BMJ Supportive and Palliative Care
Accepted version

Ethics in clinical practice guidelines on palliative sedation: a systematic review

TOMCZYK Martyna[1], JAQUES Cécile[2], JOX Ralf J.[1,3]

[1] Institute of Humanities in Medicine, Lausanne University Hospital and University of Lausanne, Rue du Bugnon 46, CH-1011 Lausanne, Switzerland
Email: Martyna.Tomczyk@chuv.ch
ORCID: 0000-0002-5824-2411

[2] Medical Library, Faculty of Biology and Medicine, Lausanne University Hospital and University of Lausanne, Rue du Bugnon 46, CH-1011 Lausanne, Switzerland
Email: Cecile.Jaques@chuv.ch
ORCID: 0000-0002-5571-5762

[3] Palliative & Supportive Care Service, Chair in Geriatric Palliative Care, Lausanne University Hospital and Faculty of Biology and Medicine of the University of Lausanne, Av. Pierre-Decker 5, CH-1011 Lausanne, Switzerland
Email: Ralf.Jox@chuv.ch
ORCID: 0000-0002-3040-4714

Correspondence to Dr Martyna TOMCZYK, Institute of Humanities in Medicine, Lausanne University Hospital, CH-1007 Lausanne, Switzerland

Email 1: Martyna.Tomczyk@chuv.ch
Email 2: martyna.tomczyk5891@gmail.com
Telephone number: +33 695118645

Word count:

Abstract

Objectives: The objective of our study was to determine whether, and to what degree, the ethical dimension was present in clinical practice guidelines (CPGs) on palliative sedation, and to identify the ethical issues with respect to the different forms of this practice. The purpose was purely to be descriptive; our aim was not to make any kind of normative judgements on these ethical issues or to develop our own ethical recommendations.

Methods: We performed a systematic review of CPGs on the palliative sedation of adults, focusing our analysis on the ethical dimension of these texts and the ethical issues of this practice. The study protocol is registered on PROSPERO.

Results: In total, 36 current CPGs from four continents (and 14 countries) were included in our analysis. Generally, ethics were rarely referred to or were absent from the CPGs. Only five texts contained a specific section explicitly related to ethics. 'Ethical issues' were named, conceptualized and presented in heterogeneous, often confusing ways. It was impossible to identify the ethical issues of each form of palliative sedation. Ethics expertise was not involved in the development of most of the CPGs and, if it was, this did not always correlate with the ethical dimension of the document.

Conclusions: Effective cooperation between palliative care clinicians and ethicists should be encouraged, in order to integrate the crucial ethical issues of continuous deep sedation until death when developing or updating CPGs on palliative sedation.

Keywords: palliative sedation, ethical issues, clinical practice guidelines, systematic review.

What is already known on this topic

- Numerous CPGs have been developed across the world to support the decision-making process on palliative sedation.
- Systematic reviews of some of these texts generally focus on the *clinical* aspects of palliative sedation and little is known about the ethical implications of the various forms of this therapy.

What this study adds

- 36 current CPGs identified from around the word attach little or no importance to ethics.
- If present (6/36), 'ethical issues' of palliative sedation were named, conceptualized, and presented in heterogeneous, often confusing ways.

How this study might affect research, practice or policy

- These findings could be useful in enriching debate at the international and national levels and foster the inclusion of an ethical dimension when developing or updating CPGs for palliative sedation.

Main text

INTRODUCTION

In the context of adult palliative care, sedation is an important treatment option that can be considered for cancer and non-cancer patients with refractory *and* intolerable physical and/or

non-physical suffering, generally in the last days of life [1-4]. The monitored use of sedating drugs is intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the suffering of the patient, not to hasten death [1, 5].

As with any medical intervention, palliative sedation must have a medical indication and must be proportionate [6-8]. Clinically, there are various modalities of sedation, depending on the individual medical and personal situation of each distressed patient. Consequently, practices differ, mainly with regard to the sedating drugs, route of administration, depth and duration of sedation, as well as the concomitant withdrawal or withholding of artificial nutrition and hydration [8]. Palliative sedation can be influenced by the culture of the country and region in which it is practised, especially by the legal and social contexts and the organization of the healthcare system, as well as the personal attitudes, beliefs, and experiences of the healthcare professionals towards this form of treatment [9-12].

Moreover, from a linguistic perspective, this treatment of last resort is named and/or defined in various, sometimes ambiguous or even contradictory ways. This is also the case in the clinical practices guidelines (CPGs), despite many attempts at clarification [13-16]. For instance, usually the term ‘palliative sedation’ is generic and encompasses a variety of different forms, such as temporary, intermittent, or permanent sedation, as well as sedation of various depths [13]. Sometimes, however, the term ‘palliative sedation’ is also used to refer to practice contrary to palliative care such as euthanasia [17, 18]. This lack of terminological and conceptual consistency is a source of much ambiguity, confusion, and controversy in clinical practice, research, and societal discussions across the world.

The ethical aspects of palliative sedation have frequently been discussed in the literature since the first such publication in 1990 [19]. A systematic literature review of this topic performed in 2010 and updated in 2016 [20] shows four main aspects of palliative sedation as controversial and lacking consensus: consistent terminology, the use of palliative sedation for non-physical suffering, ongoing experience of distress during palliative sedation, and the relation between palliative sedation, euthanasia, and the hastening of death. However, the distinct ethical aspects of the various forms of palliative sedation have rarely been explored in depth.

Ethically, continuous deep sedation until death (CDSUD) is the most controversial form, at both the clinical and ethical levels [8, 21]. This sedation is also the form legally regulated in France [22] and Quebec [23]. *Conceptually,* associations have been drawn

between CDSUD and medically assisted dying, such as euthanasia or assisted suicide [24-26]. *In practice*, this form of sedation is sometimes used as an alternative to medically assisted dying, with or without an intent to hasten death [10, 12, 27]. Moreover, it is unclear whether this form of sedation can be used for non-physical distress and, if so, whether it adequately relieves this type of suffering [28-30].

Other types of palliative sedation, such as temporary or intermittent sedation, also raise ethical questions. For instance, it is not clear when and how to inform patients and families of the option of palliative sedation, how to explain to them that lucidity may not be restored, that symptoms may recur, or that death may intervene during a type of sedation intended as temporary [9, 31, 32].

In the last three decades, numerous CPGs on palliative sedation have been published and some systematic reviews of these texts have been performed [33-36], including a recent European study [37]. However, all these reviews essentially focus on the clinical issues of palliative sedation, such as indications, choice of medication and dosage, continuation of life-prolonging therapies, timing, prognosis, and level of sedation. Only one review explored the ethical aspects of palliative sedation, but that analysis was limited to patient information and used a very general approach [35]. To the best of our knowledge, the ethical challenges in the various forms of palliative sedation have not so far been systematically and transparently explored in CPGs.

The objective of our study was to determine whether, and to what degree, the ethical dimension was present in CPGs on palliative sedation. Our study also aimed to identify the ethical issues with respect to the different forms of palliative sedation. The purpose was purely to be descriptive; our aim was not to make any kind of normative judgements on these ethical issues or to develop our own ethical recommendations. Nor was our aim to assess the quality of the CPGs.

METHODS

Study Design

This systematic review was performed between 22 June 2021 and 30 June 2022. The protocol had previously been registered on the International Prospective Register of Systematic Reviews – PROSPERO (registration number: CRD42021262571) [38] – and its integral

version was published as a preprint [39] and in a peer-reviewed journal [40]. The methods presented in the protocol were enriched as the research progressed, but were not fundamentally changed. Specifically, guidelines for palliative sedation were not sought via the websites of societies of medical ethics because a quick search showed that no CPGs were published on these sites. Some changes to the protocol concerning data extraction, analysis, and synthesis were necessary because of the poor quality of the presentation of the ethical issues in the CPGs.

Given the breadth and complexity of the results, and in order to be as rigorous and transparent as possible, we published all the steps and outcomes of the search for CPGs as well as the results of an analysis regarding the formal characteristics and thematic scope of these texts in a separate article [41]. In this paper, we present a summary of these sections, and develop section data extraction, analysis, and synthesis with respect to the importance of ethics in the CPGs and the ethical issues of palliative sedation. The review is reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [42] (see Supplementary File 1).

Information Sources and Research Strategy

First, five bibliographic databases were searched: MEDLINE ALL (Ovid), Embase.com, CINAHL with Full Text, APA PsycInfo (Ovid), and Web of Science (All Databases). Then, the following 13 guideline depository websites were consulted: Trip Medical Database Pro, ECRI Guidelines Trust, Guidelines International Network (G-I-N), NHS Evidence Search, CISMef – Bonnes Pratiques, Society guideline links (UpToDate), LIVIVO, Australia's Clinical Practice Guidelines Portal, Scottish Intercollegiate Guidelines Network (SIGN), NICE Guidance (UK), and CPG Infobase: Clinical Practice Guidelines/Canadian Medical Association, Registered Nurses Association of Ontario, and Haute Autorité de Santé [French National Authority for Health]. A search was also performed using Google Scholar and Google and was complemented by cross-referencing. CPGs were also searched for on the websites of international, national, and regional associations for palliative care. Database search strategies and a list of the websites of international/national/regional associations for palliative care consulted are available in our previous paper related to this study [41]. If no national CPGs were found on the internet, the association concerned and/or palliative care experts were contacted and asked about CPGs currently used in their country or region.

Moreover, a brief announcement of our project and an invitation to participate were published on the websites [43-45] and in the newsletters of international palliative care organizations, and on the professional and private social media of the first author. Finally, citation chasing was carried out on all the papers previously identified.

Eligibility Criteria

The following inclusion criteria were applied: 1) CPGs explicitly defined as such in the text and in line with the definition proposed by MEDLINE [46]; 2) CPGs related to palliative sedation for adults in all organizational contexts of palliative care; 3) CPGs developed by government agencies, associations, organizations, such as professional societies or governing boards, or by the convening of expert panels, and accredited at the international, national, or regional level; 4) CPGs published in English, German, French, Italian, or Polish, from 2000 to the date of the searches (June 2021-January 2022) and intended for medical and paramedical staff; and 5) only the full version of the CPGs; if there was more than one version of a specific guideline, only the latest and most up-to-date version; if a short and long version existed, only the long version; if one version was published in a journal and another on a website, only the version published in a journal, whatever the length.

Selection Process

The selection of CPGs was performed manually. Titles and abstracts were screened and relevant CPGs were retrieved. We made sure that the CPGs identified was the most recent one by contacting the respective associations that authored them. All CPGs confirmed were included in our study, even if the association didn’t respond.

Data Extraction and Analysis

In the first main step, information about the formal characteristics and thematic scope of the CPGs was extracted from these texts, analysed, and synthesized, with the use of vertical and transversal grids. This step is described in detail in a separate paper [41]. The second main step was focused on the importance of ethics in the CPGs and the ethical issues of palliative sedation.

1) Importance of ethics in the CPGs

In the first stage, textual analysis was performed using a pragmatic framework to determine the importance of ethics in these texts; a range of types of information chosen in advance was extracted from the CPGs: the title of the CPGs, presence of a specific section explicitly related to ethics (i.e., a title containing the word 'ethical'/'ethics'), its exact title, placement in the text, and length.

Next, all the CPGs identified were saved as PDFs. To conduct a quantitative analysis of the importance of ethics in the whole text of each CPG, we chose the automatic option 'search in the document', using terms with the root '*ethic*-' (i.e., 'ethics', 'ethical', 'ethically'; and their translation into German – 'Ethik', 'ethisch'; French – 'éthique', 'éthiquement'; and Italian – 'etica', 'etico', 'eticamente'). We noted all the contexts in which they were used, excluding the affiliations of the authors and bibliographic references. All repetitions of the context were removed. The total number of 'ethics' terms was also noted. It should be pointed out that two words in connection with ethics – 'principles' and 'values' – were not explored because several preliminary readings of the CPGs showed that these terms are not, or very rarely, used in the texts.

Then, using the same approach, the bibliographic references were analysed in order to identify those explicitly related to ethics. If the bibliographic references were not mentioned in the text, we noted them as 'not mentioned'. In contrast, if the bibliographic references were mentioned but without explicit ethics references, we noted them as 'no ethics reference'.

In the last step, *the list* of authors/organizations was analysed in order to determine whether and, if so, what kind of ethics expertise had been integrated into the CPGs. After the preliminary analysis, three categories of participants involved in the development of the CPGs were identified and then applied to the analysis of all the texts: 1) national societies for medical ethics; 2) regional/institutional ethics boards; and 3) individual ethicist(s). By 'individual ethicist', we understood this to be someone who has participated as an individual in the elaboration of the text, and not on behalf of a national society of medical ethics or regional/institutional ethics board.

It should be noted that two main situations, not anticipated when designing the study protocol, were observed during our analysis: 1) *a list* of the scientific societies/boards, including a national society for medical ethics/ethics board, was not provided (or was not obviously presented) in the CPGs; 2) *a list* of the scientific societies/boards was clearly

provided, but without a national society for medical ethics/ethics board. In the first case, we simply noted ‘not mentioned’ in our analysis grid. In contrast, in the second situation, we noted that a society for medical ethics/ethics board had not participated in the elaboration of the CPGs. However, in some CPGs, such a distinction was not entirely clear.

The situation was more complex when analysing the list of individual authors because the full affiliations were not systematically indicated. Consequently, we noted the participation of an ethicist *only* if her/his affiliation was *explicitly* in line with ethics and/or she/he was clearly defined as an ‘ethicist’. If there was no *list* of the authors, we noted ‘not mentioned’.

2) Content of ethical issues

a) *Terminological and conceptual framework*

In our study protocol, for the purpose of this systematic review, the term ‘ethical challenges’ was chosen, and its working definition was elaborated by our research team (MT, CB, and RJJ). However, the first analysis of the CPGs showed that this term and its definition were not applicable; the ethical challenges were named, conceptualized, and presented in various ways. For this reason, the conceptual framework was abandoned and all the analyses were performed in depth, without a framework.

b) *Analysis of specific sections*

If a specific section explicitly related to ethics was identified in a CPG, thematic analysis with continuous theming (without a framework) and line-by-line coding were used to identify all the themes mentioned in this part of the text. The type of palliative sedation was identified from the text. In accordance with this method, the elements were not identified in advance; they were inductively derived from the texts, without attempting to validate a particular theory or hypothesis. We chose this method because of the lack of research on this topic and the heterogeneity of the CPGs identified, and to enable us to explore our material in depth.

c) *Analysis of whole CPGs*

We analysed all the contexts in which ‘ethics’ terms had previously been identified. This analysis was performed without a thematic framework.

Data Synthesis

To the best of our knowledge, at the time of writing the study protocol, there were no specific methodological standards for the data synthesis of analysis that was focused on the importance and content of ethics in CPGs on a medical procedure. Our narrative synthesis explored the relationship between the CPGs included. All the elements allowing an assessment of the importance of ethics were transversally grouped and synthesized. As the purpose of the analysis was purely to be descriptive, we did not seek to develop a theory. Only the most relevant results are presented in this paper. Contrary to the methodological purpose expressed in our study protocol [38-40], it was impossible to synthesize all the elements identified in specific chapters; there were no clearly common elements between these chapters. Consequently, we decided to present the contents of each chapter separately, without a specific synthesis.

Terms with the root '*ethic*-', such as 'ethics', 'ethical', and 'ethically', were used in very inconsistent ways, which made it impossible to summarize them exactly at the qualitative level. For this reason, we only present the *main* results in the Results section, as precisely as possible, and with several examples, but without claiming exactitude. These results are, rather, approximate and aim to illustrate the complexity of the problem.

RESULTS

Sample Size

Figure 1 presents a PRISMA flow diagram that summarizes the results of the search and selection process. A detailed PRISMA flow diagram, with numerous supplementary files, is available in a separate article [41].

In total, 35 CPGs from 14 countries and one international CPG were included in the analysis. Most of the CPGs originated in Canada (10), France (6), or the USA (5). All the CPGs included in this study and analysed are listed in Table 1.

Table 1: CPGs included in the analysis	
CPGs (n = 36)	**Comments**
Australia & New Zealand, 2017 [47]	Confirmed version
Australia/ACT, 2020 [48]	Confirmed version
Australia/Victoria, 2020 (both texts) [49, 50]*	Confirmed versions * In our analysis, both texts are considered as a single text.
Australia/Western Australia, 2021 [51]	Confirmed version
Austria, 2017 [52]	Confirmed version
Belgium/French-speaking part of Belgium, 2019 [53]	Confirmed version
Canada, 2012 [54]	Confirmed version
Canada, 2017 [55]	Confirmed version
Canada/Alberta, 2018 [56]	Unconfirmed version
Canada/British Columbia, 2019 [57]	Unconfirmed version
Canada/Manitoba, 2017 [58]	Unconfirmed version
Canada/Ontario, 2018 [59]	Unconfirmed version
Canada/Ontario, 2019 [60]	Unconfirmed version
Canada/Ontario, 2020 [61]	Unconfirmed version
Canada/Prince Edward Island [62]	Confirmed version
Canada/Quebec, 2016 [63]	Confirmed version *For information* French version: Société québécoise des médecins de soins palliatifs et Collège des médecins du Québec. La sédation palliative en fin de vie, 2016. Published in French. [Quebec Society of Palliative Care Physicians. College of Physicians from Quebec. Palliative sedation at the end of life, 2016] [64].
Europe, 2009 [1]	Confirmed version
France, 2010 (1) [65]	Confirmed version
France, 2010 (2) [66]	Confirmed version
France, 2014 [67]	Confirmed version
France, 2019 [68]	Confirmed version
France, 2020 (1) [69]	Confirmed version
France, 2020 (2) [70]	Confirmed version
Germany, 2021 [71]	Confirmed version
Italy, 2007 [72]	Unconfirmed version

Italy, 2010 [73]	Unconfirmed version
Japan, 2020 [74]	Confirmed version *For information* Japanese version: Japanese Society for Palliative Medicine. Clinical practice guidelines about palliative sedation [our English translation] [75]. (Text not included in our analysis)
Netherlands, 2009 [76]	Confirmed version
Norway, 2014 [77]	Confirmed version *For information* Norwegian version: Den norske legeforenings. Retningslinjer for lindrende sedering i livets sluttfase, 2014 [78]. (Text not included in our analysis)
Scotland, 2019 [79]	Confirmed version
Switzerland, 2005 [80]	Confirmed version *For information* German version: Empfehlungen 'Palliative Sedation'. Konsenseiner Experten gruppe von palliative ch, der Schweiz. Gesellschaft für Palliative Medizin, Pflege und Begleitungzur best practice für Palliative Care in der Schweiz – Bigorio 2005 [81]. (Text not included in our analysis) Italian version: Gruppo di esperti della Società svizzera di cure palliative. Raccomandazioni 'Sedazione palliativa'. Consensus sulla best practice in cure palliative in Svizzera – Bigorio 2005 [82]. (Text not included in our analysis)
USA, 2004 [83]	Unconfirmed version
USA, 2010 [84]	Confirmed version
USA, 2014 [85]	Confirmed version
USA, 2016 [86]	Unconfirmed version
USA, 2018 [87]	Unconfirmed version

Importance of ethics in the CPGs

Detailed results are presented in Supplementary File 2.

1) Title of the CPGs

Only one CPG (1/36) clearly referred to ethics in the title [51]. Despite its title, however, there was no specific section explicitly related to ethics and terms with the root '*ethic-*' rarely appeared throughout the text. Bibliographic references in line with ethics were not cited. Finally, no ethical expertise was mentioned in this text.

2) Specific section explicitly related to ethics

Only five CPGs (5/36) contained a specific section *explicitly* related to ethics, titled 'Précautions éthiques' ['Ethical precautions'] [53], 'Einführung. Terminologie und ethisch-rechtliche Einordnung' ['Introduction. Terminology and ethical-legal classification'] [71], 'Dimensione etica' ['Ethical dimension'] [72], 'Aspetti etici' ['Ethical aspects'] [73], and 'Ethical Issues/Justification' [83]. In addition, one CPG (1/36) included a table titled 'Ethical Criterions for Continuous Sedation' [Exact title with the word 'Criterions'] [74].

The placement of the sections varied widely: they were placed at the beginning of the CPG [71, 83] or at the end of the document [53, 72, 73]. A table was placed in the middle of one article, and all the aspects summarized in the table were developed in a section titled 'Criteria for requirements of palliative sedation' [74].

The length of these sections varied, from several pages [71, 72, 83] to a few phrases [53, 73]; the chapters placed at the beginning of the text were *generally* longer than those set at the end.

Two CPGs [53, 83] with a specific section explicitly related to ethics cited no bibliographic reference in line with ethics, and very rarely used terms with the root '*ethic*-' in the whole text. Moreover, no ethical expertise was mentioned or involved in these texts.

In four other CPGs [71-74], the presence of a specific section explicitly related to ethics always correlated with ethics references, and three of these texts [71, 72, 74] were developed with the help of experts on ethics. Moreover, in two of the CPGs [71, 72], terms with the root '*ethic*-' were frequently used throughout the whole text.

3) Total number of terms with the root '*ethic*-' throughout the texts

The total number of terms with the root '*ethic*-' varied, from none to 34. More specifically, in just over half of the CPGs (20/36), these terms were not or very rarely used: six CPGs (6/36) [55, 56, 68, 70, 79, 80] used no term with the root '*ethic*-' and 14 CPGs (14/36) [47, 48, 49/50*, 53, 57-59, 61, 62, 65, 67, 77, 85, 87] (* see Table 1) used only one to three such terms. Twelve CPGs (12/36) [1, 51, 54, 60, 63, 66, 69, 73, 74, 76, 83, 86] employed these terms more frequently, the total number varying from four to nine. Finally, in four other CPGs (4/36), the use of these terms was rather frequent (12) [52] or very frequent: 17 [71], 22 [84], or 34 [72].

None of the six CPGs without '*ethic*-' terms had bibliographic references explicitly related to ethics or such references were not mentioned. Five of the texts [55, 68, 70, 79, 80] were developed without ethics expertise or such ethics expertise was not mentioned.

All four of the CPGs [52, 71, 72, 84] that contained frequent or very frequent use of '*ethic*-' terms had ethics references and were elaborated with experts in ethics. Two of them [71, 72] also had a specific section explicitly related to ethics.

4) Bibliographic references explicitly in line with ethics

Bibliographic references in line with ethics were explicitly cited in over half the CPGs (22/36) [1, 48, 49/50*, 52, 54, 57-61, 63, 65, 66, 69, 71-74, 76, 84, 85, 86].

In the other CPGs (14/36), such references were not mentioned (8/36) [55, 62, 67, 68, 70, 77, 80, 87] or there were no ethics references (6/36) [47, 51, 53, 56, 79, 83]. In this case, except for one CPG (1/14) [56], the CPGs were elaborated without ethics experts or such expertise was not mentioned.

5) Ethics expertise

Approximately one third of the CPGs (11/36) [52, 54, 56, 58, 61, 69, 71, 72, 74, 76, 84] were developed with the help of ethics expertise, such as a national society for medical ethics, regional/institutional ethics boards and/or individual ethicists.

a) *National society for medical ethics*

Only one CPG (1/36) [69] was developed with the involvement of a national society for medical ethics – the National Consultative Ethics Committee in France. However, this did not correlate with the ethical dimension of the text. This CPG had ethics references, but no specific section related to ethics. Terms related to 'ethics' were seldom used; there were only six such terms in the whole text.

b) *Regional/institutional ethics board*

Only three CPGs (3/36) [58, 72, 84] were developed with the help of a regional/institutional ethics board, listed as the WRHA [Winnipeg Regional Health Authority] Regional Ethics [58], the Study Group of the Italian Society for Palliative Care on End of Life Ethics and Culture [72], and the Ethics Committee of the National Hospice and Palliative Care

Organization [84]. In one of these CPGs (1/3) [72], the involvement of an ethics board correlated with the presence of a section related to ethics, and ethics references. Moreover, '*ethic*-' terms were frequently used in this text. In the other two CPGs (2/3) [58, 84], this type of strict correlation was not observed.

c) *Individual ethicist(s)*

One or more individual ethicists participated in the development of nine of the CPGs (9/36) [52, 54, 58, 61, 62, 71, 74, 76, 84] but in only two texts (2/9) [71, 74] did this fully correlate with the presence of a specific section related to ethics. In other CPGs (23/36) [1, 47, 48, 51, 53, 55, 57, 59, 60, 62, 63, 65-68, 72, 73, 77, 79, 83, 85-87], the participation of individual ethicists *was not mentioned*. Three CPGs (3/36) [69, 70, 80] were elaborated *without* ethicists. Finally, the participation of ethicists was reported in a confusing manner in one CPG (1/36) [49/50*]: the authors of this text clearly stated that 'an ethicist was a member of the working group and provided expertise in this area'. However, no expert was explicitly designated an ethicist in the list of experts in the working group.

Content regarding ethical issues in the CPGs

1) Sections explicitly related to ethics

Sections explicitly related to ethics were identified in six CPGs* [53, 71, 72, 73, 74, 83; * including the CPG with table]. However, as previously stated, the ethical issues of palliative sedation were heterogeneously presented in these sections. Consequently, it was impossible to synthesize the results precisely. We present the ethical issues (referred to differently in the CPGs) section by section below, with the exact titles of these sections.

a) *'Ethical precautions'* [53]

In this section of the text, which contained only a few phrases regarding 'ethics', 'ethical precautions' were only related to emergency sedation, also called a 'distress protocol'. It was stated that an emergency situation can be anticipated and that discussion with the patient, her/his relatives, and the healthcare team is important. It was outlined that the discussion should concern the objective of the 'distress protocol', its effects and risks, and should be started as early as possible. After inducing sedation, the situation should be evaluated.

b) *'Terminology and ethical-legal classification'* [71]

This long section was structured in four parts. General information was presented in the introduction, in particular, the goals of palliative care and palliative sedation, and the kind of palliative sedation. The distinction between specialized and general palliative care was made, and it was noted that palliative sedation should be realized in a specialized palliative care unit or at least discussed with palliative care specialists. In the first section, numerous *medical* and potentially ambiguous terms were defined and commented upon (e.g., 'sedated', 'sedation', 'to sedate', and 'lightly/deeply sedated'). The second section was fully related to the problem of existential suffering and the application of palliative sedation in this case. In the last section, the *legal* terminology was defined and commented upon, in line with the jurisdiction in Germany (e.g., 'suicide', 'assistance in suicide', and 'killing on demand').

c) *'Ethical dimension'* [72]

At the beginning of this long section, the following five main ethical aspects of palliative sedation were listed and then developed in the text: the ethical justification for palliative sedation (from the perspective of principlism, the ethics of the quality of life and the ethics of the sanctity of life); the distinction between palliative sedation and euthanasia; hypothetical anticipation of death; limitation of treatment; and the decision-making process.

d) *'Ethical aspects'* [73]

In this very short section, it was simply stated that, according to the ethics of the quality of life and the ethics of the sanctity of life, palliative sedation would be morally acceptable. It was also noted that palliative sedation is distinguished from euthanasia.

e) *'Ethical criterions for continuous sedation'* [74]

The following ethical criteria for continuous sedation were summarized in a table and developed in the text: proportionality, the wishes and autonomy of patients, the intent of medical staff, and the judgement of the multidisciplinary team.

f) *'Ethical issues/justification'* [86]

In this section, the justification for palliative sedation was based on the principles of autonomy, beneficence, fidelity, and non-maleficence. These four principles were briefly in the text. For example, fidelity was presented as '[t]he ethical imperative to keep promises, and it was specified that '[f]or healthcare providers, fidelity includes the promise not to abandon the patient'. In addition, the assumptions regarding the appropriateness of palliative sedation

and numerous elements of the procedure were listed. The consent form was attached to the text.

2) Whole texts

As previously noted in the Methods section, '*ethic*-' terms were used inconsistently in the CPGs and, consequently, it was impossible to synthesize all the results exactly. In this section, we only present the *main* results, without being able to be fully precise. All the contexts in which 'ethics' terms were used are presented in Supplementary File 3.

In most of the cases, 'ethics' terms were used in a general sense, without being conceptualized, such as 'ethical use of palliative sedation' [51], 'good clinical and ethical practice' [47], or 'from an ethical point of view' [74]. They were also frequently used to express the acceptability of palliative sedation, without systematically specifying the criteria of this 'acceptability'. The more common expressions were 'ethically acceptable' [47, 59], 'ethically appropriate' [54], 'ethically justifiable' [74, 77], and 'ethically defensible' [85]. In some CPGs, the ethical criteria were mentioned, but in diverse ways. For instance, the authors of the Japanese CPG [74] stated that 'Palliative sedation is ethically justified in the contexts of proportionality, patient autonomy, intent, and judgment by the team'. In CPG issued in the USA [85], 'Palliative sedation is ethically defensible when used 1) after careful interdisciplinary evaluation and treatment of the patient, and 2) when palliative treatments that are not intended to affect consciousness have failed or, in the judgment of the clinician, are very likely to fail, 3) where its use is not expected to shorten the patient's time to death, and 4) only for the actual or expected duration of symptoms. Palliative sedation should not be considered irreversible in all circumstances'. In other CPG published in the USA [83], the ethical justifications for palliative sedation were: 1) the principle of beneficence; 2) the intent of palliative sedation; 3) circumstances in which the initiation of palliative sedation would be unethical; 4) the agency's palliative sedation policy; and 5) the use of consent forms. In contrast, in Italian national CPG [72], ethical acceptability of this therapy was analysed in line with Principle-Based Ethics, Ethics of the Quality of Life and Ethics of the Sanctity of Life. Ethics of the Quality of Life and Ethics of the Sanctity of Life were also mentioned in other Italian CPG [73].

The term 'ethics' was frequent used in the context of a specific ethics board, such as a 'clinical/hospice ethics committee/service' [48, 58, 83]. It was recommended to contact such

an ethics committee, especially when uncertainty remained regarding the appropriateness of palliative sedation for a patient after clinical assessment (e.g., uncertainty of time until dying) and/or there was no consensus on decision making between the patient/family and/or members of the healthcare team.

Finally, three *main* ethics thematic groups were identified in some CPGs: 1) the use of sedation, especially CDSUD, for existential suffering; 2) the cessation of artificial nutrition and hydration; and 3) the distinction between palliative sedation and assisted suicide or euthanasia. However, several thematic analyses performed with methods other than those presented in this paper clearly showed that these aspects were discussed or simply mentioned without being associated with terms with the root '*ethic-*'. In order not to bias the results in line with the ethical dimension of the CPGs, we will present the results from this further analysis in a separate paper specifically focused on these three topics.

DISCUSSION

Our systematic review of CPGs on sedation in adult palliative care was purely descriptive and aimed to determine the ethical dimension of these clinical texts and to explore the full spectrum of ethical issues of all forms of palliative sedation. Contrary to other systematic reviews [33-37], we did not limit our search to North American or European CPGs; we included 36 current CPGs from around the world. Second, our analysis was focused on the form and content of the ethical issues of palliative sedation, and not on the clinical aspects of this therapy. Thus, direct comparison is not possible.

Our analysis shows that, in general, little or no importance was placed on ethics in the CPGs that we reviewed. In most of the texts, there was no section explicitly related to ethics and ethics expertise was not involved in the development of the texts. Numerous CPGs had no bibliographic references related to ethics. Moreover, '*ethic-*' terms were not or rarely used. On the one hand, one of our eligibility criteria was *clinical practice* guidelines; other texts, including ethical protocols, were excluded from our review. On the other hand, in order to support and manage the clinical decision-making process regarding individual patients, ethical reflection should be integrated into clinical documents. Healthcare professionals rarely examine articles in scholarly bioethics journals or specialized documents of ethics committees, but they regularly access clinical practice guidelines. In that respect, Mertz and

Strech [88] have developed a six-step approach – their 'EthicsGuide' [exact title, without a space] – for the systematic and transparent inclusion of ethical issues and recommendations in CPGs.

Given that all medical interventions must be ethically justified with regard to their benefit-risk-ratio and should be proportionate to need [6-8], not every form of palliative sedation needs a separate ethical framework. However, there is an urgent need for the development of an ethical guideline on CDSUD. Indeed, our analysis has shown three *main* ethical challenges concerning CDSUD: 1) the use of CDSUD for existential suffering; 2) the foregoing of artificial nutrition and hydration in CDSUD; and 3) the distinction between CDSUD and assisted suicide or euthanasia. An ethical guideline on CDSUS would also have to include practical advice on how to implement a shared decision-making process in this context.

In the specialist literature, several terms are used to refer to the ethical dimension of one or more elements of the decision-making process, such as 'ethical issues', 'ethical aspects', 'ethical challenges', 'ethical dilemmas', 'ethical considerations', 'ethical reflection', and 'ethical risks'; often without explicit definition. Thus, in research in the field of ethics, the most basic (and paradoxical) question would always be 'which is an ethical question, which is not?' [89]. In our study protocol [38-40], we proposed the term 'ethical challenges', which was borrowed from Kahrass et al. [90], and we elaborated its working definition. However, our *preliminary* analysis of the CPGs suggested that this conceptual and terminological framework would not operate and our *deep* analysis confirmed it. First, our study shows that the term 'ethical challenge' was not used in the CPGs. Instead, other terms were employed in the titles of sections explicitly related to ethics: 'Ethical precautions', 'Terminology and ethical-legal classification', 'Ethical dimension', 'Ethical aspects', 'Ethical criterions for continuous sedation', and 'Ethical issues/justification', without being defined. The analysis of the content of the sections did not permit us to understand exactly what these terms mean or their conceptual characteristics. For example, in the German CPGs, the ethical dimension focused on medical and legal terminology, whereas the Italian CPGs referred to three kinds of ethics. In contrast, in the Belgian CPGs, we only identified a few constants, such as the importance of providing information to the patient. Surprisingly, and contrary to our presuppositions expressed in the study protocol, some CPGs with an ethics section referred to ethical principles but not necessarily to the widely accepted 'four cardinal principles' of biomedical ethics as published by Beauchamp and Childress (i.e., beneficence, non-

maleficence, respect for autonomy, and justice) [91]. For example, one North American CPG [86] replaced the principle of justice with fidelity. In contrast, the Japanese CPGs [74] introduced new principles/criteria: proportionality, the intention of medical staff, and the judgement of the multidisciplinary team. This correlates with the results of the systematic review performed by Schofield et al. [92]. Their study focused on the ethical challenges reported by specialist palliative care practitioners in their clinical practice and shows that practitioners use different approaches to ethical reflection, not only the principles from Beauchamp and Childress.

As stated in our study protocol, in the literature, especially in publications that are purely theoretical or predominantly conceptual, the ethical issues of palliative sedation are often presented as general reflections, without referring precisely to the clinical characteristics and context of the sedation. However, 'good ethics requires good facts'; that is, empirical data must support ethical discourse [93]. As previously mentioned, there are several, and important, differences between temporary and light sedation introduced to relieve physical symptoms, and CDSUD (without proportionality) for existential distress in patients who are not imminently dying. Without clear differentiation, ethical reflection on palliative sedation will be neither correct nor practically helpful. We hoped, with our systematic review, to better understand the ethical issues of *each* type of palliative sedation. However, the thematic scope of the CPGs varied, and was often not fully obvious, even confusing. For this reason, analysing the ethical issues of each type of sedation was impossible.

Methodological Limitations

As noted above, we included 36 current CPGs from around the world: one international CPG, 34 CPGs from 'Western countries' and only one CPG from non-Western country (Japan). We identified two CPGs written in Hebrew [41]. but, unfortunately, we did not include it in our review. We did not identify any CPGs from other non-Western country. For example, we do not know if there are CPGs published in Chinese or Arabic. Indeed, contrary to articles presenting the results of empirical studies, which are mostly written in English, the guidelines are rather national and, therefore, written in the national languages (or sometimes translated into English). Given that our aim was to analyse the content of the recommendations qualitatively (including terminological and conceptual aspects of palliative sedation), we had chosen, as an inclusion criterion, our native languages or languages in which we are fluent,

i.e., English, French, German, Italian, and Polish. We chose not to work on a translation. We believe that our approach greatly reduces the risk of terminological and linguistic misinterpretation. On the one hand, this is a limitation of our review. On the other, it is important to point out that in the systematic reviews published at the time of writing our study protocol, only the guidance documents written in English [34], English and German [35], English, Dutch and Italian [33], and French [36] had been included in the analysis. More recently, when our manuscript for the *Journal of Palliative Care* was being reviewed [41], a systematic review of European CPGs was published [37]. However, only 9 CPGs were included in that European review. These texts were written in English, have an official English translation (Dutch CPGs), or were translated from Italian, Flemish, and Spanish into English by members of the research team. International collaborations should be supported in order to include and analyse CPGs from Western and non-Western countries. Such approach could facilitate exploration and understanding of cultural dimension of ethical aspects of palliative sedation.

CONCLUSION

Our systematic review of CPGs on palliative sedation, which included 36 texts from around the world and focused the analysis on the ethical dimension of these texts and the ethical issue of palliative sedation, is, to the best of our knowledge, the first in the field of palliative care. As mentioned above, the purpose of this study was to be descriptive. Despite heterogeneous and relatively poor results, we believe that some of the pieces of information that issued from this review could be useful for future research, especially in the development of an ethical guideline. Given that all medical interventions – from dental work to end-of-life care – must, as Professor Robert Twycross frequently highlights, be justified by necessity, and should, therefore, be proportionate to need, a specific ethical framework for each form of palliative sedation does not appear to be necessary, except for one form of this treatment: CDSUD. There is an urgent need for the development of a clear ethical guideline on this topic. Interdisciplinary collaboration between palliative care clinicians and ethicists should be supported by mutual respect. This type of framework could then be integrated into the CPGs, in order to improve the quality of these texts, positively stimulate ethical reflection in palliative care teams, and consequently facilitate the decision-making process required for this challenging form of palliative sedation for the benefit of distressed and dying patients.

REFERENCES

[1] Cherny NI, Radbruch L; The Board of the European Association for Palliative Care. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med. 2009;23(7):581-593. doi: 10.1177/0269216309107024

[2] Cherny NI; ESMO Guidelines Working Group. ESMO Clinical Practice Guidelines for the management of refractory symptoms at the end of life and the use of palliative sedation. Annal Oncol. 2014;25 Suppl 3:iii143-152. doi: 10.1093/annonc/mdu238

[3] Swart SJ, Rietjens JA, van Zuylen L, Zuurmond WW, Perez RS, et al. Continuous palliative sedation for cancer and noncancer patients. J Pain Symptom Manage. 2012;43(2):172-181. doi: 10.1016/j.jpainsymman.2011.04.004

[4] Rampello G, Grisetti R, Zaiat M, Leonardi P, Siddi V. Hospice palliative sedation in non-cancer patient: what symptoms to palliate? Annals of Oncology. 2016;27 (Supplement 4): iv107–iv125. doi:10.1093/annonc/mdw345.65

[5] ten Have H, Welie JV. Palliative sedation versus euthanasia: an ethical assessment. J Pain Symptom Manage. 2014;47(1):123-136. doi: 10.1016/j.jpainsymman.2013.03.008

[6] Twycross R. Second thoughts about palliative sedation. Evidence-Based Nursing. 2017;20:33-34.

[7] Twycross R. Regarding Palliative Sedation. J Pain Symptom Manage. 2017 Jun;53(6):e13-e15. doi: 10.1016/j.jpainsymman.2017.01.002.

[8] Twycross R. Reflections on palliative sedation. Palliat Care Res Treat. 2019;12:1-16.

[9] Tomczyk M, Beloucif S. Informer sur la sédation continue maintenue jusqu'au décès, en France et en Pologne : quel impact des contextes nationaux sur le contenu de l'information médicale destinée au patient ? Published in French [Information to patients about continuous sedation until death in France and Poland: What is the influence of national contexts on the content of medical information delivered to the patient?]. Ethics, Medicine and Public Health. 2018;(7):13-28. https://doi.org/10.1016/j.jemep.2018.09.001

[10] Seale C, Raus K, Bruinsma S, van der Heide A, Sterckx S, et al.; UNBIASED consortium. The language of sedation in end-of-life care: The ethical reasoning of care providers in three countries. Health (London). 2015 Jul;19(4):339-354. doi: 10.1177/1363459314555377

[11] Vissers S, Dierickx S, Robijn L, Cohen J, Deliens L, et al. Physicians' experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death: A secondary qualitative analysis of an interview study. Int J Environ Res Public Health. 2022;19(9):5472. doi: 10.3390/ijerph19095472

[12] Seymour J, Rietjens J, Bruinsma S, Deliens L, Sterckx S, et al.; UNBIASED consortium. Using continuous sedation until death for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. Palliat Med. 2015;29(1):48-59. doi: 10.1177/0269216314543319

[13] Papavasiliou ES, Brearley SG, Seymour JE, Brown J, Payne SA; EURO IMPACT. From sedation to continuous sedation until death: how has the conceptual basis of sedation in end-of-life care changed over time? J Pain Symptom Manage. 2013 Nov;46(5):691-706. doi: 10.1016/j.jpainsymman.2012.11.008. Epub 2013 Apr 6. PMID: 23571206.

[14] Tomczyk M, Viallard ML, Beloucif S. 'Sédation' ou 'pratiques sédatives à visée palliative en fin de vie' ? Une étude linguistique des recommandations francophones en matière de sédation en soins palliatifs chez l'adulte. Rech Soins Infirm. 2021 Jan 13;(143):106-117. French. doi: 10.3917/rsi.143.0106. PMID: 33485279.

[15] Rady MY, Verheijde JL. Uniformly defining continuous deep sedation. Lancet Oncol. 2016 Mar;17(3):e89. doi: 10.1016/S1470-2045(15)00585-9. Epub 2016 Mar 2.

[16] Bakogiannis A, Papavasiliou EE. Language Barriers to Defining Concepts in Medicine: The Case of Palliative Sedation. Am J Hosp Palliat Care. 2016 Nov;33(9):909-910. doi: 10.1177/1049909115586186. Epub 2015 May 13. PMID: 25972384.

[17] Smets T, Cohen J, Bilsen J, van Wesemael Y, Rurup ML, et al. The labelling and reporting of euthanasia by Belgian physicians: a study of hypothetical cases. Eur J Public Health. 2012 Feb;22(1):19-26. doi: 10.1093/eurpub/ckq180. Epub 2010 Dec 3. PMID: 21131347.

[18] Buiting HM, van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Rietjens JA, et al. Physicians' labelling of end-of-life practices: a hypothetical case study. J Med Ethics. 2010 Jan;36(1):24-29. doi: 10.1136/jme.2009.030155. PMID: 20026689.

[19] Ventafridda V, Ripamonti C, de Conno F, Tamburini M, Cassileth BR. Symptom prevalence and control during cancer patients' last days of life. J Palliat Care.1990;6:7-11.

[20] Henry B. A systematic literature review on the ethics of palliative sedation: an update (2016). Curr Opin Support Palliat Care. 2016;10(3):201-207. doi: 10.1097/SPC.0000000000000224

[21] Papavasiliou EE, Payne S, Brearley S; EUROIMPACT. Current debates on end-of-life sedation: an international expert elicitation study. Support Care Cancer.2014;22(8):2141-2149. doi: 10.1007/s00520-014-2200-9

[22] The French Law No. 2016-87 of 2 February 2016 on new rights for patients and people at the end of life [France. Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie]. Version updated on 7 September 2022. Legifrance. Available from: www.legifrance.gouv.fr (accessed 13 January 2023).

[23] Quebec Law on end-of-life care. [Québec. Loi concernant les soins de fin de vie]. Chapter S-32.0001. Version updated on 1 April 2022. LégisQuébec. Available from: www.legisquebec.gouv.qc.ca (accessed 13 January 2022).

[24] Broeckaert B. Palliative sedation, physician-assisted suicide, and euthanasia: 'same, same but different'? Am J Bioeth. 2011;11(6):62-64. doi: 10.1080/15265161.2011.577518

[25] Rady MY, Verheijde JL. Continuous deep sedation until death: palliation or physician-assisted death? Am J Hosp Palliat Care. 2010;27(3):205-214. doi: 10.1177/1049909109348868

[26] Morita T, Hirai K, Akechi T, Uchitomi Y. Similarity and difference among standard medical care, palliative sedation therapy, and euthanasia: a multidimensional scaling analysis on physicians' and the general population's opinions. J Pain Symptom Manage. 2003;25(4):357-362. doi: 10.1016/s0885-3924(02)00684-x

[27] Anquinet L, Raus K, Sterckx S, Smets T, Deliens L, et al. Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: a focus group study. Palliat Med. 2013;27:553-561.

[28] Ciancio AL, Mirza RM, Ciancio AA, Klinger CA. The use of palliative sedation to treat existential suffering: A scoping review on practices, ethical considerations, and guidelines. J Palliat Care. 2020 Jan;35(1):13-20. doi: 10.1177/0825859719827585. Epub 2019 Feb 13. PMID: 30757945.

[29] Rodrigues P, Menten J, Gastmans C. Physicians' perceptions of palliative sedation for existential suffering: a systematic review. BMJ Support Palliat Care. 2020;10(2):136-144. doi: 10.1136/bmjspcare-2019-001865

[30] Rodrigues P, Crokaert J, Gastmans C. Palliative sedation for existential suffering: A systematic review of argument-based ethics literature. J Pain Symptom Manage. 2018 Jun;55(6):1577-1590. doi: 10.1016/j.jpainsymman.2018.01.013

[31] Tomczyk M, Viallard ML, Beloucif S, Mamzer MF, Hervé C. Sédation continue maintenue jusqu'au décès : comment en informer le malade et recueillir son consentement ? Published in French. [Continuous sedation until death: How to inform the patient and obtain

consent?] Médecine palliative : Soins de Support – Accompagnement – Éthique. 2015;14(2): 111-117. https://doi.org/10.1016/j.medpal.2015.01.003

[32] Cocker A, Singy P, Jox RJ. How should health care providers inform about palliative sedation? A qualitative study with palliative care professionals. Eur J Cancer Care (Engl). 2022;31(5):e13602. doi: 10.1111/ecc.13602

[33] Abarshi E, Rietjens J, Robijn L, et al. International variations in clinical practice guidelines for palliative sedation: a systematic review. BMJ Support Palliat Care. 2017;7(3):223-229. doi: 10.1136/bmjspcare-2016-001159

[34] Gurschick L, Mayer DK, Hanson LC. Palliative sedation: an analysis of international guidelines and position statements. Am J Hosp Palliat Care. 2015;32:660-671. doi: 10.1177/1049909114533002

[35] Schildmann E, Schildmann J. Palliative sedation therapy: A systematic literature review and critical appraisal of available guidance on indication and decision making. J Palliat Med. 2014;17:601-611. doi: 10.1089/jpm.2013.0511

[36] Tomczyk M, Viallard ML, Beloucif S. État des lieux des recommandations sur la sédation palliative chez l'adulte dans les pays francophones. Published in French. [Current status of clinical practice guidelines on palliative sedation for adults in French-speaking countries]. *Bull Cancer* 2021;108(3):284-294. doi: 10.1016/j.bulcan.2020.10.011

[37] Surges SM, Garralda E, Jaspers B, Brunsch H, Rijpstra M, et al. Review of European guidelines on palliative sedation: A foundation for the updating of the European Association for Palliative Care Framework. J Palliat Med. 2022 Jul 12. doi: 10.1089/jpm.2021.0646

[38] Tomczyk M, Jaques C, Jox RJ. Ethical challenges in palliative sedation of adults: protocol for a systematic review of current clinical practice guidelines. PROSPERO – International prospective register of systematic reviews. National Institute for Health Research. Available from: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=262571 (accessed 19 January 2023).

[39] Tomczyk M, Jaques C, Jox RJ. Ethical challenges in palliative sedation of adults: protocol for a systematic review of current clinical practice guidelines. Research Square – International preprint platform. doi: 10.21203/rs.3.rs-1170023/v1

[40] Tomczyk M, Jaques C, Jox RJ. Ethical challenges in palliative sedation of adults: protocol for a systematic review of current clinical practice guidelines. *BMJ Open* 2022;12:e059189. doi: 10.1136/bmjopen-2021-059189

[41] Tomczyk M, Jaques C, Jox RJ. Clinical practice guidelines on palliative sedation around the world: A systematic review. J Palliat Care. 2022:8258597221138674. doi: 10.1177/08258597221138674

[42] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71. doi: 10.1136/bmj.n71

[43] Tomczyk M, Jaques C, Jox RJ. Current clinical practice guidelines on palliative sedative for adults: what are the ethical challenges of this practice? European Association for Palliative Care (EAPC), Blog. Available from: https://eapcnet.wordpress.com/2021/11/17/current-clinical-practice-guidelines-on-palliative-sedative-for-adults-what-are-the-ethical-challenges-of-this-practice/ (accessed 19 January 2023).

[44] Announcement: International study on clinical practice guidelines for palliative sedation – help requested. Published on the ehospice website on 04 October 2021. Available from: https://ehospice.com/international_posts/international-study-on-clinical-practice-guidelines-for-palliative-sedation-help-requested/ (accessed 19 January 2023).

[45] Announcement: Palliative sedation study seeks global input. Published on the website of the International Association for Hospice and Palliative Care (IAHPC) in October 2021 (IAHPC News, vol. 22, n° 10, October 2021). Available from: https://hospicecare.com/what-we-do/publications/newsletter/2021/10/iahpc-news/ (accessed 19 January 2023).

[46] U.S. National Library of Medicine. Definition of practice guidelines. Available from: https://meshb.nlm.nih.gov/record/ui?ui=D017065 (accessed 19 January 2023).

[47] Australian and New Zealand Society of Palliative Medicine. Guidance document – Palliative Sedation Therapy, 2017. Available from: http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1587788353&sid=. (accessed 19 January 2023).

[48] ACT Government. Canberra Health Services. Guideline use of palliative care sedation therapy (adults), 2020. Available from: https://www.health.act.gov.au/sites/default/files/2021-02/Use%20of%20Palliative%20Care%20Sedation%20Therapy%20%28Adults%29%20-%20Canberra%20Health%20Services.docx (accessed 19 January 2023).

[49] Safe Care Victoria. Palliative sedation therapy. Statewide guidance for Victoria, 2020. Available from: https://www.bettersafercare.vic.gov.au/sites/default/files/2020-03/GUIDANCE_Palliative%20sedation%20therapy%20FINAL.pdf (accessed 19 January 2023).

[50] Safe Care Victoria. Palliative sedation therapy. Evidence-based guidance supplement, 2020. Available from: https://www.bettersafercare.vic.gov.au/sites/default/files/2020-

03/SUPPLEMENT_Palliative%20sedation%20therapy%20guidance.pdf (accessed 19 January 2023).

[51] Government of Western Australia, Department of Health. Statewide guidance for the safe, effective and ethical use of palliative sedation, 2021. Available from: https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/End-of-Life/End-of-life-choices/Statewide-guidance-palliative-sedation.pdf (accessed 19 January 2023).

[52] Weixler D, Roider-Schur S, Likar R, Bozzaro C, Daniczek T, et al. Leitlinie zur Palliativen Sedierungstherapie (Langversion): Ergebnisse eines Delphiprozesses der Österreichischen Palliativgesellschaft (OPG). Published in German. [Austrian guideline for palliative sedation therapy (long version): results of a Delphi process of the Austrian Palliative Society (OPG)]. *Wien Med Wochenschr* 2017;167(1-2):31-48. doi: 10.1007/s10354-016-0533-3

[53] Fédération Bruxelloise de Soins Palliatifs et Continus, Fédération Wallonne des Soins Palliatifs, Société Scientifique de Médecine Générale. Recommandations « Sédation palliative », 2019. Published in French. [Brussels Federation of Palliative and Continuing Care, Walloon Federation of Palliative Care, Scientific Society of General Medicine. Recommendations 'Palliative sedation', 2019]. Available from: http://www.palliaguide.be/sedation-palliative/ (accessed 19 January 2023).

[54] Dean MM, Cellarius V, Henry B, Oneschuk D, Librach L; Canadian Society of Palliative Care Physicians Taskforce SL. Framework for continuous palliative sedation therapy in Canada. J Palliat Med. 2012;15(8):870-879. doi: 10.1089/jpm.2011.0498

[55] Canadian Society of Palliative Care Physicians. Statement on continuous palliative sedation therapy, 2017 (examples updated in 2020). Available from: https://www.cspcp.ca/wp-content/uploads/2020/04/CSPCP-Statement-CPST-with-2020-update-FINAL-1.pdf (accessed 19 January 2023).

[56] Alberta Health Services. Provincial clinical knowledge topic: palliative sedation, adult – all locations, 2018. Available from: https://extranet.ahsnet.ca/teams/policydocuments/1/klink/et-klink-ckv-palliative-sedation-adult-all-locations.pdf (accessed 19 January 2023).

[57] British Columbia Centre for Palliative Care. Refractory symptoms and palliative sedation, 2019. Available from: https://www.bc-cpc.ca/cpc/wp-content/ uploads/2019/06/17-RefractorySymptomsAndPalliativeSedationColourPrint.pdf (accessed 19 January 2023).

[58] Winnipeg Regional Health Authority. Sedation for palliative purposes guideline: Evidence informed practice tools, 2017. Available from: https://professionals.wrha.mb.ca/old/extranet/eipt/files/EIPT-045.pdf (accessed 19 January 2023).

[59] Champlain Hospice Palliative Care Program. The Champlain Region Palliative Sedation Therapy. Clinical practice and medication guidelines, 2018. Available from: https://champlainpalliative.ca/wp-content/uploads/2018/10/PSTGuidelines-Regional-2018_ENG-final.pdf (accessed 19 January 2023).

[60] Waterloo Wellington Interdisciplinary HPC Education Committee: PST Task Force. The Waterloo Wellington Palliative Sedation Therapy Protocol, 2019. Available from: https://wwpalliativecare.ca/Uploads/ContentDocuments/ 20191220_WW_PST_Final.pdf (accessed 19 January 2023).

[61] Division of Palliative Care, Department of Family Medicine, McMaster University, Canada. Continuous Palliative Sedation Therapy (CPST) Guidelines, 2020. Available from: https://fhs.mcmaster.ca/palliativecare/documents/McMasterPalliativeSedationGuidelines2020 31March2020.pdf (accessed 19 January 2023).

[62] Health Prince Edward Island (PEI). Provincial integrated palliative care program. Palliative Sedation Therapy (PST) Worksheet. Not available on the Internet.

[63] Société québécoise des médecins de soins palliatifs, Collège des médecins du Québec [Quebec Society of Palliative Care Physicians. College of Physicians from Quebec] Palliative sedation at the end of life: practice guidelines (English version), 2016. Available from: http://www.cmq.org/publications-pdf/p-1-2016-08-29-en-sedation-palliative-fin-de-vie.pdf (accessed 19 January 2023).

[64] Société québécoise des médecins de soins palliatifs, Collège des médecins du Québec. La sédation palliative en fin de vie, 2016. Published in French. [Quebec Society of Palliative Care Physicians. College of Physicians from Quebec. Palliative sedation at the end of life, 2016]. Available from: http://www.cmq.org/publications-pdf/p-1-2016-08-29-fr-sedation-palliative-fin-de-vie.pdf (accessed 19 January 2023).

[65] Blanchet V, Viallard ML, Aubry R. Sédation en médecine palliative : recommandations chez l'adulte et spécificités au domicile et en gériatrie. Published in French. [Sedation in palliative medicine: guidelines for adults at home and in geriatric wards]. *Médecine Palliative. Soins de Support – Accompagnement – Éthique* 2010;9(2):59-70. doi: 10.1016/j.medpal.2010.01.006

[66] Aubry R, Blanchet V, Viallard ML. La sédation pour détresse chez l'adulte dans des situations spécifiques et complexes. Published in French. [Sedation for distressed adults: specific and complex situations]. *Médecine Palliative. Soins de Support – Accompagnement – Éthique* 2010;9(2):71-79. doi: 10.1016/j.medpal.2010.01.004

[67] Blanchet V, Aubry R, Viallard ML, et al. Sédation pour détresse en phase terminale : guide d'aide à la décision. Published in French. [Sedation for distress in the final stage:

decision-making guidelines]. *Médecine Palliative. Soins de Support – Accompagnement – Éthique* 2014;13(5):278-280.

[68] Société française d'accompagnement et de soins palliatifs (SFAP). Les questions à se poser avant de mettre en place une sédation en situation palliative, 2019. Published in French. [French Society of Accompaniment and Palliative Care. The questions that should be asked before using sedation in a palliative situation, 2019]. Available from: palliativehttp://www.sfap.org/system/files/fiche-pratique-sedation-sfap-questions-prealables-v-avril19.pdf (accessed 19 January 2023).

[69] Haute Autorité de santé (HAS). Guide parcours de soins. Comment mettre en œuvre une sédation profonde et continue maintenue jusqu'au décès ? 2020. Published in French. [French National Authority for Health. Care pathway guide. How to implement continuous deep sedation until death? 2020]. Available from: https://www.has-sante.fr/jcms/c_2832000/fr/comment-mettre-en-oeuvre-une-sedation-profonde-et-continue-maintenue-jusqu-au-deces (accessed 19 January 2023).

[70] Haute Autorité de santé (HAS). Antalgie des douleurs rebelles et pratiques sédatives chez l'adulte : prise en charge médicamenteuse en situations palliatives jusqu'en fin de vie. Recommandations de bonne pratique, 2020. Published in French. [French National Authority for Health. Management of rebellious pain and sedative practices in adults: drug treatment in palliative situations until the end of life. Good practice guidelines, 2020]. Available from: https://www.has-sante.fr/upload/docs/application/pdf/2020-02/reco_fin_vie_med.pdf (accessed 19 January 2023).

[71] Deutsche gesellschaft für palliativmedizin, et al. Einsatz sedierender Medikamente in der Spezialisierten Palliativversorgung, 2021. Published in German. [German Society for Palliative Medicine, *et al*. Use of sedating drugs in specialized palliative care, 2021]. Available from: https://www.dgpalliativmedizin.de/images/210422_Broschu%CC%88re_SedPall_Gesamt.pdf (accessed 19 January 2023).

[72] Società Italiana di Cure Palliative (SICP). Raccomandazioni della SICP sulla Sedazione Terminale/Sedazione Palliativa, 2007. Published in Italian. [Italian Society for Palliative Care. Guidelines on terminal/palliative sedation, 2007]. Available from: https://www.sicp.it/wp-content/uploads/2018/12/7_ Sedazione.pdf (accessed 19 January 2023).

[73] Azienda Sanitaria Locale (ASL) della Provincia di Bergamo. Protocollo 'Sedazione palliativa a domicilio', 2010. Published in Italian. [Local Health Authority of the Province of Bergamo. Protocol 'Palliative sedation at home', 2010]. Available from: https://docplayer.it/146982260-Protocollo-sedazione-palliativa-a-domicilio.html (accessed 19 January 2023).

[74] Imai K, Morita T, Akechi T, et al. The principles of revised clinical guidelines about palliative sedation therapy of the Japanese Society for Palliative Medicine. J Palliat Med. 2020;23(9):1184-1190. doi: 10.1089/jpm.2019.0626

[75] Japanese Society for Palliative Medicine. Clinical practice guidelines about palliative sedation. Published in Japanese. Available from: http://www.jspm.ne.jp/guidelines/sedation/2018/pdf/sedation2018.pdf (accessed 19 January 2023).

[76] Royal Dutch Medical Association (KNMG). Guideline for Palliative Sedation, 2009. Available from: https://www.palliativedrugs.com/download/091110_KNMG_Guideline_for_Palliative_sedation_2009__2_%5B1%5D.pdf (accessed 19 January 2023).

[77] Norwegian Medical Association. Guidelines for palliative sedation at the end of life, 2014. Available from: https://www.legeforeningen.no/contentassets/cc8a35f6afd043c195ede88a15ae2960/guidelines-for-palliative-sedation-at-the-end-of-life.pdf (accessed 19 January 2023).

[78] Den norske legeforening. Retningslinjer for lindrende sedering i livets sluttfase, 2014. Published in Norwegian. Available from: https://www.legeforeningen.no/contentassets/cc8a35f6afd043c195ede88a15ae2960/retningslinjer-for-lindrende-sedering-i-livets-sluttfase-2014.pdf (accessed 19 January 2023).

[79] NHS Scotland. Scottish Palliative Care Guidelines: Severe Uncontrolled Distress, 2019. Available from: https://www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/severe-uncontrolled-distress.aspx (accessed 19 January 2023).

[80] Groupe d'experts de la Société suisse de médecine et de soins palliatifs. Palliative ch. Recommandations « Sédation palliative ». Consensus sur la meilleure pratique en soins palliatifs en Suisse – Bigorio, 2005. Published in French. [Expert Group of the Swiss Society for Medicine and Palliative Care. Palliative ch. Recommendations 'Palliative sedation'. Consensus on the best practice in palliative care in Switzerland. Bigorio, 2005]. Available from: https://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/E_12_4_bigorio_2005_Sedation_fr._pdf (accessed 19 January 2023).

[81] Empfehlungen 'Palliative Sedation'. Konsenseiner Experten gruppe von palliative ch, der Schweiz. Gesellschaft für Palliative Medizin, Pflege und Begleitungzur best practice für Palliative Care in der Schweiz – Bigorio, 2005. Published in German. [Expert Group of the Swiss Society for Medicine and Palliative Care. Palliative ch. Recommendations 'Palliative sedation'. Consensus on the best practice in palliative care in Switzerland. Bigorio, 2005]. Available from:

https://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/E_12_3_bigorio_2006_Sedation_de.pdf. (accessed 19 January 2023).

[82] Gruppo di esperti della Società svizzera di cure palliative. Raccomandazioni 'Sedazione palliativa'. Consensus sulla best practice in cure palliative in Svizzera – Bigorio, 2005. Published in Italian. [Expert Group of the Swiss Society for Medicine and Palliative Care. Palliative ch. Recommendations 'Palliative sedation'. Consensus on the best practice in palliative care in Switzerland. Bigorio, 2005]. Available from: https://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/BIGORIO_IT_2005_Sedation.pdf. (accessed 19 January 2023).

[83] Hospice & Palliative Care Federation of Massachusetts. Palliative Sedation Protocol, 2004. Available from: https://cdn.ymaws.com/www.hospicefed.org/resource/resmgr/hpcfm_pdf_doc/pal_sed_protocol_2004.pdf (accessed 19 January 2023).

[84] Kirk TW, Mahon MM. National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. *J Pain Symptom Manage* 2010;39(5):914-923. doi: 10.1016/j.jpainsymman.2010.01.009

[85] American Academy of Hospice and Palliative Medicine. Statement on palliative sedation, 2014. Available from: https://aahpm.org/positions/palliative-sedation (accessed 19 January 2023).

[86] Hospice and Palliative Nurses Association (HPNA). Position Statement Palliative Sedation, 2016. Available from: https://advancingexpertcare.org/position-statements/ (accessed 19 January 2023).

[87] North Carolina Board of Nursing. Palliative sedation for end-of-life care. Position statement for RN and LPN Practice, 2018. Available from: https://www.ncbon.com/vdownloads/position-statements-decision-trees/ps-palliative-sedation.pdf (accessed 19 January 2023).

[88] Mertz, M., Strech, D. Systematic and transparent inclusion of ethical issues and recommendations in clinical practice guidelines: a six-step approach. *Implementation Sci.* 2014;9:184. https://doi.org/10.1186/s13012-014-0184-y

[89] Bernabe R, van Thiel G, van Delden J. What do international ethics guidelines say in terms of the scope of medical research ethics?. BMC Med Ethics. 2016;17:23. https://doi.org/10.1186/s12910-016-0106-4

[90] Kahrass H, Strech D, Mertz M. Ethical issues in obesity prevention for school children: a systematic qualitative review. Int J Public Health. 2017;62:981-988.

[91] Beauchamp TL and Childress JF. Principles of Biomedical Ethics. 7th edition. Oxford University Press, New York, 2013.

[92] Schofield G, Dittborn M, Huxtable R, Brangan E, Selman LE. Real-world ethics in palliative care: a systematic review of the ethical challenges reported by specialist palliative care practitioners in their clinical practice. Palliat Med. 2021;35:315-334. doi: 10.1177/0269216320974277. Epub 2020 Dec 10. PMID: 33302783; PMCID: PMC7897798.

[93] Kon A. Palliative sedation: it's not a panacea. Am J Bioeth. 2011;11(6):41-42. doi: 10.1080/15265161.2011.577513. PMID: 21678216.

ACKNOWLEDGEMENTS

The authors would like to express their gratitude to Prof. Robert TWYCROSS, Emeritus Clinical Reader in Palliative Medicine at the University of Oxford in the United Kingdom, for his comments on the draft of this manuscript. In addition, the first author thanks Prof. Jacek ŁUCZAK (1934-2019) from the Palium Hospice and Chair and Department of Palliative Medicine at the Poznań University of Medical Sciences in Poland for his medical and ethical reflections on palliative sedation. The authors would also like to express their thanks to Liz EGGLESTON, native English speaker and professional proofreader, for linguistic help.

The authors are very grateful to the European Association for Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC), and the 'ehospice' for publishing an announcement about their study protocol on the websites and in the newsletters, and to Prof. Benoît BURUCOA (Bordeaux, France), Chair of the International French-speaking Federation for Palliative Care, for contacting the Committee Members working in the French-speaking countries across the world. The authors also offer many thanks to all the experts and resource personnel in palliative care and/or palliative care associations in general around the world who responded to their calls and/or email about national CPGs on palliative sedation and helped to establish the international inventory presented in this paper. They are presented below in alphabetical order, without academic or professional titles, and with their explicit consent: Susanne AMARA (ATSP-Averroès association tunisienne de soins palliatifs, Tunisia); Association for Palliative Medicine of Great Britain and Ireland, Fareham, United Kingdom; Mackuline ATIENO (Kenya Hospices and Palliative Care Association, Nairobi, Kenya); Bertil AXELSSON (Umeå University, Palliative Care Unit, Östersund Hospital, National Board on Palliative Care, Sweden); Janice BESCH (Australian and New Zealand

Society of Palliative Medicine, Australian Capital Territory, Australia); Bigorio-Guideline Group, palliative.ch, Switzerland; Lori BISHOP (Palliative and Advanced Care, National Hospice and Palliative Care Organization, Alexandria, Virginia, USA); Ogmundur BJARNASON (Palliative Care Unit, National University Hospital of Iceland, Reykjavik, Iceland); Ellen BURGERING-VAN GELDER (Royal Dutch Medical Association, Netherlands); Canadian Hospice Palliative Care Association, Ottawa, Canada; Pamela CAREY (American College of Physicians, Philadelphia, USA); Joshua COHEN (Palliative Care Nurses Australia, Australia); Gregory CRAWFORD (Northern Adelaide Palliative Service, University of Adelaide, Australia); Michel DAHER (University of Balamand, National Committee for Palliative Care, Saint George Hospital, University Medical Center, Ashrafieh, Beirut, Lebanon); Jennifer DAWSON (Provincial Palliative Care Centre, Murchison Lane, Charlottetown, Prince Edward Island, Canada); Karin DLUBIS-MERTENS (German Association for Palliative Medicine, Berlin, Germany); Teh EE VON (Assisi Palliative Care, Selangor, Malaysia); Dagny FAKSVAG-HAUGEN (Department of Clinical Medicine K1, University of Bergen, Bergen, Norway & Centre Regional Centre of Excellence for Palliative Care, Western Norway Haukeland University Hospital, Bergen, Norway); Karolina FIALOWA (Mobile Hospice Forum, Czech Republic); Benzi KLUGER (International Neuropalliative Care Society, Minneapolis, Minnesota, USA); Gulnara KUNIROVA (Kazakhstan Association for Palliative Care, Kazakhstan); Amy GADOUD (Lancaster Medical School, Lancaster University, United Kingdom); Global Partners in Care, Mishawaka, Indiana, USA; Michelle GOLD (Australasian Chapter of Palliative Medicine, Victoria, Australia); Jean-Marie GOMAS (French Society of Accompaniment and Palliative Care, Paris, France); Carolina GUZMAN (Spanish Society for Palliative Care, Spain); Flavia HURDUCAS (Palliative Medicine Study Center, HOSPICE Casa Sperantei, Brasov, Romania); Anette HYGUM (Danish Society for Palliative Medicine, Denmark); Kengo IMAI (Seirei Hospice, Seirei Mikatahara General Hospital, Hamamatsu, Japan); Glynis KATZ (Sabar Health Home Hospice and Hospital, Even Yehuda, Israel); Yoshiyuki KIZAWA (Department of Palliative Medicine, Kobe University School of Medicine, Hyogo, Japan & Japanese Society for Palliative Medicine, Osaka, Japan); Mireille LECOURS (Provincial Palliative Care Centre, Murchison Lane, Charlottetown, Prince Edward Island, Canada); Elena LOPEZ (Hospice of the Angels HOLA, Los Angeles Hospice Foundation, Morelia, Mexico); Christiane MARTEL (Quebec Society of Palliative Care Physicians, Victor-Gadbois Palliative Care Home, Quebec, Canada); Tatsuya MORITA (Palliative and Supportive care

Division, Seirei Mikatahara Hospital, Mikatahara, Kita, Hamamatsu, Japan); Tonia ONYEKA (Department of Anaesthesia/Pain & Palliative Care Unit, Multidisciplinary Oncology Centre, College of Medicine, University of Nigeria, Ituku-Ozalla Campus, Enugu, Enugu State, Nigeria); Mary-Anne PARKER (Saskatchewan Hospice Palliative Care Association, Saskatoon, Saskatchewan, Canada); Liz PARSONS (East Prince Hospice Services, Hospice Palliative Care Association of Prince Edward Island, Charlottetown, Prince Edward Island, Canada); Pedro Emilio PEREZ CRUZ (Department of Internal Medicine, Faculty of Medicine, Pontifical Catholic University of Chile, Santiago, Chile); Joe ROTELLA (American Academy of Hospice and Palliative Medicine, Chicago, USA); Kateřina RUSINOVA (Clinic of Palliative Medicine, 1st Faculty of Medicine, Charles University, General University Hospital, Prague, Czech Republic); Reena SHARMA (Organization CanSupport, New Delhi, India); Zodwa SITHOLE (Cancer Association of South Africa, Johannesburg, South Africa); Therese SMEAL (Palliative Care New South Wales, Sydney, Australia); Lameck THAMBO (Palliative Care Association of Malawi, Lilongwe, Malawi); Blaise UHAGAZE (Rwanda Palliative Care & Hospice Organization, Kigali, Rwanda); Dietmar WEIXLER (Palliativkonsilairdienst und Mobiles Palliativteam, Landesklinikum Horn – Allentsteig, Standort Horn & Austrian Palliative Society, Austria); Leeroy WILLIAM (Eastern Health Clinical School, Monash University & Public Health Palliative Care Unit, La Trobe University, Melbourne, Victoria, Australia); Athina VADALOUKA (Hellenic Society for Pain Management and Palliative Care, Athens, Greece); Céline VAN DER CAM (Brussels Federation of Palliative Care, Brussels, Belgium); Claudia VIRDUN (Palliative Care Nurses Australia, Australia); Sebastian VON HOFACKER (The Dignity Centre, Bergen, Norway).

Finally, the authors would like to give their warm and sincere thanks to the Editor of this journal and to the reviewer for their expertise and time, which helped improve the quality of the manuscript.

ACRONYMS AND ABBREVIATIONS

CDSUD: continuous deep sedation until death

CPGs: clinical practice guidelines

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROSPERO: International Prospective Register of Systematic Reviews

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Not applicable

CONSENT FOR PUBLICATION

Not applicable

AVAILABILITY OF DATA AND MATERIALS

Yes, in the supplementary files.

COMPETING INTERESTS

All the authors declare that they have no competing interests.

FUNDING INFORMATION

This systematic review is funded by a grant (grant number: not applicable) from the Pallium Foundation (Canton of Vaud, Switzerland). The research is independent of any involvement from this sponsor.

AUTHORS' CONTRIBUTIONS

MT and RJJ conceived and designed the study; they are the guarantors. MT, CJ, and RJJ contributed substantially to the development of the methodological section. MT performed all the searches for and analysed all the CPGs, with help from CJ and RJJ. All authors

participated in the interpretation and discussion of the results. MT wrote the manuscript with input from both the other co-authors. All authors read, provided feedback, and approved the final version of this manuscript.

Tables, Figures, and Supplementary Files

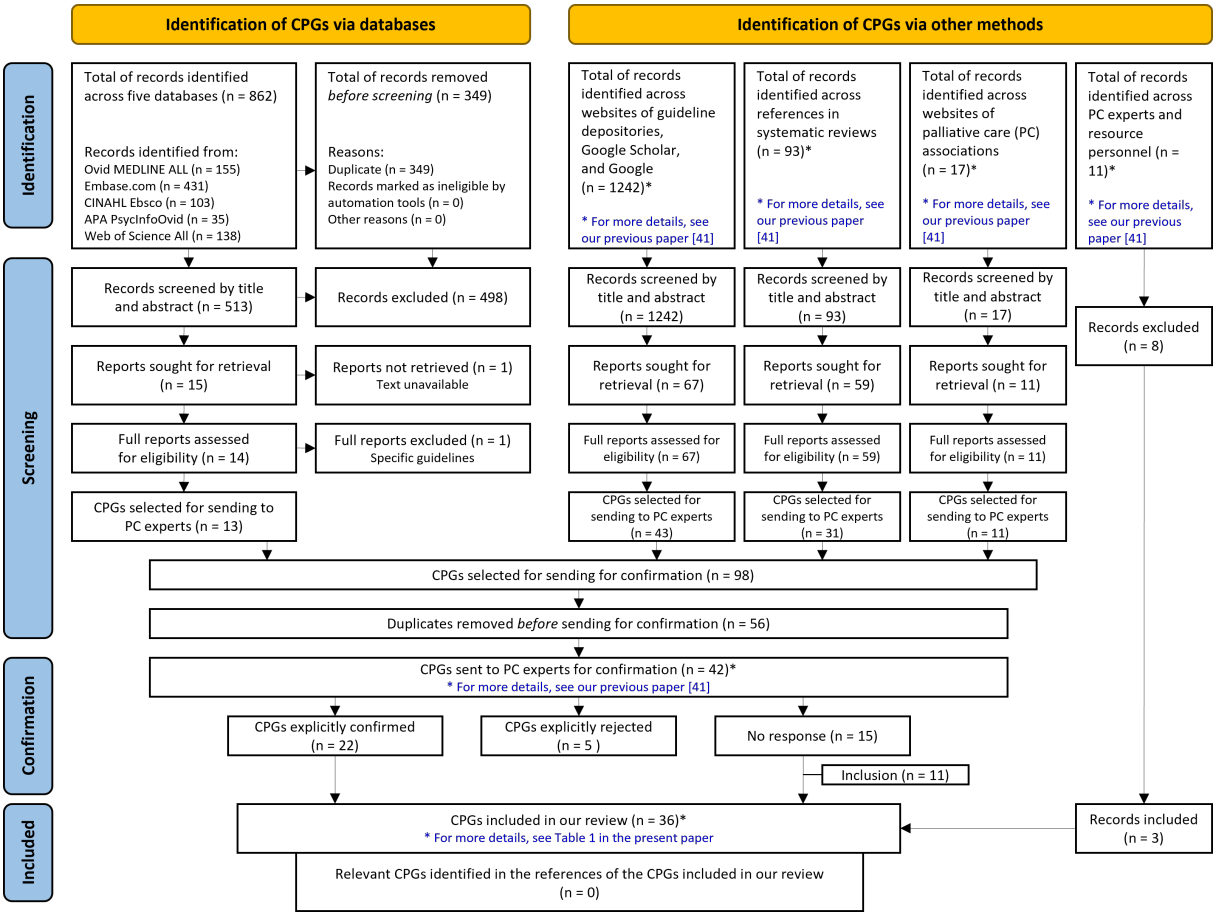
Table 1: CPGs included in the analysis

Figure 1: PRISMA flow diagram

Supplementary File 1: PRISMA 2020 Checklist

Supplementary File 2: Importance of ethics in the CPGs, detailed results

Supplementary File 3: Contexts in which terms with the root '*ethic*-' were used


Identification of CPGs via databases
Identification of CPGs via other methods
Identification
Screening
Confirmation
Included
Total of records identified across five databases (n = 862)
Records identified from:
Ovid MEDLINE ALL (n = 155)
Embase.com (n = 431)
CINAHL Ebsco (n = 103)
APA PsycInfoOvid (n = 35)
Web of Science All (n = 138)
Total of records removed *before screening* (n = 349)
Reasons:
Duplicate (n = 349)
Records marked as ineligible by automation tools (n = 0)
Other reasons (n = 0)
Total of records identified across websites of guideline depositories, Google Scholar, and Google (n = 1242)*
* For more details, see our previous paper [41]
Total of records identified across references in systematic reviews (n = 93)*
* For more details, see our previous paper [41]
Total of records identified across websites of palliative care (PC) associations (n = 17)*
* For more details, see our previous paper [41]
Total of records identified across PC experts and resource personnel (n = 11)*
* For more details, see our previous paper [41]
Records screened by title and abstract (n = 513)
Records excluded (n = 498)
Records screened by title and abstract (n = 1242)
Records screened by title and abstract (n = 93)
Records screened by title and abstract (n = 17)
Records excluded (n = 8)
Reports sought for retrieval (n = 15)
Reports not retrieved (n = 1)
Text unavailable
Reports sought for retrieval (n = 67)
Reports sought for retrieval (n = 59)
Reports sought for retrieval (n = 11)
Full reports assessed for eligibility (n = 14)
Full reports excluded (n = 1)
Specific guidelines
Full reports assessed for eligibility (n = 67)
Full reports assessed for eligibility (n = 59)
Full reports assessed for eligibility (n = 11)
CPGs selected for sending to PC experts (n = 13)
CPGs selected for sending to PC experts (n = 43)
CPGs selected for sending to PC experts (n = 31)
CPGs selected for sending to PC experts (n = 11)
CPGs selected for sending for confirmation (n = 98)
Duplicates removed *before* sending for confirmation (n = 56)
CPGs sent to PC experts for confirmation (n = 42)*
* For more details, see our previous paper [41]
CPGs explicitly confirmed (n = 22)
CPGs explicitly rejected (n = 5)
No response (n = 15)
Inclusion (n = 11)
CPGs included in our review (n = 36)*
* For more details, see Table 1 in the present paper
Records included (n = 3)
Relevant CPGs identified in the references of the CPGs included in our review (n = 0)