

# Are end-of-life practices in Norway in line with ethics and law?

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**Background:** End-of-life decisions, including limitation of life prolonging treatment, may be emotionally, ethically and legally challenging. Euthanasia and physician-assisted suicide (PAS) are illegal in Norway. A study from 2000 indicated that these practices occur infrequently in Norway.

**Methods:** In 2012, a postal questionnaire addressing experience with limitation of life-prolonging treatment for non-medical reasons was sent to a representative sample of 1792 members of the Norwegian Medical Association (7.7% of the total active doctor population of 22,500). The recipients were also asked whether they, during the last 12 months, had participated in euthanasia, PAS or the hastening of death of non-competent patients.

**Results:** Seventy-one per cent of the doctors responded. Forty-four per cent of the respondents reported that they had terminated treatment at the family's request not knowing the patient's own wish, doctors below 50 and anaesthesiologists more often.

Anaesthesiologists more often reported to have terminated life-prolonging treatment because of resource considerations. Six doctors reported having hastened the death of a patient the last 12 months, one by euthanasia, one by PAS and four had hastened death without patient request. Male doctors and doctors below 50 more frequently reported having hastened the death of a patient.

**Conclusion:** Forgoing life-prolonging treatment at the request of the family may be more frequent in Norway than the law permits. A very small minority of doctors has hastened the death of a patient, and most cases involved non-competent patients. Male doctors below 50 seem to have a more liberal end-of-life practice.

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MEDICAL progress has created new ethical dilemmas, some of which concern the need for cost containment in health care. One case in point is limitation of expensive life-prolonging treatment when the patient's prognosis is very poor. Balancing preservation of life up against rationing of healthcare resources may be experienced as especially ethically problematic.

The strengthening of patient rights in Norway has led to uncertainty among doctors concerning how much families may influence end-of-life decisions regarding their relatives who are no longer competent. Recent studies on doctors' attitudes indicate that families are granted greater decision-making power than the law permits.<sup>1–3</sup> Every health care intervention should in principle be based on informed consent. However, according to Norwegian law and national guidelines, responsible health care personnel should have the final say in medical decisions. When the patient is no longer competent, the closest

relatives must be informed and asked to elicit possible information about the patient's preferences. Advance directives or durable power of attorney are not legally binding. Health care may be provided if it is deemed to be in the patient's best interest, and it is likely that the patient would have given permission to such care.\* National guidelines regulating decision-making processes to forgo life-prolonging treatment to frail and dying patients were first published in 2009 and revised in 2013. These stress that decisions should be based on the patient's wishes and values, and that the patient's family has no decision-making role other than conveying the patient's values and opinions to the doctor.<sup>4</sup> We lack data on the extent to which these guidelines are actually abided by in Norwegian health care.

\*Norwegian Directorate of Health. Act on patient and user's rights. 1999. <http://lovdata.no/dokument/NL/lov/1999-07-02-63> [Accessed 3 August 2014].

Another ethically challenging end-of-life issue is that of euthanasia and physician-assisted suicide (PAS). Medically hastening of death is illegal in Norway and against the ethical guidelines of The Norwegian Medical Association.<sup>5</sup> While there seems to be a shift in doctors' attitudes towards such acts in many European countries, Scandinavian doctors have been found to be more reluctant.<sup>6,7</sup> The reason for this is unknown. One may, however, expect that these differences may converge in an increasingly smaller world. A Norwegian study from 2000 confirmed that few doctors had experience with euthanasia. Only 1% in a random sample of doctors admitted to ever having committed 'an act (such as a lethal injection) with the explicit purpose to end the life of a patient' once or a few times.<sup>8</sup> This question did not distinguish between life-shortening acts with and without an explicit request from the patient. Thus, interventions not included in the Dutch definition of euthanasia, non-voluntary and involuntary drug-induced death, so called life-shortening acts without explicit request (LAWER), are most likely subsumed in the 1%. A study from Belgium indicates that a substantial proportion of the physician-hastened deaths were in this category.<sup>9</sup>

More than 10 years have passed since the practice of end-of-life decisions was surveyed in Norway. It is time to re-explore end-of-life practices and to what extent decisions to limit life-prolonging treatment are influenced by both resource limitations and stronger emphasis on patient rights.

## Material and method

Since 1992, The Norwegian Medical Association, organising more than 90% of all doctors practising in Norway, has sponsored its own research institute with the main objective to study the health and behaviour of doctors. See [www.legeforsk.org](http://www.legeforsk.org) for an overview of the more than 200 publications so far. An important element of this effort has been from 1994 to follow a representative panel of approximately 1700 doctors with postal questionnaires. The panel is unbalanced, meaning that new young doctors are regularly added and retired, or diseased doctors are removed.

### *Specialist categories*

There are 45 medical specialities and subspecialties in Norway, and for the purpose of optimal statistical analyses the specialties are grouped into larger logical entities. In this study, we use the following seven categories: family medicine/general practice,

laboratory/service specialties, internal medicine specialties (including oncologists), surgical specialties, anaesthesiology and intensive care, psychiatry and community medicine/public health. Specialists in training are categorised according to their future specialty.

### *Questionnaire*

In November 2012, a postal questionnaire was sent to the 1792 panel members, with three reminders. Among several other topics, the following questions on different end-of-life practices were asked:

- Have you as a doctor experienced that treatment has been terminated for the following non-medical/non-professional reasons, with the consequence that the patient died:
  - Treatment was terminated because of resource considerations.
  - Treatment was terminated because of the patient's wish.
  - Treatment was terminated because of the wish of the patient's family, without knowing what the patient would have wanted.

Response alternatives: 'often', 'seldom', 'never', 'does not apply to my work situation'

- Have you as a doctor during the last 12 months performed an act (e.g. an injection) with the explicit aim to end the life of a patient who requested it? (Do not include the termination of life-prolonging treatment to dying patients).
- Have you performed this act on patients who were not able to ask for help (non-competent patients)?
- Have you during the last 12 months helped a patient to commit suicide?

Response alternatives: 'no', 'yes'.

### *Statistical analyses*

Responses are reported as frequencies across three group variables: gender (female and male), age (30–39, 40–49, 50–59, 60–69 and 70+) and specialty (general practice, laboratory/service, anaesthesiology/intensive care, internal, surgical, psychiatry and public health). Where appropriate, chi-squared is used to test for possible statistically significant differences between groups.

*Ethics.* The regional ethics committee has given the Norwegian physician study exemption from ethics approval (Ref IRB 0000 1870).

Table 1

Specialty	Forgoing life-prolonging treatment because of the family's request				Forgoing life-prolonging treatment because of resource considerations			
	<i>n</i>	Often	Rarely	Never	<i>n</i>	Often	Rarely	Never
	GP	258	7	36	57	251	2	8
Internal	295	5	37	59	306	1	8	91
Surgical	114	4	45	52	118	1	7	92
Anaesthesiology	51	10	45	45	52	2	22	77
All	718	6	38	56	725	1	9	90

Selected specialty groups. Doctors who answered 'not applicable' are excluded. GP, General practice.

## Results

One thousand two hundred seventy-nine of 1792 questionnaires were returned, a response rate of 71%.

### *Limitation of life-prolonging treatment for other than medical reasons*

Six per cent of the doctors reported that they often had forgone life-prolonging treatment at the request from the patient's family, anaesthesiologists more frequently than other specialists (Table 1). Fifty-six per cent reported that they had never terminated treatment at the family's request. Doctors below age 50 reported more frequently to have terminated treatment at the family's request ( $P = 0.033$ ). Fifteen per cent had often, and 50% seldom, forgone life-prolonging treatment at the request of the patient. Doctors below age 50 had more often limited life-prolonging treatment at the patient's own request ( $P = 0.002$ ).

Ten per cent of the doctors responded that they had often or seldom forgone life-prolonging treatment out of resource considerations; this was particularly true of male doctors ( $P = 0.004$ ) and anaesthesiologists ( $P = 0.007$ ) vs. all others.

### *Hastening death*

Six doctors reported to have committed actions within the last 12 months with the aim of ending the life of a patient (Table 2). Five of these were males, and all of them were younger than 50 years. Four of these doctors had shortened the life of a non-competent patient.

## Discussion

Our results must be interpreted with caution. Brief answers and fixed response categories do not

Table 2

One thousand two hundred seventy-nine Norwegian doctors' response to questions about life-shortening acts by means of drugs the last 12 months (numbers).

	Yes	No	Unanswered
Ended life on explicit request from the patient	1*	1243	35
Ended life of a non-competent patient	4†	1199	76
Helped a patient to commit suicide	1*	1236	42

\*General practice.

†General practice, internal medicine, anaesthesiology, and laboratory medicine.

capture the nuances of complex and ethically challenging interventions. We asked for reports on actions like euthanasia and PAS, which are illegal in our country. Although the respondents are anonymous, some doctors may be reluctant to report their illegal actions. On the other hand, people who are in favour of more liberal laws may be willing to report their actions to show that this is already happening in spite of the law. Another obvious weakness is that the questions on limitation of life-prolonging treatment are presented isolated without the clinical context in which such situations always occur. To this adds that single questions may be misunderstood.

Despite such weaknesses, our study is an attempt to illuminate an area in which there exists few good empirical studies outside Belgium and the Netherlands.<sup>7</sup>

### *Limitation of life-prolonging treatment*

Our results indicate that forgoing life-prolonging treatment for other than medical/professional reasons are uncommon. In clinical practice, it is usually difficult to distinguish between strictly

medical and non-medical reasoning, including resource considerations or family request, in reaching a final decision. The role of medical ethics, therefore, often becomes that of visualising the hidden values disguised as 'medical facts'.

Our results are in line with other Norwegian studies indicating that families are actually granted greater decision-making authority in end-of-life decisions than law and guidelines recommend.<sup>2</sup> Our results are also in line with a qualitative study from intensive care that indicates that next of kin are given decision-making authority in life-and-death decisions.<sup>10</sup> Greater emphasis on patient rights, misinterpretation of law, lack of legal knowledge and a wish to avoid conflicts with the patient's family are likely explanations. That anaesthesiologists and intensive care doctors more frequently report having forgone life-prolonging treatment because of the wish of the patient's family, without knowing what the patient would have wanted, is not surprising. They are responsible for acute life-prolonging treatment more often than other specialists, and their patients are often unconscious. Accordingly, in such situations the families are the patient's representatives. In a situation alluded to in our question, when the families act without knowing the patient's preferences, limitation of therapy may neither be in the patient's best interest nor according to law and guidelines. By contrast, a study from Norwegian nursing homes indicates that situations when the family requests life-prolonging treatment which the healthcare personnel consider not to be in the patient's best interest are much more common than the opposite.<sup>11</sup> Routines to explore patient values and interests are important in order to strengthen patient rights in practice as well as when it comes to including next of kin in ways that increase their trust in the end-of-life decisions being made and thus to prevent treatment not in the patient's best interest.<sup>4,12</sup>

Forgoing life-prolonging treatment due to resource considerations is less common in our study. Setting a price on life may be seen as morally wrong. Almost one out of four anaesthesiologists have abstained from treatment because of resource considerations. Again, these specialists are more often confronted with difficult decisions when they must prioritise between patients, for instance, by dismissing one patient from intensive care treatment because of the more urgent need of another patient.<sup>13</sup>

More doctors have limited life-prolonging treatment upon the patient's wish. This is in line with law and guidelines. Still a great proportion of doctors report that they have never terminated treatment

based on the patient's wish. One explanation for this may simply be that relatively few patients actually wish to have such treatment terminated; another and more disturbing reason could be insensitivity towards the patient's opinion or insufficient routines to elicit the patient's preferences.

### *Hastening death*

Our study indicates that euthanasia and PAS are uncommon in Norway. Two out of 1279 (0.0015%) doctors report having been involved in such practices during the last 12 months. Extrapolated, this adds up to 40 (95% confidence interval 7–132) doctors a year out of a work force of 26,000. This is not negligible, but lower than in several other European countries.<sup>14</sup> We do not know the number of patients involved. Four of the six doctors reported having ended the life of a patient who did not explicitly ask for it. Of the six responders who reported having performed euthanasia, PAS and LAWER, three were general practitioners, indicating that these actions have taken place in a primary healthcare setting or municipal nursing home. In Norway, more than 40% of the population die in nursing homes, fewer die in their own homes, and the 80% of the nursing home patients suffer from dementia.<sup>15</sup> Chambaere et al. argue that the patients in Belgium who die by LAWERs are old and frail patients dying in hospitals.<sup>9</sup> They were given opioids, often at the request of and out of consideration for the family. We cannot exclude that this also takes place in Norway. However, if opioids are given to frail patients, it is not obvious that these drugs actually cause death.<sup>16</sup> Future studies on life-shortening practices should include information on the drugs and dosages used.

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