The practices and attitudes of nurses regarding palliative sedation: A scoping review

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Abstract

Background: Palliative sedation is used as a last-resort option to treat refractory symptoms of dying patients. Nurses are important participants in the process of sedation. However, little is known about palliative sedation from a nursing perspective.

Objectives: To analyze the practices and attitudes of nurses concerning palliative sedation.

Data sources and review methods: A scoping review guided by Arksey and O`Malley`s methodological framework was used to analyze existing peer-reviewed empirical research on the topic of the practices and attitudes of nurses related to the palliative sedation of patients aged 18 years and older. Of the 316 publications identified from the PubMed, CINAHL and Cochrane Library, 17 full-text articles were included in this review. The data of the included articles were charted (author(s), year of publication, country, objectives**,** study design, data collection, setting, respondents, definition of palliative sedation, focus of the study and key findings), and the results were summarized with inductive content analysis. The PRISMA-ScR checklist was used as a guideline for the reporting in this review.

Results: During the decision-making concerning the start of palliative sedation, nurses usually have an advocatory and supportive role, although the role varies between different countries. This role then changes to a relatively independent performance of sedation; including administration of the medication, monitoring the effectiveness of sedation, and in some cases taking decisions concerning the medication and dosage policy. Further, nurses provide information and compassionate care to both the patient and the family during the process of palliative sedation. Most nurses view palliative sedation as a positive and sometimes necessary last resort therapy to relieve refractory suffering of dying patients. However, sedation poses ethical problems for many nurses. These problems especially concern the essential elements of deciding to use palliative sedation, the depth of sedation, the potential for shortening life, and the loss of social interaction.

Conclusions: Nurses play a key role in palliative sedation, as they often perform sedation independently and have important information about the needs and wishes of both patients and their families due to their unique position at the bedside of the patient. Although nurses generally see palliative sedation as a positive practice for selected patients, many of them feel it is ethically controversial. This scoping review reveals a great need for further research and discussion on the practices and attitudes of nurses regarding palliative sedation.

Keywords: Attitude; Hospice care; Nurses; Nursing; Palliative care; Scoping review; Sedation; Task; Terminal care

What is already known about the topic?

- Palliative sedation is an important and frequently used, but still a much debated last-resort treatment in the care of palliative care patients with refractory symptoms.

- Nurses play an important role in the provision of palliative sedation. They have a positive but cautious attitude toward the practice, and some of them experience serious emotional stress when administering palliative sedation.

- Studies focusing on the practices and attitudes of nurses regarding palliative sedation are relatively scarce.

What this paper adds

- Nurses have a key role in palliative sedation as they often perform sedation unaccompanied, while concurrently monitoring its effectiveness and in some cases taking decisions concerning the medication and dosage policy. Further, the comprehensive practices of nurses in palliative sedation include participating in decisions concerning the start of sedation as well as providing information and compassionate care to both patients and their families.

- Even if nurses generally view palliative sedation as a positive last-resort practice, many of them see it as ethically controversial. The ethical problems are related to the essential elements to be considered when deciding to use palliative sedation, the depth of sedation, the potential for shortening life, and the loss of social interaction.

- There is a need for further research and discussion on the practices and attitudes of nurses regarding palliative sedation in order to develop quality of care and patient safety, and to enable the use of palliative sedation in different situations where it is deemed necessary for the patient and has been requested by the patient.

1. Introduction

Palliative sedation is used in palliative care for the treatment of otherwise refractory symptoms, such as delirium, dyspnea, psychological distress and pain (Claessens et al., 2008; Garetto et al., 2018; Maltoni and Setola, 2015). According to World Health Organization (WHO), the aim of palliative care is to provide relief from pain and other distressing symptoms and improve the quality of life of patients and their families facing the problems associated with a life-threatening illness (WHO, 2020). Despite significant advances in the delivery of palliative care, some dying patients still experience unbearable suffering that the standard therapies do not relieve (Quill et al., 2009).

There is still no universal definition for the concept of palliative sedation, and it is defined differently in the literature (Papavasiliou et al., 2013), and practiced and perceived differently in various countries (Seymour et al., 2015). To endeavor to encompass the different variations of the concept, the definition of The European Association for Palliative Care (EAPC) is used in the context of this scoping review. Consequently, in this review palliative sedation is 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). This definition refers to all subtypes of sedation: intermittent and continuous sedation as well as superficial and deep sedation (Maltoni and Setola, 2015).

The literature shows that around 25-33 % of patients in palliative care undergo some form of palliative sedation, and about 25-33 % of these require continuous deep sedation (Garetto et al., 2018), though the prevalence of palliative sedation varies considerably between different countries (Anquinet et al., 2012; Miccinesi et al., 2006) and health care settings (Maltoni and Setola, 2015;

Seale, 2010). Although palliative sedation is a quite frequently used therapy, and there are several guidelines available (Abrashi et al., 2017), it is still a much-debated subject in legal, clinical and ethical contexts (Miccinesi et al., 2017; Raus et al., 2016; Sterckx et al., 2013). An essential reason for the debate is that even if there is a distinct line between palliative sedation and euthanasia, in actual practice, making a clear demarcation can be challenging (Anquinet et al., 2013; Rys et al., 2015; ten Have and Welie, 2014).

Studies that describe nurses` practices and attitudes regarding palliative sedation are quite limited. Further, in a notable amount of the research nurses have been examined alongside physicians or other carers (e.g. Anquinet et al., 2015; Gielen et al., 2011; Leboul et al., 2017; Raus et al., 2014; Rys et al., 2013), and separate data on the nurses` perspective is not always available. Nevertheless, to the best of our knowledge, two systematic reviews about palliative sedation from a nursing perspective already exist.

The results of both the earlier reviews were categorized into: 1) important factors leading to the patient receiving palliative sedation, 2) nurses` attitudes toward palliative sedation, and 3) nurses` experience of palliative sedation at the end of a patient`s life (Abrashi et al., 2014; Engström et al., 2007). The results of the preceding review indicated that nurses played key roles in providing palliative sedation, and they had a positive but cautious attitude toward palliative sedation. Some of them experienced delivering palliative sedation as a serious burden. (Abrashi et al., 2014.) Engström et al. noted that studies focusing on nursing care during palliative sedation were scarce and there was a need for further research to elucidate the nurses` role in palliative sedation (Engström et al., 2007). The review of Abrashi et al. developed the earlier review, but the description of nurses` practices in palliative sedation was somewhat limited (Abrashi et al., 2014). After these earlier reviews, palliative sedation from a nursing perspective has become a topic of interest, and more studies have been accomplished. This scoping review updates and constructs the previous systematic reviews, focusing precisely on the practices and attitudes of nurses concerning palliative sedation.

To improve the quality of care of patients receiving palliative sedation, it is critical to understand the practices and attitudes of nurses towards palliative sedation. Therefore, the objective of this scoping review was to analyze the practices and attitudes of nurses concerning palliative sedation. The ultimate goal was to deepen understanding of the issue in order to enhance the quality of care and patient safety by providing an overview of the practices and attitudes of nurses related to palliative sedation.

2. Methods

A scoping review methodology was chosen to describe the practices and attitudes of nurses concerning palliative sedation because knowledge about the topic is limited, and there was a desire to address the key concepts and the main sources and types of evidence available in this complex research area; as well as addressing the knowledge gaps in the evidence base. (Arksey and O`Malley, 2005; Munn et al., 2018.)

Arksey and O`Malley`s (2005) methodological framework for scoping reviews was used to analyze existing empirical research on the topic of this scoping review. The process includes five different stages: (a) identifying the research questions, (b) identifying relevant studies, (c) study selection, (d)

charting the data, and (e) collating, summarizing, and reporting the results (Arksey and O`Malley, 2005). In addition, the included articles were critically appraised for describing their quality. For the reporting in this review, the PRISMA-ScR checklist was used as a guideline (Tricco et al., 2018).

2.1 Identifying the research questions

Before beginning the searches, the authors developed research questions. To answer the objective of this review, the following research questions were identified:

1) What practices are included in the role of nurses in palliative sedation?

2) What attitudes to palliative sedation do nurses have?

2.2 Identifying relevant studies

Systematic searches in electronic databases including PubMed, CINAHL and Cochrane Library were made in February 2020. The search strategy included controlled vocabulary terms and free text words within the topics of “nursing”, “sedation” and “palliative care”, and was developed in consultation with a health sciences librarian. The complete search strategy for PubMed was identified as follows: (nurs* OR "Nurses"[Mesh] OR "Nursing"[Mesh]) AND (sedation* OR "Conscious Sedation"[Mesh] OR "Deep Sedation"[Mesh]) AND (“palliative care*” OR “terminal care*” OR “hospice care*” OR “end-of-life care*” OR "Palliative Care"[Mesh] OR "Terminal Care"[Mesh] OR "Hospice Care"[Mesh]), and it was adapted to other databases. Papers published in English without any time limitation were retrieved. The search strategy generated overall 449 hits. Duplicates were removed leading to 316 records.

After the systematic searches, the reference lists of the articles included in this review from electronic searches were individually searched for other potential articles. Second, references from the retrieved reviews on the topic of this scoping review were examined to ensure that all relevant primary studies were included. The manual searches did not lead to any more potential articles.

2.3 Study selection

The predefined inclusion criteria were: 1) an empirical study, 2) published in an international peer-reviewed journal, 3) dealt with nurses` practices and/or attitudes regarding palliative sedation, and 4) focused on palliative sedation in patients aged 18 years and older. The predefined exclusion criteria were: 1) the paper was not a research article, or it was a literature review, 2) the data did not report separate data from the perspective of nurses.

At first in the study selection process, the titles and abstracts of the papers (n = 316) were screened by one reviewer (LH) using the inclusion and exclusion criteria. Subsequently, the full texts of those papers that met or could potentially meet the selection criteria (n=37) were screened by one

reviewer (LH). After each phase, the resulting papers were confirmed within the research team. Finally, a total of 17 articles met the inclusion criteria and were included for analysis and reported in the results of this scoping review (Fig. 1.).

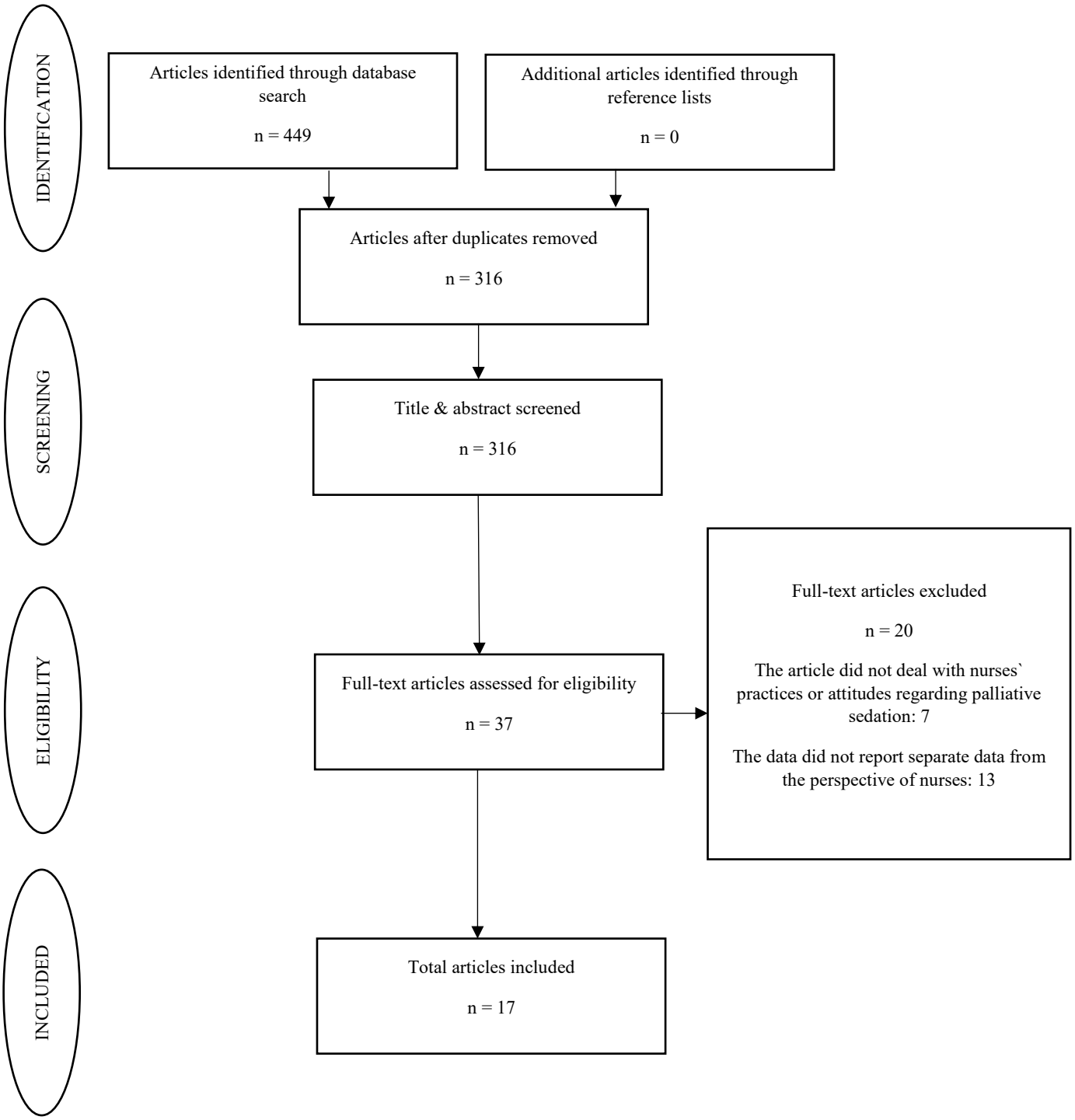

Fig. 1. Flow diagram of the literature search modified from PRISMA (Moher et al., 2010).

2.4 Charting the data, and collating, summarizing, and reporting the results

First, data of the included articles (n=17) were charted by one reviewer (LH). The data extracted from each article included author(s), year of publication, country, objectives**,** study design, data collection, setting, respondents, definition of palliative sedation, focus of the study and key findings (Table 2.).

Second, the results of the studies were summarized by one reviewer (LH) with inductive content analysis as the knowledge about the topic is fragmented (Elo and Kyngäs, 2008). Words and phrases in respect of nurses` practices and attitudes concerning palliative sedation were extracted from the text (Grove et al., 2012). Subsequently, the extracted units of analysis were identified by similarities and differences, and categorized into sub-categories and finally into major groups (Elo and Kyngäs, 2008). The research team discussed any difference in views about the categorization, and a consensus was accomplished.

2.5 Critical appraisal

The meaning of the critical appraisal was to describe the quality of the selected studies (n = 17). The studies were appraised by three reviewers (LH, MS, EH). Any divergent views concerning the critical appraisal were discussed within the research group, and a consensus was achieved. A multi-method assessment tool proposed by Hawker et al. (2002) was used to assess the quality of the studies. The quality was appraised on a fourgrade scale (1 = very poor to 4 = good). The appraising of the quality was based on 1) abstract and title, 2) introduction and aims, 3) method and data, 4) sampling, 5) data analysis, 6) ethics and bias, 7) results, 8) transferability or generalizability, and 9) implications and usefulness. (Hawker et al., 2002.)

The critical appraisal argued that, on the whole, the quality of the studies was quite good. All studies scored at least 22/36 points. Two quantitative (Arevalo et al, 2013; Inghelbrecht et al., 2011) and one qualitative (Anquinet et al., 2015) studies received the highest total score allocations (32 points). The critical appraisal demonstrated that, overall, the quantitative studies provided greater integrity of evidence compared to the qualitative and mixed-method studies. The limitations of the studies especially concerned the sampling, ethics, bias, and transferability or generalizability. (Table 1.)

Table 1. Critical appraisal of included studies.

Study	Abstract and title	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability or generalizability	Implications and usefulness	Total score allocation (Maximum score = 36)
Morita et al., 2004	3	3	3	2	3	1	3	3	4	25
Beel et al., 2006	2	3	2	2	2	2	3	2	4	22
Rietjens et al., 2007	3	3	2	2	3	4	3	2	4	26
Venke Gran and Miller, 2008	2	4	3	2	3	2	3	2	4	25

Inghelbrecht et al., 2009	2	3	4	4	4	3	3	3	4	30
Brinkkemper et al., 2011	4	3	3	3	2	2	4	3	4	28
Inghelbrecht et al., 2011	3	4	4	3	4	3	4	3	4	32
Gielen et al., 2012	3	3	3	3	3	3	3	3	3	27
Patel et al., 2012	4	3	3	3	4	3	3	2	3	28
Zinn and Moriarty, 2012	4	4	3	2	3	3	3	2	4	28
Arevalo et al., 2013	4	4	4	3	4	3	4	3	3	32
Raus et al., 2014	3	3	3	3	3	3	3	2	4	27
Anquinet et al., 2015	4	4	4	3	4	3	4	2	4	32
Dwyer and McCarthy, 2016	3	3	3	3	3	3	3	2	3	26
De Vries and Plaskota, 2017	3	2	3	2	3	2	3	2	4	24
Lokker et al., 2018	4	3	3	3	3	2	3	2	4	27
Zuleta-Benjumea et al., 2018	3	3	3	3	3	3	3	3	4	28

Good = 4, Fair = 3, Poor = 2, Very poor = 1

3. Results

3.1 Description of the studies

The results of this scoping review are based on 17 articles conducted between 2004 and 2018 (Table 2.). Most of the studies (n = 12) were published between 2011 and 2018. The articles were published in journals of nursing (n = 9) and medicines (n = 8). All papers were cross-sectional empirical studies, and nine of them were retrospective case studies. Nurses` practices and attitudes regarding palliative sedation were investigated using quantitative (n = 6), qualitative (n = 9) and mixed methods (n=2). Data collection was conducted with questionnaires (n = 7), semi-structured interviews (n = 7), unstructured interviews (n=1) and focus group interviews (n = 1). In a mixed-method study (Zuleta-Benjumea et al., 2018), both questionnaires and focus group interviews were used. There was a large variation between the definitions of palliative sedation used in the articles. Moreover, the focus of the studies ranged from palliative sedation in general (n = 9) to continuous sedation (n = 3), deep palliative sedation (n = 1), and continuous deep sedation (n = 4).

The studies included in this review were conducted in Belgium (n = 5), the Netherlands (n = 5), the UK (n = 4), the USA (n = 2), Norway (n=1), Ireland (n=1), Japan (n = 1), Canada (n=1), and Colombia (n=1). Data were generated in different healthcare settings: in hospitals, palliative care units or hospices, nursing homes and home care. The sample size in the quantitative studies varied between 199 and 3327 nurses and in the qualitative studies between five and 73 nurses. In the mixed-method studies the sample size ranged between 41 and 73 nurses.

Table 2. Study characteristics.

Author(s), Year of publication, Country	Objectives	Study design	Data collection	Setting	Respondents	Definition of palliative sedation and focus of the study	Key Findings
Morita et al. (2004), Japan	To clarify the levels of nurses` emotional burden related to sedation, and to identify the factors contributing to the burden levels.	Quantitative study	Questionnaires	Cancer centers, general hospitals and palliative care units	3187 nurses	Palliative sedation: "The continuous use of sedative medications to relieve intolerable and refractory distress by achieving almost or complete unconsciousness until death." Palliative sedation was called continuous deep sedation in this study. Focus of the study: continuous deep sedation	2607 (82 %) nurses had clinical experience in continuous deep sedation. Thirty per cent of them reported that they wanted to leave their current work situation due to the burden they experienced related to sedation (answering occasionally, often, or always); 12 % stated that being involved in sedation was a burden; 12 % felt helpless when patients received sedation; 11 % would avoid a situation in which they had to perform sedation if possible; and 4 % felt what they had done was of no value when they performed sedation. The higher burden was significantly associated with the following: shorter clinical experience, nurse-perceived insufficient time in caring for patients, lack of common understanding of sedation between physicians and nurses, team conference unavailability, frequent experience of conflicting wishes for sedation between patient and family, nurse-perceived inadequate interpersonal skills, belief that it was difficult to diagnose refractory symptoms, belief that sedation would hasten death, belief that sedation was ethically indistinguishable from euthanasia, nurse-perceived inadequate coping with their own grief, and nurses` personal values contradictory to sedation therapy.
Beel et al. (2006), Canada	To explore nurses` knowledge, attitudes and the meaning nurses attributed to the use of palliative sedation in dying adult patients in a palliative care unit.	Qualitative study	Semi-structured interviews	A palliative care unit in a long-term care faculty	10 nurses	Palliative sedation: Nurses defined palliative sedation by themselves. Nurse-generated definitions tended to include descriptions of the desired clinical outcome, a notion of timing, and a notion that palliative sedation was used "as a last resort". Focus of the study: palliative sedation	Some nurses expressed uncertainty about the appropriateness of using palliative sedation to relieve psychological or existential distress. A number of factors influenced nurses` comfort in implementing palliative sedation. These factors included: the need to create comfort for the patient, family and the nurse (a high priority identified by all the nurses); the effectiveness of sedation; the personal knowledge by staff of the patient; the perception by the nurses of their relationship with the physician; the timing; the readiness of the patient, family and team; and the presence of collaborative decision making.

Rietjens et al. (2007), the USA	To explore nurses` experiences with and attitudes towards palliative sedation, focusing on the reasons why palliative sedation was used, the nurses` perceptions about palliative sedation and their ideas about how palliative sedation affects the dying process.	Qualitative retrospective case study	Semi-structured interviews	Two units of a large urban tertiary care hospital: the Palliative Care Unit and the Medical Intensive Care Unit	16 nurses	Palliative sedation: "The use of continuous i.v. benzodiazepines, barbiturates, or other medications to bring an imminently dying patient into a state of unresponsiveness to alleviate suffering from symptoms that cannot be controlled with conventional therapies." Focus of the study: continuous deep sedation	In all of the cases, palliative sedation was used primarily to address physical suffering of the patient. Concomitant reasons for the use of palliative sedation were nonphysical suffering (n=8), patient wish (n=4), and family`s feelings of distress about the patient`s suffering (n=3). The use of palliative sedation for the patient`s nonphysical suffering was difficult for many of the nurses (4/8).  Seven nurses felt that the use of palliative sedation did not shorten the patient`s life; three nurses thought that it was possible that palliative sedation may have shortened life, but this was justified because palliative sedation was the only way to address the patient`s refractory symptoms. However, six nurses thought that palliative sedation was close to euthanasia.  Palliative sedation was considered by all the nurses to positively contribute to the patient`s quality of dying. They perceived that palliative sedation had made the dying process more comfortable and peaceful for the patient (n=15); some (n=4) felt that it honored the patient`s wish; and some (n=2) mentioned that palliative sedation made patient`s family more comfortable.
Venke Gran and Miller (2008), Norway	To explore whether or not nurses viewed deep palliative sedation as an ethical problem; and, if so, why they felt it posed a problem for them.	Mixed-method study	Questionnaires	Two general hospitals and one palliative unit in a nursing home	73 nurses	Palliative sedation: "The administration of medication to imminently dying patients with the intent of diminishing consciousness and relieving suffering." Suffering was defined as total pain, which included physical, psychological, social, emotional, and spiritual components. Focus of the study: deep palliative sedation	Most nurses (63 %) felt that deep palliative sedation posed ethical problems, 23 % answered no, and 14 % did not know. Nurses felt that it was ethically difficult when patients were not involved in the decision to sedate, when families had continued needs to communicate with their loved ones, and when nurses felt uncertain about the relief of symptoms due to patients` inability to communicate. Only one nurse stated that palliative sedation was ethically difficult because it might hasten death.
Inghelbrecht et al. (2009), Belgium (Flanders)	To investigate on a nationwide level the attitudes of nurses towards different end-of-life decisions	Quantitative study	Questionnaires	Hospitals, nursing homes and home care	3327 nurses	Continuous deep sedation: "Bringing the patient into a coma until death."	Almost every nurse (96 %) agreed that a terminally ill patient, if necessary, should receive drugs to relieve pain and suffering, even if these drugs may hasten death.

	and towards their role in those decisions, and aim to detect differences in attitudes between groups of nurses based on their socio-demographic and work-related characteristics.					Focus of the study: continuous deep sedation	Most nurses thought that they have an important role to play in end-of-life decisions. Ninety per cent agreed that they should be involved in the whole process of end-of-life decisions. Sixty-seven per cent agreed that patients would rather talk to a nurse about end-of-life decisions than to a physician. Some individual characteristics were associated with attitudes towards end-of-life decisions (e.g. religious) and towards nurses` role in end-of-life decisions (e.g. work setting). Fifty-seven per cent agreed that the administering of drugs to induce the patient into a coma until death is an optimal way of dying, and 26 % were neutral on that statement.
Brinkkemper et al. (2011), the Netherlands	To assess experiences of nurses involved in palliative sedation at home after introduction of a physicians` guideline for palliative sedation.	Quantitative retrospective case study	Questionnaires	Home	201 medical technical assistance nurses	Palliative sedation: "The intentional lowering of consciousness of a patient in the last phase of life." Palliative sedation ranges from superficial to deep sedation, and can be used intermittently and continuously. Focus of the study: palliative sedation	Majority of the nurses (93 %) agreed with the indication for palliative sedation. However, 21 % reported to have refused to carry out a palliative sedation in the preceding year. The general practitioner was not present at the start of palliative sedation in a third of the cases, but was available if needed. Seventy-one per cent of the nurses reported that the general practitioner did not stay present until a desired level of sedation had been reached. Fifteen per cent on the nurses took independent decisions regarding medication policy. The level of sedation was monitored: only by the nurses 20 %, only by the general practitioner 11 %, and by both 63 %. Some nurses (42 %) considered the sedation insufficiently effective.
Inghelbrecht et al. (2011), Belgium (Flanders)	To study the communication process between nurses and patients, relatives, or physicians before starting continuous deep sedation, and how nurses perceive	Quantitative retrospective case study	Questionnaires	Hospitals, nursing homes and home care	250 nurses	Continuous deep sedation: "The administration of drugs to keep the patient in deep sedation or coma until death, can be applied as an option of last resort in cases of refractory symptoms that cannot be adequately treated otherwise."	In 44 % of the cases, where the physician made the sedation decision without the patient but with the relatives, a nurse was also a co-decision-maker. This percentage was lower when the physician decided without the patient and relatives (14 %), or together with the patient (27 %). In 26 % of cases, the patient communicated with the nurse about the continuous deep sedation; and in 75 % relatives communicated with the nurse about the

	this end-of-life practice.					Focus of the study: continuous deep sedation	continuous deep sedation. Nurses rarely proposed the option of continuous deep sedation to the patient (6 %). In 18 % of the cases, there was no communication between the nurse and the physician about the continuous deep sedation; in 29 %, the physician and nurse only exchanged information; and in 23 %, they made the decision jointly. Nurses perceived continuous deep sedation as partly intended to hasten death partially in 48 % and explicitly in 28 % of cases, estimating possible or certain life shortening in 96 %.
Gielen et al. (2012), Belgium (Flanders)	To study nurses` attitudes to palliative sedation and assess the influence of demographic variables, including religion and world view on these attitudes.	Quantitative study	Questionnaires	Palliative care institutions	415 nurses	Palliative sedation: "The intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms." There can be different levels of palliative sedation depending on the way in which it is used (intermittent and acute) and the dosages administered (mild/light and deep). Focus of the study: palliative sedation	A significant number of nurses (76 %) disagreed that euthanasia is preferable to palliative sedation. Thirty per-cent of the nurses agreed that physicians often pretend to be practicing palliative sedation, but are in fact intentionally shortening the patient`s life ("slow euthanasia"). A large majority of the nurses (94 %) agreed that in cases of continuous deep sedation, artificial hydration or nutrition should not be given. Sixty-five per cent of the nurses thought that consent of the patient should be required before administering continuous deep sedation. Fifty-two per cent of the nurses agreed that continuous deep sedation should only be administered when life expectancy is very limited. Nurses were divided as to whether deep sedation can be administered immediately or whether it has to be preceded by mild sedation. Sixty per cent of the nurses did not consider it necessary to first attempt to control refractory symptoms with intermittent sedation before administering continuous sedation. No association was found between the palliative sedation clusters and the variables age, years of experience in palliative care, gender, religion or world view.

Patel et al. (2012), the USA	To elicit nurses` perspectives and conceptualizations of knowledge and skills needed to administer palliative sedation in order to inform development of a hospital policy that addresses identified concerns.	Qualitative study	Focus group interviews	Home hospice settings, medical and surgical intensive care units and oncology	31 nurses	Palliative sedation: Nurses defined palliative sedation by themselves, and subsequently the investigators provided definitions instituted by the Hospice and Palliative Care Nurses Association (HPNA) and a local hospital that has an existing PS policy. Nurse-generated definitions tended to include descriptions of the goals of palliative sedation, patient eligibility/symptoms, risks and concerns, and difference from procedural sedation practices. Focus of the study: palliative sedation	Nurses supported and advocated for the development of comprehensive policies related to palliative sedation. They mentioned that the key domains to incorporate as part of a policy should include a well-developed definition of palliative sedation, criteria for palliative sedation, plans for implementation, training to ensure competence in palliative sedation, and guidelines for administration and monitoring. Additionally, education in palliative sedation was a predominant theme that emergent across topics, disciplines, and level of training.
Zinn and Moriarty (2012), the UK	To describe what nurses understand by the term palliative sedation, to explore who determines intolerable suffering, and to investigate whether nurses experience any discomfort with sedating patients to unconsciousness and what support is provided to the nurses.	Qualitative retrospective case study	Semi-structured interviews	A hospice	Five nurses	Palliative sedation: “The controlled induction of sedation, sometimes to the point of unconsciousness, to relieve severe refractory suffering of a terminally ill patient.” Focus of the study: palliative sedation	Nurses viewed decisions about palliative sedation as courageous and collaborative practice and recognized the ethical implications. Nurses believed palliative sedation was sometimes necessary to ensure a peaceful death. According to most nurses (n=4), patients preferred sleep. Nurses all agreed that families could finally find peace when their loved ones were sedated. Nurses used proportionality or the doctrine of double effect to justify their actions. They had no discomfort about administering increasing doses of medication if necessary. Only one nurse mentioned euthanasia. Nurses played an important role in the provision of palliative sedation. They thought that team support, clinical supervision, and reflective practice were important to enhance their coping.
Arevalo et al. (2013), the Netherlands	To describe nurses` experiences with the decision-making and performance of continuous	Quantitative retrospective case study	Questionnaires	Home care, nursing homes/hospices and hospitals	199 nurses	Palliative sedation: “The intentional lowering of consciousness in the last phase of life.” Palliative sedation can be	Nurses felt involved in the decision to use continuous palliative sedation in 84 % of cases, albeit this proportion was lower in the home setting (69 %) than in the nursing home/hospice (88 %) and hospital settings (90 %).

	palliative sedation in terminally ill patients.					distinguished in intermittent palliative sedation for the temporary relief of suffering and continuous palliative sedation until death. Focus of the study: continuous sedation	Nurses agreed with the performance of continuous palliative sedation in 96 % of cases, and they had proposed continuous palliative sedation in 16 %. Nurses were present at the start of sedation in 81 % of cases and reported physicians to be present in 45 %. According to the nurses, physicians were present until the desired level was achieved in 11 % of cases. During sedation, nurses frequently consulted physicians (74 %) and other nurses (68 %).
Raus et al. (2014), Belgium, the Netherlands, the UK	To provide insight into what may influence how professional and/or family carers cope with distress related to continuous sedation.	Qualitative retrospective case study	Semi-structured interviews	Home, a hospital setting (mostly oncology wards) and a specialist palliative care setting (hospices for the Netherlands and the UK, and palliative care units attached to hospitals for Belgium)	73 nurses, 57 physicians, 34 relatives	Palliative sedation: "Lowering or removing consciousness so that a patient no longer experiences distressing symptoms, whose relief may be judged impossible by other means." Palliative sedation can be given intermittently or continuously until the patient`s death. Focus of the study: continuous sedation	Using the four dimensions of "closeness" it became possible to describe how physicians, nurses, and relatives experience their involvement in cases of continuous sedation until death. The emotional impact of being involved in a case of continuous sedation was highest when respondents felt emotionally and physically close to the patient. Emotional and physical closeness mostly affected relatives and nurses. Decisional closeness and causal closeness affected respondents` perceptions of moral responsibility. Nurses often reported not having final responsibility for the decisions surrounding continuous sedation, which reduced their decisional closeness. With regard to causal closeness, the difference between physicians and nurses was sometimes minimal as many nurses described being actively involved in administering sedative drugs.
Anquinet et al. (2015), Belgium, the Netherlands, the UK	To present case-based general practitioner and nurse descriptions of their collaboration, roles, and responsibilities during the process of continuous sedation until death at home in Belgium, the Netherlands and the UK	Qualitative retrospective case study	Semi-structured in-depth interviews	Home	26 nurses, 25 general practitioners	Continuous sedation until death: "A last resort option for relieving intolerable refractory (i.e., untreatable) symptoms of terminally ill patients in which the patient`s consciousness is lowered until the time of death." Focus of the study: continuous sedation	In Belgium and the Netherlands, it was the general practitioner who typically made the final decision to use sedation, whereas in the UK, it was predominantly the nurse who both encouraged the general practitioner to prescribe anticipatory medication and decided when to use the prescription. Nurses in all the three countries reported that they commonly perform and monitor sedation in the absence of the general practitioner, which they experience as "emotionally burdensome".

Dwyer and McCarthy (2016), Ireland	To explore the experiences of palliative care nurses in the utilisation of palliative sedation in end-of-life care.	Qualitative study	Unstructured interviews	A specialist palliative care center	10 nurses	Palliative sedation: "A decreased or total loss of consciousness caused by the administration and titration of sedative medications (e.g., midazolam, levomepromazine, haloperidol phenobarbital and hyoscine hydrobromide) for a patient with a life-limiting condition who is imminently dying and is experiencing physical refractory symptoms." Focus of the study: palliative sedation	Nurses were generally satisfied with the processes that underpinned decisions to introduce palliative sedation. Nurses saw palliative sedation as a highly complex intervention, in part because it involved individuals with very complex conditions and symptoms.
De Vries and Plaskota (2017), the UK	Not mentioned.	Qualitative retrospective case study	Semi-structured interviews	A hospice	7 nurses	Palliative sedation: "An important and often necessary symptom management measure in the care of palliative care patients who are experiencing uncontrollable symptoms that cause terminal restlessness." (The European Association for Palliative Care, EAPC) Focus of the study: palliative sedation	Nurses believed that palliative sedation facilitated a peaceful death. However, it posed several ethical dilemmas. The ethical dilemmas included: medication decisions: "juggling the drugs", "causing the death", sedating young people, requests for sedation from the family, and relatives conceptualizing a hospice as a place where death is hastened.
Lokker et al. (2018), the Netherlands	To explore nurses` reports on the practice of palliative sedation focusing on their experiences with pressure, dilemmas and morally distressing situations.	Qualitative retrospective case study	Semi-structured in-depth interviews	Hospitals, nursing homes/hospices and general practice/home care	36 nurses	Palliative sedation: "A medical intervention used to alleviate unbearable and refractory suffering in the last phase of life by the deliberate lowering of a patient`s level of consciousness to induce decreased awareness of symptoms." Palliative sedation includes several subtypes: intermittent and continuous sedation, as well	Nurses reported on situations in which they felt that palliative sedation was in the patient`s best interest, but where they were constrained from taking action.  Nurses also talked about situations where they experienced pressure to be involved in the provision of palliative sedation, while they felt this was not in the patient`s best interest. This kind of situation related to 1) starting sedation when the nurse felt not all options to relieve suffering had been explored yet; 2) the family requesting an increase of the sedation level where the nurse felt that this may involve unjustified hastening of death; 3) a decision by the physician to start sedation

						as deep and superficial sedation. Focus of the study: palliative sedation	where the patient had previously expressed an explicit wish for euthanasia.
Zuleta-Benjumea et al. (2018), Colombia	To explore aspects related to the fulfilment of the nursing role in palliative sedation, including their level of knowledge, confidence in skills and knowledge while performing the role, their perception about it and the emotional impact derived.	Mixed-method study	Questionnaires and focus group interviews	Three advanced-care hospitals with palliative care units	Questionnaire: 41 nurses Focus groups: 22 nurses (selected from the first phase)	Palliative sedation: "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 healthcare providers." (The European Association for Palliative Care, EAPC) Focus of the study: palliative sedation	Nurses agreed on the importance of the nursing role in palliative sedation. Nurses` knowledge regarding the basic aspects of palliative sedation was adequate, but it is primarily derived from experience and not from formal training, which impacted on nurses` perceived confidence and their distress. The nurses` level of confidence in skills was higher than their confidence in knowledge. The emotional impact of palliative sedation could positively or negatively affect the performance of the nursing role.

3.2 The practices of nurses in palliative sedation

The results concerning the practices of nurses in palliative sedation consisted of three major groups: 1) participating in the decision-making to begin palliative sedation, 2) administration of medication and monitoring the sedation, and 3) providing information and compassionate care for the patient and the family throughout palliative sedation.

Participating in the decision-making to begin palliative sedation

The physician has the final responsibility in the decision-making concerning the start of palliative sedation (Anquinet et al., 2015; Raus et al., 2014). However, compared to physicians, nurses spend more time with the patient and his/her family (Dwyer and McCarthy, 2016; Lokker et al., 2018; Raus et al., 2014), and are therefore in a unique position to understand the needs of the patient as well as the requirements of the family (Zuleta-Benjumea et al., 2018). Furthermore, the patient and especially the family often discuss their wishes about palliative sedation with nurses (Inghelbrecht et al., 2011).

The decision-making and the involvement of nurses in process is rather unequal in different countries. In Belgium and the Netherlands, nurses quite frequently participate in the decision to start palliative sedation (Arevalo et al., 2013; Inghelbrecht et al., 2011), but they have a relatively subordinate role in it (Anquinet et al., 2015; Arevalo et al., 2013; Inghelbrecht et al., 2011, 2009; Lokker et al., 2018; Raus et al., 2014). Nurses are rarely the first to propose sedation (Arevalo et al., 2013; Inghelbrecht et al., 2011). The predominant task of the nurse in these countries is to advocate for the patient and the family and affirm the physician`s decision to sedate (Anquinet et al., 2015; Inghelbrecht et al., 2011). In contrast to Belgium and the Netherlands, in the UK the use of sedation is more of a team decision (Anquinet et al., 2015; Raus et al., 2014; Zinn and Moriarty 2012), and nurses have a proactive and leading role in it by encouraging the physician to prescribe anticipatory medication (Anquinet et al., 2015) and deciding when to start palliative sedation in practice (Anquinet et al., 2015; De Vries and Plaskota, 2017).

In addition to the country, also the care setting and the individuals participating in the decision influence the nurses` involvement in decision-making. In a study conducted in the Netherlands nurses were less involved in decisions to use palliative sedation in home care situations (Arevalo et al., 2013), whereas in Belgium nurses were co-decision-makers more often in home care (Inghelbrecht et al., 2011). Further, in Belgium nurses were co-decision-makers more frequently in cases where the physician made the sedation decision without the patient but with the relatives (Inghelbrecht et al., 2011).

Administration of medication and monitoring the sedation

Nurses usually start the syringe driver and administer the medication (Anquinet et al., 2015; Arevalo et al., 2013; Brinkkemper et al., 2011; De Vries and Plaskota, 2017; Dwyer and McCarthy, 2016; Raus et al., 2014; Venke Gran and Miller, 2008; Zinn and Moriarty, 2012), often in the absence of the physician (Anquinet et al., 2015; Arevalo et al., 2013; Brinkkemper et al., 2011). Further, monitoring the effectiveness of the sedation is mostly the nurse`s task (Anquinet et al., 2015; Arevalo et al., 2013; Brinkkemper et al., 2011; De Vries and Plaskota, 2017; Venke Gran and

Miller, 2008; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018). According to nurses, a complete evaluation including the monitoring of vital signs and symptom control with an emphasis on pain, consciousness, agitation and emotional state, is important in the assessment of the effectiveness of sedation (Zuleta-Benjumea et al., 2018). During the monitoring of palliative sedation, nurses in some cases take independent decisions concerning the medication (De Vries and Plaskota, 2017) and dosage policy (Anquinet et al., 2015; Brinkkemper et al., 2011; De Vries and Plaskota, 2017; Zinn and Moriarty, 2012).

Providing information and compassionate care for the patient and the family throughout palliative sedation

Along with the other team members, nurses participate in sharing relevant information with patients and families about palliative sedation (Anquinet et al., 2015; Brinkkemper et al., 2011; Dwyer and McCarthy, 2016; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018) in order to protect patient autonomy (Dwyer and McCarthy, 2016) and to help patients and families to better adapt to the situation (Zuleta-Benjumea et al., 2018). Nurses emphasize the importance of truth telling (Zinn and Moriarty, 2012), sensitiveness (Dwyer and McCarthy, 2016) and listening to patients and families (Venke Gran and Miller, 2008) in these conversations.

The education given to the patient and family should be ongoing and include information about sedation and its goals, the physiological changes expected, reduction in consciousness and aspects related to the care, such as feeding and bathing (Zuleta-Benjumea et al., 2018). Informing families about typical symptoms at the end of life is also important because it reduces the family`s misunderstanding of the patient`s suffering. If a family member would like to participate in the care of sedated loved one, nurses can encourage him/her to assist with activities such as bathing and turning. In addition, nurses can advise family members to talk to the patient as though he or she were conscious. (Venke Gran and Miller, 2008.)

3.3 The attitudes of nurses to palliative sedation

The results concerning nurses` attitudes to palliative sedation consisted of five major groups: 1) benefits of palliative sedation, 2) essential elements of deciding to use palliative sedation, 3) concerns regarding the depth of sedation, 4) potential for shortening life, and 5) loss of social interaction.

Benefits of palliative sedation

Generally, nurses view palliative sedation as positive and sometimes necessary to ensure a comfortable and peaceful dying process (Beel et al., 2006; De Vries and Plaskota, 2017; Dwyer and McCarthy, 2016; Inghelbrecht et al., 2009; Morita et al., 2004; Patel et al., 2012; Rietjens et al., 2007; Venke Gran and Miller, 2008; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018). Palliative sedation maintains the dignity of the patient (Dwyer and McCarthy, 2016; Venke Gran and Miller, 2008) and respects his/her wishes (Rietjens et al., 2007; Venke Gran and Miller, 2008). Further, sedation creates comfort not only for the patient, but also for his/her family (Beel et al.,

2006; De Vries and Plaskota, 2017; Patel et al., 2012; Rietjens et al., 2007; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018) as well as the nurses and other staff (Beel et al., 2006; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018).

Essential elements of deciding to use palliative sedation

Nurses agree that palliative sedation is acceptable when the patient has refractory symptoms, and sedation is used as a last resort after every other treatment option has been tried (Dwyer and McCarthy, 2016; Lokker et al. 2018; Morita et al., 2004; Venke Gran and Miller, 2008; Zinn and Moriarty, 2012). In addition, the patient should be imminently dying (Dwyer and McCarthy, 2016; Gielen et al., 2012; Lokker et al., 2018).

Nurses believe that refractory physical symptoms at the end of life are appropriate reasons for using palliative sedation (Beel et al., 2006; Patel et al., 2012); however, some nurses feel uncertainty about the appropriateness of using palliative sedation in cases where the suffering is psychological or existential (Beel et al., 2006; Patel et al., 2012; Rietjens et al., 2007, Zinn and Moriarty, 2012).

Nurses consider it important that patients request palliative sedation themselves and have given their informed consent (Beel et al., 2006; Dwyer and McCarthy, 2016; Gielen et al., 2012; Patel et al., 2012; Venke Gran and Miller, 2008). As well as the patient`s informed consent, it is also important to nurses that the decision-making is shared, in addition to the patient, with the health care team including the nurses (Beel et al., 2006; De Vries and Plaskota, 2017; Gielen et al., 2012; Inghelbrecht et al., 2009; Morita et al., 2004; Patel et al., 2012; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018) and with the family (Beel et al., 2006; Dwyer and McCarthy, 2016; Venke Gran and Miller, 2008).

Concerns regarding the depth of sedation

Nurses have concerns about the appropriate depth and frequency of palliative sedation. In a Belgian study, nurses were divided as to whether deep sedation can be administered immediately or whether it has to be preceded by mild sedation. Most nurses did not consider it necessary to first attempt to control refractory symptoms with intermittent sedation before administering continuous sedation. (Gielen et al., 2012.) Nurses think that the dosage of palliative sedation has to take into account the patient`s symptoms and previous condition such as alcoholism, depression, anxiety or dependency on medication (Dwyer and McCarthy, 2016).

Potential for shortening life

Nurses have divergent views about the possibility of life-shortening through palliative sedation. In the study conducted in Ireland, it was the perception of nurses that palliative sedation did not contribute to hastening the patient`s death (Dwyer and McCarthy, 2016). However, in several studies nurses did express uncertainty as to whether palliative sedation may hasten death (Anquinet et al., 2015; De Vries and Plaskota, 2017; Gielen et al., 2012; Inghelbrecht et al., 2011; Morita et al., 2004; Raus et al., 2014; Rietjens et al., 2007; Venke Gran and Miller, 2008; Zinn and Moriarty, 2012; Zuleta-Benjumea et al., 2018).

Other nurses justify the use of palliative sedation with the view that the intention of palliative sedation is to relieve unbearable suffering, not to shorten a patient`s life, and the possibility of life-shortening is seen as an unintentional side-effect (De Vries and Plaskota, 2017; Raus et al., 2014; Rietjens et al., 2007; Venke Gran and Miller, 2008; Zinn and Moriarty, 2012). However, there were some nurses that believe that palliative sedation is ethically indistinguishable from euthanasia, and feel an emotional burden because of this (Morita et al., 2004; Rietjens et al., 2007; Zuleta-Benjumea et al., 2018).

In two Belgian studies several nurses believed that the decision about beginning palliative sedation is often made partly or clearly with the intention of hastening death (Gielen et al., 2012; Inghelbrecht et al., 2011). However, almost all nurses in the third Belgian study agreed that a terminally ill patient, if necessary, should receive drugs to relieve suffering, even if these drugs may hasten death (Inghelbrecht et al., 2009). In addition, Raus et al. (2014) found that Belgian and Dutch nurses were seemingly less troubled by the possibility of palliative sedation shortening life compared to UK nurses.

Loss of social interaction

Nurses see it as ethically controversial that palliative sedation takes away a patient`s alertness and consciousness, and during sedation the patient is unable to communicate with his/her family (Dwyer and McCarthy, 2016; Venke Gran and Miller, 2008) and the nurses (Venke Gran and Miller, 2008). Some nurses view that the patient`s loss of consciousness causes the “social death” of the patient (Dwyer and McCarthy, 2016). In respect of nurses themselves, nurses feel uncertain about the relief of symptoms due to patients` inability to communicate (Venke Gran and Miller, 2008).

4. Discussion

This scoping review added evidence specifically on the practices and attitudes of nurses related to palliative sedation of patients aged 18 years and older, and it updated the two previous systematic reviews on the same theme (Abrashi et al., 2014; Engström et al., 2007). Research focusing on palliative sedation from a nursing perspective is increasing, although it is still quite rare. The studies (n = 17) included in this scoping review were conducted in nine different countries, mostly in Belgium, the Netherlands, and the UK. The studies were heterogeneous in their objectives, design, methods and settings. In addition, the definitions of palliative sedation used in the articles varied largely, and the focus of the studies ranged between palliative sedation, continuous sedation, deep palliative sedation and continuous deep sedation. (Table 2.)

Nurses play an important role in palliative sedation, as also noted by Abrashi et al., who presented the contextual roles of nurses with respect to palliative sedation administration in selected countries. However, their presentation was quite short and chiefly based on guidelines and frameworks published in different countries rather than the nurses` own perceptions. (Abrashi et al., 2014.) In contrast, this present scoping review produced novel results from the significant and comprehensive practices of nurses in different phases of palliative sedation, and summarized them without a country context – apart from the decision-making, where the variation between different countries was quite considerable. Moreover, the results are based on nurses` own perceptions.

Accounts from the studies reviewed showed that nurses have an active role during the performance of palliative sedation. Administering the medication, monitoring the effectiveness of the sedation and in some cases taking independent decisions concerning the medication and dosage policy during sedation; these tasks engender considerable responsibility, as they involve the need to treat the refractory symptoms of dying and often unconscious patients, but without hastening their death. Even if there are some sedation scales, like the Richmond Agitation-Sedation Scale (RASS), that can be utilized in the assessment of the depth of palliative sedation (Arevalo et al., 2012), consensus about monitoring palliative sedation is still lacking (Schildmann et al., 2015). The studies included in this review did not report that nurses use specific clinical evaluation tools. Further, the independent administration of medication and the opportunity to take independent decisions surrounding the medication and dosage policy do raise questions related to the emotional distress, responsibilities and juridical protection of nurses within the scope of palliative sedation. According to the framework of EAPC, whenever possible, sedation should be started by a physician and a nurse together (Cherny and Radbruch, 2009).

There is a considerable variation in nurses` involvement in decision-making regarding the start of palliative sedation between different countries, care settings and situations. This variation may occur due to cultural, legal and organizational factors as well as due to factors relating individual values. Moreover, most sedation guidelines or the "Guide on the decision-making process regarding medical treatment in end-of-life situations" of Council of Europe do not specifically address the role of nurses in the decision-making surrounding the use of palliative sedation (Council of Europe, 2014; Schildmann and Schildmann, 2014). From a wider perspective, the relevant literature shows that there is a large variation in nurses` involvement in end-of-life decisions on the whole (Benbenishty et al., 2006; Flannery et al., 2016; Hernández-Marrero et al., 2019; Kisorio and Langley, 2016). However, as a result of their frequent contact with the patient and his/her family, nurses often have important knowledge about the needs and wishes of all those concerned, and that knowledge is necessary in discussions related to a patient`s suffering and the potential need for palliative sedation.

Moreover, nurses are an essential part of the team as regards providing information and compassionate care to patients and their families both before and during palliative sedation. Compassionate care is defined as "the recognition, empathic understanding of and emotional resonance with the concerns, pain, distress or suffering of others, coupled with motivation and relational action to ameliorate these conditions" (The Schwartz Center for Compassionate Healthcare and The Arnold P. Gold Foundation, 2014). Compassion enhances treatment outcomes and deepens the human connection between the recipient and the caregiver (The Schwartz Center for Compassionate Healthcare, 2015), and it is a core concept of palliative care (Pfaff and Markaki, 2017). However, providing compassionate care to patients and their families is a highly challenging practice, when the patient is dying and the family is distressed when losing their loved one.

Related to the attitudes of nurses, they generally see palliative sedation as a positive and sometimes necessary therapy in palliative care. This result is in agreement with Abrashi et al., who found that several nurses viewed palliative sedation as a useful "last resort" means of creating comfort for very ill patients (Abrashi et al., 2014), and Engström et al., both showed that medical professionals usually had positive attitudes to palliative sedation (Engström et al., 2007). Nurses agree palliative sedation creates comfort for the patient, his/her family and staff, as well as maintains the dignity of the patient and respects his/her wishes. These findings are in line with the ethical justification for

palliative sedation based, for example, on the precepts of dignity, autonomy, beneficence and non-maleficence (The Hospice and Palliative Nurses Association, 2003).

This review produced unique results as regards the perception of nurses concerning the essential elements of deciding to use palliative sedation - these elements comprise the obligations in respect of refractory symptoms, imminent death, the informed consent of the patient and the collaborative decision-making. These obligations are in line with the statements of several sedation guidelines (Gurschick et al., 2015). However, uncertainties regarding these obligations do exist. First, the concept of a refractory symptom is not clear, and it is used differently in sedation guidelines (Schildmann and Schildmann, 2014). According to ESMO clinical practice guidelines, a refractory symptom is "a symptom that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness" (Cherny, 2014). Second, the appropriate prognosis of the patient varies between guidelines from hours or days to a threshold of weeks (Gurschick et al., 2015), while sometimes referencing only continuous deep sedation (Cherny and Radbruch, 2009). In addition, there is inherent uncertainty as regards to prognostication (Patel et al., 2019). Finally, a number of patients are unable to participate in the decision-making when refractory symptoms appear (Ingravallo et al., 2019).

This review distinctly showed that some nurses feel uncertainty about the appropriateness of using palliative sedation in cases where the suffering is psychological or existential. This result corresponds with the results of the review by Abrashi et al., who found that some nurses had concerns about the use of palliative sedation for nonphysical symptoms (Abrashi et al., 2014), and with the wider literature that shows that palliative sedation in the management of psychological and existential distress is still a controversial issue (Gurschick et al., 2015; Schur et al., 2015; Twycross, 2019; Vouek et al., 2017).

In addition to the essential elements of deciding to use palliative sedation, nurses have concerns regarding the appropriate depth of palliative sedation and the loss of social interaction. However, the level of sedation should be the lowest necessary to provide adequate relief from suffering (Cherny and Radbruch, 2009; Garetto et al., 2018). Evidence from the family perspective shows that relatives are mostly comfortable with the use of palliative sedation, but they may feel distress when they are not able to interact with the patient during palliative sedation (Bruinsma et al., 2012).

Finally, some nurses feel uncertainty about the possibility of hastening death as a result of sedation, and they may even believe palliative sedation is ethically indistinguishable from euthanasia, as also noted by Abrashi et al. (2014). However, the intention of palliative sedation should not be to take a patient`s life but only to relieve unmanageable symptoms, whereas in the case of euthanasia the intention is the death of the patient (Olsen et al., 2010; ten Have and Welie, 2014). It was a notable finding that even if several Belgian nurses believed that palliative sedation partly or clearly intends to hasten death, nurses in Belgium and also in the Netherlands were not very concerned about the possibility of shortening life. Other studies conducted in Belgium have demonstrated that some physicians really use palliative sedation with the intention to hasten death (Anquinet et al., 2011; Rys et al. 2014). In Belgium and the Netherlands euthanasia is legal (Karlsson et al., 2012), which possibly influence the unclear line between palliative sedation and euthanasia and the relatively minor emotional stress nurses feeling in these countries because of the possibility of shortening life. Although some nurses are concerned about the potential for shortening life, the limited evidence shows that, when appropriately used, palliative sedation does not hasten death in otherwise terminally ill patients (Beller et al., 2015; Maltoni et al., 2012).

4.1 Implications for research

Further research is needed in five main areas. First, more information about the practices and the attitudes of nurses concerning palliative sedation is needed, as little is known e.g. about basic treatment during sedation or about nurses` attitudes regarding hydration and feeding during sedation. Second, it would be useful to investigate which factors related to nurses and nursing care can either promote or prevent the use of palliative sedation in situations where the patient needs and has requested the sedation. Third, it would be beneficial to explore what is the relationship between management factors and nurses` performance during palliative sedation and their attitudes towards palliative sedation. Fourth, research concerning the cooperation between nurses and physicians in the process of palliative sedation is still rare and needs to be explored. Finally, it would be important to explore the cultural, legal and organizational differences between countries and assess how these aspects may affect nurses` practices and attitudes related to palliative sedation.

The practices and attitudes should be investigated in different countries in order to provide more heterogeneous representation of nurses as most of the current studies have been conducted in certain European countries. In relation to future research methods, in order to deepen understanding, it would be useful for example to investigate nurses` practices and attitudes regarding palliative sedation with a think-aloud protocol.

4.2 Implications for policy

Even if several countries have published guidelines on palliative sedation, the role of nurses is not always specified (Abrashi et al., 2014). Thus, it is recommended that guidelines on palliative sedation, including the role of nurses, should be published in all countries where the therapy is used. Clarifying the responsibilities along with the practices is essential, because nurses often administer the sedation in the absence of the physician, and sometimes also take independent decisions concerning the medication and dosage policy.

There is still no universal definition for the concept of palliative sedation. Clarifying the terminology surrounding palliative sedation would probably, for instance, simplify the indications of palliative sedation and elucidate how it differs from other treatments, such as euthanasia.

4.3 Implications for practice

In clinical practice, it is recommended to draw attention to increased teamwork, emotional support from other team members and the supervisor as well as more education on palliative sedation. These aspects would probably have the most beneficial impact on the performance of the nursing role in palliative sedation, and as a result of that, increase quality of care and patient safety.

Concerning the increased teamwork, it is suggested that nurses should be actively involved in decision-making regarding the start of palliative sedation as they usually have important information on the needs and wishes of patients and their families. It is recommended that the

decision about palliative sedation should be made collaboratively in the presence of the patient, the family and the interdisciplinary team. Furthermore, it is suggested that physicians should be more often present during the performance of palliative sedation.

Emotional support from other team members and the supervisor is essential because of the ethical implications of palliative sedation. For example, reflecting on cases with team members and the supervisor after palliative sedation could decrease the emotional burden on nurses and improve the processes of palliative sedation.

It is also recommended that education about palliative sedation should be provided especially for nurses working in settings where the therapy is used. A high level of knowledge about palliative sedation is necessary for nurses in order to perform sedation and to provide adequate information to patients and families.

4.4 Limitations

The results of this scoping review should be interpreted cautiously because of some limitations. The first notable limitation of the scoping review is that the data of the review consisted only of empirical studies published in peer-reviewed international journals in English. Other papers, such as reviews, editorials, comments and letters, as well as empirical studies published in different languages were not included, which may have restricted the results. Second, studies that did not clearly provide separate data on the nursing perspective were excluded. Among the studies that were excluded because they did not have separate data from a nursing perspective, there may have been some nursing practices and attitudes that were not mentioned in the studies included. Third, the study selection and analysis were accomplished by one reviewer only.

Moreover, there are some limitations related to the included articles. First, the number of studies was relatively small (n = 17). Second, the majority were conducted in certain European countries, which may have restricted the results, because palliative sedation is practiced differently in various countries. Moreover, there was a variety of definitions used for palliative sedation in the articles as there is no universal definition for the concept of palliative sedation. Finally, the focus of the studies ranged between palliative sedation in general, continuous sedation, deep palliative sedation and continuous deep sedation. The various subtypes of sedation may have influenced the nurses` practices and especially their attitudes.

5. Conclusions

This scoping review offers further evidence concerning the importance of nursing care and the attitudes of nurses with regard to palliative sedation. Nurses represent a key member of the healthcare team introducing palliative sedation, as they often perform sedation independently and have important information about the needs and wishes of both patients and families because of their unique position at the bedside of the patient. Nurses generally have a positive attitude to palliative sedation, but because of some confusion about the practice, a number of them view it as ethically controversial.

There is a great need for further research and discussion on nurses` practices and attitudes regarding palliative sedation in order to improve the quality of care and patient safety, and to enable the use of palliative sedation in different situations where it is deemed necessary for the patient and has been requested by the patient. The practices and attitudes of nurses concerning palliative sedation should be investigated in different countries in order to provide more heterogeneous representation of nurses. It is to be recommended that guidelines, including the role of nurses, are published in all countries where palliative sedation is used. In order to achieve the most favorable fulfilment of the nursing role in palliative sedation in clinical practice, it is suggested that attention be paid to increased teamwork, emotional support from other team members and the supervisor, and increasing education on palliative sedation.

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