PERSPECTIVE

Clinical and ethical challenges of palliative sedation therapy. The need for clear guidance and professional competencies

Palliative sedation therapy (PST) has become a frequent practice in end-of-life care and advocated in the literature as a less problematic alternative to practices of physician-assisted dying, such as ending patients' lives on request or assisted suicide (1). However, in clinical practice, patients, healthcare professionals and other parties involved in decisions about PST are facing numerous clinical and ethical challenges. This perspective aims to analyse important challenges associated with professional decision-making about PST and to explore the recommendations of guidelines, which have been published in recent years.

Palliative sedation therapy, the need for improved guidance and education of professional competencies

Definition and current practice

Palliative sedation therapy has been defined as 'the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness' (2). Empirical research indicates considerable variations with regard to this end-of-life practice. The percentage of patients receiving PST reported varies between centres (3,4). Recent evidence from a large-scale study conducted in the Netherlands indicates that about one in eight patients received deep continuous sedation prior to death (5). Factors that may contribute to the wide range of frequency of PST are the use of different definitions of PST, differences with regard to the conditions for which PST is recommended and a heterogeneity in patient characteristics, physicians' knowledge and attitudes, as well as cultural differences between the settings researched (4). In light of the heterogeneity of PST, which may be also an indicator for substandard end-of-life care in some cases (6,7), numerous institutions have taken up the task of developing guidelines and policies. One prominent example is the European Association of Palliative Care (EAPC) Framework, which suggests that guidelines on PST may 'prevent or minimize the likelihood of bad outcomes that sometimes stem from substandard or unethical practices' (7). In the following, we will explore selected clinical and ethical challenges of PST, such as the criteria, which should guide physicians with regard to professional decisions on whether PST should be offered in a specific case or not (i), the facilitation of the decision-making process with patients or representatives and other parties possibly involved (ii), and treatment decisions, which may be associated with PST decisions, such as limitation of life-sustaining treatment (iii).

What for whom and on what grounds? Types of PST, target population and criteria for professional indication

Palliative sedation therapy can be distinguished according to the level of sedation and mode of application, in the sense of whether PST is applied intermittently or continuously. It is important to state clearly what is meant by PST in practice, because the types of PST differ with regard to clinical and ethical implications. Patients who receive intermittent superficial sedation, for example, may eat and drink well, whereas continuous deep sedation is associated with a decision whether artificial hydration and nutrition should be administered. In addition to distinctions regarding the practice of PST, the target population for PST needs to be clearly defined. Although closeness to death has often been suggested as an important criterion for PST (2,8,9), the EAPC framework mentioned already focuses on the degree of suffering as the utmost criterion, which should guide decisions about PST in general, whereas continuous deep sedation should be applied 'only in the very terminal stages of their illness with an expected prognosis of hours or days at most' (7). The criterion of suffering is often specified as 'intolerable suffering'. However, what counts as intolerable suffering is difficult to establish and only a few guidelines explore this issue in more depth (2,9). An especially controversial issue in this context, which needs to be dealt with in practice, is whether PST should be considered for psychological or existential distress. Although special precautions regarding the assessment of such suffering have been requested, there is scarcely any literature regarding the justification of a distinction of somatic vs. psychological suffering in the context of PST (10).

As with other treatment recommendations, the decision whether PST should be offered as a therapeutic

option needs to be based on a professional evaluation of signs and symptoms in the specific patient and the aims, which may be fulfilled by PST in this case. However, and as pointed out above, the difficulty concerning PST is that an important ground for such a decision is the evaluation of the degree of suffering of the patient. Such evaluation is possible only in part by referral to objective criteria, whereas the patient's perception and judgement are of utmost importance. Against this background, it is important to be aware of the patient's central role in the evaluation whether PST is indicated or not (2,9).

Who is in charge? Clarifying roles and responsibility

On one hand, the involvement of different parties is important for informed decision-making about PST. On the other hand, the involvement of several parties in decision-making also bears the risk of the blurring of roles and responsibilities. With regard to the patient, there is a clear ethical and legal requirement to inform him or her about the option of PST and to elicit consent. However, decisions about PST in clinical practice sometimes need to be made in situations in which the patient does not have the capacity to make such decisions. While relatives and other people close to the patient in such situations can inform the decision-making process by making the patient's will, preferences and values known to the healthcare team, it should be noted that only the legal representative of the patient has a formal role in the decision-making process. In light of the well-known difficulty of interpreting earlier statements with regard to present decisions about medical treatment, a number of guidelines on PST recommend that end-of-life decisions should be discussed with the patient in advance, when he or she is still able to communicate his or her wishes (2,7).

Professional expertise of a physician in palliative care and symptom management is, without doubt, important to ensure that the decision criteria for PST are known and adequately applied. However, given the challenges of evaluating suffering mentioned above, it has also been suggested that, next to the involvement of the patient perspective, the decision to offer PST should also be based on a multi-professional assessment involving members of the nursing staff, other healthcare professionals and possibly also members beyond healthcare, such as members of an ethics committee in the case of disagreement within the team (11). The emphasis of the literature on multi-professional approaches to decision-making about PST may seem somewhat surprising if compared with other medical decisions in the last phase of life (e.g. the application of another cycle of palliative chemotherapy), regarding which there seems little doubt that the professional judgement is made by the responsible physician(s). However, taking into account the difficulty of evaluating whether PST is indicated, given the lack of objective assessment and the need for value judgements in the context of decisions about PST, we argue that multi-professional case discussions, ethical case consultation and comparable value-oriented interventions are important to make explicit the normative dimension of decisions about PST and other end-of-life treatment (12).

Nutrition and hydration? PST and decisions about life-sustaining treatment

Decisions about PST in some cases inevitably require a decision to be made about life-sustaining treatment. One example is the decision about resuscitation with regard to which there has been published guidance recommending that PST should only be applied if there is a do-not-resuscitate order in place (9). Another example in this context is the decision whether a patient should receive artificial hydration and/or nutrition in the case of PST if he or she is consequently unable to drink or eat on his or her own. This issue has been analysed from a medical as well as ethical perspective (13,14). Current guidelines vary on this point. Although there are some guidelines, which do not give any recommendation at all (15,16), others state that these issues should be discussed separately of the decision for PST (2,17). From a clinical–ethics perspective and in line with more recently published guidance on this issue (7,8), we argue that any options regarding life-sustaining treatment should be evaluated firstly from a professional perspective, and, if judged to be potentially effective from a medical point of view, discussed with the patient separately from the decision about PST. It may be, for example, that the medical assessment of a patient with whom PST is considered as an option indicates that already ongoing artificial nutrition and hydration is increasingly leading to burdens, such as pulmonary oedema. In such a case, the patient (or their representative) should be informed about the professional judgement and the measure should be stopped. This situation is different from a decision whether a patient who has effectively received artificial nutrition and hydration during the last few months should continue to receive it also during PST. In this case, a patient's preferences regarding nutrition and hydration need to be explored. A wish for PST can be, but does not need to be, associated with a wish for limitation of life-sustaining measures.

Conclusions

Empirical evidence indicates that PST is a frequent end-of-life practice. At the same time, the existing variation in practice and the clinical and ethical challenges associated with PST raise issues with regard to appropriate measures to further good clinical practice of PST. Guidelines may contribute to good clinical practice, for example, by providing knowledge about medical aspects and clarification of legal roles and responsibilities. However, it should be noted that the professional competency of the individual physician and other healthcare professionals in clinical practice will contribute importantly to the quality of decision-making about PST. Such competency goes well beyond the medical, ethical and legal knowledge conveyed in guidelines.

This is especially true for the skills needed to reflect on the values that shape decisions about PST, and to make these explicit in the decision-making process. Against this background, we argue that multidisciplinary team discussions and ethics consultation, as well as training in the skills necessary for an ethically informed and structured approach are important strategies, which should complement the current focus on guidelines to ensure the good clinical practice of PST.

Author contributions

Both authors claim responsibility for the concept, drafting, critical revision and approval of the article.

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Disclosure

Both authors claim no conflicts of interest related to this manuscript.

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