Decision to resuscitate or not in patients with chronic diseases

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ABSTRACT

INTRODUCTION: Do-not-resuscitate (DNR) decisions are frequently made without informing the patients. We attempt to determine whether patients and physicians wish to discuss the DNR decision, who they think, should be the final decision maker and whether they agree on the indication for CPR in case of cardiac arrest.

MATERIAL AND METHODS: We carried out a questionnaire survey among 112 haemodialysis patients and 17 physicians at department of nephrology, Herlev Hospital. The patients were interviewed orally, the physicians responded to written questionnaires.

RESULTS: The majority of patients (86%) and physicians (88%) answered, that patients ought to be involved in the DNR decision. However they both wanted to be the final decision maker. Most patients (69%) desired CPR in case of cardiac arrest. Physicians would attempt to resuscitate 88% of the patients. In 30% of the cases, the patient and the physician disagreed on whether or not to attempt resuscitation.

CONCLUSION: Both patients and physicians think they ought to make the final DNR decision. In practice, patients are often not involved. Since the patient and the physician disagree regarding the indication for CPR in one third of the cases, we must assume that many patients are resuscitated against their wishes. National guidelines are required.

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The do-not-resuscitate (DNR) decision is an ethical dilemma that all physicians face at some point. There is oral debate among physicians on whether to inform or even involve the patients in the decision-making, but there is almost no literature in Danish on the subject. Although the Anglo-American literature on this matter is comprehensive, it cannot make up for the lack of Danish publications because there are other laws and other traditions for DNR orders in the USA and the UK.

Ballin & Gjersøe published a survey on DNR procedures in Danish medical wards in 2007. They found that competent patients were always or often involved in the decision-making at 39% of Danish medical wards and they were seldom or never involved at 52% of Danish medical wards. Moreover, 81% of the wards had no written guidelines on the issue [1].

The aim of this study was to answer two questions: 1) Do physicians and patients desire to discuss the DNR order, and who do they think should make the final decision? 2) Do patients and their physicians agree on whether resuscitation should be attempted in case of cardiac arrest?

MATERIAL AND METHODS

Background information was found by searching the PubMed database for combinations of the following keywords: DNR orders, resuscitation order, decision, cardiopulmonary resuscitation (CPR), attitude, outcome and dialysis. Only articles in English were included. The search retrieved 265 items. Relevant articles were found by reading titles and abstracts. A few articles were found by secondary search from the references of relevant articles. We also searched the Cochrane database, but found no relevant papers there.

The questionnaire survey was carried out at the Haemodialysis Unit, Department of Nephrology, Herlev Hospital, Denmark, in May and June of 2007. We chose patients treated with haemodialysis because they are chronically ill and have a mortality rate of 20% per year which makes the DNR discussion relevant. An American study indicates that dialysis patients are similar to other elderly out-patients with regard to decisions about CPR [2].

All 23 physicians in the department were asked to answer the questions shown in **Figure 1**A. Seventeen physicians (74%) responded. Five of them were specifically allocated to the Haemodialysis Unit and all patients had a contact physician among those five. They were asked to evaluate each of their patients with regard to the question: “Is CPR to be performed in case of cardiac arrest?” (Figure 1B). This question was answered for 121 of 137 (88%) patients.

The patients were interviewed orally according to Figure 1C. In order to minimize bias, all interviews were carried out by one person. This interviewer tried to standardize the dialogue as much as possible, but when a patient had elaborate questions about the DNR decision, she found herself compelled to discuss the matter before repeating the question.

At the beginning of the study, 146 patients were treated in the Dialysis Unit. Six patients started treat-

ment during the period and were enrolled in the survey. Three patients were excluded in advance because of major psychiatric disorders. Five patients died, and two were away on journeys in the period and were therefore excluded. With five patients, we tried to get the interview, but failed, so they too were excluded (one retarded patient, one patient with a new tracheostomy, one patient fell asleep many times during the interview, one patient cancelled dialysis often and we therefore did not succeed in meeting him, and with one patient we failed to provide an interpreter). Thus, a total of 137 patients participated in the study. Among these patients, 112 (82%) consented to be interviewed. The questions were not validated because of lack of time.

All answers were handled anonymously. Each patient had an identification number to ensure that the preferences on resuscitation for patients and their contact physicians could be compared. For each patient we registered gender, age and ethnicity.

The statistical calculations were carried out using the SAS software, Version 7. Permission was not requested with the Regional Research Ethics Committee since this is not mandatory for questionnaire surveys. All patients were informed that the interview was absolutely voluntary. The Danish Data Protection Agency was not notified of this questionnaire since all answers were anonymized.

Trial registration: not relevant.

RESULTS

Out of 137 patients, 112 consented to participate in the interview, and 17 out of the 23 physicians answered the questionnaire. For 13 out of the 112 patients, we obtained no response from the contact physicians with re-

FIGURE 1

A. Questionnaire for all physicians at the Department of Nephrology, Herlev Hospital. All questions concern the do-not-resuscitate decision made previous to a potential cardiac arrest. The questionnaire only applies to competent patients. Questionnaire for physicians and number of answers stated in brackets. **B.** Physicians' evaluation of the indication for cardiopulmonary resuscitation and number of answers stated in brackets. **C.** Questionnaire for the patients and the number of answers stated in brackets.

A.

1. Who do you think should be the final decision maker when deciding whether to attempt resuscitation in case of cardiac arrest? Please mark only one answer.
- ☐ The nurses at the department (0)
- ☐ Any physician at the department (1)
- ☐ The contact physician of the patient (1)
- ☐ The physicians of the department jointly (12)
- ☐ The patient (4)
- ☐ The patient's relatives (0)

(One physician marked both "Any physician at the department" and "The patient")

2. Who do you think should be involved in the decision-making? You can mark more than one answer if appropriate.
- ☐ The nurses at the department (7)
- ☐ Any physician at the department (2)
- ☐ The contact physician of the patient (8)
- ☐ The physicians of the department jointly (13)
- ☐ The patient (15)
- ☐ The patient's relatives (5)

3. In case you do not think the patient should be involved in the decision-making, should he or she be informed?
- ☐ Yes (2)
- ☐ No (6)

4. Who do you think typically makes these decisions? Please mark only one answer.
- ☐ The nurses at the department (1)
- ☐ Any physician at the department (4)
- ☐ The contact physician of the patient (0)
- ☐ The physicians of the department jointly (12)
- ☐ The patient (0)
- ☐ The patient's relatives (0)

B. Patient number: X
- ☐ This patient should have cardiopulmonary resuscitation in case of cardiac arrest (84)
- ☐ This patient should not have cardiopulmonary resuscitation in case of cardiac arrest (12)

C. Patient questionnaire

1. If you should die while you were in dialysis, would you like us to attempt resuscitation or would you rather we did not?
- ☐ Want resuscitation (77)
- ☐ Do not want resuscitation (32)

2. If you should become so ill that it was relevant to consider not attempting resuscitation in case you were dying, in a situation in which you were still mentally well: Who do you think should decide whether resuscitation should be attempted? (You may choose more than one answer if appropriate)
- ☐ You (96)
- ☐ The staff (58)
- ☐ Your relatives (65)

3. (Only if the patient chooses more than one option in question 2). Who do you think should make the final decision?
- ☐ You (42)
- ☐ The staff (17)
- ☐ Your relatives (12)

4. Would you like the staff to bring up the subject, or would you rather we only talked about it if you brought it up?
- ☐ Want the staff to bring up the subject (69)
- ☐ Do not want the staff to bring up the subject (39)

5. (Only if the patient answers "the staff" in question 2). If the staff is to decide, which staff members would you prefer? (You may choose more than answer if appropriate)
- ☐ The nurses you know best (30)
- ☐ A physician from the department (6)
- ☐ Your contact physician (33)
- ☐ The physicians of the department jointly (15)

6. (Only if the patient does not answer "you" in question 2). If the decision was taken not to attempt resuscitation in case you were dying, would you like to be informed or would you rather not?
- ☐ Want to be informed (6)
- ☐ Do not want to be informed (6)

gard to indication for CPR. The contact physicians found indication for CPR in case of cardiac arrest in 87 out of 99 cases. Out of the 112 patients, 77 (69%) desired CPR in case of cardiac arrest and 32 (29%) did not. Three patients (3%) had no clear opinion. The 13 with missing evaluations plus the three who had no clear opinion were excluded from the calculations made to compare results. Answers from patients and physicians for the remaining 96 patients are shown in **Table 1**. In 29 of 96 cases (30%), the patients and physicians disagreed on whether to resuscitate or not.

We found a statistically significant difference between how many patients desired CPR in case of cardiac arrest (69%) and how many patients the physicians would offer CPR (88%). Statistical calculations showed $Z = 2.97$; $0.002 < p < 0.005$.

Most patients, 96 out of 112 (86%), would like to take part in the DNR decision. This corresponds nicely with previously published data from the USA [2]. The physicians agreed on this: 15 out of 17 physicians (88%) answered that patients ought to be involved in DNR decisions. Contrary to the agreement between the patients and the physicians concerning the involvement of the patient in the DNR decision, patients and physicians disagree when it comes to deciding who should make the final decision. The distribution of answers among patients and physicians are shown in **Figure 2**. Out of 14 patients who did not want to be involved in the decision, six patients would like to be informed, six patients would not, and two patients had no clear opinion on this. Out of only eight physicians, who answered the question: "If the patient is not involved, do you think, he should be informed?", two physicians answered "yes", whereas six answered "no".

DISCUSSION

According to this survey, most physicians think that patients ought to be involved in the DNR decisions, but it only seems to be common practice at 40% of Danish medical wards [1]. This indicates that many physicians may find that the patient dialogue is difficult to master. In 2007 only 8% of medical wards had guidelines on this matter, and Danish law is not very specific, as also stated earlier. Hence, it is, indeed, urgent to work out national guidelines.

Another interesting question is when the dialogue between patient and physician about DNR should take place. Should it be a routine procedure when the patient is admitted to the ward? And if so, how often should the procedure be repeated afterwards? According to this survey, if the discussion is postponed until the physician no longer thinks that CPR is relevant, we must attempt to resuscitate many patients against their wishes.

This survey shows a discrepancy with regard to the expediency of CPR between patients and physicians in 30% of cases. This is interesting because the DNR decision is often made without informing the patient as also demonstrated by. Ballin and Gjersøe in Danish medical wards [1]. Similar results were found in a Swedish study from 1997 [3]. This gives us reason to believe that many patients are being resuscitated against their wishes.

The Danish Health Act "sundhedsloven" is not very specific on the matter of DNR decisions. The obligation to obtain an informed consent from the patient is an often mentioned argument both in Danish [4] and foreign literature. But this obligation only ensures that no treatment can be initiated or continued without the patient's consent [5]. It gives the patient the right to renounce an offered treatment. It does not give him or her the right to demand any treatment for which there is no medical

TABLE 1

The preferences of patients and physicians on the indication for cardiopulmonary resuscitation in case of cardiac arrest.

	The patient desires CPR	The patient does not desire CPR	Total
The physician finds indication for CPR	61	23	84
The physician finds no indication for CPR	6	6	12
Total	67	29	96

CPR = cardiopulmonary resuscitation.

FIGURE 2

Figure 2**A**. Patients' and physicians' answers to the question "Should the patient be involved in the DNR decision?"

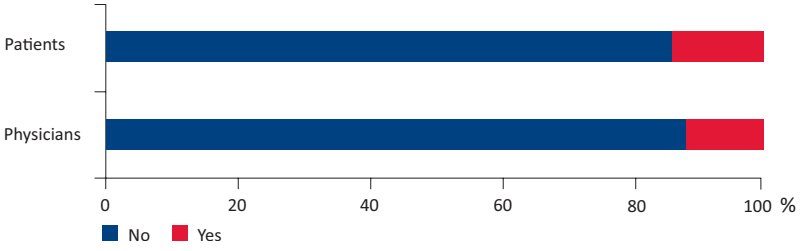
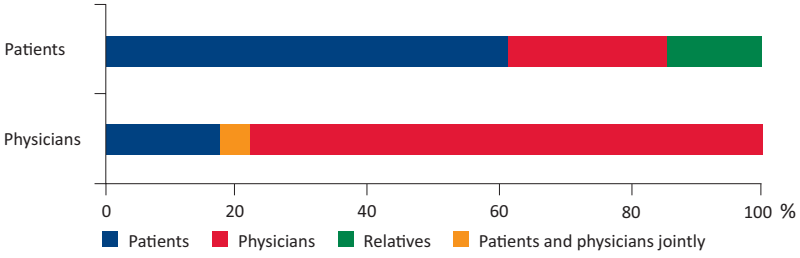


Figure 2**B**. Patients' and physicians' answers to the question "Who should be the final decision maker?"



DNR = do not resuscitate.

indication [6]. According to Danish law, patients have the right to be informed about their health, opportunities for treatment and the consequences if no treatment is initiated [7]. Consequently, the patient must be informed about the severity of his or her illness. However, Danish law does not state specifically whether he or she should be informed when the condition is so serious that some treatments are no longer considered relevant. If the patient is not informed, he or she misses both the opportunity to disagree and, furthermore, the chance of being transferred to another hospital where physicians may have another opinion. On the subject of terminally ill persons, Danish law states that physicians can omit the initiation of life-prolonging treatment in case the patient is no longer capable of exercising self-determination [8]. From this we deduce that, provided the patient is competent, he or she shall be offered life-prolonging treatment even when terminally ill. But can CPR be compared to life-prolonging treatments? If the physician is convinced that CPR is futile, it might not be.

The Danish Council of Ethics in 2002 published a report on the conditions of those who are dying. The report deals with the conflict that may arise when the choice of the competent patient runs counter to the physician's views of good medical practice. If a patient desires a treatment which the physician considers futile and of more harm than good, the council recommends that the physician take pains to accommodate the patient's wishes. It says: "If the patient is well informed and still wishes for some treatment the doctor considers unjustifiable, the doctor should seek advice from qualified colleagues and possibly entrust responsibility for treatment of the patient to another of these doctors" [9].

We have recently (January 2011) seen a public debate in the Danish media on this issue. The Secretary of Health, Bertel Haarder, stated that physicians shall generally inform patients about DNR orders. However, he also said that in specific cases, the patient ought not to be informed and that it is for the physician to decide when this is the case. Bertel Haarder advertised for guidelines and good examples to follow, but he also said that rules must not become too restrictive in this matter [10].

We suggest that all patients are offered a conversation with a senior physician about what to do in case of cardiac arrest. Of course, it must be stated as a benchmark that patients who suffer a cardiac arrest at a hospital are offered CPR. During this conversation, the physician shall clarify the patient's wishes for resuscitation and he shall contribute with his estimate of the risk for cardiac arrest and the chances for various outcomes after CPR. We believe that after listening to each other's arguments, the patient and the physician will come to an agreement in practically all cases.

Future challenges

This survey indicates a discrepancy between patients' and physicians' preferences regarding the DNR decision. This study is too limited in size to draw general conclusions, and the group of patients is too specific. Thus, to improve the situation, more research must be done with a bigger diversity of patients and physicians. Subsequently, we will need a debate among physicians which can lead to the establishment of national guidelines on how to make DNR decisions; are patients to be informed or even take part in the decision making process?

Limitations of the study

The artificial study context may have influenced both the patients' and physicians' answers since there were no consequences to the answers. If the study had dealt with real DNR decisions, both patients and physicians would have used more time for reflection. Furthermore, the dialogue between patient and contact physician about the individual patient's health and prognosis might have changed some answers. It is well-known that many patients have unrealistic expectations regarding the chances of surviving CPR [11], and that many patients change their positive attitude towards CPR after learning of the probability of survival [12]. A total of 25 patients did not wish to discuss resuscitation and it is a possibility that they, along with the non-responding physicians, differ from the responders.

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