Medical end-of-life decisions in Norway

Reidun Førde a,b,*, Olaf G. Aasland a,c, Petter Andreas Steen d

a The Research Institute, The Norwegian Medical Association, P.O.B. 1152 Sentrum, 0107 Oslo, Norway
b Center for Medical Ethics, University of Oslo, Oslo, Norway
c Center for Health Administration, University of Oslo, Oslo, Norway
d Surgical Division, Ullevål University Hospital, N-0407 Oslo, Norway

Received 20 January 2002; received in revised form 1 March 2002; accepted 17 July 2002

Abstract

Aim: Previous studies indicate that Norwegian physicians hold conservative attitudes towards ethically controversial end-of-life decisions. The present study was undertaken to explore whether in Norway euthanasia may be hidden under labels such as death after analgesic injections and withholding or withdrawing treatment. Methods: A postal questionnaire containing 76 questions on ethical, collegial and professional autonomy issues was sent to a representative sample of 1616 active physicians in Norway in 2000. Results: 83% responded. A total of 8.1% had terminated life-prolonging treatment based on the resource situation, while 53.5 and 40.1% respectively had stopped life prolonging treatment due to the wish of the patient and the wish of the patient’s relatives. Although not significantly, anaesthesiologists more often reported to have stopped treatment due to resource considerations. One percent of the physicians reported to have shortened a patient’s life intentionally (other than stopping futile treatment). All of these were men. Logistic regression showed no effect when gender, age and specialty were analysed simultaneously. 10.6%, and male more often than female physicians, had had experience of unintentional patient death in relation to pain treatment. Anaesthesiologists had had experiences of death following an analgesic injection no more than other specialists. Conclusions: Only a small minority of Norwegian physicians has committed euthanasia. However, patient death has occurred following ethically questionable decisions such as withdrawal of treatment based on resource considerations and requests from the family.

Keywords: Pain; Advanced directive; Ethics; Euthanasia

Resumo

Objetivo: Estudos prévios indicam que os médicos noruegueses têm atitudes conservadoras em relação a decisões eticamente controversas sobre o fim de vida. O presente estudo foi realizado para explorar a hipótese de a eutanásia na Noruega ser escondida sob termos como morte após administração de analgésicos e suspensão ou retirada de analgésicos. Métodos: Um inquérito postal contendo 76 questões sobre assuntos de autonomia profissional, colegial e ética, enviado a uma amostra representativa de 1616 médicos ativos na Noruega, em 2000. Resultados: Respondiram 83%. Um total de 8.1% tinham terminado tratamentos para prolongar a vida baseados nos recursos disponíveis, enquanto que 53.5 e 40.1%, respectivamente, tinham suspenso tratamentos para prolongar a vida por vontade expressa do doente e familiares. Embora sem significado estatístico, os anestesiologistas comunicaram com maior frequência terem suspenso tratamentos com fundamento nos recursos. Um por cento dos médicos afirmou ter encurtado intencionalmente a vida de um doente (para além da interrupção de tratamentos fúteis). Todos estes eram do sexo masculino. A análise de regressão logística não revelou nenhum efeito quando foram analisadas simultaneamente a especialidade, idade e sexo. 10.6%, e os médicos mais do que as médicas, tinham tido experiência da morte não intencional de um doente em relação com o tratamento da dor. Os anestesiologistas não tinham tido experiências de morte após injeção de analgésico mais frequentemente do que os outros especialistas. Conclusões: Apenas uma pequena minoria dos médicos noruegueses cometeu eutanásia. No entanto,
ocorreram mortes de doentes na sequência de decisões éticamente questionáveis tais como a retirada de tratamentos baseada em consideração de recursos e a pedido dos familiares.

© 2002 Elsevier Science Ireland Ltd. All rights reserved.

Palavras chave: Dor; Indicaciones avanzadas; Ética; Eutanasía

Resumen

Objetivo: Estudios previos indican que los médicos noruegos mantienen actitudes conservadoras hacia decisiones éticas controversiales respecto a final de la vida. Este estudio se realizó para explorar si en Noruega la eutanasia se encuentre escondida bajo etiquetas tales como una muerte después de inyecciones analgésicas y mantención o retiro de tratamientos. Métodos: En el año 2000 se envió por correo una encuesta de 76 preguntas sobre temas éticos, de colegiatura y de autonomía profesional a una muestra representativa de 1616 médicos activos en Noruega. Resultados: El 83% respondió. Un total de 8.1% ha terminado tratamientos que prolongan la vida basados en la situación de recursos, mientras que 53.5 y 40.1% respectivamente ha detenido tratamientos que prolongan la vida a solicitud del paciente y de los familiares del paciente. Anestesistas han detenido tratamientos por consideraciones de recursos con mayor frecuencia, aunque la diferencia no es significativa. Un 1% de los médicos reportaron haber acortado la vida de un paciente intencionalmente (mas allá de detener tratamiento futil). Todos ellos eran varones. La regresión logística no mostró efecto cuando se analizó simultáneamente sexo, edad y especialidad.10.6% han tenido experiencia de muerte no intencional de pacientes en relación con tratamiento de dolor, y médicos varones con más frecuencia que mujeres. Los anestesiólogos no tuvieron más experiencias de muerte después de inyecciones analgésicas que otros especialistas. Conclusiones: solo una pequeña minoría de los médicos Noruegos ha cometido eutanasia. Sin embargo, la muerte de pacientes ha ocurrido después de decisiones éticamente cuestionables tales como retiro de tratamiento basado en consideraciones de recursos y requerimientos de la familia.

© 2002 Elsevier Science Ireland Ltd. All rights reserved.

Palabras clave: Dolor; Indicaciones avanzadas; Ética; Eutanasia

1. Introduction

As medicine becomes more potent and technical, an increasing number of people die as a result of a medical decision, most frequently because medical treatment is withheld or discontinued. A decision to forego medical treatment may be ethically acceptable when the treatment is judged to be of no benefit to the patient [1,2]. Life-prolonging treatment may require additional resources, and the gap between what is technically possible on the one side, and economically feasible on the other, is probably wider than ever. Withholding and withdrawing medical treatment that can be beneficial to the individual patient, in order to save resources may be ethically problematic. The guidelines 2000 for cardiopulmonary resuscitation and emergency cardiac care [2] state that while resuscitation might not be the best use of limited medical resources, concern about cost associated with prolonged intensive care should not preclude emergency resuscitative attempts in individual patients. The failure of medicine to relieve suffering at the end of life is an important argument for legalisation of euthanasia and physician assisted suicide (PAS). Insufficient pain control may be explained by a physician’s reluctance to give adequate doses of opioids for fear of the treatment being lethal. Van der Maas shows that in the Netherlands a substantial number of patients die more or less intentionally as a consequence of the administration of opioids, without these deaths being classified as euthanasia [3]. A Swedish study found that one third of physicians working with pain relief and palliative care had given analgesics or other drugs in doses that hastened the death of some of their patients [4].

When medical treatment shortens a patient’s life it may be morally justifiable through ‘the doctrine of the double effect’ [5]. A presupposition for this moral justification is the physician’s intention to relieve pain but not to shorten life [6]. It may, on the other hand, be argued that adequate pain relief often saves life. The fear of killing a patient with adequate doses of pain relieving opioids may therefore be exaggerated.

Previous studies indicate that Norwegian physicians have more conservative attitudes towards such ethically controversial end-of-life decisions than physicians in other countries [7–9]. It may be postulated that this conservatism is hypocrisy, and that euthanasia is hidden under labels such as death after analgesic injections and withholding or withdrawing treatment. In a questionnaire study of 1476 Norwegian physicians (around 10% of the physician population) six percent stated that they had performed an act that hastened a patient’s death [7]. The study has been criticised for the questions being too vague [10].

In the present study we have tried to use less ambiguous questions in our attempt to assess the extent that Norwegian physicians perform euthanasia, how often they experience a death following an analgesic injection, and to what extent and for what reasons medical treatment is forgone.
2. Material and method

In 1993, the Research Institute of The Norwegian Medical Association recruited a Reference Panel by inviting a random sample of 2,000 active physicians to participate. A total of 1,272 agreed, and have during subsequent years received questionnaires more or less annually. 21 subjects have since dropped out, due to death or voluntary withdrawal. In January 2000 another 795 randomly selected physicians who had received their license after 1993 were invited to join the panel, of which 365 agreed. Hence the total number of panelists by early 2000 was 1,616.

In March the Panel received a 15-page questionnaire with 76 questions, with focus on medical ethics, collegiality and professional autonomy. Data from this survey is the main source of information for the present study.

The 43 medical specialties and subspecialities in Norway have been contracted into the following eight categories: non-specialist, family medicine/general practice, laboratory medicine (including radiology), internal medicine (including neurology and ophthalmology), surgical disciplines (including otorhinolaryngology and obstetrics/gynaeceology), anaesthesiology, psychiatry and community medicine (public health physicians). Anaesthesiology is kept as a separate category since these physicians more often are responsible for pain relief and most often are responsible for the intensive care units in Norwegian hospitals and thus for life prolonging treatment.

The physicians’ experience of foregoing medical treatment was assessed through the following question: ‘Have you as a physician experienced that medical treatment has been forgone for other than medical reasons with the result that the patient died?’ Three different situations were then presented, each to be answered on a frequency scale: ‘often’, ‘seldom’, ‘never’, and ‘not applicable’. The three situations were:

- Termination of treatment due to restricted resources
- Termination of treatment according to the patient’s wish
- Termination of treatment according to the family’s wish

The experience of having performed euthanasia was assessed through the following question: ‘Have you as a physician ever committed an act (for example given an injection) with the explicit purpose of shortening the life of a patient? (Do not include termination of life-sustaining treatment to dying patients)’.

Experience with ‘the double effect’ of opioids was assessed through the following question: ‘Have you ever injected a drug in order to relieve pain which had as an unintended result that the patient died?’. On these two questions the response alternatives were ‘never’, ‘a few times’ and ‘several times’.

We also included two questions on advance directives:

- Have you ever met patients with advance directives to protect them from overtreatment at the end of life? (Response alternatives were ‘never’, ‘a few times’ and ‘several times’)
- Do you consider advance directives useful when difficult end of life decisions have to be made? (Response alternatives ‘yes’, ‘no’, and ‘uncertain’)  

Results are presented as proportions, where appropriate with 95% confidence intervals, or as estimated probabilities based on logistic regression models.

3. Results

3.1. Response rate and representativity

A total of 1,318 completed and 27 blank forms were returned, a response rate of 83% (1,318/1,589). Table 1 compares the respondents with the population of active Norwegian physicians in April 2000. General practitioners and older physicians are slightly overrepresented, while the age group 35–44 is somewhat underrepresented.

3.2. Foregoing treatment

For 31% of the physicians the question about termination of life-prolonging treatment based on the resource situation leading to the death of a patient was ‘not applicable’. Of the remaining 883 (69%) physicians one had ‘often’ and 71 had ‘seldom’ had this experience, as opposed to 811 who answered ‘never’. Likewise, 53.5% of those who did not answer ‘not applicable’ had experienced termination of life-prolonging treatment based on the patient’s own wish, and 40.1% based on the wish of the patient’s relatives. Comparing specialty groups, the estimated probability of having terminated life-prolonging treatment due to the resource situation was highest among anaesthesiologists, although not significantly higher than any other specialty. Table 2 gives estimated probabilities of having terminated life-prolonging treatment for 50–54 year old male physicians according to specialty and the three named reasons (resources, patient’s wish and family’s wish).

3.3. Experience with euthanasia

One percent (13/1,298), all men, stated that they had committed an act (for example given an injection) with the explicit purpose of shortening the life of a patient, and only ‘a few times’. 5.5% (4/74, 95% CI 1.4–16.7) of
the anaesthesiologists reported to have done this, compared with 0.8% (10/1258, 95% CI 0.5–15.3) of the other categories together. However, when analysed together in a logistic regression model, there were no significant differences in effect between gender, age or specialty categories.

3.4. Pain relief leading to death

A total of 10.6% (137/1295) had experienced unintended patient death in relation to pain treatment. The rate was higher among males than females, 12.3% (95% CI 10.2–14.7) versus 6.6% (95% CI 4.4–9.6), also when age and specialty were controlled for. The difference between anaesthesiologists, 18.5% (94% CI 9.7–31.9), and the other specialties combined, 10.2% (95% CI 8.6–12.1), was not significant.

3.5. Advance directives

A total of 23% of the physicians had seen patients with written advance directives. 47% felt that such a document might be useful when faced with difficult medical dilemmas, while 12% did not think so, more males, 14% (95% CI 12–17) than females, 8% (95% CI 6–11).

4. Discussion

Overtreatment is a major ethical dilemma in modern medicine [7,11]. Physicians are often accused of making death unnecessarily technical and undignified. Treatment may be continued contrary to the patient’s presumed wish, against the relatives’ wish, and even

| Table 1 | A comparison between the respondents and the complete Norwegian physician workforce |
|-----------------------------|------------------------------------------|---------------------------------|
| Respondents (N = 1318) | All physicians (N = 14 400) | % | % |
| Females | 31.4 (28.9–34.0) | 30.4 |
| Males | 68.6 (66.0–71.1) | 69.6 |
| < 35 years | 18.1 (16.1–20.3) | 16.9 |
| 35–44 years | 26.4 (24.1–28.9) | 30.8 |
| 45–54 years | 31.2 (28.7–33.8) | 32.0 |
| 55+ years | 23.4 (21.2–25.8) | 20.3 |
| Senior consultants | 27.2 (24.8–29.7) | 29.1 |
| Junior registrars | 19.5 (17.4–21.8) | 19.7 |
| General practitioners | 20.7 (18.6–23.0) | 15.9 |
| Private practice specialists | 5.3 (4.2–6.7) | 5.6 |
| Others | 27.3 (25.9–29.8) | 29.7 |
| Non-specialist* | 46.5 (44.0–49.0) | 40.9 |
| PHC specialists | 15.7 (14.0–17.6) | 13.6 |
| Laboratory specialists | 4.4 (3.5–5.6) | 5.4 |
| Surgical specialists | 14.6 (12.9–16.5) | 15.8 |
| Internal medicine | 6.1 (5.0–7.4) | 8.7 |
| Anaesthesiology | 2.5 (1.8–3.4) | 3.1 |
| Gynaecology | 2.1 (1.5–3.0) | 3.0 |
| Psychiatry | 6.0 (4.9–7.4) | 6.3 |
| Community medicine | 2.0 (1.4–2.9) | 3.1 |

* Non-specialists are mainly young specialists in training, but also some practicing physicians without a formal specialty.

| Table 2 | Estimated probabilities for male physicians, 50–54 years, of having ever terminated life-sustaining treatment of dying patients for three different non-medical reasons |
|-----------------------------|------------------------------------------|---------------------------------|
| Due to lack of resources | According to the patient’s wish | According to the family’s wish |
| Not specialist | 0.20 | 0.48 | 0.41 |
| Family medicine | 0.09 | 0.54 | 0.43 |
| Laboratory medicine | 0.08 | 0.34 | 0.29 |
| Internal medicine | 0.13 | 0.61 | 0.41 |
| Surgical disciplines | 0.14 | 0.59 | 0.41 |
| Anaesthesiology | 0.28 | 0.75 | 0.38 |
| Psychiatry | 0.06 | 0.36 | 0.30 |
| Community medicine | 0.08 | 0.63 | 0.36 |
| All specialties | 0.13 | 0.55 | 0.40 |

Based on logistic regression.
contrary to the individual clinician’s wish. Thus, a Norwegian study from 1993 showed that one out of three Norwegian physicians claimed that they sometimes or often had continued treatment beyond meaningfulness [7].

In the present study more than half of the physicians, and three out of four anaesthesiologists had experienced that life-prolonging treatment had been terminated based on the patient’s own wish. A possible explanation to why community medicine physicians frequently have experienced medical treatment being terminated according to the patient’s wish may be that they act as medical consultants to nursing homes. The phrasing of the question (‘have you ever experienced...’) may catch both physicians who have themselves been responsible for termination as well as those who have observed such decisions from a distance. This survey was conducted before the recent passing of a new Norwegian law where physicians are obliged to respect a dying patient’s wish if the patient declines potentially lifesaving treatment.

It may be considered more controversial that 40% of the physicians have complied with relatives’ wishes when difficult life-and-death decisions are made, especially when treatment is considered medically meaningful. At the time of the study, relatives had no legal rights as surrogates by Norwegian law [12]. There is also substantial evidence that surrogates do not adequately reflect the wish of a patient [13–15]. Thus, it is important that the physician is aware of this possibility. On the other hand, in a study of patients with chronic renal disease, 31% of the patients preferred that the physician followed the decision of the surrogate even if it conflicted with the patient’s own expressed wish [16].

It is, however, much more problematic that the results of the present study indicate that treatment actually may be terminated on resource considerations. Norway has a public health care system with free hospital treatment for patients, but also shortage of nurses, intensive care beds, medical equipment and above all, nursing homes. The ethical council of the Norwegian Medical Association has stated that resource considerations are unacceptable reasons for terminating life-sustaining treatment if the treatment is considered useful to the individual patient [17]. The estimated probability of having terminated treatment to save medical resources for middle-aged male anaesthesiologists is 0.28, twice the estimate for physicians working in other major specialties. It is not surprising that the anaesthesiologists have the highest estimated probability. They have the medical responsibility for most intensive care units, and are also involved in palliative care in Norway. Anaesthesiologists are therefore probably more often confronted with situations where patients do not get potentially useful treatment due to lack of equipment or personnel [18]. Internationally, in many hospitals the capacity of the intensive care units is the most critical capacity factor. In spite of this it has been found that 73% of intensive care physicians admit hopelessly ill patients to intensive care units [18]. New York Times stated on a front page 22.08.1989: ‘As hopeless victims fill units, hospitals adapt makeshift settings and turn people away...The unseen victims are the people who are dying outside the unit on the hospital floor.’ On the other hand a recent newspaper article indicates increasing worry about physicians sacrificing lives in order to save resources [19]. Conscientiousness and rigid routines safeguarding that decisions to forego medical treatment are not made by one physician alone are necessary to prevent unethical practice.

Due to confusing terminology and variation in question formulation it is problematic to compare attitudes towards and practice with end-of-life decisions between studies [10]. We did not ask whether the deliberate induction of death which was admitted by 1% of the Norwegian physicians, was done with or without the patient’s explicit wish. If this number is reliable it indicates a conservatism of Norwegian physicians regarding euthanasia. That the 1993 study [7] showed that 6% of Norwegian physicians had committed an act which could be classified as euthanasia compared to 1% of the respondents in the present study underlines the importance of unambiguous question formulation in studies of ethical dilemmas. Euthanasia is illegal in Norway and strongly condemned by the Norwegian Medical Association. Although the study was anonymous, physicians were likely to be reluctant to admit that they have committed such an act. One may therefore speculate that euthanasia in Norway is sometimes categorised as death following an analgesic injection, which 10.6% of the respondents had experienced at least once. Whether this should be considered a high or a low fraction is not easy to assess, but the number is certainly not negligible. On the other hand, it may be argued that it may be impossible to know with certainty that an analgesic injection is the actual reason for death in a patient who is close to dying.

The word ‘unintentionally’ should exclude euthanasia and injections intentionally given to shorten life for patients who have not asked for help to die. We cannot explain why male physicians more often have experienced this when age and specialty are controlled for. Because anaesthesiologists often are responsible for treatment of intractable pain, they may be more likely to have experienced ‘the double effect’. However, this does not seem to be the case. One explanation could be that anaesthesiologists are more skilled in handling the side effects of strong analgesic injections. If euthanasia in Norway is sometimes given the double effect label, it does not appear to be especially prevalent among anaesthesiologists.

In emotionally and ethically difficult end-of-life situations patients are frequently incompetent.
Although having no formal and judicial status in Norway, advance directives may be of help to assure that the decision taken is in accordance with the patient’s wish. However, if such a document is not acknowledged and respected by the responsible health care personnel it is of no use, and may even give false relief to the patient.

In the present study only half of the physicians indicated that an advance directive might be useful, 12% that it would be of no value. This might be a reflection of advanced directives being relatively new in Norway; only one in four physicians had ever been presented with such a document. It is also important that in the competent patient an advance directive may be a useful starting point for a dialogue between physician and patient around the patient’s preferences in end-of-life care [20].

References