

P. Sjökvist
T. Nilstun
M. Svantesson
L. Berggren

Withdrawal of life support – who should decide?

Differences in attitudes among the general public, nurses and physicians

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P. Sjökvist (✉) · M. Svantesson ·
L. Berggren
Department of Anesthesia and Intensive
Care, Örebro Medical Centre Hospital,
SE-701 85 Örebro, Sweden

T. Nilstun
Department of Medical Ethics,
Lund University, SE-222 22 Lund, Sweden

Abstract *Objective:* To examine the attitudes of the general public regarding who should decide about the withdrawal of life support and to compare these attitudes with those of intensive care personnel.

Design: Nationwide postal questionnaire survey.

Setting: Sweden.

Participants: One thousand one hundred ninety-six randomly selected persons from the Swedish population register, 339 nurses and 121 physicians from 29 randomly selected intensive care units (ICUs).

Measurements and results: Respondents' answers to questions related to two clinical scenarios: one with a conscious and competent patient and one with an unconscious patient. The response rates were 64 % for the general public, 86 % for the nurses and 88 % for the physicians. Concerning the competent patient, 48 % of the public, 31 % of the nurses and 8 % of the physicians were of the opinion that a decision about continued ventilator treatment should be made by the patient alone

or together with the family, but without the physician. The vast majority of physicians (87 %) wanted to make the decision themselves, either alone or together with the patient or family. Concerning the incompetent patient, 73 % of the general public and 70 % of the nurses advocated a joint decision made by the family and the physician together. The majority of the physicians (61 %) regarded themselves as the sole decision-maker, a view supported by only 5 % of the public and 20 % of the nurses.

Conclusions: While existing Swedish guidelines recommend that the physician should be the sole decision-maker, the general public favour more patient and family influence on the decision to withdraw life support as compared with intensive care physicians.

Key words Decision-making · Ethics medical · Intensive care · Life support · Questionnaire · Public opinion

Introduction

There is disagreement over the roles of the physician, the patient and the patient's family in making decisions to limit life-sustaining treatment [1]. For instance, British and Swedish guidelines acknowledge the right of a competent patient to refuse treatment, but both emphasize the physician's role as decision-maker, especially in

the case of an unconscious or otherwise incompetent patient [2, 3, 4, 5]. In contrast, North American guidelines stipulate that the decision lies with the competent patient or with the family in the case of an incompetent patient [6, 7, 8].

It is important that both official policy and the existing practice of the health care system is in agreement with the values of the people in the community in ques-

tion. Part of the solution to the disagreements about end-of-life decisions would thus be to explore the views of the people in different societies. However, few surveys have been conducted concerning the attitudes of the general public regarding the decision to withdraw life support [9, 10, 11, 12, 13]. Public opinion in most countries remains unknown.

In this paper we examine the attitudes of the general public in Sweden regarding who should make the decision about withdrawal of life support and compare these attitudes with those of intensive care personnel and with existing guidelines.

Material and methods

Questionnaire

To survey the attitudes, we used a questionnaire with two scenarios, the first involving a conscious and competent patient and the second describing an unconscious patient (see Appendix). We focused on ventilator treatment, which is a form of life support well known among the general public.

The questionnaire was developed in co-operation with Statistics Sweden, the governmental agency that conducted the survey among the public. A preliminary version was pre-tested by the agency using a cognitive method [14]. In this pre-test, 15 randomly selected persons completed the questionnaire under the direct observation of the personnel administering the test. While completing the questionnaire, they voiced their associations and reactions. In addition, they were interviewed specifically about potential problems with the design of the questionnaire. The conclusion was that the technique with case scenarios was well accepted, but some elucidation of the questions was needed. All suggested modifications were implemented in the final version of the questionnaire. The questionnaire was distributed during the autumn of 1997. The survey was approved by the Research Ethics Committee of the Örebro County Council.

Respondents

A sample of 1200 adults, aged 25–74, was randomly selected from the general population register in Sweden. The questionnaires were mailed and, when necessary, two reminders were sent by mail.

A random sample of 30 of 61 intensive care units (ICUs) in Sweden with the capacity to care simultaneously for at least three ventilator-dependent patients were included. These 61 ICUs represent the great majority of Swedish ICUs of this size. Twenty-nine of the 30 ICUs agreed to participate in the survey. One third of the nurses at these ICUs were selected at random from lists of employees.

In Sweden almost all ICUs are staffed by anaesthesiologists. However, a sample from the list of employees at a department of anaesthesia would include many anaesthesiologists who work only occasionally in the ICU. Instead of a random selection of anaesthesiologists, we thus surveyed specialists and residents who were on duty in the ICU during certain weeks which were determined beforehand. From each centre, the number of physicians included in the study was twice the number of physicians working day-time in the ICU. For example, in a centre with an ICU usually

staffed by two physicians, four physicians were surveyed. The numbers of ICUs, nurses and physicians surveyed were selected to allow us to cover all areas in Sweden and to get appropriate sample sizes of both nurses and physicians.

The questionnaires were mailed to 339 nurses and 121 physicians by the authors. The respondents returned the questionnaires in coded envelopes to allow follow-up, but the questionnaires and the respondents' answers remained anonymous to the investigators. One mail reminder was sent when necessary.

Statistical methods

According to standard practice at Statistics Sweden, a non-response study was conducted. In this non-response study [15] 212 of the 425 persons not responding after two mail reminders in the public survey were approached by phone. Eighty-four of the 212 persons approached in this follow-up completed the questionnaire by mail or phone. Their answers were used to calculate a weighted result for each question. In this calculation, a higher weight was given to the answers collected in the non-response study than to the answers from the regular survey. The rationale behind giving higher weight to those who responded after being reminded by telephone, is the assumption that the answers of non-responders are more in concordance with those responding after several reminders, than to those who answer immediately or following only a few reminders. These weighted results did not differ from the results in the regular survey by more than three percentage points for any question. Thus, if these assumptions are true, a higher response rate would not have significantly altered the results.

A chi-square test was used to test the null-hypothesis that the distribution of answers from the three groups were the same. When the null-hypothesis was rejected ($p < 0.005$), a subsequent analysis was made to determine which answers contributed to the differences among the groups.

Results

Of the 1200 persons in the general public sample, four had died or emigrated. Of the remaining 1196 eligible persons, 771 (64 %) answered the questionnaire. The response rate for the nurses was 290/339 (86 %) and for the physicians it was 107/121 (88 %).

Respondent characteristics

Table 1 summarizes the demographic characteristics of the respondents. The data from those of the general public that responded were compared with the whole sample of the general public, regarding age, gender and community size. No significant differences were found, indicating that the respondents were representative of the general public of Sweden regarding these factors. Among the respondents from the public, 31 % had up to 9 years of education, 42 % had 10–12 years of education, and 27 % had university education. According to the definitions used, all nurses and physicians had university education. The nurses and the physicians had a

Table 1 Characteristics of the respondents

	Public n = 771	Nurses n = 290	Physicians n = 107	P-value
Age, years mean (SD)	50 (13.5)	41 (7.1)	42 (7.1)	< 0.001 ^a
Female %	49	90	33	< 0.001 ^b
Community size %:				0.58 ^b
Major cities	36	35	38	
Other cities	34	36	39	
Towns and country	30	29	22	

^a F-test, ^b Chi-square test

Table 2 Scenario with competent patient. Who should decide about continued ventilator treatment?

n (%)	Public n = 758	Nurses n = 289	Physicians n = 107
Patient only	227* (30)	66 (23)	7* (7)
Family only	15 (2)	0 (0)	0 (0)
Physician only	16* (2)	27* (9)	27* (25)
Patient and family together	134* (18)	23* (8)	1* (1)
Patient and physician together	83* (11)	39 (13)	41* (38)
Family and physician together	42 (6)	11 (4)	1 (1)
Patient, family, physician together	217 (29)	115* (40)	25 (23)
Uncertain	24 (3)	8 (3)	5 (5)

P < 0.001 for the rejection of the null-hypothesis that the distribution of answers from the three groups were the same

* when statistically significant differences between the three groups were found these frequencies contributed to those differences

mean of 13 and 12 years of ICU experience, respectively. Eighteen percent of the respondents from the public and 16–17 % of the health care professionals stated that they had experience with ventilator treatment, either as a patient or as a close relative.

Decision-making when the patient is competent

The majority of the general public, the nurses and the physicians (87 %, 81 % and 77 %, respectively) were of the opinion that the physician should raise the question about continued ventilator support, with either the patient or the family, or both. However, the number of respondents who answered that the question should not be raised was significantly larger among the nurses and physicians, than among the general public (14 %, 16 % and 8 %, respectively) ($p < 0.001$).

Fifty percent of the general public, as compared to 8 % of the physicians and 31 % of the nurses, were of the opinion that a decision about continued ventilator treatment should be made by the patient or the family alone or by the patient and the family together, but with-

Table 3 Scenario with incompetent patient. Who should decide about continued ventilator treatment?

n (%)	Public n = 763	Nurses n = 290	Physicians n = 107
Family only	148* (19)	17* (6)	0* (0)
Physician only	39* (5)	57* (20)	65* (61)
Family and physician together	554 (73)	204 (70)	38* (36)
Uncertain	22 (3)	12 (4)	4 (4)

P < 0.001 for the rejection of the null-hypothesis that the distribution of answers from the three groups were the same

* when statistically significant differences between the three groups were found these frequencies contributed to those differences

out the physician. In contrast, 25 % of the physicians saw themselves as the sole decision-maker, an alternative preferred by only 2 % of the public (Table 2). The combination of the patient and/or the family together with the physician as decision-makers were supported by 46 % of the general public, 57 % of the nurses and 62 % of the physicians.

Decision-making when the patient is incompetent

A large majority of the general public the nurses and the physicians (86 %, 82 % and 85 %, respectively) agreed that the physician should raise the question about continued ventilator support with the family.

Of the physicians, 61 % answered that they alone should be the ones to make the decision, a view held by 5 % of the general public and 20 % of the nurses. In contrast, twice as many persons among the general public and the nurses, as compared to the physicians, advocated a joint decision made by the family and the physician (73 %, 70 % and 36 %, respectively) (Table 3).

Discussion

The strengths of this study include a pre-tested questionnaire, a high response rate among physicians and nurses, and results confirmed by a non-response study for the general public. This study is limited in that the respondents reacted to hypothetical scenarios and their attitudes might be different if they themselves or a close family member became seriously ill. Another limitation is that the questionnaire was not tested for reliability and that we do not know the stability of the views expressed in the survey. This survey focused on physicians, patients and families. Thus, we have no data regarding other participators in decisions to limit life support. For instance, the role of nurses was not assessed in the questionnaire despite their important role in end-of-life decisions.

Our findings indicate that there is a difference between the attitudes of the Swedish population and both the official policy and the existing practices in the health care system regarding who should make the decision to withdraw life support [16, 17].

First, there is a difference in attitude between the general public and the intensive care physicians. The former are more in favour of patient and family influence in the decision to withdraw life support, while the physicians emphasized that they should make the decision. The view of the Swedish general public displayed in this study is also in agreement with findings in one American poll and two Canadian polls. In these surveys between 83 and 87 % of the general public favoured the family, either by themselves or together with the physician, as the decision-maker in the case of an incompetent patient [10, 11, 12]. Self-determination by the patient is also acknowledged in an Australian survey of the general public, where 91 % of the respondents acknowledged the right of the patient to refuse life-sustaining treatment [9].

Second, descriptive studies from two Swedish ICUs both show that nearly half of the decisions to withhold or withdraw life support were made without a documented discussion with the patient or the family [16, 17]. Clinical practice thus seems to differ from the almost unanimous view of our respondents that the physician should raise the question about continued ventilator treatment. We have no data to explain this difference. One speculation might be that the descriptive studies include not only the withdrawal of ventilator treatment, but also other decisions to limit life support. Thus, the discrepancy between the physicians' answers in this survey and how they really act might be explained by a belief that they should always inform about overt decisions, i.e. withdrawal of ventilator treatment, but feel less inclined to inform about more hypothetical decisions, i.e. do not resuscitate (DNR) orders. Paternalistic attitudes may also influence behaviour and make physicians less inclined to inform even if they, in principle, think that the patients and their families should be informed. Regardless of the explanation, our findings indicate that the general public wish to be more frequently informed about decisions to limit life support than is currently the practice in Swedish ICUs.

Third, the view of the majority of the respondents from the general public and of the nurses, that the family and the physician should make the decision together in the case of an incompetent patient, expresses the value of shared decision-making [18], but differs from the recommendations of the two existing Swedish guidelines [4, 5]. Both the official guideline issued by the National Board of Health and Welfare and the one issued by the Swedish Society of Medicine state that there is no ethical difference between withholding and withdrawing life support. Both practices are acceptable. A

competent patient always has the right to refuse treatment, including life support. In the case of an incompetent patient the guidelines differ slightly, although both sets of guidelines emphasize that the physician is the one to make the decision. However, the Society of Medicine states only that the relatives should be informed, while the Board explicitly states that the physician should always obtain the viewpoint of the relatives. In contrast, both the American Thoracic Society's and the Society of Critical Care Medicine's official statements regarding withholding and withdrawing therapy stipulate shared decision-making between physician and surrogate when the patient is incompetent [8, 19]. Thus, a greater agreement seems to exist between the preferences of the Swedish general public and American guidelines than between the Swedish population and the Swedish guidelines.

The ideal of more direct or indirect patient input in decisions to forego life-sustaining treatment is supported by American findings indicating that such decisions are often incongruent with a patient's prior preferences [20]. However, there are also arguments supporting the discretionary power of physicians. First, participating in the decision might be harmful to the patient. For example, in a British study, 19 elderly patients participated in a cardiopulmonary resuscitation decision concerning themselves and none of the patients seemed upset by the discussion. However, 1 week later six of them appeared distressed by the decision-making, two patients in an unequivocal fashion [21]. Second, although many members of the general public wish to make an advanced directive [22], many seriously ill patients do not wish to participate in end-of-life decisions. In a large American study more than 70 % of a group of patients with life-threatening diseases did not wish to discuss their preferences for mechanical ventilation with their physicians [23]. Third, it has been argued that it should not be the responsibility of the family members of an incompetent patient to make these decisions. In a Canadian study some family members thought that involving them in DNR decisions placed them unfairly in the role of deciding if their loved ones should live or die [24]. Fourth, close relatives often have poor ability to predicate a patients' life support preferences [25, 26] and therefore have difficulties acting as surrogates of the patient.

This study also has another interesting aspect. It challenges the idea of a north-south axis in Europe, in which North European physicians are more inclined to respect patient autonomy, while their South European colleagues have more paternalistic attitudes. For instance, one study showed a greater inclination of the former to inform their patients [27]. The present survey confirms that there is agreement in Sweden about the duty of physicians to inform their patients. However, the current study suggests that many Swedish intensivists feel an obligation to decide themselves when to withdraw

life support. This indicates that the principle of beneficence (in this situation) is more important than the principle of patient autonomy among physicians in Sweden.

In this article we have assumed that both the official policy and the existing practices of the health care system ought to be in harmony with the values of those involved in, or affected by, the decision to withdraw life support. Given this assumption, the results from our survey of the three different groups are obviously relevant to the ethical question: who should decide? However, those who answered our questionnaire only expressed their preferences, not their more basic values. These preferences may sometimes be due to inadequate knowledge about the hypothetical situation. Other arguments against increased patient and family influence are also indicated above. Thus, our results do not show that changes in policy and practice are required, but that such changes should be discussed. Health care professionals in general and physicians in particular should initiate this discussion both among themselves and in society at large.

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Appendix

Scenario with competent patient and questions

A 60-year-old married woman with severe cancer and pneumonia needs the assistance of a ventilator in order to breathe. The woman will die within 24 h if the ventilator is withdrawn. The woman's physician is completely convinced that she will die within a period of 1 month regardless of what treatment she receives. The woman is exhausted by her severe disease but *fully conscious* and able to express her wishes. The physician is considering withdrawing the ventilator and allowing her to die, so she will no longer have to suffer.

Do you believe that the physician should raise the question of continued ventilator treatment with the patient and family, i. e. the patient's husband and children?

1. Yes, with the patient only
2. Yes, with the family only
3. Yes, with both the patient and the family

4. No, the physician should not raise the question with the patient and the family
5. Uncertain

Assuming that the physician has brought up the question of ventilator treatment for discussion, who do you believe should decide whether or not the ventilator treatment should be continued?

1. The patient only
2. The family, i. e. husband and children, only
3. The physician only
4. The patient and the family together
5. The patient and the physician together
6. The family and the physician together
7. The patient, the family and the physician together
8. Uncertain

Scenario with incompetent patient and questions

A 60-year-old married woman was in a serious accident in which she suffered head injuries. One month later she is still unconscious and needs the assistance of a ventilator in order to breathe. The woman will die within 24 h if the ventilator is withdrawn. The physician is completely convinced that *she will not wake up*, although she might live for a while if the ventilator is kept in place. The physician is considering withdrawing the ventilator treatment and allowing her to die.

Do you believe that the physician should raise the question of continued ventilator treatment with the family, i. e. the patient's husband and children?

1. Yes
2. No
3. Uncertain

Assuming that the physician has brought up the question of ventilator treatment for discussion with the family, who do you believe should decide whether or not the ventilator treatment should be continued?

1. The family only
2. The physician only
3. The family and the physician together
4. Uncertain

References

1. Sprung CL, Eidelman LA (1996) Worldwide similarities and differences in the foregoing of life-sustaining treatments. *Intensive Care Med* 22: 1003–1005
2. Doyal L, Wilsher D (1994) Withholding and withdrawing life-sustaining treatment from elderly people: towards formal guidelines. *BMJ* 308: 1689–1692
3. Williams R (1993) The 'do not resuscitate' decision: guidelines for policy in the adult. *J R Coll Physicians Lond* 27: 139–140

4. The Swedish Society of Medicine (1991) When is physicians allowed to refrain from treatment (in Swedish)? *Lakartidningen* 88: 2165
5. The Swedish Board of Health and Welfare (1991) When should physicians refrain from treatment (in Swedish)? *Nord Med* 106: 239–240
6. American College of Physicians (1998) American College of Physicians Ethics Manual, 4th edn. *Ann Intern Med* 128: 576–594
7. American Medical Association Council on Ethical and Judicial Affairs (1991) Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA* 265: 1868–1871
8. The Society of Critical Care Medicine Task Force on Ethics (1990) Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. *Crit Care Med* 18: 1435–1439
9. Ashby M, Wakefield M (1993) Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: public opinion survey for a parliamentary select committee. *Palliat Med* 7: 273–282
10. Blendon RJ, Szalay US, Knox RA (1992) Should physicians aid their patients in dying? The public perspective. *JAMA* 267: 2658–2662
11. Genuis SJ, Genuis SK, Chang WC (1994) Public attitudes toward the right to die. *Can Med Assoc J* 150: 701–708
12. Singer PA, Choudhry S, Armstrong J (1993) Public opinion regarding consent to treatment. *J Am Geriatr Soc* 41: 112–116
13. Zweibel NR, Cassel CK, Karrison T (1993) Public attitudes about the use of chronological age as a criterion for allocating health care resources. *Gerontologist* 33: 74–80
14. Sudman S, Bradburn NM, Schwarz N (1995) Thinking about answers. The application of cognitive processes to survey methodology (1st edn). Jossey-Bass Publishers, San Francisco
15. Hansen MH, Hurwitz WN (1946) The problem of nonresponse in sample surveys. *J Am Stat Assoc* 41: 517–529
16. Sjkovist P, Sundin PO, Berggren L (1998) Limiting life support. Experiences with a special protocol. *Acta Anaesthesiol Scand* 42: 232–237
17. Melltorp G, Nilstun T (1996) Decisions to forego life-sustaining treatment and the duty of documentation. *Intensive Care Med* 22: 1015–1019
18. US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) Making health care decisions. A report on the ethical and legal implications of informed consent in the patient-practitioner relationship. Washington D. C.: U. S. Government Printing Office
19. American Thoracic Society (1991) Withholding and withdrawing life-sustaining therapy. *Am Rev Respir Dis* 144: 726–731
20. Alpert HR, Emanuel L (1998) Comparing utilization of life-sustaining treatments with patient and public preferences. *J Gen Intern Med* 13: 175–181
21. Sayers GM, Schofield I, Aziz M (1997) An analysis of CPR decision-making by elderly patients. *J Med Ethics* 23: 207–212
22. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ (1991) Advance directives for medical care – a case for greater use. *N Engl J Med* 324: 889–895
23. Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF Jr, Desbiens N, Lynn J, Phillips RS (1997) Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med* 127: 1–12
24. Webster GC, Mazer CD, Potvin CA, Fisher A, Byrick RJ (1991) Evaluation of a “do not resuscitate” policy in intensive care. *Can J Anaesth* 38: 553–563
25. Layde PM, Beam CA, Broste SK, Connors AF Jr, Desbiens N, Lynn J, Phillips RS, Reding D, Teno J, Vidaillet H, et al. (1995) Surrogates' predictions of seriously ill patients' resuscitation preferences. *Arch Fam Med* 4: 518–523
26. Suhl J, Simons P, Reedy T, Garrick T (1994) Myth of substituted judgement. Surrogate decision making regarding life support is unreliable. *Arch Intern Med* 154: 90–96
27. Thomsen OO, Wulff HR, Martin A, Singer PA (1993) What do gastroenterologists in Europe tell cancer patients? *Lancet* 341: 473–476