

# A Pragmatic Review of the General Population's Attitude, Knowledge and Representations with Regard to Continuous Palliative Sedation

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## ABSTRACT:

*Continuous palliative sedation is an end-of-life practice that consists of inducing a state of unconsciousness in patients who are approaching death to relieve them of severe and refractory symptoms. The Act Respecting End-of-life Care has provided a framework for continuous palliative sedation in the Canadian province of Quebec since 2015. Understanding the general population's complex attitudes, and knowledge and representations with respect to continuous palliative sedation can contribute to more informed end-of-life care decision-making. Social workers play a crucial role in promoting and implementing enlightened end-of-life choices. The aim of this paper is to explore the general population's attitude, knowledge and representations with regard to continuous palliative sedation. We used a pragmatic methodology, seeking to explore a real-life knowledge gap while considering resource and time constraints. Two research team members independently selected related studies and extracted their content. We included eight articles involving a total of 18,961 participants. Participants with a positive attitude towards continuous palliative sedation represented 25% to 81% of the study populations. Attitude seems positively affected by the use of euphemisms (i.e. sleep) to describe the intervention. The term "continuous palliative sedation" is unfamiliar to most and is often confused with euthanasia. In the discussion, we offer recommendations for social workers when accompanying patients and families in making end-of-life decisions.*

## KEYWORDS:

*Continuous palliative sedation, palliative care, end-of-life care, informed decision-making, general population*

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## INTRODUCTION

In Western Europe and North America, death is increasingly preceded by numerous clinical decisions and a majority of people die in medical institutions (Rietjens et al., 2018). Continuous palliative sedation (CPS) is an end-of-life practice that involves generating a state of unconsciousness until death in patients with poor prognosis who are approaching death (Bobb, 2016; Gurschick et al., 2015; ten Have & Welie, 2014). It should be used as a last resort when the patient is experiencing intolerable or refractory pain (van Delden, 2013). The percentage of deaths involving CPS reported in studies or on nationwide platforms monitoring end-of-life practices varies from 7% (Deschepper et al., 2013) to 18% (Seymour et al., 2015). According to other studies, the use of CPS for terminally ill patients is increasing globally (Heijltjes et al., 2020). In the province of Quebec, as in Canada, a person who wishes to receive CPS must consent to the administration of medications and acknowledge that they obtained satisfactory answers to their questions. If the person is unable to consent to care, consent to CPS can be obtained from a supportive decision-maker (*Act Respecting End-of-life Care*, 2014). As such, CPS must be preceded by an informed consent conversation. Five elements are essential to an informed consent conversation: a discussion of the patient's health status as it relates to the procedure, a description of the procedure itself, a discussion of the procedure's benefits, alternatives and risks (Ripley et al., 2015).

Social workers play an important role in promoting and implementing informed end-of-life decisions (Head et al., 2019). They have holistic expertise in the psychosocial aspects of health, communication skills, and the ability to foster interprofessional collaboration that may make them central to the development of daily practices and delivery of end-of-life decision-making (Fortin & Dumont, 2021). They are comfortable with legal processes and forms, possess good facilitation and advocacy skills, and are able to counsel effectively on issues such as family conflict and grief (Black, 2005).

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Therefore, our objective is to review the scientific literature on the general population's attitude, knowledge and representations with regard to CPS in order to provide recommendations for social workers when accompanying patients and families in making informed decisions pertaining to end-of-life practices.

## 1. Methods

For this literature review, we used a pragmatic methodology. The steps of a pragmatic review are similar to those of a systematic review but are tailored to allow for the exploration of a targeted and real-life knowledge gap when facing resource and time constraints (Sagliocca et al., 2013). We used the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) to report our findings.

### 1.1 Eligibility criteria

Participants in included studies had to be from the general population, that is, defined as people who do not identify as health care or social professionals, or as students in the health and social services field.

The studies that were included had to address CPS. We defined CPS as an end-of-life practice that involves generating a state of unconsciousness in order to relieve severe and refractory symptoms in patients nearing death (Bobb, 2016; Gurschick et al., 2015; Morita et al., 2002; ten Have & Welie, 2014).

Included studies needed to assess attitude, knowledge or representations with regard to CPS. We defined attitude as a dichotomic response (favourable or unfavourable) and knowledge as the ability to describe CPS or identify its characteristics. Representation was conceptualized as an organized and structured set of information, beliefs and opinions (Abric, 2003).

We only included peer reviewed articles published in English or French after 2000. This period coincides with the strengthening of CPS regulations through, among other things, the creation of international guidelines (Gurschick et al., 2015).

Articles relating to intermittent sedation, light sedation, and sedation administered in a context other than end-of-life care, were excluded. Writings pertaining solely to health professionals and students in the health field, as well as studies where the main eligibility criterion was to have accompanied a person who received CPS, were also excluded.

## 1.2 Search strategy

We developed the search strategy in consultation with a librarian specialized in health sciences (Table 1). We launched the search strategy in PubMed and Cinahl databases on September 19, 2021.

**Table 1** Search strategies

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### Search strategy in Cinahl

("General population" OR "public" OR "non-professional" OR "non-professionals" OR "general public" OR "Citizen" OR "Citizens" OR (MH "Population") OR (MH "Urban Population") OR (MH "Suburban Population") OR (MH "Rural Population")) AND ("palliative sedation" OR "deep sedation" OR "continuous sedation" OR "terminal sedation" OR (MH "Sedation")) AND ("Attitudes" OR "attitude" OR "perceptions" OR "perception" OR "opinions" OR "opinion" OR "preferences" OR "preference" OR "thoughts" OR "feelings" OR "feeling" OR "beliefs" OR "believe" OR "believed" OR "social representation" OR "social representations" OR "representation" OR "representations" OR "knowledge" OR "knowledges" OR "understand\*" OR "convictions" OR "conviction" OR "awareness" OR "view" OR "views" OR (MH "Attitude") OR (MH "Knowledge") OR (MH "Health Knowledge"))

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### Search strategy in PubMed

(attitudes OR attitude OR perceptions OR perception OR opinions OR opinion OR preferences OR preference OR thoughts OR feelings OR feeling OR beliefs OR believe OR believed OR "social representation" OR "social representations" OR representation OR representations OR knowledge OR knowledges OR understand\* OR convictions OR conviction OR awareness OR view OR views OR "Attitude"[Mesh] OR "Health Knowledge, Attitudes, Practice"[Mesh]) AND ("palliative sedation" OR "deep sedation" OR "continuous sedation" OR "terminal sedation" OR "Deep Sedation"[Mesh]) AND ("General population" OR "public" OR "general public" OR "Citizen" OR "Citizens" OR "Population"[Mesh])

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## 1.3 Study selection

Two research team members independently carried out study selection. First, they applied the eligibility criteria to titles and abstracts. Then, they screened the full text of the remaining studies. During both steps, they submitted disagreements to the principal investigator. They used Covidence to select and manage the eligible studies. Covidence is an online tool that facilitates the different steps of systematic or non-systematic reviews (Babineau, 2014).

## 1.4 Data extraction

The two researchers used an Excel sheet to extract the main characteristics of the included studies (author, country, year, study design, objective, sample composition, sample size, methods used to assess attitude and wording used to describe the intervention), study participant characteristics (gender, age and educational level), and the main findings of the three variables.

## 1.5 Analysis process

Various scales had been used in the included studies to assess participants' educational level. The results for this variable were dichotomized to create two categories. High level of education included intermediate vocational education or general high school education, higher vocational education and university. Low level of education included lower vocational education, general junior high school education and elementary school.

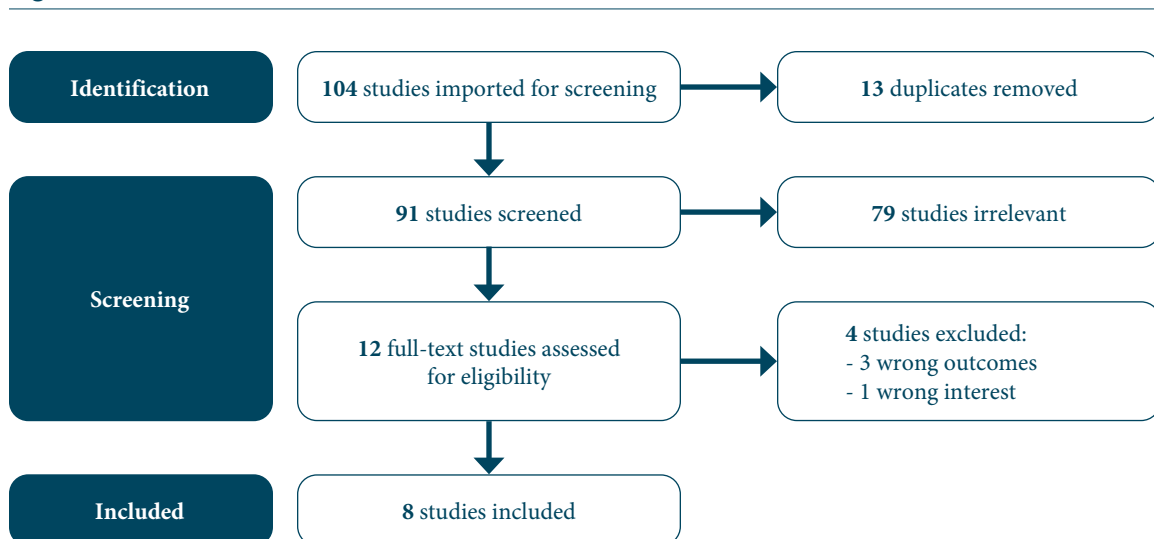
Results relating to attitudes were dichotomized based upon the predominant classification system used in the studies: "yes" and "probably yes" were considered favourable attitudes, as opposed to "no" "probably not" and "perhaps" which were considered unfavourable attitudes.

For the representations variable, a deductive thematic analysis was conducted. Thematic analysis is the process of identifying patterns or themes in qualitative data. The researchers used Braun and Clarke's six-step process: familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up (2006).

## 2. Results

The search strategy retrieved 104 articles, including 13 duplicates. As a result, we screened 91 titles and abstracts, and then screened 12 full texts. We excluded one study where the main eligibility criterion was to have accompanied a person who received CPS and three studies that did not address any of our variables of interest. Therefore, we retained eight articles for full analysis (Figure 1).

**Figure 1** Flow chart



Studies were published between 2002 and 2018. In total, 18,961 participants took part in the eight studies (Table 2).

**Table 2** Study characteristics

Author and country	Study design	Objective(s)	Sample composition	Sample size
Morita et al., 2002, Japan	Quantitative: Descriptive correlational cross-sectional	Determine the type of sedation preferred by the general population, what factors influence their preferences, and how clinicians should inform patients about sedation therapy.	General population that attended health-related lectures for non-professionals	n = 457
Rietjens et al., 2005, Netherlands	Quantitative: Comparative descriptive, cross-sectional	Compare the attitudes of the Dutch general population and physicians towards three end-of-life practices: euthanasia, CPS, and increasing the dosage of morphine, with premature death as a likely consequence	Members of the Dutch general public (Panel of the Consumers' Association)	n = 1,388
Rietjens et al., 2006, Netherlands	Quantitative: Descriptive correlational cross-sectional using a vignette	Gain insight into the characteristics of a "good death" for the Dutch general population, and identify whether attitudes towards euthanasia, CPS and high dosages of morphine influence attitudes towards a "good death"	Members of the Dutch general public (Panel of the Consumers' Association)	n = 1,388
Sanjo et al., 2007, Japan	Quantitative: Comparative/ correlational - cross-sectional	Explore the associations between preferences and comprehensively conceptualize a "good death" in a representative sample of the Japanese population	Nonbereaved members of the general population, members of the general population who had been bereaved because of cancer and bereaved family members of cancer patients who died in 12 certified palliative care units	n = 3,061
Lindblad et al., 2010, Sweden	Quantitative using a vignette	Investigate the attitudes among Swedish physicians and the general population towards CPS as an alternative treatment for a competent, not imminently dying patient with Huntington's disorder requesting physician-assisted suicide and euthanasia	General population and physicians	General population: n = 625
Van der Kallen et al., 2013, Netherlands	Mixed: Qualitative part: qualitative descriptive Quantitative: Explanatory using a vignette	Provide insight into the attitudes of the general population towards CPS; inform healthcare professionals about how to adequately communicate and make end-of-life decisions with patients and relatives	General population members of the panel "CentERpanel"	Quantitative data: n = 1,960
			General population members of the panel "CentERpanel"	Qualitative data: n = 16

Author and country	Study design	Objective(s)	Sample composition	Sample size
Toporski et al., 2017, France	Qualitative: Textual data analysis software, supplemented by a thematic analysis to identify the perception Internet users had of this practice.	Assess the French population's comprehension of CPS	General population that participated on an Internet panel	n = 1,819
Scherrens et al., 2018, Belgium	Quantitative: Descriptive correlational cross-sectional assessing participants' preferences	Explore whether end-of-life decisions were related to sociodemographic characteristics, social support and current physical and mental health status	General population (data from the National Health Interview Survey 2008)	n = 9,651

## 2.1 Participant characteristics

One study's data was collected through an Internet panel that did not gather socio-demographic information, which led to the unavailability of participant characteristics (Toporski et al., 2017). Two studies (Rietjens et al., 2005 et Rietjens et al., 2006) were conducted on the same sample, and therefore participant characteristics are included here only once.

Participant ages varied from 15 to 93 years old. The proportion of participants with a low level of education was similar to the proportion of participants with a high level of education in two samples (Morita et al., 2002; Rietjens et al., 2005), while a high level of education predominated in two samples (van der Kallen, et al., 2013; Scherrens et al., 2018) (Table 3).

**Table 3** Participant characteristics

Author and country	Gender %	Age (mean) range	Educational level %
Morita et al., 2002	F = 68 M = 32	(51) under 30 - over 70	Low = 51 High = 47
Rietjens et al., 2005	F = 61 M = 39	(47) 20-93	Low = 50 High = 50
Rietjens et al., 2006	F = 61 M = 39	(47) 20-93	Low = 50 High = 50
Sanjo et al., 2007	F = 61 M = 39	(NA) 49-70	NA
Lindblad et al., 2010	F=50 M=50	(49) 20-84	NA
Van der Kallen et al., 2013	F = 46 M = 54	(NA) 50-70	Low = 32 High = 68
	F = 50 M = 50	(NA) 50-70	Low = 31 High = 69
Toporski et al., 2017	NA	NA	NA
Scherrens et al., 2018	F = 51.9 M = 48.1	(NA) 15-75	Low = 27.5 High = 72.5

## 2.2 Attitude

Six studies (Morita et al., 2002; Rietjens et al., 2005; Sanjo et al., 2007; Lindblad et al., 2010; van der Kallen et al., 2013; Scherrens et al., 2018) assessed attitude.

### *Attitude according to patient life expectancy*

A slight but significant difference was observed in attitude based on the patient's life expectancy in the clinical vignette by Van der Kallen and his colleagues who reported that 81% of respondents had favourable attitudes towards the use of CPS for a patient whose life expectancy was less than a week, as compared to 74 % when life expectancy was less than a month (2013).

### *Attitude based on personal experience*

One study reported statistically significant differences in participants' attitudes between those who had accompanied a relative until death (Sanjo et al., 2007) and those who had not. According to Sanjo and his colleagues, 75 % of participants who had never accompanied a dying person had a favourable attitude towards CPS as compared to 85 % who had had such an experience (2007).

### *Attitude according to respondent age*

Four studies (Morita et al., 2002; Rietjens et al., 2005; Sanjo et al., 2007; Scherrens et al., 2018) identified an association between respondent age and attitudes towards CPS.

Of these, three studies reported an association between a favourable attitude towards CPS and older participants (Morita et al., 2002; Sanjo et al., 2007; van der Kallen et al., 2013). On the other hand, the fourth study (Rietjens et al., 2006) reported that participants under 50 were slightly more supportive of CPS than those between 50 and 70 years old.

### *Attitude based on methods and wording*

Three studies used vignettes presenting a hypothetical clinical situation that did not involve participants (Rietjens et al., 2005; Lindblad et al., 2010; van der Kallen et al., 2013). These studies reported predominantly favourable attitudes to CPS, ranging from 57 % to 81 %. In the three other studies, participants were questioned about their own preferences regarding CPS. In two studies, researchers used the words *continuous deep sedation* and *administration of drugs that will keep you unconscious* in their data collection tools (Morita et al., 2002; Scherrens et al., 2018) which led to a predominantly negative attitude towards CPS (30 % and 26 %). In the third study, researchers used the words *sleeping* and *sleepiness* (Sanjo et al., 2007). The results of this study showed a predominantly favourable attitude towards CPS (Table 4).

**Table 4** Feedback from methods and wording to assess attitude

Source	Favourable (%)	Methods for assessing attitude	Wording
Morita et al., 2002	30	Assessing participants' preferences	<i>continuous deep sedation</i>
Rietjens et al., 2005	57	Using a vignette	<i>condition of unconsciousness</i>
Sanjo et al., 2007	79	Assessing participants' preferences	<i>sleeping and sleepiness</i>
Lindblad et al., 2010	61	Using a vignette	Not available
Van der Kallen et al., 2013	81	Using a vignette	Sedation medication /deep sleep
Scherrens et al., 2018	26	Assessing participants' preferences	<i>administration of drugs that will keep you unconscious</i>



## 2.3 Knowledge

One study assessed participants' perception of their knowledge of CPS using a structured online questionnaire and interviews (van der Kallen et al., 2013). The questionnaire results showed that the term *palliative sedation* was unknown to many, with 40 % of people stating they had never heard of it and only 22 % confirming knowing what it referred to. Seventy-six percent (76 %) of participants correctly identified the legal status of the practice within their legislation (Netherlands). However, 67 % of participants wrongfully stated that administering CPS with the intention to hasten death was legal (van der Kallen et al., 2013). Forty-one percent (41 %) of participants were able to identify the intervention described in accordance with current guidelines using a vignette. However, 18 % of participants thought the practice described was euthanasia and 2 % associated the described practice with euthanasia performed without a patient's consent (van der Kallen et al., 2013). Interview results showed that relatives of the persons who received CPS knew and used the term *palliative sedation*, although the use of generic or vague terms such as *sleep* had been identified (van der Kallen et al., 2013).

## 2.4 Representation

Representations were assessed in two studies, one through semi-structured interviews (Rietjens et al., 2005; van der Kallen et al., 2013) and another through an Internet forum (Toporski et al., 2017). Two themes emerged from our thematic analysis, namely, references to a medical procedure and to a peaceful, yet perhaps inhumane, procedure.

### *A medicalized death*

62 Some representations were linked to the objective of preventing or reducing discomfort, and of restoring comfort (van der Kallen et al., 2013; Toporski et al., 2017). Others were linked to the use of medication such as sedatives (van der Kallen et al., 2013) and opioids (van der Kallen et al., 2013; Toporski et al., 2017) and to the medical protocol surrounding the practice and cessation of eating and drinking (van der Kallen et al., 2013; Toporski et al., 2017).

### *A peaceful, yet perhaps inhumane death*

For some participants, CPS echoed a gentle and natural process contributing to a good death (van der Kallen et al., 2013). Some also referred to a dignified, painless death honouring the person's wishes (van der Kallen et al., 2013; Toporski et al., 2017).

In contrast, CPS was also perceived as an inhumane practice (van der Kallen et al., 2013) associated with starvation (van der Kallen et al., 2013; Toporski et al., 2017). For some participants, the dying process following CPS was considered prolonging agony (van der Kallen et al., 2013; Toporski et al., 2017).

Lastly, CPS was also sometimes portrayed as a disguised form of euthanasia or as a synonym for euthanasia (van der Kallen et al., 2013; Toporski et al., 2017).

## 3. Discussion

The purpose of this study was to review the scientific literature on the general public's attitude, knowledge and representations with respect to CPS in order to provide recommendations for social workers assisting patients and families in making informed decisions about end-of-life



practices. We analyzed and synthesized the findings of eight primary studies conducted in Japan, the Netherlands, France, Belgium and Sweden to create a new body of evidence on an understudied topic. The analysis led to observations worth mentioning. Some observations are likely to be transposable to the context of clinical end-of-life decision-making.

### 3.1 Attitude differs based on wording

In two studies, researchers used the words *continuous deep sedation* and *administration of drugs that will keep you unconscious* in their data collection tools (Morita et al., 2002; Scherrens et al., 2018), while in a third one, they used the words *sleeping* and *sleepiness* (Sanjo et al., 2007). Using coded and euphemistic language instead of the official terms can create misunderstandings according to guidelines on end-of-life communication (Sutherland, 2019). The fact that Sanjo et al. (2007) used euphemisms in their data collection tools to describe CPS may have led to misrepresentation and confusion in their results. Indeed, in previous studies, word choice had proven to influence attitude. In a study conducted in Quebec, Canada about medical aid in dying (similar to euthanasia), Marcoux, Mishara and Durand found that attitudes towards the intervention could vary considerably depending on how the question was phrased (2007). In two studies regarding the choice of words when deciding whether or not to attempt cardiopulmonary resuscitation in the case of cardiac arrest, it was demonstrated that the attitude towards attempting cardiopulmonary resuscitation could be influenced by the choice of wording. Participants were more likely to have a favourable attitude towards *allowing a natural death* than *not attempting cardiopulmonary resuscitation* (Fan et al., 2018; Miljković et al., 2015).

### 3.2 Confusion between euthanasia and continuous palliative sedation

In the study conducted by van der Kallen et al., many participants wrongfully stated that CPS used for the purpose of hastening death was legal (2013), suggesting confusion between CPS and euthanasia. In a study we conducted in Quebec, people living with situational social and economic vulnerabilities had less knowledge about end-of-life practices and a positive attitude towards medical assistance in dying and assisted suicide, but a negative attitude towards CPS (Bérubé et al., 2022). The definitions of those two practices have led to vivid controversy among experts (Carvalho et al., 2011; Hahn, 2012; Janssens et al., 2012). It has also been reported that some physicians and nurses consider CPS and euthanasia to be essentially the same (Anquetin et al., 2013; Papavasiliou et al., 2014; Tapp et al., 2016), and that clinicians themselves are confused between the two practices (Booker & Bruce, 2020; Deyaert et al., 2014; Rys et al., 2015). The findings of a study that interviewed clinicians in Flanders, Belgium, Oregon and Quebec revealed that the relationship between CPS and euthanasia is frequently perceived as fluid and intricate, which contrasts with current laws and ethical and clinical guidelines (Koksvik et al., 2022).

### 3.3 Clinical recommendations

Five elements are essential to an informed consent conversation: a discussion of the patient's health status as it relates to the procedure, a description of the procedure itself, a discussion of the procedure's benefits, alternatives and risks (Ripley et al., 2015). When it comes to accompanying patients and their families in making end-of-life decisions, social workers could play a role in explaining and comparing the various choices. But if the patient, or even the clinician, is confused about these choices, even the most thorough informed consent conversation would be rendered ineffective (Ripley et al., 2015).

Our findings highlight the importance for clinicians, including social workers, to be able to explain the various end-of-life practices in simple terms, differentiate between the practices, and adapt their language to the clientele in order to encourage informed choices in end-of-life care practices and ultimately to promote person-centered end-of-life care.

### 3.4 Study strengths and limitations

This review has several strengths. This is the first study assessing the general population's attitude, knowledge and representations with regard to CPS. We used a rigorous methodology with two reviewers involved in each step of data collection and analysis.

This review also has several limitations. Considering the varying terms referring to CPS, it is possible that our search strategy failed to find all the articles published on this topic. Furthermore, we carried out our searches in only two databases and did not search the references of the included articles nor in the gray literature. However, we used free and controlled vocabulary and the services of a specialized librarian to bolster our search strategy. Until now, appraisal of CPS literature remains challenging due to several longstanding confusions and debates regarding its definition, terminology and ethical aspects (Kremling & Schildmann, 2020).

## CONCLUSION

Social workers play a critical role in promoting and carrying out informed end-of-life decision conversations. Given the widespread misunderstanding of euthanasia and continuous palliative sedation, as well as the evolving nature of end-of-life practices, it becomes critical for clinicians to educate themselves on the various end-of-life practices. Furthermore, communication skills and tools are required to assist clinicians in accompanying patients and families as they make complex end-of-life decisions.

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### RÉSUMÉ :

*La sédation palliative continue est une pratique de fin de vie consistant à induire un état d'inconscience pour soulager les patients approchant la mort de symptômes sévères et réfractaires. La Loi concernant les soins de fin de vie encadre la sédation palliative continue dans la province canadienne du Québec depuis 2015. Comprendre l'attitude, les connaissances et les représentations complexes et multiples de la population générale concernant la sédation palliative continue permet de promouvoir des décisions plus éclairées concernant les soins de fin de vie. Les travailleurs sociaux jouent un rôle crucial dans la promotion et l'actualisation de choix éclairés en fin de vie. L'objectif de cet article est donc d'explorer l'attitude, les connaissances et les représentations de la population générale à l'égard de la sédation palliative continue. Nous avons utilisé une méthodologie pragmatique, visant à combler un manque dans les connaissances avec des contraintes de ressources et de temps. Deux membres de l'équipe ont indépendamment sélectionné les articles et extrait le contenu. Nous avons inclus huit articles couvrant un total de 18 961 participants. Vingt-cinq pour cent (25) à 81 % des répondants avaient une attitude positive envers la sédation palliative continue. L'attitude semble affectée positivement par l'utilisation d'euphémismes (ex. sommeil) pour décrire l'intervention. Le terme sédation palliative continue n'est pas familier à la plupart des gens et est souvent confondu avec euthanasie. En discussion, nous offrons des recommandations aux travailleurs sociaux afin d'accompagner les patients et les familles lors des décisions de fin de vie.*

## MOTS-CLÉS :

Sédation palliative continue, soins palliatifs, soins de fin de vie, prise de décision éclairée, population générale

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