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A case study of Muslims' perspectives of expanded terminal sedation:addressing the elephant in the room

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Abstract

Background Recently, the concept of expanded terminal sedation emerged to describe using sedation at the end of life in cases beyond the usual use. Using this sedation could be a stressful ethical encounter for healthcare providers.

Case In this paper, we describe a case of a Muslim palliative care nurse who cared for a patient with cancer who requested expanded terminal sedation. The palliative care nurse described that his initial response to the expanded terminal sedation order was refusing to start the sedation because he believed the patient was not terminally ill and was concerned about killing him, which is prohibited according to his religious beliefs. Further, the nurse perceived the patient's psychological distress and his verbalization of wishing to die peacefully as a concealed request for euthanasia, especially since he was not imminently dying. Finally, the nurse reported being frustrated and uncertain about the care, especially since he did not receive appropriate psychological counseling from professional personnel.

Conclusions any case beyond the usual conditions for terminal sedation should be carefully examined, especially when nurses' religious beliefs or moral values contradict it. If sedation should be administered, adequate preparation of healthcare providers should be arranged, including discussing with them the goals of care and the rationale for sedation before and after initiating it. Generating a policy for conscientious objections, allowing nurses to express their own emotions and concerns in a supportive environment are suggested approaches to preserve their wellness.

Keywords End-of-life care, Ethics, Case study, Euthanasia, Hospice, Muslims, Palliative care, Palliative sedation, Physician-assisted dying, Terminal sedation

Background

Terminal sedation in palliative care is used for approximately 12–18% of all terminally ill patients with severely distressing symptoms, especially during the last hours or days of life [1], aiming to reduce symptoms rather than ending patients' lives [2]. Terminal sedation is defined as "the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms" [3]. Along the same line, Kremling and Schildmann [4] emphasized that the administration of sedation to terminally ill patients aims to treat intolerable symptoms through the reduction of consciousness. Delirium, pain, and dyspnea are considered the most typical indications for terminal sedation [5].

Noticeably, terminal sedation has been a debatable issue as many healthcare providers (HCPs) consider it an

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ethical concern. To overcome this longstanding debate, researchers and institutions published several standards for initiating terminal sedation to highlight the appropriate circumstances to use it [6–10]. This includes conditions such as the presence of refractory symptoms, administering a proportionate dose of sedatives, and that the patient should be imminently dying. Where these criteria are met, terminal sedation is usually considered acceptable medical practice by ethicists, judiciaries, and HCPs [11, 12].

Recently, the term Expanded Terminal Sedation has emerged to describe the use of sedation at the EoL outside the recommended circumstances. In their argument, Gilbertson et al. [13] considered that using terminal sedation can be morally acceptable in cases beyond the usual use, such as for patients with non-refractory suffering when administering gradual sedation is not likely effective to alleviate the suffering or to a patient who is suffering but not imminently dying. On the other hand, several scholars argued that even though expanded terminal sedation is a promising solution to relieve suffering and maintain patient autonomy, it should be clearly defined and used cautiously. They asserted that, by definition, expanded terminal sedation ignores the principle of using sedation as the "last resort", which can blur the line between palliative care and euthanasia [14–16].

Dealing with the ethical implications of terminal sedation could be a stressful encounter for HCPs, especially since many consider it a disguised form of euthanasia [6, 17]. Nurses' concerns evolved around the initial decision to start the sedation and the potential for hastening death [18], in situations when the patient had already requested euthanasia [19], when the family requested the sedation [20], or due to a lack of communication with the patient and interfering with continuous nursing assessment and follow-up [21]. In addition, Muslim HCPs who believe that life is given and taken by God usually oppose to participating in any procedure that may hasten death [22], although palliative sedation, when appropriately indicated and correctly used, does not have any detrimental effect on the patient's survival [23].

Islamic ethical and legal stances regarding palliative and terminal sedation

The differentiation between various forms of terminal sedation and euthanasia, as well as the perception of these practices, may have implications for how such practices are viewed in different cultural and religious contexts [24]. In the context of Islamic ethics, administering terminal sedation is challenging [25]. This discussion is important as it involves the intersection of medical practices with religious beliefs and cultural considerations. New applied Islamic ethics could offer guidance on the acceptability of terminal sedation within Islamic frameworks [26]. Among Muslims, it is of great importance to keep the patient as conscious as possible before death, to be able to engage in worship rituals [27]. Dying patients are encouraged to cite the *shahadah* (which reads "I bear witness that there is no God but Allah, and that Muhammad is the Messenger of Allah") as they take their last breath [28]. Islam also emphasizes ease and comfort, as mentioned in the Holy Quran (The religious book of Muslims): "*Allāh (God) intends for you ease and does not intend for you hardship*" (Al-Baqarah: 185). This verse means that Allah's intentions for people are centered around their well-being and ease, rather than unnecessary suffering.

Understanding the Islamic perspective on terminal sedation could be achieved by analyzing the five major legal maxims of Islamic law (*Al-qawā'id al-fiqhiyah*), which constitute the general principles that formulate Islamic law [29]. These five principles are (1) Matters are determined according to intention *(al-umūr bi maqā'idihā)*, (2) Hardship begets facility *(Al-mashaqqatu tujlab at-taysir)*, (3) Harm should not be inflicted nor reciprocated *(La darar wa la dirar)*, (4) What is certain cannot be removed by doubt (*Al-yaqinu la yazulu bish-shakk)*, and (5) Custom is arbitrary *(Al-'addatu muhakkamatun).*

The first principle (the intention of acts is what matters) directly aligns with terminal sedation that aims to alleviate suffering, not to hasten death. Therefore, the primary goal of administering terminal sedation should be the comfort of the patient rather than any unintended consequences. Further, according to the second principle, when someone is facing difficulty, the application of legal rules should be flexible to ease their burden [30]. This applies to palliative patients who suffer at the end of life (EoL), as terminal sedation might preserve their comfort and peace during dying. In summary, palliative sedation, when approached with care and intention, aligns with the principles of alleviating suffering and compassion in Islamic jurisprudence.

To date, despite the scarcity of studies about Muslim nurses' practices and experiences related to terminal sedation, it seems that their role is essential at every point in the process. They have adequate knowledge focused on the needs and preferences of both patients and their families that make them participate in terminal sedation procedure including administering sedation, monitoring patients, and assessing their comfort. However, this type of involvement, based on their experiences rather than training, may impact their perceived confidence and distress [18, 19]. Moreover, compared to traditional terminal sedation, we expect that expanded terminal sedation could be more stressful to nurses, which is consistent with the findings of Gallagher and Wainwright [31], who claimed that the preemptive use of sedation to

prevent potential suffering, may raise ethical concerns and contribute to emotional and moral strain on nurses. Therefore, the current study explored the experience of a Muslim palliative care nurse who cared for a patient with cancer who requested expanded terminal sedation. However, this paper does not discuss the Islamic perspective on terminal sedation, as this was already established through previous research [26, 30, 32–34].

Case description

A 25-year-old male nurse, who worked in a palliative care unit specializing for patients with cancer. The hospital where the nurse worked had a policy for terminal sedation administration for palliative patients near EoL and all nurses in the unit were educated about the policy. The decision to start terminal sedation is made after careful assessment of the patient. The interdisciplinary palliative care team, including physician, nurse, psychologist, social worker, and religious advisor, meet with the patient (if applicable) and/or the legal guardian to discuss the options and obtain consent form. The shared decision will be then communicated with the entire team and documented on patient's records.

The nurse was providing care for a patient diagnosed with stage-four Colon cancer who developed intestinal obstruction. The palliative care physician ordered starting the patient on continuous terminal sedation with Midazolam infusion, and the nurse was requested to administer the medication. The nurse deemed that the patient was not having refractory symptoms nor imminently dying, yet he requested sedation to "die peacefully". The initial response of the nurse was to refuse administering the sedation because he believed the patient was not terminally ill and still had good days to live. He was worried about the consequences of the sedation on hastening death, which is considered a prohibited act (Haram) by Muslims. The nurse was worried about the ethical burden he would carry if the patient died after starting terminal sedation, especially since he perceived him as a "non-eligible patient". He described how it contradicted his personal values and religious precepts.

The nurse felt the order was not bound to usual terminal sedation circumstances. Further, he described attending a previous family meeting where the patient's family reported that their patient was desperate because of the cancer complications and that he wanted to die peacefully. The nurse felt that the patient's psychological distress and his verbalization of wishing to die peacefully was a concealed request for euthanasia, especially since he was not imminently dying. The nurse communicated his concerns with the charge nurse, who changed the assignment, and the patient care was transferred to another staff member who started the terminal sedation. The nurse explained that the nurse educator, unit manager, and resident physician provided him with access to the policy and research studies about medical indications for terminal sedation. However, he claimed he did not receive formal psychological counseling, even though he needed it since he felt frustrated and uncertain. Surprisingly, he stated that he was afterward reassigned to provide direct care to the same patient while receiving the midazolam infusion; making him feel frustrated and helpless.

Discussion

The current paper addresses the case of a Muslim palliative care nurse who encountered the situation of initiating expanded terminal sedation for a patient with cancer. HCPs are concerned about causing or accelerating death by administering the sedation and fear being held responsible for its consequences [35]. We expect that these fears are similar or perhaps higher among Muslim nurses who may view it as a contradiction to their religious beliefs.

According to Muishout et al. [26], Muslim physicians working in Western contexts may experience tension between their religious beliefs and the professional norms of administering palliative sedation when medically indicated. Despite potential conflicts with their beliefs, these physicians prioritize their professional responsibility and moral obligation to alleviate patient suffering, ensuring that the sedation does not accelerate death. Similarly, the nurse in our study was worried about the ethical burden if the patient died after starting the sedation, especially since he perceived him as a "non-eligible patient". He described how administering terminal sedation for patients beyond the recommended circumstances contradicted his personal values and religious precepts and that he feared moral consequences. In the same assertion, a narrative analysis conducted by Douglas et al. [36] revealed that HCPs perceive terminal sedation as an act that can be linked to death; at least patients would survive for weeks if they could drink or eat, which is not happening during terminal sedation.

How to distinguish between terminal sedation and euthanasia

Expanded terminal sedation that is not initiated according to the usual circumstances might be debated by some HCPs and confused for euthanasia. According to Broeckaert [37], HCPs can distinguish between terminal sedation and euthanasia based on the intention, action, and results. The first one (terminal sedation) intends to relieve refractory symptoms; action is carried out by administering a proportionate dose of sedatives for an imminently dying patient, meaning that death is a result of the disease progression rather than the sedation itself [4]. Any case beyond these conditions should be carefully

examined, and if sedation should be administered, adequate preparation of HCPs should be arranged.

In another argument, Rietjens et al. [38] found that reasons for seeking sedation differ significantly between terminal sedation and euthanasia. More specifically, patients request euthanasia for reasons related to loss of dignity, fear of suffering without improvement, and control of the dying process. This statement might intersect with our case study, as the family clearly described how their patient was desperate because of colon cancer complications and wanted to die peacefully. Once again, this sheds light on the argument of Gilbertson et al. [13] that expanded terminal sedation could be ethically permissible for patients who meet al.l criteria for assisted dying.

Obviously, the nurse experienced frustration and uncertainty due to the expanded terminal sedation order considering that from a Muslim perspective, no one should hasten death or help someone to end his/her life, as these acts are Haram (prohibited) by Allah (God). Once again, this is a long-standing issue in terminal sedation per se. Nurses try to avoid involvement in terminal sedation as much as possible; they reported feeling helpless when sedation was administered to their patients, and occasionally, this sedation-related burden caused them to think about leaving their current work [39]. According to De Vries et al., [20] nurses experience distress and ethical dilemmas due to the decisions associated with terminal sedation, such as titrating the sedation, hastening the death, and when family members request the sedation. Apparently, these decisions are similar to the circumstances associated with our case, indicating that expanded terminal sedation exposes nurses to ethical dilemmas.

Due to his personal and religious beliefs, the nurse in this case declined to give the sedative. This is known as "conscientious objection," in which medical professionals refuse to give certain treatments to their patients, based on reasons of morality or "conscience" [40]. Opponents of conscientious objection assert that consciousness is a fundamental human good, and thus, aiming to suppress it may not be justifiable [41]. Therefore, it is suggested that HCPs should inform patients of their options and refer them to other providers if they cannot participate in the treatment due to conscientious objections [42]. The intersection of conscientious objection and terminal sedation presents complex challenges for healthcare professionals. While the moral integrity of physicians is crucial, it must be balanced against their ethical obligations to provide comprehensive care to patients facing terminal conditions. Ongoing discussions and research are essential to navigate these ethical issues and ensure that patient care remains at the forefront of medical practice.

Approaches for conflict resolution

Addressing conflicts related to conscientious objection in terminal sedation requires a multifaceted approach that balances ethical considerations, patient rights, and HCPs' beliefs. Healthcare institutions should provide support systems for HCPs facing moral dilemmas. This includes access to counseling services, peer support groups, and resources for managing stress related to ethical conflicts. By fostering a supportive environment, institutions can help HCPs navigate their conscientious objections without compromising patient care.

The European Association for Palliative Care (EAPC) framework for terminal sedation addressed the emotional distress experienced by HCPs when delivering care for a patient under terminal sedation [43]. They recommended discussing with them the goals of care and the rationale for sedation before and after initiating the sedation. As well as allowing for expressing own emotions and concerns in a supportive environment. Further, HCPs should engage in open dialogues with patients and families. This involves explaining the rationale behind their conscientious objections while ensuring that patients are informed about all available options. Regular discussions can help clarify misunderstandings and align expectations between patients and HCPs.

Establishing clear institutional policies can guide healthcare providers on how to handle conscientious objections while protecting patient rights and respecting HCPs' moral beliefs [44]. These policies should outline procedures for managing conscientious objections, including referral mechanisms to ensure patients receive timely care from other providers who do not share the same objections. Besides, providing training for healthcare professionals on ethical decision-making and conflict resolution can enhance their ability to navigate conscientious objections [45]. Educational programs can cover topics such as the ethical principles of palliative care, the implications of conscientious objection, and effective communication strategies. This training can empower clinicians to address their moral concerns while still prioritizing patient welfare.

Further, encouraging a collaborative approach among healthcare teams can mitigate conflicts. By fostering an environment where team members can discuss their ethical and religious concerns openly, institutions can develop a shared understanding of patient care priorities [46]. In cases where conflicts escalate, involve an ethics committee or palliative care specialists who can mediate discussions and provide additional perspectives on patient needs and ethical obligations. These discussions between the concerned parties help to explore the underlying values and beliefs that contribute to the conflict. An ethics consultation can provide a neutral perspective and assist in finding a resolution that respects both patient

rights and clinician beliefs [47]. By employing these strategies, healthcare providers can work towards resolving conflicts related to conscientious objection in terminal sedation, ensuring that patient care remains the central focus while respecting the moral beliefs of healthcare professionals.

Clinical implications

If expanded terminal sedation should be administered, adequate preparation of HCPs should be arranged, and the practice should be covered by the laws and institutional policy. Special attention should be given to religious beliefs that affect HCPs' reactions to such sedation. To alleviate the sedation-related burdens, nurse managers should consider providing nurses with appropriate education and training, opening proper communication channels between physicians and nurses, conducting team conferences, and discussing with them the goals of care and the rationale for sedation before and after initiating the sedation. It is also essential to allow for expressing their own emotions and concerns in a supportive environment and provide adequate ethical advice and counseling to help nurses cope with their emotions.

Conclusion

Using expanded terminal sedation could be a stressful ethical encounter for HCPs, especially among Muslims, who may consider it a prohibited act (Haram). Expanded terminal sedation could be perceived as a disguised euthanasia, leading to unresolved emotional burdens and religious conflict. Any case beyond the usual conditions for terminal sedation should be carefully examined, and if sedation should be administered, adequate preparation of HCPs should be arranged including considering their religious belief system.

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E. O, M A: Study design, data collection and analysis, manuscript writing.

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Data availability
The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
The study was performed in accordance with the Declaration of Helsinki.

Consent for publication
Written informed consent for publication of clinical details was obtained from the participant. A copy of the consent form is available for review by the Editor of this journal.

Competing interests
The authors declare no competing interests.

Informed consent
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