

**\*\* Postprint version. Published online first in Clinical Ethics, 28**

**July 2020. <https://doi.org/10.1177/1477750920946613> \*\***

**Refractory suffering at the end of life and the assisted dying  
debate: An interview study with palliative care nurses and doctors**

**Kristine Espegren Gustad** ([k.e.gustad@medisin.uio.no](mailto:k.e.gustad@medisin.uio.no))

**Åsta Askjer** ([aasta\\_91@hotmail.com](mailto:aasta_91@hotmail.com))

**Per Nortvedt** ([per.nortvedt@medisin.uio.no](mailto:per.nortvedt@medisin.uio.no))

Centre for Medical Ethics

Institute of Health and Society

University of Oslo, Oslo, Norway

**Olav Magnus S. Fredheim** ([olav.m.fredheim@ntnu.no](mailto:olav.m.fredheim@ntnu.no))

Department of Palliative Medicine

Akershus University Hospital

Lørenskog, Norway

and

Department of Circulation and Medical Imaging

Faculty of Medicine and Health Sciences

Norwegian University of Science and Technology

Trondheim, Norway

**Morten Magelssen** ([morten.magelssen@medisin.uio.no](mailto:morten.magelssen@medisin.uio.no))

Centre for Medical Ethics  
Institute of Health and Society  
University of Oslo, Oslo, Norway

**Corresponding author:**

Morten Magelssen

Centre for Medical Ethics

University of Oslo

Pb. 1130 Blindern

N-0318 Oslo

NORWAY

Email: [morten.magelssen@medisin.uio.no](mailto:morten.magelssen@medisin.uio.no)

Phone: +47 48 22 35 80

## **Abstract**

*Background.* How often does refractory suffering, which is suffering due to symptoms that cannot be adequately controlled, occur at the end of life in modern palliative care? What are the causes of such refractory suffering? Should euthanasia be offered for refractory suffering at the end of life? We sought to shed light on these questions through interviews with palliative care specialists.

*Methods.* Semi-structured interviews with six nurses and six doctors working in palliative care in five Norwegian hospitals. Transcripts were analysed with systematic text condensation, a qualitative analysis framework.

*Results.* Informants find that refractory suffering is rare, and that with palliative sedation satisfactory symptom control can nearly always be achieved at the end of life. However, the process of reaching adequate symptom control can be protracted, and there can be significant suffering in the meantime. Both somatic, psychological, social and existential factors can contribute to refractory suffering and potentiate each other. However, informants also place significant weight on factors pertaining to the organization of palliative care services as contributing to insufficient symptom control.

*Conclusions.* If refractory suffering is indeed rare, then this arguably weakens a common *prima facie* argument for the legalization of assisted dying. However, the process of reaching adequate symptom control can be protracted and involve significant suffering. The experiences of palliative care clinicians constitute important empirical premises for the assisted dying debate. The study points to several areas in which palliative care can be improved.

## **Introduction**

Modern specialist palliative care is potent, but apparently cannot prevent some patients from experiencing refractory suffering during the disease trajectory <sup>1</sup>. Refractory suffering can be defined as suffering due to symptoms that cannot be adequately controlled despite state-of-the-art palliative care <sup>2</sup>. Understanding this phenomenon is important for at least two reasons. Most obviously and importantly, an understanding of how and why palliative care sometimes does not succeed in achieving symptom control can inspire novel advances and improvements in clinical care. Yet also, knowledge about the successes and shortcomings of palliative care is arguably a significant empirical premise for debates about legalization of assisted dying (euthanasia and assisted suicide): In brief, the less potent palliative care is in providing relief for suffering and the more patients that will have to experience unbearable suffering, the stronger is the case for legalization of assisted dying – and vice versa. Assisted dying is illegal in Norway. In a recent poll of Norwegian doctors, 9% strongly agreed and 22% partially agreed to the statement that ‘Physician-assisted suicide should be permitted for persons suffering from a fatal disease with a short remaining life expectancy’; 47% strongly disagreed, 11% partially disagreed and 11% neither agreed nor disagreed <sup>3</sup>.

Previous studies have examined the most frequent symptoms and complaints of patients with refractory suffering. White et al.’s 2004 Australian interview study with experienced nurses working in palliative care found that suffering was experienced to be complex and multidimensional, with a close relationship between physical suffering and existential, spiritual, psychological, metaphysical and emotional suffering <sup>4</sup>. Typical contributing factors were pain, nausea and emesis, fear of the unknown, ‘losing oneself’ and losing purpose, thoughts about how and that one will die, unresolved family conflicts, unfulfilled dreams and the general feeling of loss. The study also found that health professionals’ main emphasis was

to manage physical symptoms and that the palliative nurses interviewed felt they had little knowledge of suffering in a broader sense. In a study conducted in Belgium, the Netherlands and the UK in 2014, Anquetin et al. found that existential and psychological suffering in terminally ill patients could either come as a direct result of their disease, stem from psychological problems prior to their disease, or develop during their disease trajectory as a reaction to being ill <sup>5</sup>. Among patients with refractory suffering they found dyspnoea, terminal agitation, cachexia, fatigue, panic, anxiety, depression, sadness, paranoia, demoralization, hopelessness, sense of dependency, decay, loss of will to live, exhaustion of fighting and fear of death. Swart and Van der Heide's 2014 Dutch study found that refractory suffering could be physical (e.g., due to metastases), psychological, and existential (e.g., due to fear) <sup>6</sup>. Refractory suffering entailed that there was one particularly significant symptom or many symptoms that cumulatively caused suffering.

White et al. concluded that there were only a few patients that died with unrelieved pain <sup>4</sup>. However, these particular patients became a significant burden on the health professionals working with them, leaving these feeling helpless, frustrated and with a sense of failure. For the professionals these experiences could further entail crying, poor sleep, headaches, and burnout and other reactions. Another Australian study described helpful coping strategies for health professionals working with refractory suffering <sup>7</sup>. In particular, the study recommended developing knowledge of the nature of suffering and awareness that refractory suffering might happen despite state-of-the-art care. Further strategies were the ability to not panic, but slow down, take time, learn to face the patient's painful emotions, and balance engagement with suffering and detachment. This study also described the importance of communication skills and the ability to facilitate shared decision-making with patients and next of kin. Another Australian study found that an interdisciplinary team is an essential tool for handling

refractory suffering<sup>2</sup>. Cohesion within the team was a principal factor for consistent communication with the patient, which was described as an important way of building trust with patients. The study also spoke to the importance of setting shared goals of care within the care team as well as with patient and next of kin.

The purpose of the present study was to take an even broader perspective on refractory suffering in palliative care, zooming out from the patients themselves to include their next of kin, their situations and the healthcare system from which they receive help. We wanted to explore how palliative care specialists (doctors and nurses) characterize situations where patients have refractory suffering at the end of life despite having received specialist palliative care. In these situations, what are the main obstacles for successful symptom control? How often do health professional experience that patients must endure refractory/unbearable suffering despite state-of-the-art palliative care? We also asked the informants if they thought euthanasia could sometimes be required or appropriate in situations of refractory suffering that cannot be properly alleviated.

## **Methods**

A qualitative approach was chosen, as the purpose was to explore experiences in depth. Doctors and nurses working in specialized palliative care wards or hospices were recruited through inquiries to department heads in hospitals and hospices in Norway's greater Oslo region. Six nurses and six doctors from five institutions were interviewed in audio-recorded interviews lasting 45-60 minutes. A semi-structured interview guide was used, and informants received the interview questions by e-mail beforehand. The main purpose of the interviews was to explore informants' experiences with situations where patients had refractory suffering – whether in the terminal phase or in earlier stages of the palliative trajectory – despite

specialist palliative care. When further interviews were felt not to provide significant new information, a point of saturation was judged to have been reached.

Transcripts were analysed using systematic text condensation, a qualitative analysis framework<sup>8</sup>. Involving four steps, the method began with (1) gaining an overview of the material, then proceeded to (2) the identification of units of meaning which were then coded according to topic. (3) Next, each coded group was condensed into so-called artificial quotations in which the meaning contained in the code was summarized. Finally, (4) the analytic text constituting the basis for the Results chapter was developed from the artificial quotations.

#### *Ethics approval*

The study was evaluated and approved by the Data Protection Official at the Norwegian Centre for Research Data (ref. 56075). According to Norwegian regulation, no further research ethics approval was required. Respondents were informed about the project in writing and signed a voluntary, informed consent.

#### *Researchers' normative preconceptions*

For the sake of transparency, we state that all authors are opposed to the legalization of assisted dying.

## **Results**

#### *Refractory suffering as a rare situation*

A main finding is that palliative care clinicians only on rare occasions handle patients with refractory suffering at the end of life that cannot be alleviated. When asked to provide an

estimate, most informants said they would encounter approximately 1-5 cases yearly where adequate symptom relief either takes too long to achieve or is not achieved at all in the terminal phase. Yet although rare, such cases could be distressing to the clinicians. One doctor stated, “As you see there are not many such situations throughout the year. That is why I remember [them] so well, because there are some who make a great impression”.

Several emphasized that even when adequate symptom relief is achieved in the end, the process of getting there can take a long time, and the patient would suffer in the meantime. One doctor stated,

The criteria for palliative sedation [include] that you should actually have tried all other possibilities. And that is what you have to be sure of. And that is why it is important that there is an interdisciplinary discussion about the patient, [and] that one has actually tried [all alternatives]. What is a bit demanding in such processes is that it takes an awful long time.

Most informants stated that with recourse to palliative sedation – which was seldom used – it would be possible to achieve adequate relief in the terminal phase in all cases. Yet, one informant recounted a case in which standard palliative sedation did not succeed at first and they gave what the informant described as unusually high doses of palliative medications and anaesthetics to finally achieve adequate sedation.

Situations of refractory suffering appeared to be caused by three main group of factors, related to *the diseases, the patient and next of kin, and the healthcare system*, respectively. These will now be treated in turn.



*Causes of refractory suffering: Factors pertaining to the diseases*

Informants did not identify specific diagnoses as particularly difficult for them; instead, as one doctor said, “Patients with advanced cancer become relatively similar after a while ... the principles for symptom relief become somewhat the same”. The informants pointed to pain, dyspnoea and fear of suffocation, and nausea as the most common symptoms when adequate symptom relief was hard to achieve. When a tumour caused a problem locally, such as with ingrowth of a nerve plexus or bone metastases, this could present a particular challenge.

*Causes of refractory suffering: Factors pertaining to the patient and next of kin*

Several informants expressed the view that the patient’s pain would be worse when the patient lacked a feeling of assurance in the situation; this could for instance include a feeling of being unsure whether they would receive adequate help if the suffering got worse. According to informants, if this basic trust and experience of care and security was in place, then pain would be easier to alleviate.

The absence of this security, then, and more in general, the presence of existential challenges and existential suffering, contributed significantly to refractory suffering, according to informants. For instance, one nurse recounted a case: “there was a pretty strong component of existential anxiety and a lot of conflicts in relationships, but it manifested as physical pain”.

One doctor stated,

What I think is typical is that the patients we struggle the most to palliate have a large component of existential, psychological problems ... Most patients who have somehow managed to work it out and somehow relate to it ..., these I feel we are able to palliate.

Informants also stated, however, that the causality would be difficult to determine; existential suffering and insecurity could be a cause of refractory suffering, but also a consequence of it. The main existential challenges raised in the interviews were the patients' processes of reconciliation with their situations (inability to 'let go') and unresolved issues (e.g. economic challenges, family conflicts etc.). One doctor described a specific case thus:

[The patient] never gave up hope and he also couldn't let go, I think. And I believe that in addition to the strong physical pain, there was very much the existential concerns that made it so that we never succeeded in achieving the goal [of adequate symptom control].

There was consistent agreement that symptom relief would be more successful if physical symptoms, existential and interpersonal concerns were all addressed. The importance of reconciling with a bad prognosis was also highlighted.

Disagreements between patients and next of kin could complicate alleviation. A typical scenario was that the palliative team and the patient had agreed on shifting the focus of the treatment to palliation, yet the relatives were not ready for this. According to informants, the necessary processes leading to acceptance and mutual agreement among the interdisciplinary team, the patient and the next of kin could require a lot of time. Meanwhile, persistent disagreement could contribute to the patient's suffering, through delaying the application of measures which could provide symptom control.

*Causes of refractory suffering: Factors pertaining to the healthcare system*

Informants pointed to five factors pertaining to the organization of care, interdisciplinary cooperation and the healthcare system in which they worked, that would sometimes contribute to patients experiencing refractory suffering: Staff competence, conflict within the team, lack of continuity, lack of time or staffing, and lack of planning ahead. Notably, these kinds of shortcomings could also occur in the informants' own specialist wards, and not only in other hospital wards with which informants cooperated.

Several informants lamented a lack of medical knowledge among colleagues. In particular, some nurse informants claimed that some doctors did not have enough knowledge about medications used in palliative medicine. This would sometimes lead to underdosing and/or too slow dose titration, leading to unnecessary suffering. One informant stated, "How often we don't succeed with alleviation is dependent on the kind of health professionals that are on duty and what kind of knowledge they have". Another claimed, "I think we could have alleviated better – more of our patients – if the competence had been better". A fear of hastening death was also pointed to as a factor, as here by one of the doctors: "I am more afraid that [the patients] do not receive enough medication [referring to opioids and benzodiazepines] because health professionals are afraid that the doses they receive can shorten life".

Relatedly, disagreements and conflicts within the palliative team (especially between nurses and doctors) could also contribute to inadequate alleviation. Disagreements could especially be centred around the medication doses, where the nurses typically would be frustrated that the doctors would prescribe too low doses and that the doctors only observe the patients for a short while. Speaking about patients in significant pain, one nurse noted, "and then you have a

doctor who comes in for a moment and gets a snapshot of the patient who might just then lie calmly in their bed ... we see a different patient”.

Lack of continuity was pointed to as a significant problem. Discontinuity with regards to medical personnel could lead to discontinuity in medication; one typical situation could be when a new doctor in charge disagrees with the previous colleague’s plan and alters the drug regimen. A graver kind of discontinuity stemmed from patients being moved between different institutions and wards several times throughout their illness trajectory. Different departments involved did not necessarily cooperate well, the patient had to relate to many different professionals, and the professionals would not have the time to get to know the patient well. A nurse stated, “[these patients] belong nowhere, they fall between the cracks”. Apart from threats to the quality of medical and nursing care, the most important problem with discontinuity is that it would make the patients feel unsafe, potentially leading to distress and increased symptoms as discussed above.

The health professionals wanted to be present at the bedside as much as possible to give care and comfort, yet often found that they lacked time. It was reported that this was a bigger problem in hospitals than in hospices.

A major ethical dilemma can be time pressure ... the nurses, or the doctors for that matter, want to provide good care, want to provide a calming, affirmative presence, but they do not have time. And they know that the time they spend there should also be spent on other [patients].

Many informants thought that efficient palliative care was often commenced too late. One important reason for this would be a lack of planning, including the specific advance care planning that is recommended when the patient has an incurable disease. When the patient then undergoes a medical emergency or the condition suddenly deteriorates, there would not be time for proper decision-making. Decisions about, for instance, withdrawal of potentially life-prolonging treatment, or palliative sedation, might then not have been prepared, and one might not know the patient's preferences. If such questions were not discussed, it could contribute to more suffering for the patient.

#### *Euthanasia as an unnecessary option*

Only one of the 12 informants (a nurse) thought that euthanasia would sometimes be an appropriate solution for refractory pain. The other 11 stated that they viewed euthanasia as never appropriate. One nurse's statement was representative of this group: "I can understand the wish for it [euthanasia] and the wish for thinking it is okay, but I think we have so much more to offer ... I think we are helping people more by giving better alleviation and to face spiritual-existential needs better."

The informants also had other arguments for opposing euthanasia: patients' wishes might fluctuate from one day to another, depending for instance on the burden of symptoms. When euthanasia is not an option then there are incentives to enhance palliative care. One nurse stated:

I am really glad that I work in a country and in a healthcare system that do not give me that opportunity [for euthanasia]. It makes me have a different room for action when working with palliation. I always have to have something to offer!

Some informants argued that assisted dying would break with the Hippocratic oath, go against the tasks of healthcare professionals and might threaten patient trust. Some informants were opposed to assisted dying on religious grounds, while some thought that it will be difficult to regulate in practice. Informants also feared a development where patients would request assisted dying due to perceiving it as next of kin's or society's expectation.

The nurse in favour of euthanasia reasoned as follows:

If [the patients] continuously experience a lack of quality of life, and only have suffering – then I would do it [euthanasia] ... there are patients that go through so many painful [procedures] and that unfortunately get a very long death, dominated by confusion and side effects from medications, expressing several times that they want to die.

## **Discussion**

### *Main findings summarized*

The study shows that informants find that situations of refractory suffering are rare, and that with palliative sedation one can most often achieve satisfactory symptom control. For many of the informants this was their main reason to dismiss euthanasia as, in effect, unnecessary. The process of reaching adequate palliation, however, can be protracted, and there can be significant suffering in the meantime. When significant suffering does occur, it causes severe distress and is a heavy burden for patients, relatives and professionals. The finding that both somatic, psychological and existential factors can contribute to refractory suffering was expected, and in line with previous research introduced above<sup>4-6</sup>. An important and

apparently novel finding, however, is the significant weight that informants place on factors pertaining to the organization of the services as contributing to insufficient palliation, even for patients who are treated within specialist palliative care services.

### *Significance for palliative care*

The study is potentially significant for palliative care in identifying problem areas in which care can improve. With regard to refractory suffering it is important to distinguish between cases where symptom relief could have been achieved if required action had been taken at the appropriate time, and cases which are genuinely refractory to treatment. The latter is probably extremely rare at the end of life when terminal sedation can be effectively applied, but more common earlier in the disease trajectory when palliative sedation is not an option according to Norwegian guidelines<sup>9</sup>. The importance of a holistic approach, emphasizing both somatic, psychological, social and existential factors is emphasized. However, there might also be important gains by working to improve the five problem areas pertaining to the organization of the services. The palliative care competence of professionals involved in care was identified as a problem. Because the informants in this study were employed in palliative care services, this study highlights that even in some palliative care services effective measures can be delayed because of lack of qualified staff. Only the largest palliative care services have senior consultants in palliative medicine available around the clock. Guidelines stating that decisions about palliative sedation should be multidisciplinary and involve more than one physician are obviously important<sup>9</sup>, but may also delay the application of palliative sedation at the end of life. Effective symptom control with palliative sedation at the end of life requires competent nursing staff which identifies suffering, competent doctors available around the clock, efficient clinical decision processes in line with current guidelines and a readiness to apply palliative sedation immediately after the decision has been reached. Clearer clinical

guidelines, and education about these and the medical state of the art can be important, as can dispelling the myth of the potential of opioids and benzodiazepines to hasten death <sup>10</sup>.

Informants also lament the fragmentation of the health system and that no single department or professional takes an overall and comprehensive responsibility for the patients in need of palliative care. Here, structural changes to the services might be called for, such as more robust and predictable clinical pathways. Finally, more systematic advance care planning, cooperation with next of kin throughout the illness trajectory, and frank discussions of prognoses and the way ahead might be of help in preventing conflict, overtreatment, and ill-considered decisions <sup>11 12</sup>. This need for advance planning throughout the palliative disease trajectory is reflected in the increasing emphasis on integration of palliative medicine in oncology <sup>13</sup>.

#### *Significance for the assisted dying debate*

Arguably, the findings are also significant as empirical premises in the assisted dying debate. Assisted dying is often advocated as a necessary option for patients who are suffering unbearably and where there appear to be no acceptable options for alleviation and improvement <sup>14</sup>. Yet, the study indicates that – at least according to our informants – unbearable/refractory suffering is rare, and might be adequately relieved, if necessary with recourse to palliative sedation. The question is, then, how often truly unbearable suffering which cannot be adequately palliated actually occurs. If it is indeed exceedingly rare, then it can be argued that legalizing assisted dying – with the potential adverse consequences this has been argued to bring for society and the healthcare services – is not justified. A critical question in return, however, is whether the time required to titrate doses and reach adequate symptom control – and the suffering experienced in this time – is acceptable to all or most patients, or whether suffering here sometimes rises to the level of the unbearable. As



palliative sedation is effective, perhaps the threshold for instigating it ought to be lowered compared to the restrained practices that the informants tell of. This would be likely to reduce the extent of experienced suffering in patients with short life-expectancy.

The informants claimed that refractory suffering was not exclusively, perhaps not even primarily, due to the somatic disease; rather, they pointed to several sets of other factors that might often contribute to the total experience of suffering. If this is indeed so, then it could be argued that strong efforts should be directed at these factors in lieu of legalizing assisted dying. In this perspective, competence in palliative care should be strengthened and become more widespread, and resources for this service should be drastically improved. If so, the rationale for offering assisted dying might shrink or disappear altogether. In response to this line of argument it might be said that every complex healthcare system will have shortcomings, and considering the scarcity of resources a radical improvement of the services might not be realistic. In addition, improving palliative care should not necessarily preclude the legalization of assisted dying; countries such as Belgium have experience in integration of the offer of assisted dying within quality palliative care services<sup>15 16</sup>. Furthermore, even if it is conceded that the arguments advanced here weaken the argument from unbearable suffering, they do not impact the argument from autonomy.

Finally, if refractory suffering is caused by many factors beside the somatic disease itself, and the suffering of somatic origin can indeed be adequately palliated, would it be right to offer assisted dying when the other factors – including psychological, social and existential factors – are the main causes of the patient's distress? This can appear as a more controversial proposal than to justify assisted dying primarily in suffering of somatic origin. In a Dutch interview study with patients who had requested assisted dying, it was found that it was

especially when psychological and existential suffering were present that the sum total of suffering was experienced as unbearable <sup>17</sup>. However, at the end of life when communication is affected by the disease, drugs and suffering, it can be difficult to identify the contribution from somatic, psychological and existential factors respectively in the suffering.

The rejection of legalization of assisted dying by the clear majority of informants corresponds well with the opposition to legalization found among a majority of Norwegian doctors <sup>3</sup>, and by the more marked opposition to legalization among palliative care staff in many countries.

### *Strengths and limitations*

As a qualitative interview study with a limited number of informants, the study has both strengths and weaknesses compared to other potential research designs. We have interviewed experienced experts in palliative care from two professions, and received in-depth accounts and viewpoints about the challenges they face in their work. However, our data consist of a limited number of informants' subjective experiences and viewpoints, and generalization is therefore difficult. A selection bias cannot be excluded. The findings from this Norwegian study were consistent with findings from other studies conducted in other Western countries <sup>4</sup> <sup>6</sup>, yet the findings about the organization of the services are likely to have been coloured by the specifics of the Norwegian services. Even though informants thought refractory suffering to be rare at the end of life, the study was not designed to estimate the prevalence of refractory suffering.

### **Conclusion**

Although refractory suffering is rare at the end of life, the process of reaching adequate symptom relief can be protracted and involve significant suffering. Informants' accounts of

challenges with the most difficult palliative care patients can inspire improvements of the palliative care services. In addition, the experiences of palliative care clinicians constitute important empirical premises for the assisted dying debate.

### **Contributors**

MM and PN conceived of the study and designed it together with KEG and ÅA. KEG and ÅA performed the interviews and analysed the data as a medical student research project. PN, OMSF and MM contributed to the analysis. KEG and ÅA wrote the first draft. All authors contributed to revision of the article, and all authors read and approved the final version. KEG and ÅA have contributed equally to the article.

### **Funding**

This study received no specific funding.

### **Conflicts of interest**

The authors declare that they have no competing interests.

### **References**

1. Cherny NI, Fallon M, Kaasa S, Portenoy R, Currow DC (eds). Oxford textbook of palliative medicine. 5th ed. Oxford: Oxford University Press, 2019.
2. Swetenham K, Hegarty M, Breaden K, Grbich C. Refractory suffering: the impact of team dynamics on the interdisciplinary palliative care team. *Palliative & supportive care*. 2011;9(1):55-62. doi:10.1017/s1478951510000544.
3. Gaasø O, Rø K, Bringedal B, Magelssen M. Doctors' attitudes to assisted dying. *Tidsskr nor legeforen*. 2019;139(1). doi: 10.4045/tidsskr.18.0391.

4. White K, Wilkes L, Cooper K, Barbato M. The impact of unrelieved patient suffering on palliative care nurses. *Int J Palliat Nurs*. 2004;10(9):438-44.  
doi:10.12968/ijpn.2004.10.9.16049.
5. Anquinet L, Rietjens J, van der Heide A, Bruinsma S, Janssens R, Deliens L et al. Physicians' experiences and perspectives regarding the use of continuous sedation until death for cancer patients in the context of psychological and existential suffering at the end of life. *Psychooncology*. 2014;23(5):539-46. doi:10.1002/pon.3450.
6. Swart SJ, van der Heide A, van Zuylen L, Perez RS, Zuurmond WW, van der Maas PJ et al. Continuous palliative sedation: not only a response to physical suffering. *J Palliat Med*. 2014;17(1):27-36. doi:10.1089/jpm.2013.0121
7. Hegarty MM, Breaden KM, Swetenham CM, Grbich C. Learning to work with the "unsolvable": building capacity for working with refractory suffering. *J Palliat Care*. 2010;26(4):287-94.
8. Malterud K. Systematic text condensation: A strategy for qualitative analysis. *Scandinavian journal of public health*. 2012;40(8):795-805.
9. The Norwegian Medical Association. Guidelines for palliative sedation at the end of life. 2014.  
<https://beta.legeforeningen.no/contentassets/cc8a35f6afd043c195ede88a15ae2960/guidelines-for-palliative-sedation-at-the-end-of-life.pdf>. Accessed 31 Oct 2019.
10. Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *The Lancet Oncology*. 2003;4(5):312.
11. Brinkman-Stoppelenburg A, Rietjens JA, Van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliative Medicine*. 2014;28(8):1000-25.

12. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
13. Kaasa S, Loge JH, Aapro M, Albrecht T, Anderson R, Bruera E et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *The Lancet Oncology*. 2018.
14. Tallis R. Should the law on assisted dying be changed? Yes. *BMJ*. 2011;342:d2355.
15. Chambaere K, Bernheim JL. Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. *Journal of Medical Ethics*. 2015;41(8):657-60.
16. Vanden Berghe P, Mullie A, Desmet M, Huysmans G. Assisted dying—the current situation in Flanders: Euthanasia embedded in palliative care. *European Journal of Palliative Care*. 2013;20(6):266-72.
17. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C. 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics*. 2011;37(12):727-34. doi:10.1136/jme.2011.045492.