

Do-not-resuscitate orders

Ethical aspects on decision making and communication
among physicians, nurses, patients and relatives

BY
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.ABSTRACT

Löfmark Rurik. *Do-not-resuscitate orders. Ethical aspects on decision making and communication among physicians, nurses, patients and relatives.*

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The purpose was to describe ethical aspects on how do-not-resuscitate (DNR) decisions are made, established, and communicated between physicians, nurses, patients and relatives.

A random sample of 220 physicians and nurses answered a questionnaire about their attitudes to and experiences of the making and communication of a DNR decision. The response rate was 73%. Twenty seriously ill patients, and 21 relatives of patients who died with a DNR order, were interviewed. The literature on medical futility was searched for conditions for futility and moral consequences.

The results showed that many physicians and nurses are uncertain about the rules and ethics of DNR orders. There are discrepancies between guidelines and attitudes regarding DNR orders, as well as between attitudes and behaviour. Seriously ill patients estimate open and straightforward conversations about treatments in the end of life. Relatives seem to get acceptable information and counselling. Conditions and consequences of medical futility may be approached in a new clinical way. There are numerous possible ethical conflicts within and between the principles of autonomy, non-maleficence, beneficence, and the virtues and ideals of the profession.

Start a dialogue about end-of-life support with chronically ill and elderly patients, and their relatives, while they still are capable of understanding and authorisation. The clinical conversation model may make it easier. All involved should understand why certain decisions are made. Conditions and consequences of futility should be ascertained together with the patients, the relatives and the staff, after which a joint decision can be reached.

Key words: DNR orders, futility, decision making, communication, physicians, nurses, patients, relatives, ethics

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ORIGINAL PAPERS

The dissertation is based on the following papers, which will be referred to in the text by their roman numerals:

- I Löfmark R, Nilstun T. Do-Not-Resuscitate orders - should the patients be informed? *J Intern Med* 1997; 241: 421-5
- II Löfmark R, Nilstun T. Deciding not to resuscitate. Responsibilities of physicians and nurses – a proposal. *Scand J Caring Sci* 1997; 11: 207-11
- III Löfmark R, Nilstun T. Informing patients and relatives about Do-Not-Resuscitate decisions. *J Intern Med* 1998; 243: 191-5
- IV Löfmark R, Nilstun T. Not if, but how: one way to talk with patients about forgoing life support. *Postgrad Med J* 2000; 76: 26-28
- V Löfmark R, Nilstun T. Experiences and attitudes of relatives: expectations of care are firm and diverse, but do-not-resuscitate orders are almost invisible. Submitted for publication.
- VI Löfmark R, Nilstun T. Conditions and consequences of medical futility – a proposal for a new clinical approach. Submitted for publication.

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PREFACE

After its introduction in 1960, cardiopulmonary resuscitation (CPR) became a treatment for more and more patients whose heart stopped to beat, but eventually the use of CPR for "all patients" was called in question. It became the attending physician's task to decide whether CPR should be attempted or not. "Do-not-resuscitate" (DNR) orders were introduced and decided without being documented, or even communicated to patients or relatives, as if the decision not to use CPR was something that should be concealed.

According to my personal experience, it was not always easy to make such a decision. In many situations the decision was requested offhand by the nurses, who otherwise were supposed to start the CPR. Some physicians regarded a DNR order equal to a death sentence, or to take away the last hope from the patient. Thus the patient was usually not informed about the DNR order.

That is why I decided to find out whether other physicians also thought this was a hard decision to make, and how they and other affected dealt with the situation. The subsequent period was filled with new perspectives from other physicians, nurses, patients and relatives, perspectives I had never thought about before. Many physicians and nurses were bothered with the decision making and the communication of this decision, but the final answer was not there. It then became a challenge to find a deeper understanding.

Abbreviations

CCU	Coronary Care Unit
ICU	Intensive Care Unit
CPR	Cardiopulmonary resuscitation
DNR	Do-not-resuscitate
APACHE	Acute Physiologic And Chronic Health Evaluation
PAM	Pre-Arrest-Morbidity
PAR	Prognosis-After-Resuscitation

BACKGROUND

The closed-chest cardiac massage (later called cardiopulmonary resuscitation, CPR) was introduced by Kouwenhoven *et al.* in 1960 [105], and this opened up for immediate resuscitative measures. Of their first 20 patients with cardiac arrest, three were defibrillated by a closed-chest defibrillator shock. All 20 patients were primarily resuscitated, and 14 were alive without central nervous system damage 10 months later. "All that is needed are two hands", the authors stated.

Initially, the method was used in the coronary care units and in the emergency departments, for patients without underlying chronic disease. Despite extensive training of physicians, nurses, paramedics and family members, this high success rate has never been reproduced for in-hospital patients. Today, survival until discharge is rather 0 - 20 per cent, depending on the cause of the cardiac arrest [12, 133, 159, 182, 203].

Instruments to predict the outcome after cardiac arrest treated with CPR have been developed: Acute Physiologic And Chronic Health Evaluation (APACHE), Pre-Arrest-Morbidity (PAM), and Prognosis-After-Resuscitation (PAR) [44, 66, 102, 140]. The studies are small, retrospective and largely uncontrolled, which limit the usefulness, and the scores seem not to have been used very much. However, they all give the same message: the older and sicker the patient, the worse is the prognosis. This prognosis can be calculated using the PAM and PAR scores in relation to survival after a cardiac arrest, at least for groups of patients (Tables 1a and 1b).

Experiences of DNR decision making and communication

The decision not to resuscitate is unique in health care as it is the only treatment decision that has to be made beforehand, i.e. before the event has occurred. Without a DNR decision by the physician, all staff are required to start CPR in the case of a heart stop even if it is obvious that this is not the best choice. Therefore, the DNR decision must be communicated at least to the staff. Eventually, patient autonomy has been emphasised and the demands to be informed have increased.

Decision making

After its introduction, cardiopulmonary resuscitation soon became "obligatory" for all hospitalised patients suffering from cardiac arrest, at least from the point of view of public relations [125]. It became an "open secret" within the profession in the US that withholding life-sustaining therapy was practised [60]. Also in UK, a notice was debated, directing which patients – in the case of cardiac or respiratory arrest – should be resuscitated and which should be not; those over 65 years of age or those with certain diseases fell under the interdict [100]. This happened in the beginning of the organ transplantation era,

Table 1a. The pre-arrest-morbidity (PAM) index and the prognosis-after-resuscitation (PAR) score. The range of scores for the PAM index is 0-25, while for the PAR score it is -2 to 28. [From O’Keeffe and Ebell, 1994]

Clinical characteristic	PAM index	PAR score
Malignancy	3	
Metastatic		10
Non-metastatic		3
Sepsis	1	5
Homebound lifestyle	3	5
Pneumonia	3	3
Creatinine >130 µmol/l		3
Creatinine >220 µmol/l	3	
Age over 70 years		2
Acute myocardial infarction	1	-2
Hypotension (systolic < 90 mmHg)	3	
Heart failure (NYHA class III or IV)	1	
Angina pectoris	1	
S3 gallop	1	
Oliguria (<300 ml/day)	1	
Mechanical ventilation	1	
Recent cerebrovascular event	1	
Coma	1	
Cirrhosis	1	

Table 1b. Survival to discharge following in-hospital CPR at each level for the PAM index and the PAR score. [From O’Keeffe and Ebell, 1994]

Score	Survivors/Total (%)	
	PAM index	PAR score
2-3	9/111 (8)	3/80 (4)
4-5	1/45 (2)	5/53 (9)
>5	0/17 (0)	0/59 (0)
>8	0/5 (0)	0/24 (0)

and the debate was often biased in that direction.

In 1974, the results of a questionnaire were published, showing that nearly half of the physicians in Iowa revealed that they frequently omitted life-prolonging procedures or medications in the care of these patients. The physicians believed that "terminal patients often realise that they are dying, though they rarely speak of it" [199].

In reports from USA, 6 to 22 per cent of the patients and 86 per cent of the relatives participated in the DNR decision [13, 111]. If the patients should become too sick to participate in decisions, 79 per cent wanted their relatives to make decisions, but 13 per cent preferred their physicians [111]. Of 322 outpatients, 97 per cent would opt for CPR in their current state of health. In the hypothetical circumstance of having senile dementia only 10 per cent would definitely want CPR, and 75 per cent preferred not to have CPR [158]. Among 371 geriatric, ambulatory patients 41 per cent opted for CPR before learning that the probability of survival until discharge is 10-17 per cent. Thereafter, only 22 per cent opted for CPR. The conclusion was that older patients have no problems to understand prognostic information. The more facts they get about the efficiency of CPR, the less they want it [134].

In UK, the traditional view has been that British patients are more likely than the American patients to trust their doctors to decide on their behalf [10]. One study has shown that patients are not distressed when discussing resuscitation [88]. This study indicated that most physicians (33 of 34) believe that patients do not want to discuss DNR orders. Another study showed that nearly half of 134 geriatric patients were unaware of the possibility of having CPR applied to themselves. The majority of them felt that selective application of CPR in the elderly was appropriate [75]. Later, British physicians have stated that it is important to find out what any individual patient would wish about participation in the DNR decisions [56, 69, 127]. However, some would not consider initiating a discussion about CPR with elderly patients where resuscitation would probably fail [181]. In another study, eight of the 13 patients with DNR orders wanted to undergo CPR, whereas 35 of the remaining 87, who would have been resuscitated in the event of an arrest, did not want CPR. In practice the patient is rarely consulted about CPR even if he or she is mentally competent [131].

Relatives are more likely to be consulted. However, one study has shown a lack of concordance about the patient's wish and the relative's idea of that wish (in 43 of 100 pairs) [131].

In Holland, one study has shown that DNR decisions are made in 6 per cent of all admissions to hospital, and that 61 per cent of all in-hospital deaths were preceded by a DNR decision. One third of the patients were able to participate in the decision, but of them, only a third were consulted or informed [205].

One study from the US has shown that only 24 per cent of the patients are mentally competent at the time the DNR order is made, compared to 79 per cent of the same patients on admission to the hospital [13].

The attitudes and experiences of nurses have also been studied. One study reported that about ten per cent of the initiatives to DNR decisions came from nurses [34]. In a Dutch study, 20 per cent of the nurses disagreed with the residents' DNR decisions for 68 of 148 patients [38]. In an American study, 50 per cent of the nurses (n=759) reported that they had acted against their conscience in providing care to the terminally ill. Seventy per cent of the house officers had the same experiences, mostly because of "overly burdensome" treatments. Twenty-five per cent of the nurses were satisfied with the patient involvement in treatment decisions, compared to 40 – 50 per cent of the physicians. Only 20 per cent of the nurses were satisfied with how patients' wishes were recorded in the medical journal [178].

Communication of DNR orders

Interviews with patients, family members, physicians and nurses about DNR decisions in USA have shown that 67 per cent of the patients wanted involvement in the discussions and 66 per cent did not think that discussing resuscitation was cruel and insensitive. However, 30 per cent of the physicians said they were uncomfortable discussing resuscitation with patients, compared to 9 per cent when discussing with family members [183]. Many patients want to discuss resuscitation [111, 183], but some do not [57]. Few, however, are involved in such a discussion, only 6 per cent of the patients according to one study [111]. In one study, 100 alert patients and their next of kin were interviewed, and almost all (88%) thought that doctors should discuss plans for CPR with them [131]. After the Patient Self-Determination Act in the US [141], more, but not all patients seem to be involved [109].

In Holland, only 14 per cent of the patients, (32% of the competent patients) had been involved in the discussion about their DNR order [205]. Another Dutch study showed that only 3 per cent of geriatric patients and 24 per cent of their families were involved [38].

A survey on DNR procedures in Swedish medical wards showed that advance DNR orders were used in almost all hospitals [7]. The most common procedure was an 'oral direction' by a superior physician to the nurse, who documented the order in the nurses' day-to-day work sheet. The DNR orders were signed by 28 per cent (80 of 286) of the physicians. A wide range of symbols and code words were used, and there was a considerable disagreement regarding the meaning of a DNR order. Such orders were often associated with withdrawal and withholding of life-sustaining treatments other than cardiopulmonary resuscitation. Seven per cent of the physicians stated that they always or often discussed the DNR order with the patients, and 33 per cent with the relatives. Eighteen per cent of the physicians commented that the question of withholding resuscitation treatment was discussed with the patient only on the initiative of the patient. There was considerable conflict with regard to DNR order procedures not only between internists in different hospitals, but also within individual hospitals. The more exact procedure for the DNR decision was not asked for, but some respondents spontaneously commented that the decision

of the senior internist was always made in consultation with the other ward staff, or only on the initiative of the ward staff.

Some authors have dealt with the views of the relatives before and after the death of the patient [88, 110, 127, 131, 215]. In one study, 461 relatives were asked about treatment and decision making during the patients' last month of life. Of them, 23 per cent could not recall any discussion about treatment decision, 44 per cent wanted better communication and 17 per cent wanted more time with the physician [79]. In another American study, 32 family members wanted advance planning, timely communication, clarification of the relatives' roles, facilitating family consensus and accommodating family's grief. "Behaviours that made families feel excluded, or increased their burden, included postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the full burden of decision making on one relative, withdrawing from the family, or defining death as a failure" were not appreciated [195].

Ethical considerations

The hindrance of a dialogue does not seem to have come from the patients, but from the physicians, as expressed by Thomas Percival in 1803, and transmitted through the generations:

"To a patient, therefore, perhaps the father of a numerous family, or one whose life is of the highest importance to the community, who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to reveal the truth. His right to it is suspended, and even annihilated; because, its beneficial nature being reversed, it would be deeply injurious to himself, to his family, and to the public. And he has the strongest claim, from the trust reposed in his physician, as well as from the common principles of humanity, to be guarded against whatever would be detrimental to him. The only point at issue is, whether the practitioner shall sacrifice that delicate sense of veracity, which is so ornamental to, and indeed forms a characteristic excellence of the virtuous man, to his claim of professional justice and social duty " [148].

According to Percival, the patient's best interest was the true goal of medicine. He stated that the authority of the professionals should guide the comprehension of the good attributes of medicine, and they are without exception bound to the medical responsibility. Since then, the autonomy of the patient has been strengthened, and paternalism diminished, at least in the guidelines.

One reason often used by physicians to avoid talking with patients about limiting life support, especially DNR orders, is that it will harm the patient [164, 196]. Other explanations may be that physicians feel uncomfortable [183], or that they simply do not know how to talk about such issues. The latter is in line with a proposal that "ideally, experienced clinicians should undertake such discussions to determine how much the patient wishes to get involved" [180]. However, many patients want to be informed and of 270 patients asked verbally if they found the questions disturbing, none said they did [158].

There are reports of physicians who state that the patients should be involved in the decision making and communication, but for some reasons this does not occur [34]. In these cases there is a discrepancy between guidelines and opinions, and/or between opinions and action. These acts of omission or negligence have not been studied in detail.

Earlier many physicians had a strong paternalistic approach to their patients. Most decisions were regarded as purely medical and made without informing or asking the patient. This was also generally accepted by most patients, and information about for instance prognosis was given only if the patient asked for it. Eventually, it was realised that many of the issues faced by physicians were not purely medical, but included different sets of values, not only the physicians' but also the values of the patients. The *autonomy* of the patient was emphasised, and the right to be informed strengthened. The awareness of medical ethics in clinical practice increased and old ethical principles were reformulated to suit the modern society. Besides autonomy, the principles of *non-maleficence* (avoid harm), *beneficence* (do good), and *justice* (do not discriminate and sometimes also the duty of solidarity) ought to be considered. Also *professional virtues*, e.g. respectfulness, truthfulness, faithfulness, responsibility, advocacy, persistence, courage, compassion, discernment, trustworthiness, integrity and conscientiousness, have been called to attention [11].

Possible ethical conflicts

At times, two or more of these principles cannot be fully respected and an ethical conflict is at hand. There may also be conflicts within the same principle, for instance when a DNR decision is made. Such a decision raises the question of who is authorised to make it, and a conflict within the principle of autonomy, more precisely between the patient's and the physician's autonomy, is evident. Other ethical principles and virtues are also relevant to DNR orders and may also conflict with each other, for example autonomy and non-maleficence, autonomy and beneficence, or truthfulness and non-maleficence.

Guidelines

In 1981, a woman died in New York as she was not offered CPR. A covert system of purple dots affixed to her chart was discovered, which started the first legislation on DNR [218]. This law [6] stated that every patient who had not consented to the issuance of a DNR order was presumed to consent to CPR. The patient's consent to a DNR order must be obtained by the attending physician in the presence of two witnesses. If the patient lacked decision making capacity, the attending physician and a concurring physician must certify in writing their opinions of the cause and probable duration of the patient's incapacity. The surrogate could consent to a DNR order only after a written certification by the two physicians that the patient has a terminal condition (that is expected to result in death within one year), that the patient is irreversibly comatose, or that resuscitation would be medically futile, or would impose an extraordinary burden in the light of the expected outcome. In the case of acute care hospitalisation, the DNR order must be reviewed every

three days.

Most countries have no legislation about DNR orders, but several have issued national guidelines, and there are also many guidelines at hospital level.

Over the world, guidelines have been up-dated continuously. A National Conference on Standards for Cardiopulmonary Resuscitation and Emergency Cardiac Care in the US had in 1974 made the following statement: "The purpose of cardiopulmonary resuscitation is the prevention of sudden and unexpected death. Cardiopulmonary resuscitation is not indicated in certain situations, such as in cases of terminal, irreversible illness where death is not unexpected" [136].

The first hospital policies on DNR orders appeared in 1976. One stated that these decisions were to be made by the responsible physician, whose only consultative duty was to answer questions about management raised by the patient and family. Active consultation with the family, but not the patient, was required only for acts of commission [142]. By contrast, another policy allowed a refusal of CPR initiated by the patient, regardless of the medical situation [153].

In the US, consent to administer CPR on hospitalised patients who suffer cardiac or respiratory arrest is presumed. However, two exceptions have been recognised. First, a patient may express in advance his or her wish that CPR be withheld. Second, CPR may be withheld if, in the judgement of the treating physician, an attempt to resuscitate the patient would be futile. Guidelines suggest that physicians should discuss the possibility of cardiopulmonary arrest with the patient or a surrogate if the patient is incapable of rendering a decision. DNR orders should not influence other therapeutic interventions that may be appropriate for the patient [34].

In UK, guidelines on CPR state that hospitals need to have policies of when to start resuscitation. There are three occasions when they consider non-resuscitation to be acceptable. First, when competent patients refuse resuscitation after having been told about the probable consequences by means of an "advance directive". Second, a DNR-order is also acceptable when a patient is not competent to give consent and a clinician judges CPR to be against the patient's best interests, e.g. some neonates and patients with persistent vegetative states. The third acceptable situation is when CPR is said to be futile as it will not benefit the patient [42, 209].

In relation to the four *prima facie* moral principles of *autonomy, non-maleficence, beneficence and justice*, world-wide guidelines discussed decisions to forgo treatment [193]. The target groups were a) patients who have decision-making capacity, b) patients who have executed an advance directive before losing this capacity, c) patients who have not, and cannot execute an advance directive, and d) patients who have never achieved decision-making capacity. Furthermore, decisions to forgo life-sustaining treatment under conditions of scarcity are discussed.

After some controversial cases of end-of-life care got publicity in Sweden, the Swedish Social Board of Health and Welfare formulated guidelines on life support in the end of

life [65]. They point out that the patient should decide, if possible, about forgoing treatment. The physician has a duty to "make the right diagnosis, a true prognosis and to communicate with the patient, the family and the staff about these issues" (sic!). The physician has to make the crucial decision and document the procedure of decision making.

Some guidelines have recommended that all patients should not be informed of their DNR status because of the distress to the patient. Any information must be given incrementally, and be guided by the patient's reaction to earlier information. The physicians have a duty to determine whether the patient wishes to enter into this discussion. Various strategies are available, of which the most common is to invite the patients to ask questions. Other approaches are to ask patients what sorts of interventions they are prepared to permit the doctor to undertake, or to ask patients well in advance. It is important to find out what any individual patient would wish [69, 140, 144, 164].

Most of the patients who die in the Intensive Care Unit (ICU) do so during the withholding or withdrawal of life support, and most of them are considered incapable of making medical decisions due to disease, medications and other factors [116]. This paper proposed that regular meetings should be held with experienced clinicians and the families from the time of ICU admission to discuss all medical matters including prognosis. Consensus should be reached by the clinicians regarding prognosis and other medical matters before they communicate with the family. Family members should be informed that they can help the patient best by articulating his or her wishes, instead of expressing their own wishes and what they themselves would want to be done. Discussions should be frank, informative and as consistent as possible. Withholding or withdrawal of life support should be recommended once clinicians agree that life support should be withheld or withdrawn, but CPR should not be the focus of discussions. Clinicians should inform the family that they are not obliged to provide unbeneficial care if the issue arises. Families should be told that life support will be withheld or withdrawn as humanely and expeditiously as possible. Clinicians should be as available to the family after the patient is diseased as they were previously [116].

Guidelines, specific for DNR orders have also been proposed in Sweden, suggesting that all patients should get an information letter at admission to the hospital saying that they are presumed to accept CPR unless they say no. All elderly patients, e.g. over 75 years, and patients with chronic, severe diseases should be involved in discussions at admission [58].

Futility as a reason for the DNR order

The concept of futility is frequently invoked by doctors as providing ethical justification for the unilateral withholding or withdrawing of treatment of marginal effect, for instance CPR. During the 1990's there was an intensive debate about both the meaning and the usefulness of the term "medical futility". Several books and hundreds of articles on "medical futility" have been published. Different perspectives and conclusions, theoretical

as well as empirical, have been put forward. Helft *et al.* [87] have called these discussions “The rise and fall of the futility movement” and grouped them into four main categories: definitions of medical futility, empirical data about futility, patients’ autonomy versus physicians’ autonomy, and attempts to resolve disputes over futility. In their opinion the term “futile” is very useful to describe how the physician feels about the patient’s care, but talking to patients and their families “should remain the focus” of the process for discussing futility.

Lack of knowledge about DNR decision making and communication

At the time for the planning of the present studies in early 1995 there was already a fair knowledge about the attitudes to and experiences of DNR orders. Some national guidelines were issued and a shift in the views on autonomy was noticed. However, in Sweden only one survey had been performed and the national guidelines were quite unspecified regarding the DNR orders. Almost nothing was known about the perspectives of the patients, nurses or relatives, and the procedure of DNR decision making was largely unknown.

AIMS

The overall aim of this thesis was to focus on ethical aspects on decision making and communication in the process of refraining from cardiopulmonary resuscitation in a Swedish context.

The following subsidiary aims were formulated:

- to explore whether the current recommendations are accepted by the health care professionals (I)
- to analyse the ethical implications of informing patients about their DNR order (I)
- to discuss some possible ways to distribute or share the responsibility to participate in a DNR decision among physicians and nurses (II)
- to suggest how these ideas may be incorporated in future guidelines (II)
- to survey the attitudes of Swedish physicians and nurses regarding information about a DNR decision to patients and their relatives (III)
- to test whether or not the clinical conversation may be used to explore if seriously ill patients want to talk about possible limitations of life support (IV)
- to explore the relatives' experiences of the situation before, at and after the death of a patient with a DNR order, and their attitudes based on these experiences (V)
- to study factual conditions for medical futility, and moral consequences that are permissible, desirable or required when medical futility is at hand (VI)
- to propose a clinical method which may be useful in "futility situations" (VI)

MATERIAL AND METHODS

This multitude of research questions and aims needs an approach with various methods. Thus, questionnaires, interviews and conceptual analysis were used to study the experiences and attitudes of the different study populations and of texts. To enable an ethical analysis, an ethical framework had to be established.

Ethical framework

The principles of autonomy, non-maleficence, beneficence and justice have been chosen. These describe the different sets of values and perspectives among those involved in decision making and communication of a DNR decision. The principle of *autonomy* requires respect for patients' deliberated choices to be made in accordance with their own values, consciences, and religious convictions. To effect such a respect, it is the responsibility of health care professionals to share information honestly and fully with patients, to enable them to collaborate fully in determining the course of their care, and to maintain patient confidentiality. The principle of *non-maleficence* declares that all persons have a moral obligation not to harm each other. Risks of medical practice can only be justified by the pursuit of other ethical values, i.e. benefits to patients sufficient to outweigh the harm. All persons have a prima facie moral obligation to benefit others, *beneficence*. Health care providers acknowledge a particular obligation to benefit their patients and to do so with minimal harm. Finally, the principle of *justice* states that all persons have an obligation to act justly or fairly to others [11].

However, in clinical practice these principles are not enough. Decisions have to be realised and communicated by the professionals, who consequently must have the ambition and ability to carry this out. In this context, the 'professional virtues' of ambition and ability are called *attitudes* and *behaviour* [52].

Subjects

In *studies I, II, III*, a comparison between physicians and nurses was projected, and it was desirable to find a group of respondents with experiences of the same kind of patients. The Swedish Cardiac Society is unique in this respect (in Sweden), that both physicians and nurses are members of the same society. A random sample of 10 per cent of all members, 104 cardiologists and 196 cardiology nurses was addressed. The response rate was 73 per cent.

In *study IV* the setting was a department of general internal medicine with 108 beds in a secondary hospital. Twenty-one consecutively admitted and seriously ill patients were asked to take part in the study. Three patients had a DNR order and the others fulfilled the criteria of serious illness, as indicated from the instrument called "Prognosis-After-Resuscitation" (PAR) [44]. A patient was regarded as seriously ill if he or she had six or

more PAR points. At this level, there is almost no chance of surviving a cardiac arrest, despite attempts of resuscitation (see Table 1, page 7).

Study V recruited relatives of patients who had died with a DNR order. A close relative of 59 of these "DNR-patients", not treated by the author, was asked to be interviewed, and 21 accepted. The 38 relatives who did not answer the invitation to be interviewed, were six months later approached with a short questionnaire, answered by 22 relatives, to investigate the reason or reasons why they did not participate (Appendix 5).

Data collection

Inspired by earlier surveys [7, 205], a questionnaire to elucidate the experiences and attitudes of physicians and nurses was developed (paper I and II). The purpose was to describe how these physicians and nurses regard their roles, their attitudes and duties towards patients and relatives, and their mutual relation in connection with DNR decisions. The questionnaire was tested in pilot studies with cardiologists and cardiology nurses not involved in the studies (Appendix 1). The respondents were asked to recall their latest patient with a DNR order, and with reference to this, answer questions about the involvement of patients, relatives, physicians and nurses, and if the respondents thought that the DNR decision was ethically right and well timed. It was also asked how the decision was documented and communicated, and what an ideal procedure would be like.

One year later a new set of questions regarding the attitudes to informing patients and relatives of a DNR order was sent to the same respondents, described in paper III. The analysis of the answers aimed at finding differences rather than similarities, to point at uncertainties in knowledge, attitudes and norms, and to identify issues in need of improvement. This questionnaire was inspired by Thomsen et al. [201] (Appendix 2).

In paper IV, an interview method close to clinical conversation was used in order to resemble clinical praxis. The patients received a written information with the following questions: "*Do seriously ill patients want to talk about their future prospects? And if so, how?*" (Appendix 3). All but one of the patients accepted to participate. The length of the interviews varied between 20 and 45 minutes. They were tape recorded and transcribed.

The relatives were invited by letter telling that "*the aim of the study is to investigate how the information to, and the dialogue between, seriously ill patients, their relatives, physicians and nurses can be improved in the end of life*" (paper V; Appendix 4). The interviews lasted between 40 and 85 minutes, they were tape recorded and transcribed. The 38 relatives who did not answer the invitation to be interviewed, were six months later approached with a short questionnaire to investigate why they did not participate (Appendix 5).

In *study VI*, the literature was searched with regard to the concept of 'medical futility'. An article was included if (1) the text was written in English, French, German or some Scandinavian language, (2) it was published between August 1980 and August 2000, and

(3) the main theses put forward regarding conditions and/or consequences of medical futility expressed the opinion of the authors. Thus, 43 articles were identified.

The regional ethical review board in Uppsala has approved studies IV and V. In studies I – III, no ethical conflicts were anticipated and ethical approval was not applied for.

Methods of analysis

In studies I – III descriptive statistics was used. Discrepancies from expected findings and patterns of uncertainties were searched for, and possible reasons for the divergences were analysed, using the ethical framework described above.

In study IV, recurrent themes in the interviews were identified and organised into eight main categories with the use of content analysis [55]. The aim was to identify different reaction patterns among “typical DNR patients”.

In study V, recurrent themes in the interviews and questionnaires were identified and organised into four main categories. For each of the categories, the text was searched for "meaning units", i.e. words or sentences indicating different themes [70, 119]. Finally, the text was examined in order to find factors that seemed to promote or impede good communication.

In study VI, the aim was to present a clinical alternative to formal definitions of futility. A combination of a method for conceptual analysis [210] and empirical statements on futility from the literature was used. The statements about futile measures were analysed using the scheme: "If certain conditions are satisfied, then a particular measure is futile" and "If a particular measure is futile, then certain moral consequences are implied".

Thus, the multitude of research questions and aims were approached in different study populations and texts, and analysed with various methods. The studies I - VI complement each other according to Table 2.

Table 2. Overview of study populations and methods considered in the various papers.

Paper	Focus on					Methods used		
	P	N	Pat	Rel	ME	Q	I	CA
I	x	x				x		
II	x	x				x		
III	x	x				x		
IV	x	x	x	x			x	
V	x	x		x			x	
VI	x	x	x	x	x			x

(P = physicians, N = nurses, Pat = patients, Rel = relatives, ME = medical ethicists, Q = questionnaire, I = interview, CA = conceptual analysis).

Time table for the studies in this thesis

1995 Questionnaire I, II

1996 Questionnaire III

1998 Interviews with patients

1999 Interviews with relatives

2000 Conceptual analysis of "futility"

RESULTS

The *experiences, attitudes and behaviour* of the study populations with regard to DNR orders were inquired for in two aspects, decision making and communication. The question of *timing*, i.e. the point of time when the DNR decision is made and communicated, good or bad, was also of interest.

Decision making

Experiences

The great majority (84%) of the physicians and 8 per cent of the nurses had made a DNR decision, and most of the respondents had participated in a discussion prior to a DNR decision. They were asked to recall their latest patient with a DNR order and 81 per cent could do so. At the time of the DNR decision 20 per cent of the patients were able to take part in the decision making, but only a third of these patients were included. However, almost all of the respondents (96%) stated that the decision was ethically right.

Attitudes

Half of the physicians and nurses (56%) thought that the patient should make the DNR decision themselves, or at least be included in the decision making (53%), but a substantial part (28-38%) were uncertain. Almost all (96%) were of the opinion that the physician should participate in the decision making, and most of the physicians (81%) and the nurses (92%) thought that the nurses should participate too. However, some physicians (13%) stated that the nurses should not be involved. There was a general agreement that physicians should make the DNR decision, but more than one third of the nurses answered that they could sometimes make such decisions, albeit not alone, and some of the physicians (16%) were of the same opinion. Half of the physicians and little more than half of the nurses thought that the patient should be consulted.

When deciding about the conditions for futility, certain facts and values must be ascertained. The type of measure and its effect in the individual situation have to be united with the goals, specified by the patient and/or the physician. Most of the authors of the 43 articles expressed more or less theoretical statements, but a few presented empirical data. Most authors also stated that they thought of physicians as decision makers, in three cases together with patients and in one case together with relatives. Six articles mentioned the health care team or guidelines. In two single cases the patient's or family's opinion were exclusive. In one article the authors stated that if no medical benefit was expected, the physician should decide, while the patient was to determine whether he or she would expect "an unacceptable quality of life". All but one article implied that some kind of treatment might be futile. Two articles mentioned diagnostic measures, and one article included caring measures. Also the possible goals have to be stated as conditions for futility, which 40

of 43 articles did, six of them physiological goals and 11 of them life prolonging goals. Most often "quality of life" was emphasised and in four articles patient's or surrogate's goals were mentioned. The probability of success in relation to the measure and the goal of the individual situation was to be stated in numerical terms, according to four articles, while 29 described different semi-quantitative probabilities. In ten articles there were no suggestions at all, and four gave more or less qualitative descriptions.

When deciding about the moral consequences of futility, 13 of 43 articles did not mention any options. One stated that it was not permissible at all to withhold or withdraw treatment, while three articles discussed differences related to "permissible, desired or required" to do so.

Regarding the final decision making, 19 articles recommended that the physician makes a unilateral decision to withhold or withdraw a futile measure. Four proposed the possibility of a second opinion or appeal if the patient or surrogate disagreed. Advance directives were recommended by three, of which one also recognised that they were not always followed. Over the years more and more articles recommended joint, "group process" or compassionate decision making, physicians and patients together.

Differences of attitudes between American and British physicians were also noticed. According to the authors, the former are more patient oriented, implying that the patient should decide, and the latter seem to be more paternalistic [128].

Behaviour

The precise procedure for the DNR decision was not asked for in the questionnaires. Three of the 20 interviewed patients had got a DNR order, although all of them were seriously ill, according to the prognostic index.

Timing

Most of the responders thought that the DNR order was well timed, or perhaps somewhat late. However, quite a few were uncertain. Of all 59 patients with a DNR order in study V, the point of time of the order was documented for 40. The mean was five days before death and the median two days before death.

Communication

Experiences

Almost all patients were positive about the opportunity to talk about their future prospects: "This was the best talk I ever had" (patient 4), "I think you should talk with all patients in this way" (patient 5). Two patients thought it was difficult and one patient avoided answering the questions. Most patients seemed to be relaxed when talking about their situation, but a few said that certain issues were difficult to discuss.

The communication was influenced by the moving around of the patient who met new doctors and nurses, "First in the surgical ward, then the medical, and the geriatric, and back to medicine again. Different rooms in every ward. Each time she [the patient] appeared to be more confused" (I10). Some relatives got no or only little information, but other relatives were very pleased. Many relatives felt reasonably well informed about the diagnosis, prognosis and treatment by the doctors and nurses and quite a few had discussed forgoing of CPR or other forms of life support. Only one mentioned spontaneously that withholding of CPR was ordered, "Over the phone a nurse told us that they were not going to do anything. So we hurried to the hospital" (I12). One relative was ill at ease having to be a proxy, "My brother was very headstrong and had never listened to me, but when he went ill I had to make the decisions" (I09).

After 3 - 6 months many of the relatives had reflected upon unanswered questions and some wanted to get in touch with the hospital to have more information. Some relatives were also offered such a meeting. Some relatives met the doctor afterwards and this was much appreciated, "We had got some distance to it and could sort out some misunderstandings" (I06).

Attitudes

Half of the respondents stated that DNR orders should be discussed with the competent patient, while nine per cent thought that the patient should not be involved. About half of the physicians and nurses thought that the patients should be included into the discussion. However, about one-third of them were uncertain. Almost all thought that the physician should participate, and 80 to 90 per cent that the nurses also should be involved.

The intention of the physicians and nurses to communicate a DNR order was influenced by the patients' and relatives' interest to know. If they did not ask, about one third to half of them would not be informed.

Most of the interviewed patients wanted an open and straightforward discussion. Some patients expressed that it is the physician's responsibility to create an open and straightforward discussion. "It is the doctor's responsibility to tell" (patient 7), "You should not sneak about it" (patient 15), "You should not keep it secret" (patient 19).

A few patients believed talking might be too painful for others. Only one patient said it was not a good idea to talk about his prognosis. Some patients would accept a family member joining in the conversation. A few patients suggested that the physician should talk to the family alone. Others hesitated: "My wife, yes, but you mustn't worry her" (patient 5). A few were not interested: "No, I think that you should talk in private" (patient 10). The reasons for participation varied, but no patient said that it would be solely for his or her own good.

Most patients would accept a nurse to participate in the discussion. Some were less certain, and others were negative. Some patients considered that the district nurse or dea-

coness was the best one to participate. No one named any of the attending staff nurses.

Many relatives commented on situations and attitudes influencing the communication. Personal relation with the staff and accessibility of information were important. Some emphasised the reassurance, "All the time we felt that everything was done" (I10).

The communication of facts and values regarding the conditions and consequences of futility was also studied. In 27 articles (of 43) the authors recommended a dialogue with the patient and family before decision making, but quite a few (9 of 43) stated that no information was needed when a futile measure was to be withheld or withdrawn. Seven of the nine articles were published before 1994. Unidirectional information was recommended by four, and in one article the authors tried to make a distinction between "full information" and "dialogue" in relation to the goals (physiological goals versus goals expressed by the patient).

Behaviour

Of the nurses, 36 per cent stated that they had initiated the discussion within the health care team and another 45 per cent answered that some other nurse had taken the initiative. The physicians believed that they initiated most of the discussions. Usually, one nurse and more than one physician seem to have participated in the discussion.

The prognosis was discussed with all the 30 patients judged to be competent, and the DNR order with 10 of them, usually by the initiative of the patient.

One third of both the physicians and nurses believed that there are patients who want information about DNR, but do not receive it. A sixth of them thought that some patients get information that they do not want. Half of the respondents were uncertain.

Three of the 20 patients who were interviewed had a DNR order. None of them had talked with the physician about it, and none of the other 17 patients had heard of the possibility. Almost all patients were positive about the opportunity to talk about their future prospects, for instance: "This was the best talk I ever had" (patient 4), "I think you should talk with all patients this way" (patient 5).

Some relatives were very pleased when coming to the emergency department, "They stood there waiting for us" (I13). Some seemed to have high expectations, which often were fulfilled, "If you just told them, you got a pain killer at once" (I02).

Of the 21 patients who died with a DNR order, only two were informed about the DNR order, according to the case book.

Timing

One relative who had not been in the hospital was informed at the deathbed, not only about the cause of death, but also that an autopsy was planned (I01). One wanted to talk with a doctor or a chaplain, "But it was not an option in the middle of the night, so I became angry" (I15). Some relatives were informed over the phone, and some of them hur-

ried to the hospital only to be too late.

To confirm death in front of the relatives or to ask about autopsy at deathbed caused negative feelings, "When we took farewell a doctor came to certify the death - that was not good" (Q09). "We disliked that the physician within minutes after the death brought up the question of an autopsy" (Q10).

DISCUSSION

The ethical framework will be discussed first. This will be followed by a discussion of the different persons involved in the DNR decision making and communication process. Their experiences and attitudes can hardly be investigated in one single study. That is why several different inquiries have to be made. Several methods have been used and the pros and cons are weighted. Finally, the results of the present studies regarding decision making and communication are scrutinised and compared with relevant data from other studies.

Ethical framework

Most of the articles about DNR orders have explicitly or implicitly touched upon ethical principles. Decision making and communication are both related to the ethical principle of autonomy. To enable the patient to make use of his or her autonomy, the physician should, if possible, communicate adequate information to the patient, who must be capable of understanding and authorisation. This communication may cause damage to the patient if made in a wrong way, and according to the principle of non-maleficence, harm is to be minimised. Both decision making and communication have also connections with the principles of beneficence and non-maleficence. The physician's autonomy is often related to beneficence, which encompasses fundamental goals of medicine: preservation of life, restoration of health, relief of suffering, restoration or maintenance of function. When a physician makes a decision without hearing the patient, the physician is acting paternalistic even though beneficence is invoked. Moreover, the ethical principle of justice may be overridden when, for instance, patients with different diseases but similar prognosis are treated unequally.

These four principles, though individually ancient, have been re-articulated in the bioethics literature by Beauchamp & Childress [11] and they are widely accepted over the medical world [193]. Besides these principles, there are moral philosophical theories that may be used for ethical analyses, for instance, utilitarianism (consequence-based theory) and Kantianism (obligation-based theory). Both try to deny much of what the other affirm, and none of them is sufficient to solve all the subtle variations of ethical problems in health care. There are also many ethical rules, such as veracity, confidentiality and fidelity, which are important in health care, but they are not enough for a comprehensive ethical frame-

work. Instead, they may correspond to several of the virtues invoked in health care ethics [11].

Subjects

A representative sample of the respondents is needed to be able to generalise the results. In this case both physician and nurse members of Swedish Cardiac Society were addressed as they were expected to meet the same kind of patients, but nevertheless have different perspectives. The Swedish Cardiac Society is the only professional federation in Sweden that includes both physicians and nurses. However, members of a professional federation are not identical with non-members, which may limit the representativity. Some physicians declined to answer the questionnaires as they had no responsibility for DNR decisions. Some were researchers or in other ways no longer clinically active. The main part of the nurse members worked in CCUs, and some were engaged in research.

The patients interviewed were, according to a prognostic instrument, "typical DNR patients", with very low probability to survive a heart stop. They were consecutive in-hospital patients from a department of medicine in a secondary hospital. After six months half of them were dead, which was anticipated from the prognostic instrument. A sample of this kind is not unique, and can probably be found in every department of medicine.

The relatives who were interviewed are hardly representative for all relatives of patients who have died with a DNR order. Only one third of all invited volunteered to be interviewed. Another third of the relatives answered a questionnaire and gave similar reports. However, they seemed to be better informed during the hospital care. They were also less often children of the patient, which may signal a difference of generations.

The authors of the articles on futility were composed of both experienced physicians and moral philosophers. In this study, the main objective was to find the variety of conditions and consequences of futility, and the representativity of the authors is less important.

Data collection

The methods most often used in empirical research of ethical issues are surveys, interviews and conceptual analysis, often in combination with empirical data. Sometimes also field research or historical-comparative research methods are used [137]. In the present studies (I-VI), surveys, interviews and conceptual analysis have been used in an attempt to illuminate a multitude of perspectives. The nature of the studies is mostly explorative.

The face validity of the questionnaires was increased by pilot studies carried out among cardiologists and cardiac nurses of two different hospitals. Many questions were derived from other surveys with similar ends [7, 205]. However, the content validity of some of the questions in the first questionnaire (Appendix 1) ought to have been better controlled. For instance the questions about the initiative to the DNR decision making, which gave rise to answers difficult to interpret.

The reliability of the questionnaires can be assessed by comparing the results with

other studies, performed in a similar way [7, 13, 88, 111, 131, 205].

The interviews with the patients were close to the clinical conversation in order not to deviate from clinical practice. This is an approach all physicians have learnt and one with which all patients are familiar with and expect. The structure of this method proved to be very successful and made most of the patients ready to talk about fundamental questions of life and death. It was also quite easy to get an idea of the patient's values and understanding of medical issues. Most of the patients did not think that the conversation was bothersome. On the contrary, it was met with approval.

The interviews with the relatives also resembled the clinical conversation. The aim was to collect as many different experiences and opinions as possible. Thus, an open hearted and free discussion was desirable. A survey to the relatives had probably not given such in-depth results. However, the "drop-out questionnaire" with one open-ended question also gave some information, although little additional.

In the data collection for the futility study, the relevant literature was used. Medline was searched, giving many hundred "hits" for "medical AND futility", and two books were incorporated in the material. Again, the purpose was not to identify frequencies, but to find as many different statements as possible to be able to create a useful clinical approach to the problem.

Methods of analysis

The purpose of these empirical investigations was not to generalise the frequencies of different answers. Instead, it was to identify issues for open and professional discussions about possible differences between the ideal situation and the reality. It was therefore desirable to find a multitude of experiences, opinions and problem areas. In this survey, "uncertain" is an answer of the same dignity as "yes" or "no", since special actions may be warranted, e.g. education.

Descriptive statistics have been used in paper I-III. As there was no intention to generalise frequencies, inference statistics and significance analysis are not relevant.

In the interview studies, IV and V, two slightly different methods of content analysis of the texts have been used. The texts were searched by both authors to find "meaning units", i.e. words or sentences indicating different themes. The texts were also examined in order to find factors that seemed to affect communication among patients and relatives, physicians and nurses.

Regarding the conditions and consequences of futility (paper VI), a conceptual analysis was performed, using a method first described by Wedberg [210], which includes a two-step scheme. From the collected data four kinds of conditions and three kinds of consequences were extracted. Usually there was no difficulty to understand the positions expressed by the authors, but in some cases the interpretations were uncertain. A few authors focused solely on conditions, others on consequences, although the two are always related

in the clinical situation.

Results

Decision making

The following section, discussing decision making, will be structured with regard to the different agents and affected. Regarding futility, the decision making involves two different types of decision. First, who has the authority to decide about what conditions make a particular measure futile? Second, who is to decide the proper moral consequences, i. e. if it is permissible, desirable or required to withhold or withdraw the measure?

Physicians

The physician has the duty to make the final decision to use or forgo CPR in case of heart arrest. When forgoing CPR, the physician should, if possible, know the diagnosis and prognosis for certain and that efficient treatment is unavailable, according to Swedish recommendations. The patient, the staff and the family should be consulted. Good care must always be given and the autonomy of the patient respected [65]. These recommendations are much more patient-oriented than those of the 1970s [142, 153], and were in force in 1995-6 when studies I-III were performed.

Still, at the time for the studies, only one third of the competent patients were included in the DNR decision making in Swedish hospitals. Contrary to the recommendations, only half of the physicians thought that the patient should be consulted. Of interest is also that over a third of the physicians were uncertain about involving the patient in the decision making. The reason for this is unknown, but it has over the years been said that patients must not be worried with unpleasant issues [10, 148, 164]. Another reason may be that physicians feel uncomfortable discussing CPR with patients [183]. Furthermore, physicians have perhaps not been trained to discuss such issues [180]. Another explanation may be that physicians are not familiar with the rules. However, in 1990 a Swedish survey [7] showed that involvement of patients was less than ten per cent. This shows that a development of patient's rights has occurred over the years. Both in the US and UK the situation as to the guidelines is similar [34, 127, 141], but when it comes to practice many patients are still unheard [117].

The patients in study IV assumed that the physician has a duty to give information, and they also wanted to take part in the decision making.

Diagnosis, treatment and prognosis are important factors in DNR decision making, as well as the goals of treatment. This is discussed in paper VI, where a new clinical approach concerning "futility" is proposed. It separates conditions for futility from its moral consequences. Used systematically, this method may make it easier to gather the necessary conditions for futility, and make the relevant values visible.

Most of the medical ethicists, many of them are physicians as well, regarded the physi-

cians to be the final decision makers, in almost half of the cases in a unilateral and paternalistic manner. However, joint decision making seems to increase with time.

Patients

Half of the physicians and nurses believed that the patients should be consulted or make the DNR decision themselves (paper I), but only one third of them were involved. Furthermore, over one third of the responders were uncertain. This may reflect that the physicians and nurses do not know, or fully accept, the official recommendations.

Only one of the 20 interviewed patients (paper IV) had any substantial knowledge about CPR. There are studies showing that television programmes are the main source of information and education about CPR [127, 166, 167]. In UK, one study showed that a quarter of patients in British television medical dramas who received CPR on screen seemed to survive. The overall survival rate of patients after CPR seems to be more realistic than in American medical dramas [73]. Thus, all patients are not sufficiently informed to make a well-founded decision to forgo CPR.

Some of the medical ethicists emphasised that the patient should make an advance directive, or take part in a joint decision making, but thought that the patients' view did not count too much anyway (paper VI).

A recent Swedish study about CPR on heart failure patients [219] gives the possibility of comparison with study IV, in certain aspects. The patients in their study were not as ill as the patients in paper IV. Only one of the 40 patients had discussed CPR with the physician. Their knowledge about CPR performance was quite good, but almost all of the patients overestimated the good effect, and half of them were unaware about the risk of suffering severe brain damage due to a protracted period of oxygen deficit. The majority of the patients would like the physician to bring up the question of CPR and welcomed the opportunity to discuss the issue. However, they seemed to be pleased with the information, and said they would, in the end, leave the final decision to the physician. Most patients had never thought about CPR, but 90 per cent of them were willing to undergo CPR at the present time, and two thirds would opt for CPR even though the chance of survival was five per cent or less. None of the patients felt uncomfortable or distressed whilst discussing the subject with the interviewer. Apart from the better knowledge and willingness to receive CPR, the results of this study are very similar to those of paper IV. Also the method of 'clinical talk' is presented in a similar way, and together the two articles increase the validity of the method [219, IV].

In some countries there is an opportunity for patients to make advance directives, i.e. to sign a document telling the health care givers what the patient wants, in the case he or she no longer is capable of decision making or communicating. In Sweden, the possibility of advance directives has not been developed to the same level as the US, where they are strongly recommended [27, 28, 29, 45, 74, 76, 83, 93, 99, 132, 145, 147, 149, 155, 186, 192, 213].

The clinical impression in Sweden is that more and more patients want to declare their opinion of rejecting life support in certain situations. This possibility is mentioned in recent guidelines on CPR [187], but there is also stated that advance directives, or living wills, have no legal validity in Sweden. However, a statement from the patient opens up for a discussion in the future, and advance directives are thereby desirable.

In UK, a recent paper shows that 82 per cent of medical in-patients (n=76) had not heard of living wills, advance directives, or advance statements. However, after explanation, 74 per cent expressed interest in writing a living will, most commonly because their views would be known, and to relieve the burden of decisions on their family [165].

Nurses

The Swedish recommendations state that the staff should be consulted before a DNR order is issued. This was found to be well recognised among both nurses and physicians (paper II). In this survey many nurses declare that they can make such a decision themselves and some physicians think so too. However, this statement must be confirmed by more refined methods, e.g. with interviews. To include nurses in DNR decision making does not seem to have been an option in other countries, but there are several studies where nurses' views on DNR orders are compared to physicians' [22, 31, 41, 120]. Most of them report minor differences ($\pm 20\%$) between physicians' and nurses' views. One of them [43], focuses on the "*slow codes*", which are CPR efforts "that involve a deliberate decision not to attempt aggressively to bring a patient back to life. Either because the full armamentarium of pharmacological and mechanical interventions is not used or because the length of the effort is shortened, a full attempt at resuscitation is not made". This is a wellknown concept in the US, but it has not been studied in Sweden.

Some patients in study IV allowed nurses to take part in the DNR information but did not regard them as decision makers. A few of the medical ethicists mentioned nurses as a part of the health care team, who might have a decision making authority (paper VI).

The clinical impression is that nurses often have more information about the views of the patient and the family than the physician, and it is therefore important to use this information in decision making.

Relatives

Relatives are not often mentioned as decision makers in Sweden. The situation is different in US, where they may become legal surrogates. About 10 per cent of the responders in paper III were "relative-oriented", but we do not know if they would allow the relatives to make the decision.

Only a few of the interviewed patients thought that the family should decide in their place (paper IV). Some relatives were happy that they did not have to take responsibility to withhold or withdraw treatment. However, one of them was distressed when her "head-

strong” brother was not competent any more, and she felt obliged to make decisions for him (paper V).

Among the medical ethicists, only one article proposed that relatives should be decision makers (paper VI). Some others thought that the patient and family should make joint decisions.

Different aspects on DNR decisions

After the studies I-III were performed, the literature was again searched for DNR decision making. Many aspects of this theme have evidently gained interest, e.g. *DNR decision making in general* [31, 32, 54, 109], the *timing of the DNR decision* [40, 77, 169], the *autonomy of the patient* [53, 150, 162], *patient’s consent* [5, 96, 106, 177], *competence* [22, 39, 129], and *understanding of a DNR order* [62, 97, 113, 169, 191, 211].

Also *DNR against the wish of patients* or relatives [107], and *changes in preference of patients* [72, 160] have been discussed in recent years. Some papers have focused on the *frequency of DNR orders* [59, 95, 171, 175, 179, 197, 206, 212, 216], and *compliance with DNR orders* [67, 157, 176, 197], *the age of the patient* [19, 24, 33, 36, 61, 64, 78, 138, 161, 181], as well as *cultural* [63, 68, 81, 90, 104, 115, 124, 152, 163], *ethnic* [194], *racial* [64, 172], *psychosocial* [143], *economic* [8, 17], or *sociodemographic* [194] influences. Other papers have described special problems: *DNR orders in the operating room* [1, 9, 18, 30, 35, 71, 121, 130] or *X-ray department* [86, 93, 135]. *Iatrogenic heart arrests* [26] or patients with *various diagnoses* [2, 3, 91, 108, 117, 126], and *prognosis* [15, 122, 156, 173, 211, 214] have also been discussed. Furthermore, *influences of private care* [103] and *workload for the nurses* in intensive care units [154, 182] have been presented, as well as *effects of DNR-audit* [82, 115, 192] and *computer based DNR orders* [85].

Very few of the perspectives mentioned in these two paragraphs have so far been studied in Sweden.

Possible ethical conflicts

An ethical conflict arises when two or more ethical obligations are not fully respected, or when the interests of two or more affected persons are difficult to fulfil.

Most respondents in paper I thought that the latest DNR decision was ”ethically right”, Most also stated that it was well timed or perhaps somewhat late. As more than half of the patients were not included in the discussion, the procedure can hardly be ”ethically right” because the autonomy of the patient was not respected. However, the respondents may have misunderstood the word ”ethically”, and thought of ”timely”, ”medically”, ”emotionally” or ”psychologically” etc. More discussions about ethical issues in health care may put the terms in order.

The potential conflict between the autonomy of the patient or surrogate and of the physician in life support decision making is evident. In the clinical setting, however, serious

conflicts seem to be uncommon. Only one case has been brought to court in Sweden [220]. This low number may depend on an ambition of consensus between all agents and affected, or perhaps on lingering paternalistic attitudes, desired or not.

There is also a risk of conflict between the principles of autonomy and non-maleficence, in that the patient may be harmed if he or she is not included in the decision making against his or her wish.

A death with dignity is desirable, and if the patient has had the opportunity to decide for himself, the distress for himself, the family and the staff is diminished. Substituted judgement by the family may not be needed [146]. This is presumably good for all parties. Several studies have shown that many relatives have never discussed preferences of treatment with the patient, and they may have different opinions compared to the patients [80, 110, 170].

Communication

The communication of facts and values regarding the conditions and consequences of futility is a critical issue. To create a dialogue about this is perhaps one of the most challenging tasks in health care. At the same time this is one of the most important tasks, as the autonomy of the patient has been increasingly emphasised in the western countries.

Communication is difficult to separate from joint decision making, especially when performed in the most comprehensive form, the free, open, and iterated dialogue. Earlier, the most common communication was unidirectional, from physician to patient. When a DNR order was issued ten years ago, the dialogue was uncommon both in USA and in Europe.

The latest British guidelines on DNR orders state that "Good communication, both within the health care team and with the patient and those close to the patient, is an essential part of decision making. Wherever possible, consensus should be sought..." [16].

Physicians

In America (in 1991), 90 per cent of the physicians had an ambition to involve the patients, but only 10 per cent of them were involved [34]. In paper I (in 1995) the corresponding numbers were 50 and 33 per cent, the latter most often by the initiative from the patient. There was a remarkable uncertainty of 37 per cent among the Swedish cardiologists. In 1990, only 7 per cent of Swedish internists used to talk about DNR orders with their patients [7]. Although the material in paper I is small, two points are obvious, the uncertainty and the discrepancy between the ideals and the reality. Both may be dealt with by education and discussing different attitudes.

The prognosis was discussed with all the 30 patients judged to be competent by the respondents (paper I). This may be regarded as the first step of a possible dialogue about a DNR decision. Exactly why the dialogue did not progress is not known from this study. First, one can speculate if the patients gave signals to stop the dialogue, which is unlikely

when compared with patients in Europe [21, 88, 127, 131, 152], in USA [57, 111, 134, 183], and also when compared to the opinions of the patients in paper IV. Second, the physicians may be embarrassed when talking with the patients about DNR orders [183]. Third, the physicians do not know how to proceed. To elucidate this, an interview study with follow-up questions is presumably a better method than a questionnaire. Hopefully, patients and physicians might be helped by the method of "clinical conversation", described in paper IV.

Patients

Most of the interviewed patients wanted an open and straightforward discussion (paper IV). This is confirmed by practically all other studies on DNR communication, and also when communication with cancer patients has been studied [118]. In an interview study including 206 physicians, patient disclosure was promoted by the use of open questions, by focusing on and clarifying psychological aspects, by empathic statements, by summarising and making educated guesses. Leading questions, talking about physical aspects, moving into advice and reassurance mode inhibited patient disclosure.

Almost all patients in paper IV were positive about the opportunity to talk about their future prospects. Only a few patients said that certain issues were difficult to discuss. This response was so surprising and encouraging to the interviewer that this may have caused overenthusiastic interpretations. Other researchers have to confirm the usefulness of the "conversation method". As mentioned earlier, Ågård *et al.* [219], have used a similar method, 'clinical talks', with comparable results.

Nurses

The uncertainty of the nurses about the opinions of the patients are equal to that of the physicians [paper II], which again may be dealt with by education.

Most patients would accept a nurse to participate in the discussion, but when asked, none of them named any of the attending staff nurses. Instead, some patients considered that the district nurse or deaconess was the best one to participate. This may depend on the short stay in hospital, or perhaps that the patients were moved around, meeting a large number of different nurses (and doctors). When organising the hospital care, efforts to facilitate communication with the staff ought to be considered, for instance to ensure continuity and privacy, and to increase the available time for communication.

Relatives

Relatives are very important for the communication in several aspects. They may for instance influence the communication with the patient if they ask about already issued DNR orders, for instance oppose information to the patient, according to paper III.

Some patients in paper IV would accept a family member joining in the conversation, not primarily for his or her own sake, but to give sufficient information to the relatives.

Many relatives in paper V felt reasonably well informed about the diagnosis, prognosis and treatment, despite the fact that they also were embarrassed by perpetually meeting new doctors and nurses. Quite a few of the relatives were obviously not aware of the DNR order and those who were did not seem to be worried about being informed. The results of paper V are similar to American studies focusing on relatives [79, 195]. Luce & Fink [116] has also recommended preparations to counsel relatives in end-of-life situations in the intensive care unit.

Documentation

Regarding the internal staff communication, over two thirds of the physicians stated that they had documented the DNR decision, both in the case record and the nurses' case sheet [paper I]. Thus, there seems to have been a considerable development from 1990, when 28 per cent of the physicians signed the DNR order [7], until 1995, when 72 per cent said they did so. The paper by Asplund & Britton [7] and Swedish recommendations [58, 65] have probably caused an increased awareness.

In Sweden, we do not know whether the preferences of the patients are in agreement with the ward notes. In the US, however, this has been studied. Nineteen consecutive patients with DNR orders and the consultant physician, house officer, primary nurse were all interviewed. The agreement with the ward notes and the staff was good (77 – 82%), better than that with the consultant (59%) [184]. Another American study [109] showed that chart orders to limit therapy are common, but physician-patient discussions about life-sustaining treatments are not. A Canadian retrospective study of 53 patients with high risk of cardiopulmonary arrest showed that 19 per cent had preferences addressed before the arrest, and 43 per cent after arrest. Of the 23 patients initially surviving cardiac arrest, all were subsequently given DNR orders [101].

Efforts to improve communication

Quite a few of the responders in papers I-III are uncertain about the rules surrounding DNR orders, their own attitudes, and how to communicate DNR orders. It seems that this situation needs to be improved.

There have been many efforts to study and to improve communication about DNR orders between physicians and patients in the last decade. Unfortunately, many results are not encouraging.

One American, 2-year prospective observational study with 4301 patients followed by a 2-year controlled clinical trial with 4804 patients failed to show that specially trained nurses actually improved the patient-physician communication. The nurses had multiple contacts with the patient, family, physician and staff to elicit preferences, improve under-

standing of outcomes, encourage attention to pain control, and facilitate advance care planning. Nor was the incidence or timing of written DNR orders, physicians' knowledge of their patients' preferences not to be resuscitated improved [185].

Other studies have reported that written information is a poor method of communicating DNR orders with patients [191], or that physicians often did not provide essential information about CPR [208]. Education for physicians to discuss with patients has not been efficient [202]. Hospital based regulatory and educational interventions have failed to encourage physicians to discuss end-of-life care with their patient [174]. Advance directives have not increased CPR discussion between physicians and patients [37, 49, 109, 207], although they have been increasingly recommended [41, 48, 49, 89].

There is also the possibility that sick people change their minds [151], which may seem like a problem, but has opened for further discussions. Even if they are not legally accepted in Sweden, they "may open the door to a positive, caring approach to death", as they do in USA [51].

A specific form for "Resuscitation Status and a Treatment Plan" has been used in clinical practise. It included 93 per cent of the patients with decision making capacity. Approximately 65 per cent of all DNR orders were supported by the forms, compared to earlier charts, when less than five per cent of the patients were included [99]. Another structured DNR order form improved agreement in understanding of some, but not all components of the DNR order [84].

Possible ethical conflicts

Both discussing CPR and not discussing CPR may be harmful, which means that the principle of non-maleficence is invoked in two ways (non-maleficence versus non-maleficence). In the short term patients may be happy without dreary information, but in the long term it is usually harmful not to know. It is therefore no good that one third of the responders (paper I) believed that there are patients who want information about DNR, but do not receive it. Some of them also thought that patients get information that they do not want. The most distressing results is however, that half of the respondents are uncertain about the patient's wish. How much harm is caused by this ignorance? In the SUPPORT study [185], the physicians often neglected the patients' wishes about CPR, and many of the patients missed the opportunity to discuss the DNR order when they were still capable of communication. The physicians also seem to have neglected the patients' pain. Ignorance of the patients' treatment preferences have been observed many times, for instance by Uhlmann *et al.* [204], who reported that physicians and nurses correctly predicted the patients' treatment preferences in 53 – 84 per cent of the cases, but they did not significantly agree with each other.

The patients may be harmed not only by the disclosure of unpleasant news but also by not being informed about prognosis and treatments. This possibility of harm can get into

conflict with the ambition to inform, and thereby to increase the patient's opportunity to decide for himself, i.e. non-maleficence versus autonomy.

The patient has a right to know, but also a right not to be informed if he or she wishes, and the physician should take that into consideration as well.

There is also a risk that every single patient does not become informed in the same manner, depending on various attitudes or routines. This has not been shown, or even suspected, in the present studies, but it has been reported elsewhere that patients with cancer are managed differently from other patients with the same prognosis [208]. Also the age of the patient may be a cause of discrimination [25]. In such cases the principle of justice is violated, and conflicts with autonomy as well as non-maleficence may arise.

One reason not to inform the patient about a bad prognosis has been that this will take the hope away from the patient [164]. The Swedish geriatrician Beck-Friis holds that few, if any, dying patient hopes for health and cure. Instead, "the hope in the end of life is to get acknowledged, that someone is caring, that the patient is respected, that he or she gets true information. Truth and hope does not exclude each other. When the truth is that the illness gives difficult symptoms, then the hope is be spared from pain, to be spared from abandonment, to dare to live until death" [14].

Informing about CPR and the possibility of DNR may also be beneficent. Despite the fact that not much concrete or individual information was handed over to the patients during the 'clinical conversations' discussed in paper IV, they were pleased with them, and wanted such a conversation with their own physician, for themselves as well as for others. They wanted to know the truth and seemed to be sorry that their physician had showed little interest in a dialogue. A good relation with physicians and nurses was emphasised by both patients and relatives. Perhaps, they did not feel abandoned when invited to a conversation, which otherwise seem to be an obvious risk, according to the relatives who complained about moving around the patients. All this is in line with the principle of beneficence, and with good professional virtues of, for instance, responsibility and patient-oriented attitudes.

Guidelines, attitudes and behaviour

According to, Beauchamp & Childress [11], there are many professional virtues, e.g. respectfulness, truthfulness, faithfulness, responsibility, advocacy, persistence, courage, compassion, discernment, trustworthiness, integrity and conscientiousness. Put together in the clinical situation they may be described in terms of attitudes and behaviour. These two concepts have to be clearly distinguished as there are many examples of *intentions to act* (attitude) that are not *realised in action* (behaviour).

Guidelines and attitudes – discrepancies

All Swedish, British and American guidelines now recommend that patients should be

included in the decision making on DNR. However, in the literature there are several examples of a discrepancy between guidelines and attitudes.

Most of the responders in paper I thought that DNR orders were right to use, but only two thirds of the responders had a firm opinion about the participation of the patient. The earlier Swedish study reported 98 per cent application in medical wards, but very few patients were involved. Almost all of the physicians (93%) stated that they never, or in the minority of cases, included the patient in the discussion [7].

There seems to be a great difference in attitude to inform the patient about a DNR order whether someone asks for it or not (paper III). When in conflict about who ought to be informed, the physicians and nurses are more patient-oriented than relative-oriented. The reason of this difference of informing is not known, and ought to be studied more in detail. Withholding disquieting information ought to diminish psychological harm, at least in the short term. In the long run, the non-informed patient (or relative) may be upset and lose confidence in health care.

Paper VI gives an intimation about the attitudes of the different authors arguing for unilateral decisions by the physicians or unidirectional information to the patients in 13 out of 43 articles. Most articles (32 of 43) stated that the physicians should be the decision makers. Very few treated the patients' perspectives [134]. However, there has been a development towards patient autonomy the last two decades. Until recently, Percival's view from 1803 seems to have been prevailing.

Of 52 burn nurses, 88 per cent thought that DNR decisions should not be made solely by physicians, and 75 per cent opposed decisions from ethics committees. Half of them (56%) felt that nurses should be involved, but 21 per cent opposed that. There was a considerable uncertainty about what a DNR order included [152].

A comparison of medical and nursing attitudes to resuscitation and patient autonomy has been made between a British and an American hospital [128]. It included 34 physicians and nurses in each hospital and showed that British physicians often made DNR decisions unilaterally, while the American physicians sought the patient's or surrogate's consent in most instances, even where it was not legally required.

Of 640 US physicians, 20 per cent wanted CPR for themselves in the setting of chronic end stage organ failure. A significant number were in favour of active euthanasia. The study suggests that it is unlikely that physicians' personal beliefs regarding end-of-life care, result in the failure to discuss these issues with their patients [123].

One study has attempted to influence the attitudes. Twenty surgical residents got interactive teaching episodes regarding withdrawing and withholding treatment, advance directives, DNR orders, informed consent, and communicating bad news. They showed significant improvement for 13 of 23 items in pre-test compared to post-test surveys [4].

Attitudes and behaviour - discrepancies

In the present studies, discrepancies of attitudes and behaviour were not inquired for in detail, but the patients could tell that very few physicians had actually talked with them about DNR decisions. Of the relatives, almost two thirds were informed, according to the case books. The patient's goals should determine or at least influence the timing and sequence of withdrawing interventions [20], why they ought to be known.

Advocacy for the patients is a hallmark in modern nursing ethics [11]. In paper II, 36 per cent of the nurses stated that they had initiated the discussion about DNR within the health care team. Another 45 per cent answered that some other nurse had taken the initiative. The precise reason for this was not asked for in this study, but the clinical experience is that nurses often state that the patients must be allowed to 'die with dignity'. Usually, it seems that one nurse and more than one physician participated in the decisions. There is not much information in the literature about the nurses' actual involvement in DNR decision making, but according to one report [34], only ten per cent of the nurses initiated the decision making. This difference of taking the initiative (81% versus 10 %) is probably due to the greater subordination of the nurses in USA.

There are also examples in the literature of the discrepancy between attitudes and behaviour. A large prospective observational study failed to show that specially trained nurses actually improved the patient-physician communication [185].

Of 69 physicians in a general hospital, 33 felt that CPR should be offered only to patients likely to benefit from it, while 36 physicians said CPR should be offered to all patients, regardless of benefit. In effect, CPR was offered to 41 patients of whom 27 were considered to be unlikely to benefit from CPR [188].

Of 368 admissions to ICU, 23 per cent were designed DNR. In 7 per cent of these cases, the responsible nurse did not agree with the decision. In 3 per cent the patient or family did not concur. In 12 per cent of the cases not designed DNR, there was a disagreement between physicians and nurses. Physicians were significantly more pro DNR [46].

To determine the reasons why attending physicians do not write DNR orders, a 5-member panel identified 149 consecutive patients for whom DNR orders were indicated. In 88 of these, DNR orders were absent. The physicians' explanations included the belief that the patient was not in imminent danger of death (n=49), that the primary physician should discuss DNR issues (n=43), and the lack of an appropriate opportunity to discuss end-of-life issues (n=38). In 11 of the 88 cases, patients or their families did not accept the recommendation of a DNR order. No physicians expressed concerns regarding the morality of DNR orders, discomfort discussing end-of-life issues, or the threat of litigation as reasons for not writing a DNR order [47].

IMPLICATIONS FOR CLINICAL PRACTICE

- Start a dialogue about end-of-life support with chronically ill and elderly patients, and their relatives, while they still are capable of understanding and authorisation
- The clinical conversation model may make this easier
- Ask if the patients would appreciate a nurse to participate in the conversation
- All involved ought to understand why certain decisions are made
- The use of a prognostic index may sometimes facilitate decision making
- Conditions and consequences of futility should be ascertained together with the patients, the relatives and the staff, after which a joint decision may be reached

FUTURE RESEARCH

- Is it possible to start a dialogue about DNR orders earlier? If yes, how? when? by whom?
- Does the described model for futility discussion work?
- Does joint decision making work?
- May advance directives about forgoing life-sustaining treatment work in Sweden?
- Which ethical conflicts do the affected actors actually experience?
- Why is the willingness to inform about a DNR depending on whether someone asks for information or not?

SUMMARY IN SWEDISH

Hjärt-lungräddning (HLR) introducerades 1960 och fick genast stor betydelse vid behandlingen av hjärtinfarkt. Så småningom kom metoden att användas vid nästan alla tillfällen då hjärtat stannade. I mitten av 70-talet började man i USA utfärda ordinationer till sjuksköterskorna att HLR inte skulle startas på vissa patienter i händelse av att hjärtat skulle stanna. Detta beslut fattades av läkaren, oftast utan att vare sig patient, anhöriga eller sjukvårdspersonalen tillfrågades. Beslutet dokumenterades inte sällan med hjälp av koder i journalen.

Under 80-talet utvecklades riktlinjer om att patienten, anhöriga och sjukvårdspersonalen skulle involveras i beslutet att avstå från HLR (ej-HLR). Detta berodde främst på ökad respekt för patienternas självbestämmande, enligt den etiska "autonomi-principen". Röster höjdes att information om "ej-HLR" till patienten själv skulle skada honom eller henne psykologiskt. Detta borde undvikas enligt "icke-skada-principen". Andra ansåg att det gynnar patienten att få kännedom om, och helst kunna påverka, planerad behandling, enligt "godhets-principen". "Rättvis-principen" framhåller att alla patienter, oavsett t ex diagnos, kön eller ålder bör behandlas lika. Principer om att sjukvårdspersonalen ska vara sanningsenlig, trofast, modig, pålitlig och agera samvetsgrant ansågs också viktiga i sammanhanget. Alla dessa etiska principer och ideal kan råka i konflikt med varandra i olika situationer.

I Sverige presenterade Asplund och Britton år 1990 en studie som visade att läkare på medicinklinikerna sällan talade med sina patienter om "ej-HLR". Läkarna talade oftare, men ej alltid, med de anhöriga om saken. Inte sällan var det sjuksköterskorna som förde "ej-HLR" på tal, eftersom de hade ansvaret för att starta HLR då hjärtat stannade. Råd om livsuppehållande åtgärder i livets slutskede gavs ut av Socialstyrelsen 1992. Grunden för "ej-HLR" skulle vara att patienten inte ville ha behandlingen eller att läkaren efter att ha ställt en säker diagnos och prognos, kunde veta att HLR inte skulle lyckas. Patientens, anhörigas och personalens åsikter skulle inhämtas inför beslutet, som också måste dokumenteras tydligt.

Det saknades dock kunskap om hur beslut om "ej-HLR" fattades, kommunicerades och uppfattades av läkare, patienter, sjuksköterskor och anhöriga. Det var utgångspunkten till att dessa studier startades 1995. Syftet var att undersöka om gällande rekommendationer accepterades av vårdpersonalen och att analysera etiska aspekter rörande beslut och information. Vidare var syftet att kartlägga läkares och sjuksköterskors inställning till att informera patienter och anhöriga, att se om det kliniska samtalet kan användas för att ta reda på om svårt sjuka patienter vill tala om att avstå från livsuppehållande åtgärder. De anhörigas erfarenheter av situationen kring patientens dödsfall och deras inställning med hänsyn till dessa var också av intresse. Ett ytterligare syfte var att beskriva villkor för och konsekvenser av "meningslösa vårdinsatser" och att föreslå en kliniskt användbar metod att hantera "meningslösa vårdinsatser".

Trehundra läkare och sjuksköterskor i Svenska Cardiologföreningen fick besvara en enkät om sina erfarenheter av och attityder till att avstå från HLR och deras inställning till att informera patienter och anhöriga om "ej-HLR"-beslutet. Svarefrekvensen var 73%. Därefter intervjuades 20 svårt sjuka patienter och 21 anhöriga till patienter som avlidit efter ett beslut om "ej-HLR". Slutligen granskades litteraturen beträffande "meningslösa vårdinsatser" för att söka efter vilka villkor och moraliska konsekvenser som beskrivits i sammanhanget.

Resultaten visade att 84% av läkarna och 8% av sjuksköterskorna själva fattat beslut om att avstå från HLR. De ombads erinra sig det senaste tillfället då förhandsbeslut fattats om detta. Endast en femtedel av de svarande bedömde att den aktuella patienten var kompetent att delta i ett beslut av detta slag. En tiondel av läkarna angav att de diskuterat beslutet med sina patienter, och men över hälften med de anhöriga. Nio av tio läkare och hälften av sjuksköterskorna hade själva deltagit i diskussionen. I de flesta fallen hade minst en läkare och minst en sjuksköterska hade deltagit i beslutet.

Nästan alla ansåg att beslutet i det aktuella fallet var etiskt rätt. Ungefär hälften av de svarande ansåg att samråd bör ske med patienten och att beslutet bör tas av patienten. Samtidigt ansåg nästan alla, att läkare skall fatta beslutet. En tredjedel av sjuksköterskorna ville själva ta ansvar för beslutet.

I intervjuerna med patienterna framkom att identifieringen av olika reaktionsmönster ger ökad förståelse och förbättrad kommunikation. Mönster, men ej frekvenser, kan generaliseras. Det "kliniska samtalet" är ej tidsödande, utan en enkel och av patienterna uppskattad metod. Det är inte oroande för patienten att tala om behandling i livets slutskede på detta sätt. Samtalet ger svar på och en bild av patientens kunskaper, värderingar och emotionella reaktioner.

I intervjuerna med de anhöriga framkom att de flesta var nöjda med vård och terapi, information och kommunikation. Nästan alla föreföll välinformerade om diagnos och prognos och menade att livsförlängande behandling inte varit aktuellt. Åtta av 21 anhöriga hade diskuterat HLR eller informerats om att HLR ej skulle ges. Ingen kände sig tvingad att fatta beslut. En del var överraskade över att de fick så mycket tid och engagemang av läkare och personal. Andra var besvikna på organisationen genom att patienterna flyttades runt mellan olika salar och avdelningar. För att få en förbättrad kommunikation behövs en personlig relation, god lättillgänglighet, uppmuntran och möjlighet att vara på sjukhuset.

I litteraturgenomgången beträffande "meningslösa vårdinsatser" var avsikten att finna en metod att systematiskt kunna analysera och hantera sådana situationer. Fyra grupper av faktiska villkor och tre grupper av moraliska konsekvenser kunde spåras i 43 artiklar. De flesta författarna ansåg att läkare skulle besluta om villkoren. Vårdinsatsen var oftast någon form av behandling och målen för behandlingen var "livskvalitet", fysiologisk förbättring (t ex bättre blodtryck) eller livsförlängning. Sannolikheten att lyckas med

behandlingen beskrevs oftast i semi-kvantitativa termer. Konsekvenserna var att det kunde vara etiskt försvarbart, önskvärt eller nödvändigt att avstå från eller avbryta ”meningslösa vårdinsatser”. I de flesta artiklarna (29 av 43) angavs att besluten borde fattas i en dialog med patienten, medan fyra framhöll att det räckte med envägsinformation. Nio angav att patienten inte behövde informeras alls om beslutet. Nitton artiklar förespråkade att läkaren ensam fattar det avgörande beslutet.

Följande konklusioner och rekommendationer från studierna kan framhållas:

- Läkare och sjuksköterskor är osäkra beträffande regler och etiska aspekter när det gäller att avstå från HLR.
- Det finns skiljaktigheter mellan riktlinjerna för och inställningen till ej-HLR likaväl som mellan inställningen och genomförandet av beslutet hos läkare och sjuksköterskor
- Allvarligt sjuka patienter uppskattar öppna samtal om behandling i livets slutskede
- Anhöriga får godtagbar information och stöd, trots att de personliga relationerna ofta inte har möjlighet att utvecklas
- ”Meningslösa vårdinsatser” kan hanteras genom systematisk analys av villkor för, och konsekvenser av, den speciella vårdinsats som anses meningslös
- Patienter, anhöriga, läkare och sjuksköterskor bör skapa en förtroendefull dialog om de nödvändiga besluten i livets slutskede
- Läkare och sjuksköterskor behöver utbildning och träning i etiska frågeställningar i vården
- Det finns flera möjliga etiska konflikter inom och mellan de etiska principerna självbestämmande, göra gott, icke skada och de professionella idealen
- Genom att starta en dialog med patienterna medan de fortfarande är kompetenta att förstå och att fatta beslut, får de möjlighet att själva påverka vården
- Den kliniska samtalsmodellen kan göra det enklare att kommunicera om frågor i livets slutskede
- Alla inblandade bör vara insatta i varför beslut om ”ej-HLR” fattas
- Användandet av prognostiska instrument kan underlätta beslutsfattandet
- Villkor och konsekvenser för ”meningslösa vårdinsatser” bör analyseras tillsammans med patienten, anhöriga och sjukvårdspersonalen, varefter ett gemensamt beslut kan fattas

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