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Ethically challenging end-of-life situations

INVITERT KOMMENTAR

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Decisions regarding the initiation of end-of-life palliative sedation are difficult. Guidelines are helpful but cannot replace doctors' clinical judgement and experience.

In 2000, the Norwegian Medical Association began working on ethical guidelines for palliative end-of-life sedation, and a preliminary final revision of these was adopted by the central board in 2014 (1). The guidelines have been published on the Norwegian Medical Association's website, and are not part of the Norwegian Directorate of Health's national clinical guidelines (2). They take the form of a two-page poster with a brief explanation of purpose and scope, followed by twelve points clarifying concepts and requirements for the process and the documentation needed when carrying out palliative sedation. It is important that the guidelines are viewed in conjunction with the Norwegian Directorate of Health's guide on decision-making processes for limiting life-sustaining treatment.

This edition of the Journal of the Norwegian Medical Association includes a study by Schaufel et al. of pulmonologists' experiences with palliative sedation and their awareness of the guidelines (3). The study provides a good opportunity to discuss both the content and a potential revision of the guidelines.

«Although healthcare personnel recognise the usefulness of guidelines, they can be difficult to implement in both primary care and the specialist health service»

Of the 50 pulmonoligists in the survey, half were not familiar with the guidelines, which may be an indication of poor implementation. This should not be surprising; although healthcare personnel recognise the usefulness of guidelines, they can be difficult to implement in both primary care and the specialist health service (4). The increasing multimorbidity among the growing ageing population means that multiple guidelines need to be consulted (5). The findings must therefore be viewed in light of the debate about the number of guidelines that doctors must constantly navigate.

In Schaufel et al.'s article, the guidelines for palliative sedation are linked to two other guidelines from the Norwegian Directorate of Health. This raises the question of the number of guidelines from various sources that clinicians need to be familiar with and consult in order to provide good clinical follow-up. This can be viewed in relation to the concept of 'time needed to treat'. Given the dynamic nature of guidelines, how much clinical time must each doctor dedicate to keeping themselves informed (6)?

«When palliative sedation is normalised in clinical practice, it is applied more liberally»

The limited implementation indicated by the study raises the question of whether palliative sedation takes place more or less frequently than provided for in the guidelines. Some of the doctors in the survey reported that palliative sedation occurred more often than might be expected, which may indicate ambiguity in the definition. This finding can also be interpreted in light of a study showing that when palliative sedation is normalised in clinical practice, it is applied more liberally (7). This is partly because clinicians better recognise refractory suffering and because the concept is expanded to include psycho-existential suffering.

«Although clinical markers can be identified through studies, prognostication remains closely linked to doctors' clinical judgement and experience»

The informants in the study sought help with prognostication and practical advice. It is tempting to subscribe to this notion. The appealing brevity of the guidelines must be weighed against the need for more comprehensive guidance. However, guidelines cannot capture the complexities involved in estimating a patient's life expectancy. Although clinical markers can be identified through studies, prognostication remains closely linked to doctors' clinical judgement and experience (8).

When it comes to distinguishing between different interventions, palliative sedation must be interpreted as appropriate and correct when unbearable suffering cannot be alleviated in any other way. This is distinct from euthanasia and drowsiness induced by symptomatic treatment (1). The fact that these distinctions are not clear enough to healthcare personnel is consistent with other studies and is an important finding (9). This lack of knowledge about what palliative methods are permissible within Norway's legal and ethical framework hinders meaningful discourse on complex issues like euthanasia.

Doctors need support in ethically challenging end-of-life situations. It would be wise to preserve and further develop the guidelines, primarily as an advisory ethical and legal framework for us as final decision-makers in an ethical quagmire.

REFERENCES

1. Førde R, Materstvedt LJ, Markestad T et al. Lindrende sedering i livets sluttfase - reviderte retningslinjer. Tidsskr Nor Legeforen 2015; 135: 220–1. [PubMed][CrossRef]

2. Den Norske Legeforening. Retningslinjer for lindrende sedering i livets sluttfase. https://www.legeforeningen.no/contentassets/cc8a35f6afd043c195ede88a15ae2960/retningslinjer-for-lindrende-sedering-i-livets-sluttfase-2014.pdf Accessed 15.10.2024.

3. Schaufel MA, Førde R, Sigurdardottir KR et al. Lungelegar sine erfaringar med lindrande sedering i livets sluttfase. Tidsskr Nor Legeforen 2024; 144. doi: 10.4045/tidsskr.23.0778. [CrossRef]

4. Austad B, Hetlevik I, Bugten V et al. Implementing guidelines for follow-up after surgery with ventilation tube in the tympanic membrane in Norway: a retrospective study. BMC Ear Nose Throat Disord 2013; 13: 2. [PubMed][CrossRef]

5. Pedersen RA, Petursson H, Hetlevik I. Stroke follow-up in primary care: a Norwegian modelling study on the implications of multimorbidity for guideline adherence. BMC Fam Pract 2019; 20: 138. [PubMed][CrossRef]

6. Johansson M, Guyatt G, Montori V. Guidelines should consider clinicians' time needed to treat. BMJ 2023; 380. doi: 10.1136/bmj-2022-072953. [PubMed][CrossRef]

7. Heijltjes MT, van Thiel GJ, Rietjens JA et al. Continuous deep sedation at the end of life: a qualitative interview-study among health care providers on an evolving practice. BMC Palliat Care 2023; 22: 160. [PubMed][CrossRef]

8. Gibbons S, Sinclair CT. Demystifying Prognosis : Understanding the Science and Art of Prognostication. Cancer Treat Res 2023; 187: 53–71. [PubMed][CrossRef]

9. Lucchi E, Milder M, Dardenne A et al. Could palliative sedation be seen as unnamed euthanasia?: a survey among healthcare professionals in oncology. BMC Palliat Care 2023; 22: 97. [PubMed][CrossRef]

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