,36,39–41} Consent was sometimes not obtained from relatives because it was already obtained directly from patients.²⁹ The relatives were informed about the decision in 95%–100%.^{26,44} Further, studies showed that the relatives proposed or requested the use of palliative sedation in 9%–41%.^{11,32,34,41} One study provided information about the phase before the proposal to use sedation and showed that, in 70%, the relatives were involved in the assessment of intolerable suffering.²⁴ According to one study, physicians were more willing to provide palliative sedation on their own initiative than at the request of relatives.³³ Another study showed that 38% of the physicians and pharmacists attributed an important role to the family in the process of deciding whether to choose sedation or not.⁴⁶ Further, the well-being of relatives was an indication for the use of palliative sedation in 12%–22%.^{25,31} Disagreement about the use of sedation was found among relatives in 10%–17%, between the patient and relatives in 8%–11% and between relatives and medical staff in 10%.^{32,42,43} According to one study, 14% of the physicians and 3% of the nurses reported that they felt pressure to start sedation from patients and/or relatives⁴⁴ (Table 2).

The qualitative data additionally showed that physicians acknowledged the importance of involving the relatives in the process of deciding whether to use sedation or not, but that the patient typically remains top priority.⁴⁵ Nurses sometimes felt that patients and/or their relatives should decide when suffering is intolerable and palliative sedation is necessary, instead of the physicians⁴⁸ (Table 3).

Information/Communication

Eight studies reported specifically on the information relatives received about palliative sedation or about communication issues. Of these, five were quantitative,^{31,32,39,42,49} two were qualitative,^{50,51} and one used mixed methods.⁴⁸ The eight studies yielded a combined total of 738 respondents or studied cases (quantitative, $n = 448$; qualitative, $n = 217$; mixed methods, $n = 73$).

Overall, the quantitative data showed that relatives received information from professional caregivers in 60%–100%.^{31,32,39,42,49} In these studies, the type of information ranged from explanations about the reduction in consciousness, patients' inability to communicate, life-threatening complications, physical changes, physical status, and the prognosis of the patient. Relatives were reported to understand the information in 89%–100%^{39,42} and one study found that relatives experienced the provided information as sufficient in 75%, slightly insufficient in 22%, and insufficient in 2%.⁴² Further, prior discussions about end-of-life issues and/or the choice of sedation between medical staff and relatives took place in 75%–82%^{32,42} (Table 2).

The qualitative data additionally showed that relatives have needs for specific types of information concerning the patient's symptom distress and treatment, the dying process, and when the patient was expected to die.⁵⁰ Also, relatives reported a desire to know that the maximum efforts have been made and that there were no other methods available for symptom relief; to prepare for the patient's death; to tell the patient something important before the start of sedation; to understand the nature of the patient's suffering; and expressed wishes that medical professionals treat the patient with dignity⁵¹ (Table 3).

Involvement During the Provision of Sedation

Only two studies (both quantitative) reported on the involvement of relatives in the provision of sedation ($n = 305$): one study reported that patients were monitored by relatives in 42% (but under supervision of professional caregivers),⁵² and another that relatives were involved in the care for the patient in 17%⁵³ (Table 2).

Emotions and Evaluation

Of the 39 studies included, 14 studies provided information about relatives' emotions regarding sedation. Of these, nine were quantitative^{16,39,41,42,44,49,52,54,55} and five were qualitative.^{18,50,51,56,57} The 14 studies yielded a combined total of 2022 respondents or studied cases (quantitative, $n = 1730$; qualitative, $n = 292$).

According to seven quantitative studies, the majority of the relatives were reported to have

Table 2
Results of Quantitative Data (n = 32)

Core Themes	No. (%) of Studies Reporting	Range of Answers	References
Decision-making process	27 (84%)		(11,16,22–44,46,47) ^a
<i>Involvement in decision-making process</i>			
Relatives involved in decision-making process	6 (19%)	81%–100%	(22,28,32,36,44,47) ^b
Relatives consent	10 (31%)	69%–100%	(16,23,29,31,35,36,39–41)
Decision discussed with relatives	4 (13%)	90%–93%	(27,32,37,38)
Relatives informed of decision	2 (6%)	95%–100%	(26,44)
<i>Other findings</i>			
Sedation proposed (requested) by relatives	4 (13%)	9%–41%	(11,32,34,41)
Well-being of relatives was an indication for sedation	2 (6%)	12%–33%	(25,31)
Conflicts about the use of sedation between people involved	3 (9%)	8%–17%	(32,42,43)
Information/communication	5 (16%)		(31,32,39,42,49)
Information provided to relatives (about indication, goal, expected course; reduction in consciousness, ability to communicate, life-threatening complications; effects on survival, life-supporting functions, treatment options other than PS; physical changes and physical status, and prognosis if PS not induced; risks, benefits)	5 (16%)	60%–100%	(31,32,39,42,49)
Relatives understood the information	2 (6%)	89%–100%	(39,42)
Prior discussion about end-of-life issues between relatives and medical staff	2 (6%)	75%–82%	(32,42)
Information sufficient for relatives	1 (3%)	75%	(42)
Involvement in the sedation process	2 (6%)		(52,53)
Monitoring patient by relatives	1 (3%)	42%	(52)
Involvement of relatives in caring for patient	1 (3%)	17%	(53)
Emotions and evaluation	9 (28%)		(16,39,41,42,44,49,52,54,55)
<i>Positive emotions or evaluation</i>			
Satisfied (or “fair”) with PS	3 (9%)	78%–93%	(42,44,49)
PS decreased symptom distress of patient	1 (3%)	88%	(42)
Decision to start sedation in accordance with family’s wish	1 (3%)	100%	(52)
PS is appropriate for relatives	1 (3%)	98%	(41)
Timing of PS is appropriate for relatives	1 (3%)	77%	(42)
Ethically acceptable (right or might be right to use sedation)	1 (3%)	93%	(16)
Peaceful death because of PS	1 (3%)	91%	(54)
<i>Negative emotions or evaluation</i>			
Relatives experienced distress	1 (3%)	25%	(42)
Relatives expressed concerns	1 (3%)	51%	(39)
Relatives are unsatisfied with PS	1 (3%)	5%	(42)
Relatives asked to stop the sedation	1 (3%)	5%	(41)
PS negatively associated with good death	1 (3%)	—	(55)
Delirium, ambivalence of patient’s wishes, and lack of objectivity of distress associated with difficulty in making decision for family members	1 (3%)	—	(49)
Support	0 (0%)		

PS = palliative sedation.

^aNot all the reporting studies are discussed in the table, some only in the text.

^bMixed-methods studies.^{46,47}

positive feelings regarding the use of palliative sedation.^{16,41,42,44,49,52,54} Relatives seemed to be satisfied with the use of palliative sedation in 78%–93%.^{42,44,49} One study found that 88% of

relatives felt that palliative sedation helped to decrease the patient’s symptom distress.⁴² Another study showed that relatives reported that palliative sedation was appropriate in 93%

Table 3
Results of Qualitative Data (n = 7)

Core Themes	No. (%) of Studies Reporting	Aspects	References
Decision-making process	3 (43%)	Importance of role of relatives, but patient is top priority	(45)
		Well-being of relatives was an indication for sedation	(18)
		Relatives should decide whether or not to use PS	(48) ^a
Information/communication	3 (43%)	Kind of information relatives received (clinical aspects and physical aspects of dying process)	(48) ^a
		Relatives reported desire to know that the maximum efforts had been made, to prepare for the patient's death, to tell the patient something important before sedation, to understand the nature of the patient's suffering, and wishes that medical professionals treat the patient with dignity	(51)
		Relatives differ in type of information they need	(50)
Involvement in sedation process	0 (0%)		
Emotions and evaluation	5 (71%)	<i>Positive emotions or evaluation</i>	
		Sedation made relatives feel more comfortable, because it offered them a sense of peace and closure	(18)
		Relatives wanted the patient's suffering to end	(50,51,57)
		Relatives are grateful for caregivers who treated patient with respect	(50)
		<i>Negative emotions or evaluation</i>	
Relatives experienced distress, e.g., anger, frustration, disappointment, concerns, struggles, guilt, helplessness, and physical and emotional exhaustion	(18,50,51,56,57)		
Distress as a result of: inability to interact with patient, feelings that sedation possibly hastened death, longer duration of sedation, well-being of patient, information not easily obtained or not relevant to needs at that moment	(18,50,51,56,57)		
Support	0 (0%)		

^aMixed-methods study.⁴⁸

because it ended the patients' suffering,⁴¹ and one study showed that the timing of the sedation was seen as appropriate in 77%.⁴² In another study, relatives described palliative sedation as "ethically acceptable" in 93%,¹⁶ and results from another study showed that palliative sedation was associated with a peaceful death in 91%.⁵⁴ According to one study, the decision to start sedation was in accordance with relatives' wishes in 100%.⁵² However, five quantitative studies showed that relatives also experienced negative emotions as a result of the use of sedation.^{39,41,42,49,55} In one study, relatives were

unsatisfied with the sedation therapy in 5%.⁴² Low-level satisfaction was significantly associated with poor symptom palliation after sedation, insufficient information giving, concerns that sedation might shorten the patient's life, and the feeling that there might be other ways to provide symptom relief. In the same study, relatives expressed high levels of emotional distress about sedation in 25%: 10% of the relatives reported to be very distressed and 15% to be distressed.⁴² This distress was significantly associated with poor symptom palliation, feeling the burden of responsibility for the decision after sedation,

feeling unprepared for changes in patient conditions, feeling that the physicians and nurses were not sufficiently compassionate with the patient, and a shorter interval to the patient's death.⁴² One other study found that relatives expressed concerns between the start of the sedation and the death of their loved ones in 51%;³⁹ these concerns were in regard to the aim of the sedation, the well-being of the patient, and the well-being of the relatives themselves (feelings of exhaustion because of sleep deprivation, or unbearable feelings of watching their loved one die).³⁹ Another study showed that relatives asked to stop the sedation in 5% because they wanted to communicate with the patient before death and wanted to take the patient home⁴¹ (Table 2).

The qualitative data provided more insight in the type of negative emotions relatives experienced because of the sedation. "Distress" was described in terms of anger, frustration, disappointment, concerns, struggles, guilt, helplessness, and physical and emotional exhaustion^{18,50,51,56,57} (Table 3).

Support

No studies reported specifically about the support provided to the relatives.

Quality Assessment

The total scores are presented in Table 1. One article was rated between "very poor" and "poor;" 11 articles were rated between "poor" and "fair;" and 27 articles were rated between "fair" and "good."

Discussion and Conclusions

Professionals working in palliative care stress the importance of good care for the patient's relatives because they are the ones who are often present during the last period of the patient's life, and obviously, the most closely involved with the patient.³⁹ The World Health Organization's definition of palliative care incorporates providing a support system to help the relatives cope during the patient's illness and during their own bereavement.⁵⁸ Patient and relatives together are "the unit of care." The importance of relatives is also reflected in guidelines, which stress that relatives should be involved in the decision-making process, that they can assist in monitoring the patient, and that they should

be clearly informed and supported.^{4,17,19} The results from this review suggest that the majority of relatives are adequately involved in the decision making and receive adequate information, although there seems room for improvement. However, hardly any information is available about relatives' involvement in the provision of sedation and no studies report specifically about the support provided to relatives. Furthermore, despite the fact that the majority of relatives reported to be comfortable with the use of palliative sedation, our review shows that the relatives may express distress before or during the application of sedation.

Several findings deserve particular attention. The first concerns the role of relatives in the decision making. Guidelines recommend that physicians actively involve relatives in this process, but because palliative sedation is a medical procedure, it is the physician who bears final responsibility for assessing the indications.⁴ According to the results of this review, relatives sometimes seem to play a rather decisive role in the decision to use sedation, sometimes even more decisive than guidelines recommend. Relatives are, for instance, often involved in the assessment of intolerable suffering²⁴ and quite often propose or request the use of palliative sedation.^{11,32,34,41} On the one hand, caregivers sometimes feel that it should be possible or necessary for relatives to decide when suffering is intolerable and palliative sedation is necessary.⁴⁸ On the other hand, physicians and nurses sometimes feel pressured by relatives to start sedation.⁴⁴ However, it is shown that relatives sometimes feel the burden of responsibility for the decision to use sedation, which may lead to feelings of distress.⁴²

Secondly, there is a large variation in the "needs" relatives express. Relatives want specific types of information; the information needs to be easily available and relevant to their needs at a particular moment in time. The nature of the desired information shows that it includes many facets of the sedation process, concerning both patients' well-being and relatives' well-being, and that provision of information is important during the whole process of sedation.

Finally, it was striking that although the majority of relatives reported to be comfortable with the use of sedation, a substantial number expressed distress as a result of its use. On the

one hand, relatives want the patients' suffering to end; on the other hand, they expressed concerns regarding the aim of sedation, the patients' well-being, and their own well-being. Apparently, both emotions can exist simultaneously. This is in line with findings that relatives generally report to be satisfied with the care received at the end of life, even when they have unmet needs.⁵⁹ Relatives express anger, frustration, disappointment, concerns, struggles, guilt, helplessness, and physical and emotional exhaustion. The reasons for such distress were the inability to interact with the patient, concerns about a possibly hastened death, a longer duration of the sedation, and the fact that information about the sedation was not easily obtained or less relevant to needs of the relatives at that moment. The fact that relatives experience distress because of the use of sedation is not surprising. Being a close relative of someone in the final phase of life is often complicated in general. Relatives must handle both their own sorrow and that of the dying person, in addition to solving a multitude of practical problems.⁶⁰ Aside from these difficulties, relatives of patients who receive palliative sedation also face issues such as the inability to communicate with the patient because of the patient's reduced consciousness; being awake for several days, leading to exhaustion; the unfamiliarity with sedation, after sometimes an extended period of severe suffering; and functional decline of the patient.

Our study has some limitations. In the literature, several terms are used for palliative sedation, for example, continuous deep sedation and terminal sedation, potentially limiting full comparison and extrapolation of the studies. Second, "experiences" is not a clearly definable entity. Third, whether facts presented about relatives' involvement in decision making can be interpreted as "experiences of relatives" can be debated. We interpreted the concept of experience broadly and also included, for instance, relatives' views on palliative sedation. Fourth, not all the included studies appeared to be of "good" quality. Finally, the majority of papers analyzed did not have as a main aim the investigation of relatives' experiences with palliative sedation. If the focus of the research had been this, data may have been different.

The results of this review show that there seem to exist some discrepancies between the recommendations made in guidelines and the actual experiences of relatives with the practice of palliative sedation. First, it seems that recommendations are not always followed. For instance, relatives do not always perceive the provision of information as sufficient.³⁹ Second, there obviously is a lack of evidence about some aspects of the recommendations made in the guidelines. Considering the fact that all the guidelines about palliative sedation stress the importance of involving relatives in the sedation process and supporting the relatives before, during, and after the sedation of their loved ones, it is a remarkable finding that there is no evidence about these issues. In conclusion, we found that relatives' experiences with the practice of palliative sedation are mainly studied from the perspective of proxies, mostly professional caregivers. Studies show that the majority of relatives is involved in the decision-making process. The majority of relatives receives adequate information, although there is room for improvement. Hardly any information is available in the literature about relatives' involvement in the sedation process and no studies report specifically about the support provided to the relatives. Despite the fact that the majority of relatives seems to be comfortable with the use of palliative sedation, there are indications that several of them experience substantial distress with its use.

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