Tidsskriftet Tidsskrift for Den norske legeforening

Death awaits

INVITERT KOMMENTAR

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The author has completed the ICMJE form and declares the following conflicts of interest: he has received speaker fees or instructor fees for communication training from the Norwegian University of Life Sciences, CoreMine, Takeda, Pfizer, the Regional Centre of Excellence for Pain, the Norwegian Veterinary Institute and the Norwegian Association for Community Medicine, as well as fees for filmmaking from the Norwegian Brain Tumour Association.

Simply having guidelines for effective advance care planning is not enough. This is a sacred space.

Hugo Simberg, The Garden of Death, 1896. Photo: Finnish National Gallery / Jenni Nurminen

In December 2023, the Norwegian Directorate of Health issued national clinical guidelines on advance care planning (ACP) for patients with a short life expectancy (1). A prerequisite for ACP is real patient involvement. Two relevant articles on the topic are published in this edition of the Journal of the Norwegian Medical Association.

In a survey of healthcare personnel in geriatric wards, participants reported limited confidence in conducting ACP (2). Between 21 and 34 % of the doctors in the survey gave this response to questions about conversations concerning future deterioration of a patient's condition and life-sustaining treatment. Not surprisingly, a secondary finding was that limited confidence was more common in discussions with the patient and their family together.

Interviews with ten general practitioners (GPs) revealed that they feel they lack formal competence in conversations about death, and that these discussions are challenging but rewarding (3). They also find that the lack of clarity from the specialist healthcare service regarding treatment intensity makes it harder to talk about death with patients. Given how hospitals are organised, this is understandable. Per Fugelli suggested introducing a GP provision for severely ill patients in hospitals (4). As a relative of patients, ten years after Fugelli's article, I have found that recurring contact with the same doctor in the hospital setting is still a rarity. This raises the question of whether an established relationship is a prerequisite for effective ACP.

It is probably beneficial, but hardly a necessity. The Norwegian Directorate of Health has a focus on competence development (1) and sets out some sensible measures. However, neither the directorate, the ministry, nor politicians seem to grasp *how much effort will be required* to make communication competence an integral component of specialist training. One of the main challenges is that even experienced specialists and GPs who are skilled at conducting such conversations rarely have training in how to teach their less experienced colleagues. Communication remains a neglected aspect of medical training worldwide.

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You might think that since ACP takes place when it is already known that the patient is seriously ill, the conversation would be easier than delivering the initial bad news. The emotional pressure is often less apparent. However, this does not mean that every seriously ill patient is ready to discuss the future any time soon. A clumsy start to the conversation can lead to irritation, withdrawal, resistance or open anger. The study by Brunsvig-Engemoen et al. highlights how GPs search for natural entry points into the conversation (3). Some patients require a subtle approach to the discussion, while others can handle open, direct questions. However, if the doctor does not feel confident in the situation, it can cause anxiety in the patient. Supervision and guidance are needed.

Respect for the patient's autonomy as one of the justifications for ACP is both correct and important, but not easy to apply. Ellen Kristvik, a Norwegian anthropologist, has written extensively on this topic after following cancer patients and their families from the moment they received the terminal diagnosis up to the time of death and beyond (5). The focus on autonomy in the conversation can sometimes hinder the crucial *sense of belonging*. Many patients place their fate in the hands of the doctor and do not necessarily want to participate in the decision-making. Having someone present who listens and is able to react to whatever arises is often sufficient support. In this situation, family members can be a great help but can also cause unpredictable anxiety. Envisioning one's own death is entirely different from imagining the loss of a loved one. Family members often bear a significant responsibility whilst also having an urgent need for information – even if they do not have the right to receive it. They may be at the mercy of the patient's inability or unwillingness to discuss the future. In ACP, it is important to consider the experiences of those closest to the patient, including minors, and not just focus on the patient (6).

In her dissertation, my colleague Margrethe Aase Schaufel discusses the existential challenges faced by doctors and patients, highlighting the ambiguous position of death in medicine, where mortality is seen as both acceptable and unacceptable (7). She is now introducing this concept to doctors in Bergen through her regular 'powerlessness seminars', which I believe serve as an important counterbalance to the omnipotent image of the practice of medicine often portrayed by modern medicine, both in society and among medical students.

I like to think of ACP as a cathedral of uncertainty, a high and deep sacred space. You know you must enter, but you need to search for a suitable entry point. Once inside, the cathedral is confusing, perhaps dark. Is the patient there? Are you welcome? Does lighting a candle help? Can you sit down for a while with the other person? Discuss various possibilities? Be present. What about others who are there? How are *they* doing? What do *they* need? Are you able to feel secure in the uncertainty, knowing that the only certainty in the cathedral is the exit?

REFERENCES

1. Helsedirektoratet. Nasjonale faglige råd. Forhåndssamtaler og planlegging ved begrenset forventet levetid. https://www.helsedirektoratet.no/faglige-rad/Forhandssamtaler-og-planlegging-ved-begrenset-forventet-levetid Accessed 10.10.2024.

2. Ihle-Hansen H, Ihle-Hansen H, Rostoft S et al. Forhåndssamtaler om siste livsfase. Tidsskr Nor Legeforen 2024; 144. doi: 10.4045/tidsskr.24.0105. [CrossRef]

3. Brunsvig-Engemoen F, Romøren M, Skjeie H. Samtaler med pasienten om døden – erfarne fastlegers refleksjoner og erfaringer. Tidsskr Nor Legeforen 2024; 144. doi: 10.4045/tidsskr.24.0093. [CrossRef]

4. Fugelli P. Engangsleger. Aftenposten 3.2.2011. https://www.aftenposten.no/meninger/kronikk/i/7w7o/engangsleger Accessed 14.10.2024.

5. Kristvik E. For whom and for what? Exploring the question of 'informed consent' in treatment decision making processes. Medische Antropologie 2011; 23: 29–43.

6. Røkholt EG, Sandvik O, Bugge KE et al. red. Sorg. 2. utg. Bergen: Fagbokforlaget, 2018.

7. Schaufel MA. Å dele uvissa og ansvaret. Ein kvalitativ studie av livets grunnvilkår i medisinsk praksis. Doktoravhandling. Bergen: Universitetet i Bergen, 2010. https://bora.uib.no/bora-xmlui/handle/1956/4856 Accessed 14.10.2024.

Publisert: 4 November 2024. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.24.0535