END OF LIFE

End of life decisions: attitudes of Finnish physicians

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Objectives: This study investigated Finnish physicians' experiences of decisions concerning living wills and do not resuscitate (DNR) orders and also their views on the role of patients and family members in these decisions.

Design: A questionnaire was sent to 800 physicians representing the following specialties: general practice (n=400); internal medicine (n=207); neurology (n=100), and oncology (n=93).

Results: The response rate was 56%. Most of the respondents had a positive attitude toward (92%), and respect for (86%) living wills, and 72% reported situations in which such a will would have been helpful, although experience with their use was limited. The physicians reported both benefits and problems with living wills. Thirteen per cent had completed a living will of their own. Half did not consider living wills to be reliable if they were several years old. Do not resuscitate orders were interpreted in two ways: resuscitation forbidden (70%) or only palliative (symptom oriented) care required (30%). The respondents also documented DNR orders differently. Seventy two per cent discussed DNR decisions always or often with patients able to communicate, and even 76% discussed DNR orders with the family members of patients unable to communicate. Most respondents were able to approach a dying patient without difficulty. They also felt that education in general was needed.

Conclusions: In general Finnish physicians accept living wills, but find they are accompanied by several problems. Many problems could be avoided if physicians and patients conducted progressive discussions about living wills. The differing interpretations of DNR orders are a matter of concern in that they may affect patient treatment. The promotion of patient autonomy with respect to treatment seems rather good, but the limitations of the study need to be kept in mind.

Finland has a long tradition of discussing and accepting various forms of end of life decisions. It was—for example, the first country (as early as 1971) where a diagnosis of brain death could be used to determine the official death of the patient. Assisted suicide is not unlawful, and a ventilator can be disconnected after repeated requests by a severely disabled but fully conscious patient. Euthanasia, however, is not legal. It is therefore surprising that little is known about the views of Finnish physicians in regard to these decisions.

Both health care professionals and lay people have generally positive attitudes toward living wills. In spite of these attitudes, however, few people have actually completed a living will themselves. According to our pilot study—for example, less than 5% of hospital patients at a university hospital had completed a living will.¹ According to studies in the United States, physicians generally have positive attitudes toward living wills. They are seen as a means of promoting the autonomy of patients, helping to improve decisions about treatment and helping to improve communication.^{2–3}

Living wills are often ignored, however, in decision making.^{4–6} Possible reasons for this discrepancy are the vagueness of the text of the standard living will and the non-availability of the will when needed.⁷ In addition physicians may think that patients do not adequately understand the content of the will or that patients may change their minds.^{2–3} A question has also been raised about the stability of living wills. In a study by Danis *et al* the living will was proved to be quite stable at two years' follow up.⁸ In Finland some organisations have instructed physicians not to trust a living will that is several years old.⁹

Do not resuscitate (DNR) orders are frequently used nowadays, but in practice there are wide local differences in their implementation. Who decides about the order, how it is noted, and what it really means in practice are often

questions to which there are no clear answers. According to studies in the United States, the DNR order is often the first step toward a palliative care policy.^{10–12} Ethical guidelines emphasise the autonomy of the patient in these decisions, but DNR orders are often given at a time when the patient's mental capacity has already decreased.¹³ Ashby *et al* found that physicians consider discussing DNR orders with a patient to be difficult and that they are afraid that the discussion may have a negative effect on physician-patient relationship.¹⁴ In another study, physicians considered conflicts with family members the most difficult aspect of DNR decisions.¹⁵ Usually patients wish to participate in the decision making,¹⁶ but some patients may misunderstand discussions on resuscitation, and, at worst, anxiety may be provoked in others.¹⁷

According to several studies, family members, physicians, and nurses cannot predict patients' treatment choices with sufficient accuracy.¹⁸ In addition patients do not necessarily consider autonomy very important. For instance, in the study of Puchalski *et al*, severely diseased older patients wanted the physician and family members to make the decisions concerning their care.¹⁹ Social reasons may sometimes count more than autonomy for patients—for example, a patient may say she wishes to receive active treatment because her husband is fearful about her death.²⁰

The aim of our study was to investigate Finnish physicians' experiences of decisions concerning living wills and DNR orders and their views on the role of patients and family members in these decisions.

MATERIALS AND METHODS

The questionnaire was pilot tested and then sent to 800 physicians who represented the following specialties: general practice (n=400); internal medicine (n=207); neurology (n=100), and oncology (n=93). After the first round, a new

questionnaire was sent to those who had not yet replied. The addresses were collected at random from the register of the Finnish Medical Association. We guaranteed the anonymity of the respondents by destroying the identification data of the questionnaires at the time they were returned. The ethics committee of the Helsinki University Hospital approved the study protocol.

The statistical significance of the results was tested using the Spearman correlation coefficient for numeric variables and the χ^2 test for categorical variables. We used the SPSS Windows version 9 to perform the tests.

The questionnaire covered the following categories of issues: living will, DNR orders, and common experiences and attitudes in decision making at the end of life. In addition, background information concerning the age, sex, specialty and work of the respondents was gathered. The Likert scale was used as the answering format for most questions.

RESULTS

The response rate was 56%. In addition, 45 questionnaires were returned without being filled in because the work addresses we used were out of date. The response rate of the general practitioners was slightly above the total response rate and that of the internists was slightly below it.

There were slightly more men than women among the respondents (52% versus 48%). The largest age group was composed of the 45 to 54 year olds (45%). The 35 to 44 year olds comprised one third of the respondents, those over 55 years of age accounted for one quarter and those under 35 years of age made up only 2% of the total.

Living wills

The majority of the respondents (92%) had a moderately or highly positive attitude toward living wills and only 2% had a moderately or highly negative attitude. Those who often cared for severely diseased patients in their work, had a positive attitude even more often ($p = 0.028$). One tenth of the respondents were often in a situation in which a living will would have been helpful in decision making, and 72% were sometimes in such situation.

The physicians' experience with living wills was limited. Less than half (45%) had been in a situation in which the will had been active during the process of decision making, and most of them had been in such a situation fewer than five times. In Finland a form for a living will has been published by the Ministry of Social Affairs and Health, and it has been made available—for example, in pharmacies. This was the one the physicians had encountered the most often (34%). Living will forms published by other organisations had been seen by one tenth of the physicians who replied that they had dealt with living wills, and wills formulated by the individual patients themselves had been seen by one fifth of this group. One third had accepted a verbal living will from a patient. Every third physician replied that not all of the living wills had been available when needed. If the living will was available, 86% of the respondents said it had, in general, some or a marked effect on the treatment of the patient. According to 14%, it did not usually affect decisions.

The questionnaire included, as an appendix, a copy of the form for a living will published by the Ministry for Social Affairs and Health. Altogether 77% agreed either totally or partially with the claim that it is easy to interpret and 16% disagreed.

Slightly over half of the respondents did not consider the will trustworthy if it was several years old, whereas 36% would still have had confidence in it. Older physicians were more suspicious ($p = 0.011$).

According to our study, most physicians respect the living will. A great majority (86%) agreed totally or partially with the statement that "by the time the living will is needed it should unconditionally be respected". One tenth disagreed with this statement. If the patient had no living will and was unable to communicate, most of the physicians (65%) were either totally or partially of the opinion that the family members' view would be conclusive. One third disagreed.

The most important advantages and problems associated with the living will according to the respondents are presented in tables 1 and 2.

Thirteen per cent of the respondents had completed a living will themselves, 60% having been documented orally and 40% being in written form. Physicians who often cared for severely diseased patients more often had a living will than other physicians ($p = 0.006$).

DNR orders

The purpose of a DNR order was interpreted in two ways, 70% considering that it forbade resuscitation and 30% believing it implied palliative (symptom oriented) care. The corresponding documentation in the case records also varied, 40% of the physicians simply having used the abbreviation DNR, 26% having used a red heart or other symbol, and 30% having written down the DNR order, including justifications for it and the name of the decision maker.

Two out of three respondents made the DNR decision usually or always alone. Physicians who often cared for severely diseased patients made the decision alone more often than others ($p < 0.001$).

Seventy two per cent of the physicians reported that they discussed the DNR decision always or often with a patient who was able to communicate and understand. One third discussed it sometimes or never. Those who often treated seriously diseased patients discussed DNR decisions with their patients less often than others. Even more physicians (76%) discussed DNR orders with family members in a situation in which the patient was unable to communicate. The majority (78%) also agreed totally or partially with the statement "the patient's view is decisive in the decision on DNR orders". Those who often treated seriously diseased patients disagreed with this statement more often than others ($p = 0.009$).

The most notable problems associated with DNR decisions, according to the respondents, are presented in table 3.

Experiences and attitudes

In their work the majority of the respondents had encountered seriously ill patients for whom withdrawal of active treatment may have become an option. Half of them had been in this situation sometimes, and 45% reported having confronted it often or very often.

Two thirds had sometimes been in a situation in which a patient with a poor prognosis would have wanted more active treatment than the physician offered. Even more (76%) had

Table 1 The most important advantages of the living will according to the respondents and the numbers of responses for each statement

Response	N
Promotes patient autonomy	363
Acts as an ice breaker in discussing end of life treatment	275
Makes decision making easier	261
Decreases stress	116
Total responses	432

Table 2 The most notable problems associated with the living will according to the respondents and the numbers of responses to each statement

Responses	N
"Wrong" reason for making the will (depression, fear of being a burden to the family)	236
Insufficient discussion of the content of the will due to lack of time	195
Possibility of the patient changing his or her mind	191
Patients poor understanding of the meaning of the will	183
Possibility of a family member affecting the will	111
Patient prevented from receiving needed care because of the will	83
Total responses	436

sometimes been confronted by a patient who wished for less treatment than was offered.

Half of the respondents reported that they always or often tried to discuss treatment decisions with a patient who was at high risk of becoming unable to communicate during the treatment. Younger physicians did this more often than others ($p = 0.038$).

Seventy per cent of the physicians agreed totally or partially with the claim that their ability to make decisions about end of life treatment was sufficient, whereas 16% disagreed. Those who often cared for seriously diseased patients agreed more often ($p < 0.001$). Sixty seven per cent would, however, have welcomed education on these decisions. Those who often cared for seriously diseased patients wished for education less often than others ($p = 0.036$), and younger physicians would have liked it more than others ($p = 0.026$). Most of the respondents (56%) considered it easier to withhold treatment than to withdraw it.

Two thirds of the respondents did not find it very difficult to approach a dying patient. Those who often cared for seriously diseased patients found it less difficult than others ($p = 0.002$). Still, however, 57% found that giving dying patients their prognosis provoked some anxiety. This step was easier for those who often cared for seriously diseased patients ($p = 0.003$). Slightly over half of the physicians tended to tell the prognosis to their patients as soon as possible; one third did not consider such immediacy to be important.

The respondents also had the opportunity to comment freely on the study issues. Their daily work was reflected in their comments: communication about DNR orders between different levels of health care was insufficient; decisions were made while on call without previous knowledge of the patient; haste and stress were prevalent, and guidance at work and basic education with respect to making decisions about end of life treatment were insufficient. One of the respondents wrote that the knowledge and skill related to making decisions about end of life treatment seemed to be transferred as a "tradition" from more experienced physicians to less experienced ones. Many felt that physicians did not dare take the responsibility of withdrawing treatment and that the consideration of palliative care alternatives began too late.

The living will was seen as problematic in that it offered the temptation to transfer the responsibility of treatment decisions to the patient, and also because it could be misinterpreted as a means of cutting costs and reducing physicians' workloads.

Some respondents also mentioned that discussing end of life decisions with patients and family members was very time consuming in that it had to be repeated over and over

Table 3 The most notable problems associated with DNR decisions according to the respondents and the numbers of responses to each statement

Responses	N
Difficulties in evaluating the patient's prognosis	221
Conflicts with family members	169
Uncertainty of sufficient justification for issuing a DNR order	124
Lack of general instructions for DNR decisions	103
Psychological stress associated with DNR decisions	52
Conflicts with the patient	24
Total responses	352

again in spite of a tight schedule. Even then, some patients never accepted the poor prognosis of their disease and that they could not be cured: some denied its existence. The physicians believed that the media supported the illusion that all ills could be cured, and they thought the expectations of family members, in particular, were often too high. Judicial claims of malpractice were also feared.

DISCUSSION

Living wills

As with studies done in other countries, Finnish physicians had, in general, a positive attitude toward living wills.²⁻³ They were considered helpful in decision making concerning the end of life. When they considered them more carefully, however, physicians also found many problems associated with living wills.

According to some studies in the United States, the most notable problem associated with living wills is how small an effect they have on patient care.⁴⁻⁶ From that point of view, it is surprising that most of the physicians in our study believed it was important to respect living wills, and also found them to have a moderate or major effect on the planning of treatment. We do not know, however, how such an effect works in practice. In addition, experience with living wills was limited among the respondents.

The living will is a general statement about the principles of care, and its vagueness may be a possible reason for its ineffectiveness in the United States.⁷ Therefore, it is also surprising that the physicians in our study considered the standard format of a living will to be easy to interpret. Again, it is not clear how easy such an interpretation is in real life decisions.

Emanuel²¹ has stated that ideally, the living will would be a continuing discussion process between the physician and the patient during the course of the disease. This would mean that the patient would have a better basis for deciding what they wanted concerning care, and the physician would acquire more information about, and become more confident of his understanding of, the patient's will. This step by step progress would help the will to be more effective. In our study only one fifth of the physicians reported having enough time to discuss the content of a living will with patients before its activation.

According to our pilot study, less than 5% of patients have completed a living will. The physicians in our study seem to be more active in this area, in that 13% of them had signed a living will. The physicians who often treated seriously diseased patients were more likely to have made a will than others.

Most of the physicians in our study did not consider living wills to be reliable if they were several years old. This attitude seems to be in line with some of the guidelines published in our country.⁹ Most living will formats do not, however, include instructions to renew the will. As physicians expect

wills to be renewed, patients should be instructed to do so when signing the will. Physicians should also estimate patients' capacity to renew the will, especially where patients are demented.

DNR orders

The original purpose of a DNR order was to forbid resuscitation, and this has remained its primary purpose as the use of such orders has developed. The physicians' views on the interpretation of DNR orders and their purpose were, however, divided. Almost one third of the respondents thought DNR orders implied palliative care. If the persons participating in patient care interpret DNR orders differently, the patient may not be treated optimally. If a DNR order is documented without any discussion about why it is being put in place, consideration of its necessity in the follow up stage, as well as the interpretation of its purpose, are difficult. One should also be able to dissolve a DNR order if necessary.

According to our study the need to promote patient autonomy seems well understood and respected in Finland. The majority of our respondents reported that they discussed DNR orders with patients always or often when patients were able to understand and communicate, and that they carried out this discussion with family members in other cases. This finding contrasts with the results of studies in the United States, according to which discussions with patients about DNR orders are rare.²²⁻²³ Some studies maintain that this rarity may be explained by the fact that, at the time the decision is being made, the majority of patients are unable to participate in the discussion.¹³⁻²⁴ In our study, half of the physicians reported that they tended to discuss treatment decisions in advance if the patient was at high risk of becoming unable to communicate. It is surprising that the physicians who often treat severely diseased patients discussed DNR orders with their patients less often than the other physicians, and also considered it less important than others. There are two possible explanations for this difference. Firstly, in the care of dying patients a palliative care orientation may be so clear to all parties that the DNR orders may not be needed. Secondly, Linkola found, in his study, that some physicians who treated dying patients became insensitive toward the needs of patients and the ethical aspects of their care, while others became more sensitive toward patients and more critical and careful about their care.²⁵

CONCLUSION

In summary, this was the first Finnish study to evaluate physicians' views about patient participation in decisions related to end of life care. Its weakness was the small number of specialties, and its strength was the high number of responding physicians. Another limitation is the fact that responses to a questionnaire may give a too positive picture of practice. In real life, haste, stress, uncertainty, and demands from different parties may seriously compromise the issue in question. In addition physicians responding to a questionnaire on ethical decision making probably also tend to pay more attention to the ethical aspects of their work. Furthermore, the respondents were specialist physicians. Thus the results of the study cannot be generalised to physicians with less experience. We have no information on the proportion of decisions made by senior versus junior physicians with respect to end of life treatment.

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