The population's knowledge of and attitudes towards end-of-life decisions

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Background: End-of-life medical decisions sometimes give rise to ethical problems. The purpose of the study was to survey the knowledge and attitudes of the population on the subject.

Material and method: An online survey of a representative sample of adults in Norway. The respondents were asked to take a position on four statements about Norwegian health legislation, and to answer eight statements about their attitudes towards end-of-life care and decisions. The responses were analysed using descriptive statistics.

Results: A total of 1167 people completed the survey (response rate 23.7%). Seventy-eight per cent mistakenly believed that when a patient can no longer make decisions about their care, it is their next of kin who makes the decisions. A majority of respondents answered correctly in relation to the other statements relating to knowledge. Attitudes towards end-of-life care varied. While a majority (67%) believe that many patients are kept alive against their will, a full 79% trust that they will receive good palliative care if they become terminally ill.

Interpretation: The survey shows a widespread misconception about the role of the next of kin in healthcare decisions. It is important that healthcare personnel communicate the division of responsibilities clearly and clarify what the next of kin's right to participation entails.

Decisions about end-of-life care are sometimes fraught with uncertainty, disagreement and ethical problems for healthcare personnel, patients and next of kin. Patients are often unable to express their choices in the end-oflife phase, and sometimes their treatment preferences are also unknown. Life-prolonging treatment is one of the most frequently discussed issues in clinical ethics committees (1). Knowledge of the preferences, knowledge and attitudes of the patient and their next of kin is useful, particularly for the doctor with responsibility for the patient. This can help provide individualised information that enables the patient and their next of kin to participate in a useful way, and facilitates a good decision-making process.

In this connection, it is also useful for doctors and other healthcare personnel to be aware of the general population's attitudes towards and knowledge of the legislation on end-of-life care. Healthcare personnel should understand the variation in knowledge, perceptions and attitudes among patients and their next of kin when informing and making decisions on such issues. Attitudes towards and knowledge about end-of-life decisions are also important for the discourse on assisted dying.

In this study we sought to obtain knowledge of and understand attitudes towards key topics in the field. The topics for the survey were chosen based on the authors' knowledge of what gives rise to problems and disagreements in clinical practice, as well as public discourse on the subject.

We are not aware of similar surveys of the Norwegian population's attitudes towards or knowledge of the legislation in this field. Many international studies have been carried out, particularly of the population's attitudes (2, 3). In these, questions are formulated and topics are selected based on the specific national context. Comparisons across countries are therefore often a challenge.

Material and method

The statements put to the respondents were formulated with a view to understanding the core aspects of end-of-life decisions. The questionnaire was devised by the authors, with input from other research colleagues. In the first of two sets of statements, the respondents were asked to take a position on four factual statements about Norwegian health legislation. The response alternatives were 'Yes', 'No' and 'Don't know'. In the second set of statements, they were asked to indicate whether they agreed or disagreed with eight statements about end-of-life care and decisions. The response alternatives were 'Strongly disagree', 'Disagree to some extent', 'Neither agree nor disagree', 'Agree to some extent' and 'Strongly agree'.

The survey was conducted by Kantar, a data analysis company, and was initiated and financed by the Medical Ethics Council. This was reflected in the questionnaire. Kantar's Gallup panel consists of approximately 40,000 people and strives to be representative of the adult population. An invitation was emailed to members of the panel with a request to answer an online questionnaire. Responding to the survey was considered implicit consent to participate. The data protection officer at the Norwegian Centre for Research Data (NSD, ref. 629574) considered the survey to be in accordance with data protection legislation.

In panel surveys, a higher weighting is normally given to the answers of respondents who belong to groups that are underrepresented in the sample. In line with this, the answers are weighted with regard to age, gender and region of residence (Table 1). The data were analysed using SPSS 27 and presented in the form of descriptive statistics.

Results

In August 2021, the questionnaire was sent to 4929 people, 1167 of whom completed the survey (response rate 23.7%).

Table 1 shows the demographics of respondents.

Table 2 shows the breakdown of responses to the statements on health legislation: 62% answered (correctly) 'No', while 14% answered (incorrectly) 'Yes' to the statement that Norwegian citizens have a legal right to take their own life. A total of 78% answered (incorrectly) in the affirmative, while only 9% (correctly) rejected the idea that a patient's next of kin makes the decision on end-of-life care when the patient is no longer able to make such decisions. Seventy per cent answered (correctly) that it is permitted to administer large doses of palliative medication to relieve pain, even if it may have the unintended effect of hastening death, while 13% answered (incor-

Table 1. Demographics of the respondents. (Number (%))

| | | Unweighted (N (%)) | Weighted (N (%)) | |
|---------------------|--|--------------------|------------------|--|
| Age | Below 30 years | 128 (11.0) | 230 (19.7) | |
| | 30–44 years | 330 (28.3) | 299 (25.6) | |
| | 45–59 years | 320 (27.4) | 299 (25.6) | |
| | 60 years and over | 389 (33.3) | 340 (29.1) | |
| Gender | Female | 610 (52.3) | 579 (49.6) | |
| | Male | 557 (47.7) | 588 (50.4) | |
| Education | Primary/lower secondary school | 48 (4.1) | 44 (3.8) | |
| | Upper secondary school | 268 (23.0) | 283 (24.2) | |
| | Vocational college | 107 (9.2) | 115 (9.8) | |
| | University/university college <5 years | 401 (34.4) | 398 (34.1) | |
| | University/university college ≥5 years | 343 (29.4) | 328 (28.1) | |
| Region of residence | Oslo and area | 304 (26.0) | 296 (25.3) | |
| | Remainder of Eastern Norway | 295 (25.3) | 300 (25.7) | |
| | Southern and Western Norway | 353 (30.2) | 361 (30.9) | |
| | Trøndelag/Northern Norway | 212 (18.2) | 208 (17.8) | |

Table 2. Knowledge of legislation on end-of-life care. (Number (%))

| | Yes | No | Don't know | Did not answer | All |
|--|---------------|---------------|---------------|----------------|---------------|
| It is permitted to turn off the ventilator at the patient's request, even if it results in the patient's death. (Sections 4.1 and 4.9 of the Patients' Rights Act) | 674 (57.8) | 164 (16.6) | 293 (25.1) | 5 (0,4) | 1167 (100) |
| It is permitted to administer large doses of medication to relieve pain and other symptoms, even if it may have the unintended effect of hastening death. | 813 (69.6) | 149 (12.8) | 201 (17.2) | 5 (0.4) | 1167 (100) |
| When a patient can no longer make decisions about their care, it is the patient's next of kin who makes the decisions. (Sections 4.6 and 4.9 of the Patients' Users Rights) | 904 (77.5) | 108 (9.2) | 154 (13.2) | 1 (0.1) | 1167 (100) |
| Norwegian citizens have a legal right to take their own life. (Section 277 of the Penal Code) | 165 (14.2) | 721 (61.7) | 279 (23.9) | 2 (0.2) | 1167 (100) |

rectly) that this is not permitted. A total of 58% answered (correctly) 'Yes' and 17% answered (incorrectly) 'No' to the statement on whether it is permitted to turn off a patient's ventilator even if it results in death.

Table 3 shows the results for the statements about attitudes towards endof-life care. Sixty-nine per cent of respondents strongly agreed or agreed to some extent that turning off a ventilator at the patient's request is considered a form of assisted dying. Seventy-nine per cent trusted that they will receive good palliative care if they become terminally ill (strongly agreed/agreed to some extent). Fifty-six per cent strongly agreed or agreed to some extent that patients can no longer lead a dignified life once they lose control of their bladder or bowels. Forty-one per cent strongly agreed or agreed to some extent that they believe there are many cases of assisted dying in Norway, despite it being illegal. Forty-nine per cent strongly agreed or agreed to some extent that administering analgesics as part of palliative care often hastens death. Fifty-two per cent strongly agreed or agreed to some extent that taking one's own life should be a human right. Forty-two per cent strongly agreed or agreed to some extent that it is common at the end of life to have severe pain that cannot be relieved. Sixty-seven per cent strongly agreed or agreed to some extent that many patients are kept alive against their will. There was no correlation between gender, knowledge and attitudes.

The exception was for the statement that patients can no longer lead a dignified life once they lose control of their bladder or bowels. Here, more

Table 3. Attitudes towards end-of-life decisions. (Number (%)).

| | | Disagree | Neither | Agree to | | | |
|--|-------------------|----------------|--------------------|----------------|----------------|----------------|---------------|
| | Strongly disagree | to some extent | agree nor disagree | some extent | Strongly agree | Did not answer | Total |
| I consider turning off a ventilator at the patient's request a form of assisted dying. | 93 (7.9) | 136 (11.6) | 126 (10.8) | 475 (40.7) | 333 (28.5) | 4 (0.4) | 1167 (100) |
| I trust that I will receive good palliative care if I become terminally ill. | 18 (1.6) | 85 (7.3) | 135 (11.6) | 437 (37.5) | 487 (41.7) | 4 (0.4) | 1167 (100) |
| I believe that patients can no longer lead a dignified life once they lose control of their bladder or bowels. | 136 (11.6) | 193 (16.5) | 185 (15.8) | 372 (31.9) | 280 (24.0) | 1 (0.1) | 1167 (100) |
| I believe there are many cases of assisted dying in Norway, despite it being illegal. | 116 (9.9) | 190 (16.3) | 385 (33.0) | 396 (34.0) | 80 (6.9) | 0 | 1167 (100) |
| I believe that administering analgesics as part of palliative care often hastens death. | 64 (5.5) | 163 (14.0) | 369 (31.6) | 416 (35.7) | 152 (13.0) | 2 (0.2) | 1167 (100) |
| I believe that taking one's own life should be a human right. | 158 (13.5) | 150 (12.9) | 251 (25.1) | 332 (28.4) | 273 (23.4) | 3 (0.3) | 1167 (100) |
| I believe it is common at the end of life to have severe pain that cannot be relieved. | 97 (8.3) | 224 (19.2) | 355 (30.4) | 339 (29.0) | 152 (13.0) | 0 | 1167 (100) |
| I believe that many patients are kept alive against their will. | 59 (5.0) | 107 (9.2) | 216 (18.5) | 507 (43.5) | 275 (23.6) | 3 (0.3) | 1167 (100) |

men than women agreed with the statement (61.7% and 49.9% of men and women, respectively, strongly agreed/agreed to some extent).

Respondents in the higher age group responded correctly to more of the knowledge statements than younger respondents. For example, 67% of respondents over the age of 60 correctly indicated that it is permitted to turn off the ventilator at the patient's request, while the corresponding proportion for those under the age of 30 was 50%. Compared to younger respondents, the higher age group were more likely to agree that palliative care often hastens death and that they trust they would receive good palliative care if they became terminally ill. More of the younger respondents indicated that they believed it is common at the end of life to have severe pain that cannot be relieved.

Discussion

As many as 78% mistakenly believed that when the patient can no longer make decisions about their own treatment, it is the patient's next of kin who makes the decisions. A majority of respondents answered the other knowledge statements correctly. Attitudes towards end-of-life health care varied. While a majority (67%) believed that many patients are kept alive against their will, as many as 79% trusted that they would receive good palliative care if they became terminally ill.

Strengths and weaknesses

One of the weaknesses of the study is the low response rate. This means that response bias cannot be ruled out. Low response rates are a problem in many surveys (4), but analyses indicate that the responses may still be representative (5). The sample was drawn from a panel that is representative of the population, and the answers were weighted based on demographic parameters.

Next of kin have no legal decision-making authority

The survey shows a widespread misconception about the role of next of kin in decisions about health care. Section 3-1 of the Patients' Rights Act stipulates that if a patient is not competent to give consent, the patient's next of kin is entitled to participate in decisions relating to their health care. However, participate in this context mainly entails providing information on what the patient would have wanted (section 4-6 of the Patients' Rights Act). Where a dying patient is unable to express their wishes, healthcare personnel must give most weight to what the next of kin expresses as the patient's wish and their own wish. However, it is the doctor responsible for treating the patient, not the next of kin, who must make the decision, based on an independent assessment (sections 4-6 and 4-9 of the Patients' Rights Act). This is also clearly stated in a circular setting out how the Act should be interpreted and practised (6). In a survey of a representative sample of Norwegian doctors from 2012, 44% of respondents stated that they had withdrawn treatment at the request of a patient's next of kin without knowing the patient's wishes (7). Correspondingly, it was found that nursing home doctors often gave weight to the next of kin's view without trying to clarify the patient's view (8). It is important to be aware that such practices are based on a misconception, which it transpires is at least as widespread among the general population as among doctors. When relevant, the doctor should communicate the division of responsibilities clearly and clarify what the next of kin's right to participation entails. This may help prevent misunderstandings and conflicts.

About 70% of respondents knew that it is permitted to administer large doses of palliative medication, even if it may have the unintended effect of hastening death. Nearly half believed that palliative medication often hastens death. There is no evidence to suggest that palliative medication has a systematic, predictable, life-shortening effect. Although such medication can lead to death, it is unknown how often this happens in practice (9, 10).

A small proportion mistakenly believed that Norwegian citizens have a legal right to end their own life. However, there is also no law against suicide that does not involve other parties. Section 277 of the Penal Code does not cover a person's own suicide, but it is a criminal offence for both healthcare personnel and ordinary citizens to contribute to another person's suicide. The health service's task is to deter suicide and prevent the loss of life as a result of attempted suicide. This is reflected in, inter alia, section 7 of the Health Personnel Act, which imposes a duty on healthcare personnel to provide health care when it must be assumed that the health care is of vital importance. It is also reflected in provisions that cover the treatment of patients under compulsory mental health care where there is imminent and serious danger to their own life (sections 3-2, 3-3 and 4-4 of the Mental Health Care Act), in the Norwegian Directorate of Health's guide (11) and in the Solberg Government's "zero vision" for suicide (12). Although there is no law against suicide that does not involve other parties, this does not represent a legal right that can be respected or enforced in the same way as for rights granted in health legislation.

Just over half of the respondents knew that it is legal to withdraw ventilator support at the patient's request even if it will result in the patient's death. This is based on the premise that a patient who is kept alive with the aid of a ventilator is to be considered dying, and dying patients are entitled to refuse life-prolonging treatment under section 4-9 of the Patients' Rights Act. Cases can be envisaged where the response would be different if the patient was not considered dying, and special circumstances dictate that the patient's autonomous wishes can be overridden. We did not include such a nuanced situation because it is not certain whether there is even a legal right to put patients on ventilators if they object.

Differing attitudes to statements about end of life

In the statements relating to attitudes, the respondents were generally distributed across the entire spectrum of response alternatives. Two-thirds strongly agreed or agreed to some extent that turning off a ventilator at the patient's request should be considered a form of assisted dying. In support of this, Gamlund and Solberg argue that there are no ethically relevant differences between what they call 'passive euthanasia' (withdrawing or withholding of treatment) and 'active euthanasia' (13). We disagree with that. In assisted dying, the doctor administers an injection with the express purpose, and predictable effect, of inducing death. If treatment for a life-threatening illness is withdrawn or withheld, the patient will die of the disease. Both the cause of death and the intention behind the act are different (2, 14). The doctor's perspective is also the complete opposite in the two situations: in the case of assisted dying, the doctor's perspective is that the patient's life should be ended before the time of natural death. However, in the withdrawing or withholding of treatment, the doctor's perspective is that the patient's life should not be extended beyond natural life expectancy. In practical terms, there is also a difference between the specific act of euthanasia and the broad term 'withdrawing or withholding of treatment'. Euthanasia entails the administration of medication where the only intention and effect is imminent death. The withdrawing or withholding of treatment includes a myriad of choices that healthcare personnel face about withholding, abruptly withdrawing or tapering off a broad spectrum of treatment options, ranging from administering antibiotics and supplying fluids and nutrients, to cardiopulmonary resuscitation and mechanical ventilation (15).

The vast majority trusted that they would receive good palliative care if they became terminally ill. In contrast to this, nearly half strongly agreed or agreed to some extent that it is common at the end of life to have severe pain that cannot be relieved. This is reflected in the public discourse on assisted dying where the belief is that this relates to a patient population that cannot be helped by palliative care, and where assisted dying should be an option. In a survey from 2019, 62% of respondents agreed with a similar question (16). Medical professionals have differing views on the issue of whether good palliative care can make assisted dying redundant (8, 17). Many professionals believe that there are still major challenges within

palliative care in Norway (18). For example, one study found that a large proportion of nursing home patients in the end-of-life phase suffered considerable pain that could not be relieved (19).

Updated guidelines for palliative sedation will make the treatment more accessible (20), but professionals are concerned that not enough patients are given this treatment (21).

More than half of the respondents felt that lack of bladder and bowel control (incontinence) meant a patient could no longer lead a dignified life. Incontinence is not specific to the end-of-life phase. Among people who were granted physician-assisted suicide in Oregon, 38% cited loss of control over bodily functions as one of their concerns. Loss of control over bodily functions can be understood to constitute a loss of independence and dignity. Significantly reduced quality of life has been reported in patients with urinary incontinence (22).

Almost half of the respondents believed there are many cases of assisted dying in Norway, even though it is illegal. As 'assisted dying' was defined in the introduction to the survey as an umbrella term for 'euthanasia' and 'physician-assisted suicide', which were also precisely defined, we assume that the respondents had a sufficient understanding of the concept of assisted dying to answer the statements. There is a lack of reliable figures that can shed light on the reality of the situation. Only three doctors in Norway (one of whom was convicted) are officially known to have performed assisted dying (23). A survey from 2002 showed that a small number of respondents had performed assisted dying (24), while in a follow-up survey from 2012, six out of 1279 doctors indicated that they had hastened a patient's death in the past year (7). Assisted dying (and unsolicited mercy killing) does therefore take place in Norway, but as far as we know, it is rare.

Well over half of the respondents believed that taking one's own life should be a human right. Neither Norwegian law nor international conventions with which we are affiliated legislate against suicide without the involvement of other parties. It is, however, prohibited under Norwegian law to assist in suicide, and although the act itself is not sanctioned by law, there are several laws that seek to discourage suicide. The European Court of Human Rights has tried cases relating to whether the individual's right to self-determination in issues of life and death includes the right to receive assistance to end one's own life. In the so-called Pretty judgment, however, it was concluded that the European Convention on Human Rights does not grant the right to receive assistance in taking one's own life (25). Nevertheless, in cases dealing with the withdrawing or withholding of treatment, the same court has ruled that the right to personal autonomy is strong, and that withdrawing treatment or nutrients and fluids is not to be regarded as a violation of the Convention for the Protection of Human Rights and Fundamental Freedoms (26).

Two-thirds of respondents believed that many patients are kept alive in the end-of-life phase against their will. How often patients 'at the end of life' are kept alive against their will is unknown. Doctors claim that such overtreatment often occurs following pressure from patients' families, but there are also stories of doctors who refuse to let the patient die (27). A perhaps greater problem in clinical practice is patients who lack the competence to give consent but are subject to life-prolonging treatment far beyond what patients who are competent to give consent tend to want. The Patients' Rights Act states that all treatment requires explicit or presumed consent (sections 4-1 and 4-2). This is also linked to core principles of medical ethics such as beneficence, nonmaleficence and autonomy. Giving life-prolonging treatment to patients who do not want it cannot be said to be beneficient, and may actually be harmful to the patient. Under section 4-9 of the Patients' Rights Act, a dying patient has the right to refuse lifeprolonging treatment. This delimits the duty to provide necessary health care under section 7 of the Health Personnel Act. A dying patient has the right to object to treatment, and where the patient is unable to communicate their wishes, healthcare personnel have a duty to clarify what the patient would have wanted in such situations. In our experience, reassuring patients that their wish not to be kept alive against their will shall be respected can in itself help lessen the patient's thoughts about suicide and assisted dying. In a resolution from the National Council of the Norwegian Medical Association, the medical professions have called on effective procedures to be drawn up aimed at counteracting overtreatment in the end-of-life phase (28).

Conclusion

The population's knowledge of central health legislation is incomplete. Many people mistakenly believe that when a patient is not competent to give consent, it is their next of kin who makes the decision about treatment. It is therefore particularly important that doctors and other healthcare personnel are aware of where the responsibility for such decisions lies, and that they have effective procedures and formulations in place for informing patients' families of this. Dying patients are well protected in Norway, and it can be reassuring to know this. Many regard the withdrawing or withholding of treatment to be a form of assisted dying, although this is something quite different. Seventy-nine per cent trust that they will receive good

palliative care if they need it, but there is still a need to better educate the public about palliative care in the end-of-life phase.

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