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COMPETENCE AND COMMUNICATION

Do Not Resuscitate Decisions in Cancer Care

MONA PETTERSSON



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Abstract

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Within cancer care, do not resuscitate (DNR) decisions are frequently made. DNR decisions can be ethically difficult and lead to conflicts of interest and disagreements within the medical team. This thesis brings together empirical knowledge of DNR decisions in cancer care and theoretical discussions on the ethical aspects and the competence needed to make such decisions.

The overall aim of this project was to investigate the clinical and ethical aspects of DNR decisions from the perspectives of nurses and physicians working in hematology and oncology care. The methods used were qualitative, with individual interviews, and quantitative, using a web survey. Ethical theories, principles and models were used in the planning of the studies and to explain and discuss the results.

Fifteen nurses in **Study I** expressed a close relationship with their patients. They expressed how they needed clear and well-documented decisions on DNR to provide good care to patient and relatives. Sixteen physicians participated in **Study II**. They described how they made decisions on DNR mainly on medical grounds, but reflected on ethical aspects of the decision, weighing maleficence and beneficence. In **Study III**, the interviews from Study I and II were analyzed from the perspective of ethical competence. The results showed that physicians and nurses were able to reflect on their ethical competence in relation to DNR decisions and described ethical competence as both being good and doing right. Also knowledge in ethics was emphasized. In **Study IV**, 216 nurses and physicians participated. Most respondents thought it was important for patients and relatives to participate in, and be informed about, a DNR decision, but fewer thought that this was likely to happen. Nurses rated the importance higher than physicians did. The most important attributes in relation to DNR decisions for both nurses and physicians pertained more to medical viewpoints than to ethical values.

DNR decisions in cancer care can be associated with ethical conflicts of interest, and nurses and physicians have different perspective of DNR decisions which they need to share. Competence in ethics and inter-professional communication are crucial for nurses and physicians participating in such decisions.

Keywords: DNR decisions, do not resuscitate, end-of-life, hematology, oncology, cancer care, medical ethics, nursing ethics, ethical conflicts of interest, communicative ethics, ethical values, ethical competence, palliative care, nurses, physicians, moral distress.

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To Theodor and Emilia

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Pettersson, M., Hedström, M. & Höglund, A. T. (2014). Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care. *Nursing Ethics*. doi: 10.1177/0969733014533238

- II Pettersson, M., Hedström, M. & Höglund, A.T. “Not the most difficult decision”. Physicians’ experience of Do-Not-Resuscitate (DNR) orders in hematology and oncology care. *Manuscript*

- III Pettersson, M., Hedström, M. & Höglund, A.T. (2018). Ethical competence in DNR decisions - a qualitative study of Swedish physicians and nurses working in oncology and hematology care. *BMC Medical Ethics*. doi: 10.1186/s12910-018-0300-7

- IV Pettersson, M., Höglund, A.T. & Hedström, M. Perspectives on the DNR decisions process: a survey of nurses and physicians in hematology and oncology. *Submitted, under review*

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Abbreviations

CPR	Cardiopulmonary resuscitation
DNR	Do not resuscitate
EOL	End of Life
QoL	Quality of Life
STC	Systematic Text Condensation
ICU	Intensive Care Unit
DNAR	Do not attempt resuscitation
DNACPR	Do not attempt cardiopulmonary resuscitation
AND	Allow Natural Death

Prologue

As a newly graduated nurse, I started working at a hematologic ward. The first year was dedicated to learning the medical technology used for hematological diagnoses and treatments. When most of the first year was completed, I was able to focus on aspects of nursing other than my own learning and began to train students and new colleagues. At the same time, more severely ill patients approached me with conversations about existential questions, worries, and death – I think I sent them signals that I had passed the first levels and had developed enough in my role as a nurse to be a good support. The ward also performed bone marrow/stem cell transplantations for children with cancer who otherwise were cared for at the children's clinic. This experience gave me the opportunity to care for people of all ages, from six months to almost 100 years. Even in this first turbulent year, I experienced problems that were often associated with “Do not resuscitate” (DNR) decisions. Through the 15 years I worked as a nurse in the ward, situations around DNR decisions were often associated with silent frustration over late and unclear decisions and anxiety about acting in ways that caused unnecessary suffering for patients and relatives.

When I started teaching at the nursing program, I began supervising students who were writing their final papers. On one occasion, two students had interviewed nurses at a hematology ward about their experiences with DNR decisions, and I realized that others shared my experiences of problems with DNR decisions. I wanted to learn more about how health care providers experienced DNR decisions, and maybe be able to improve end-of-life care. Since my experience was in cancer care, we applied for funding from the Swedish Cancer Society and, after 19 years as a nurse, I became a PhD candidate.

In Sweden, the debate about treatment limitations and DNR decisions are periodic. The latest reports, in June 2018, concerned relatives not receiving information [1]. In one case, the relatives discovered that the patient's DNR decision was made on incorrect grounds and they were able to communicate that to responsible physician. In another case, an old person died without relatives present, because they were not informed about the DNR decision and did not understand that the end was imminent. A review of 187 medical records, made

after these reports, found that the request for treatment limitations was made after discussions with the patient in 16% of cases. In addition, 62% of the decisions about treatment limits not discussed with the patients or their relatives had no documented reason for not sharing this information. The report also investigated several mistakes around life-sustaining treatments made during hospital care, mostly when there had been a mix-up of patients. The debate included key persons in Swedish politics and health care and used sensational headlines e.g., "Vital Decision Withheld from Patients "; "Neglect Threatens Patients Lives"; and "This Concerns Decisions About Individuals Lives and Deaths".

Poor communication and documentation about DNR decisions sometimes lead to devastating consequences for patients and relatives. The deficiencies in communication and documentation need to be acknowledged, and routines ensuring the right decision for the right patient need to be created for the entire patient care process. In addition, the debate needs to focus on what is important. Physicians do not make DNR decisions for healthy people and the debate is not really about life or death. The debate should be more about what kind of death a patient desires and expects and about a patient's right to be informed about their options so they can make informed decisions about their own end of life.

Sweden's legislation is clear in terms of documentation of DNR decisions, patient participation, and right to information, but laws and guidelines also emphasize the need to customize information for the individual patient. Physicians and nurses have a great responsibility to assess the conditions of the patient and relatives and to weigh if information is likely to be beneficial or harmful. To avoid ethical conflicts associated with DNR decisions, nurses and physicians need to share each other's different perspectives and roles in these situations. To enable this, a continuous discussion is needed that addresses all involved in the care and a working environment is needed that allows communication and development. Knowledge about the problem is the first step. Through this work, I hope to contribute to this development.

Introduction

DNR in the Swedish context

Decisions about “Do Not Resuscitate” (DNR) are frequently made in oncology and hematology care. Patients are sometimes considered to have such a poor prognosis that Cardiopulmonary Resuscitation (CPR) in case of a cardiac arrest is not justifiable, as survival would not mean the patient would have a high quality of life. Patients can express a desire for such a decision early in their care that can lead to a DNR order from the responsible physician. In Sweden, the Swedish Council for Resuscitation has defined DNR as a prior decision that means advanced life-saving procedures are not to be used, including basic CPR (chest compressions with or without simultaneous ventilation) and advanced CPR (defibrillator and drugs) [2]. According to Ethical Guidelines for CPR [3], the definition of DNR pre-determines that in the event of a cardiac arrest CPR is not to be performed. Other questions concerning the patient’s care are not included [3]. If a patient does not have a DNR order, CPR must start within 60 seconds and defibrillation within three minutes [2].

According to the National Board of Health and Welfare, citizens in Sweden do not have the right to choose care or treatment that is not supported by science and experience [4]. In 1982, the Health Care Act [5] became a legal document that described goals for the entire health care system in Sweden, highlighting human rights and respect for the patient’s autonomy and integrity. In 2017, the regulation was updated. [6]. On January 1, 2015, the Patient Act [7] was adopted. This act puts even more emphasis on the right of patients to be informed about their health care and to participate in their own health care decisions. If patients are unable to process information, the patients’ relatives can receive information.

The National Board of Health and Welfare has elaborated regulations for life-sustaining treatment [8]. If life-sustaining treatment is not considered appropriate, the responsible physician will decide not to initiate treatment. This should be done in consultation with another licensed practitioner. The care should as much as possible be planned together with the patient. The National Board of Health and Welfare does further recommend that the responsible

physician also takes advice from other members of the medical team. If a responsible physician is not available, another physician should fulfill the necessary procedures. In 2017, an update of the regulation was added, referring to the Patient Act [7], and the updated version of the Health Care Act [6]. The documentation should contain information about how the decisions were made, who were involved in the decision, whether the information was given to the patient/family, and whether the patients and their relatives had expressed their views regarding life-sustaining treatment [8].

The Swedish Society of Medicine, the Swedish Society of Nursing, and the Swedish Resuscitation Council launched guidelines for CPR in hospitals in May 2013 [3]. According to these guidelines, DNR decisions should be made in consultation with the patient and/or the patient's family. In addition, the staff concerned should be informed and the decision should be made by the responsible physician. The decision should also be reconsidered on a regular basis. The guidelines also discuss ethical aspects of DNR, such as the risks and benefits of making a DNR decision and risks and benefits of providing information to patients and their relatives. It is also stated that DNR decisions should be documented in a safe manner and that it is important that units be provided common and clear terminology in these cases.

DNR in the clinical context

DNR decisions are made for patients with different diagnoses at hospitals all around the world. In early 1970, DNR was first described by the American Medical Association (AMA) who gave recommendations for documentation of a DNR decision, and recommended that health care staff should be informed of the decision [9]. Problems and disagreements around DNR decisions are frequently reported from different countries and different specialties. These tensions are described below.

Definition, interpretation, and documentation of DNR orders

Several studies report that DNR is not interpreted consistently [10-14]. Although DNR should not affect the patient's general care, physicians might withhold blood transfusions or antibiotics to patients with DNR and change their treatment plan without informing patients and/or their relatives [10]. In addition, differences in what the physicians assumed to be included in the concept can affect the care of patients with DNR orders [15, 16]. Moreover, DNR orders can be unclear [17] and can be documented in different ways [11, 14, 15, 18], which can lead to confusions about CPR/DNR [15, 19], including patients receiving unwanted CPR [20, 21]. According to Duplan and Pirret

[22], documentation seldom reveals whether the patient or relatives have been informed about DNR options.

The timing of DNR decisions

It has been reported that physicians believe that DNR decisions should be made during the treatment earlier than is usually the case [23]. In fact, DNR decisions are often made late in the patient's care [24, 25], sometimes on the day the patient dies [26, 27]. Difficulties with the timing of the DNR decision have been reported as a barrier to making the decision [28-31] as well as a risk of making the wrong decision [29].

Participation in DNR decisions

Previous studies have shown a variety of results regarding the participation of patients, relatives, and members of the medical team in DNR decisions. For example, Löfmark and Nilstun [32, 33] have shown that half of the 300 studied cardiologists and nurses believed that a DNR option should be discussed with any patient with the cognitive abilities to understand the implications of a DNR; however, only one-third of those patients were actually involved. De Gent et al. [34] found that 75% of 94 nurses were involved in the decision-making process around DNR. However, in Svantesson et al. [35], physicians mostly made the DNR decisions without patients, families, and nurses. When comparing how confident physicians and nurses were about speaking with patients and families about DNR, one study [36] found that the nurses had less confidence about discussing DNR issues with patients than the attending internists, but more confidence than the medical house officers. In addition, the nurses had a more positive attitude towards discussing DNR than the physicians did [36]. Other studies have also revealed that physicians do not always discuss DNR decisions with their patients [11, 25, 37]; however, some physicians discussed this issue with the patient's family [25]. It has been argued that nurses can help involved family members to accept palliative and end-of-life care [38-40].

Information about DNR decisions

There may be several barriers to informing patients and their relatives about DNR decisions: a physician's desire not to take away the patient's hope [41-43], a physician's desire not to cause anxiety in the patient [41], and a physician's feelings of discomfort and lack of experience [10, 41]. Löfmark et al. [32, 33] found that 97% of 300 cardiologists and nurses thought that relatives of a non-competent patient should be informed if they ask for information, and

67% thought that relatives should be informed even if they do not ask for information.

Disagreements and ethical conflicts around DNR decisions

DNR decisions might imply difficult choices including severe ethical conflicts of interest for both physicians and nurses, such as deciding when a DNR order should be made or how to inform patients and relatives of the decision [30, 44, 45]. Jezewski and Finnell [46] found that the DNR situations were highly affected by the fact that there were many different meanings of the concept of DNR among the actors involved (patient, family, and health care providers). Because of these disagreements, conflicts arose, in which the nurses had a mediating role. According to Robinson et al. [15], nurses reported stress and fear associated with decisions on DNR, which the physicians did not; not even on direct questions about this. Other studies of nurses and physicians have shown that representatives of these professions may have different approaches to DNR decisions [30, 41]. Therefore, DNR decisions can be difficult and lead to ethical conflicts of interest, such as disagreements in the team [30].

Theoretical framework

Different theories, principles, and models have been used in different parts of the project, such as inspiration to plan studies and deductively develop interview questions or to relate to and explain results in the discussion.

Medical ethics

Medical ethics formed the theoretical base throughout this project. Ethics deal with questions such as “What should we do?” and “How should we lead our lives?” as well as notions of ‘good’ and ‘right’, which are at the core of any ethical decision. Ethical dilemmas can arise from conflicting values, norms, and interests, where there may be good reasons for more than one course of action; however, choices must be made and the loss of at least one value or interest is unavoidable when attempting to resolve ethical dilemmas. Hence, ethics is not only about making the right decision in a given dilemma but also about justifying decisions and choices. According to well-established theories (e.g., utilitarian theories), actions are guided as right or wrong according to their consequences. Actions can also be seen as right or wrong according to how the actions conform to ethical rules or duties, so-called deontological argumentation. These traditions are mirrored in the four ethical principles: autonomy, non-maleficence, beneficence, and justice [47]. The principles of autonomy and justice are mainly derived from deontological reasoning, broadly

meaning that the moral agent has a duty to respect human dignity in every person as well as to act justly even if this means that the realization of welfare is sub-optimal. However, these principles could also be justified with reference to consequences. The principles of non-maleficence and beneficence are central in a utilitarian framework, as they imply that the best action maximizes total welfare for all concerned parties by promoting good consequences and limiting harm.

Deontological and utilitarian theories focus on how to act in ethically difficult situations. Another approach – virtue ethics – argues that the character of the moral agent should be at the fore. Virtue ethics assumes that a good person performs good actions. Virtues (i.e., desirable character traits) such as empathy, courage, and patience are learned through experience, practice, observing others, and good examples [48, 49]. Furthermore, virtue ethics values self-reflection, dialogue, and critical thinking.

When it comes to the end-of-life decisions, severe ethical dilemmas in the form of conflicting values and norms might arise for both physicians and nurses. Primarily, ethical concepts such as autonomy, integrity, dependence/independence, dignity, and quality of life should be considered when these decisions are made. For example, a patient's wish to receive a specific and expensive treatment (autonomy) must be weighed against the possibility of giving treatment to others (justice), and the medical team's wish to help a patient recover (beneficence) must be weighed against the patient's right to refuse life-sustaining treatment (autonomy) [8, 47, 50]

Nursing theory

In Study I, Virginia Henderson's theory of nursing was used as a theoretical framework. This theory states that "the unique function of the nurse is to assist the individual sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death)" [51] p.15). Henderson's theory can be understood as a model for how a nurse should work with severely ill or dying patients. Henderson has also categorized nursing activity into three types: the substitutive role (doing for another person); the supplementary role (helping the other); and the complementary role (working with the other person) [51]. The nurse should get "under the patient's skin", to be able to know what help the patient needs. In certain situations, the nurse should also strive to help the patient and family face death with dignity and ensure harmony in the bedside scene [51].

Communicative ethics

In Study I, the theory of communicative ethics [52] and its model of a democratic dialogue was also used. In different health care settings, ethics rounds (i.e., inter-professional discussions on moral dilemmas) have been used, an approach that staff have experienced as positive. Previous research has reported that such rounds may stimulate moral thinking and insight and thereby increase ethical responsibility [53, 54]. The form of such discussions often abides by the norms of a democratic dialogue, where everyone who is concerned has the right to participate where the strength of the argument, not who delivers it, is what counts. Furthermore, everyone who participates has the right to influence the agenda, and the goal is to reach an agreement so that the dialogue can continue and lead to practical actions [52].

Ethical competence

In Study III, a model of ethical competence for health care staff [55] was used to investigate how nurses and physicians perceive the concept of ethical competence. In the model, ethical competence includes three main aspects: being, doing, and knowing. In short, this means that ethical competence requires character, action, and knowledge. Character, or in Eriksson's et al. [55] words, the ethics of being, can be understood as a form of virtues ethics, which concerns good character traits. The ethics of doing, on the other hand, are concerned with how to act in ethically challenging situations. According to Eriksson et al. [55], ethical competence also needs to include knowing – i.e., not only knowledge of ethical theories such as deontology and utilitarianism but also of relevant ethical guidelines.

Empirical ethics

Because this project combines empirical results and philosophical arguments, this project should be understood as an example of empirical ethics [56]. Empirical ethics can be defined in many ways. In the present project, we primarily rely on the work of Musschenga [56] and regard it as a project in health care ethics that aims to be both descriptive and normative, where an important aim is to improve the context-sensitivity of the ethical discussion. For this aim, empirical ethics in our view consists of a description and analysis of the actual moral conduct of a group, an identification of moral issues that have escaped the attention of ethicists but are morally relevant in a specific context and a description and analysis of the actual moral opinions of those involved in a certain practice [56]. Based on previous research [57], we also include a description and analysis of how practitioners in a certain context define and un-

derstand morally relevant concepts (in this case the DNR decision) to empirical ethics as well as investigation of the consequences of moral judgments and the use of ethical guidelines in a certain field [58].

Rationale for the project

Decisions about DNR are frequently made in oncology and hematology care but have not been investigated much in this context. DNR studies have been performed earlier in Sweden such as within cardiology [32, 33]. Since then, new regulations and guidelines have been developed and others have been revised. There is a lack of current and comprehensive research concerning attitudes to and perceptions of DNR decisions among Swedish nurses and physicians working in cancer care. More knowledge is needed to increase awareness in nurses and physicians of the ethical conflicts of interest that can exist in relation to DNR decisions, of the ethical competence they need in these situations, and of the importance of communication when making DNR decisions.

Aims

Overall Aim

The overall aim of this project was to investigate the clinical and ethical aspects of DNR decisions from the perspective of nurses and physicians working in hematology and oncology care.

Specific Aims of Studies I – IV

- I To investigate hematology and oncology nurses' experiences and perceptions of DNR orders, in order to achieve a deeper understanding of the nurses' specific roles in these decisions.

- II To investigate physicians' experiences and perceptions of DNR orders within hematology and oncology care, in order to achieve a deeper understanding of their specific roles in the decision-making process with a focus on the ethical aspects of these decisions.

- III To investigate how nurses and physicians in oncology and hematology care understand the concept of ethical competence in order to make DNR decisions or be involved in DNR decisions and how such skills can be learned and developed. A further aim was to investigate the role of guidelines in relation to the development of ethical competence in DNR decisions.

- IV To investigate how important, and how likely to happen, nurses and physicians working in oncology and hematology consider various aspects of the DNR decision process; which attributes they find most important in relation to DNR decisions, and whether there are any differences in ratings between nurses and physicians.

Methods

Since the aims of Study I, Study II, and Study III were to explore nurses' and physicians' experiences and perceptions about DNR decisions and the concept of ethical competence in relation to such decisions, qualitative methods were chosen for these studies using individual, semi-structured interviews (Table 1). The aim of Study IV was to rate nurses' and physicians' views on various aspects of the DNR process so a quantitative method using a web survey was used.

Study sample I

The participating nurses in Study I included three men and 12 women (n=15) working in hematology and oncology wards at four hospitals in Sweden. The inclusion criteria included working at their ward for at least one year. The participants' median age was 29 years, (23-55), their median work experience was four years (1-29), and their median work experience at the department was three years (1-11).

Study sample II

The participating physicians in Study II included eight men and eight women (n=16) working in hematology and oncology wards at seven hospitals in central Sweden. The participants' median age was 46.5 years (28-64), their median work experience as a physician was 21.5 years (3-39), and their median work experience at the department was 11.5 years (10 months to 35 years).

The informants consisted of two senior house officers, two specialists, and 12 senior specialists. The specialist trainings were hematology, oncology, internal medicine, surgery, geriatrics, and palliative care. At the time of the study, all physicians were working with oncology and/or hematology in-patients and out-patients, although some wards had other specialties included. Some wards had a partial palliative unit, and three physicians worked exclusively on palliative units. Most physicians had scheduled shifts in an emergency room.

Table 1. Description of design, data collection, participants, and analysis in Studies I-IV

Study	Design	Data collection	Participants	Data analysis
I	Qualitative	Individual semi-structured interviews	Nurses (n=15) working in hematology and oncology at four hospitals in Sweden	Thematic content analysis
II	Qualitative	Individual semi-structured interviews	Physicians (n=16) working in hematology and oncology at seven hospitals in Sweden	Thematic analysis with systematic text condensation
III	Qualitative	Individual semi-structured interviews	Nurses (15) and physicians (n=16) working in hematology and oncology at seven hospitals in Sweden	Thematic content analysis
IV	Quantitative	Web survey	Nurses (132) and physicians (84) working in hematology and oncology in 16 wards at seven hospitals in Sweden	Descriptive statistics, Mann-Whitney U test, and Chi-square test

Study sample III

The participants in Study III were the same participants as in Study I and Study II: three male and 12 female nurses (n = 15) and eight male and eight female physicians (n=16) who worked in hematology and oncology wards at seven hospitals in central Sweden. The overall median age was 37 years (23-64), the overall median work experience was 9.5 years (1-39), and the overall median work experience at the department was six years (10 months to 35 years).

Study sample IV

In Study IV, a web survey was sent to 206 physicians and 295 nurses. The response rate was 84 (41%) for physicians and 132 (45%) for nurses (21 nurses responded via paper surveys). A total of 216 (43%) participants were included in the study (Table 2).

Table 2. Enrollment of participants

Asked for participation	Declined participation
8 hospitals in Uppsala-Örebro region	
7 hematology wards	
9 oncology wards	1 hematology ward abstained
1 hematology/oncology ward	due to few patients
7 hospitals	
6 hematology wards	
9 oncology wards	
1 hematology/oncology ward	
295 nurses	1 nurse and 3 physicians
206 physicians	refrained from participation
294 nurses	141 nurses and 109 physicians
203 physicians	did not respond
153 nurses (52%)	
94 physicians (46%)	
21 nurses	
10 physicians	
did not complete the survey	
132 nurses (45%)	
84 physicians (41%)	

In Study IV, the majority of the respondents were female (nurses 96%, physicians 57%): 69 nurses and 59 physicians (n = 128, 59%) worked in oncology and 63 nurses and 25 physicians (n = 88, 41%) worked in hematology. The mean age for physicians was higher (47 years) than for nurses (37 years) and the physicians had worked longer in their profession (mean 18 years) than the nurses (mean 10 years). The nurses had less specialist training (14%) than physicians (76%) (Table 3).

Table 3. Background variables for the sample of Study IV (n=216)

		<i>Respond- ents (n)</i>	Total sample	Working in oncology	Working in hematology
Physicians	n (%)	84	84	59 (70)	25 (30)
Age	M (range)	82	47 (27-67)	46 (27-65)	49 (30-67)
Gender	F/M (%)	84	48/36 (57/43)	36/23 (61/39)	12/13 (48/52)
Years in profession	M (range)	84	18 (1-41)	16 (1-39)	20 (6-39)
Specialist training	n (%)	NA	64 (76)	40 (68)	24 (96)
Years in oncol- ogy/hematology	M (range)	80	NA	11 (0.5-33)	12 (1-31)
Nurses	n (%)		132	69 (52)	63 (48)
Age	M (range)	128	37 (22-66)	39 (22-66)	36 (23-64)
Gender	F/M (%)	131	126/5 (94/6)	67/2 (97/3)	59/3 (95/5)
Years in profession	M (range)	108	10 (0.5-44)	10 (0.5-45)	10 (0.5-38)
Specialist training	n (%)	NA	18 (14)	11 (16)	7 (11)
Years in oncology/ hematology	M (range)	108	NA	8 (0-31)	7 (0.5-33)

Data collection Study I

A semi-structured interview guide was developed for Study I. The questions were based in part on previous studies on the subject and in part on the theoretical frameworks that were considered for the study, namely Virginia Henderson's theory on nursing [51], communicative ethics [52], and medical ethics [47].

Some questions were formulated to allow the informants to freely share their experiences, and other questions dealt with specific aspects of the DNR situation (Table 4).

Table 4. Interview questions Study I

Main questions

Can you describe a situation you experienced when a DNR order was made?

Can something be ethically difficult when deciding whether a patient should have a DNR order or not?

How are DNR orders documented in the department?

How do you define the term DNR order?

How much chance of survival do you think the patient should have, for you to perform CPR in order to start the heart after a cardiac arrest?

Do you think that a DNR order affects the nursing situation for the patient, or the behavior towards the patient's relatives? Why/why not?

Do you know of any guidelines about DNR? If yes, which guidelines?

Does a nurse need ethical competence to participate in decisions on DNR? Why or why not?

Probing questions were asked when needed for clarifying the question and/or deepening the answer. The interview guide was tested on a nurse eligible for the study and then slightly changed per the nurse's suggestions. The interviews took place in a room close to the ward. The interviews lasted between 23 and 62 minutes and were recorded and transcribed verbatim.

Data collection Study II

For Study II, a semi-structured interview guide was developed. The questions were based on the interview guide developed for the previous study, as described in Study I.

Some of the questions were open, so the informants could answer more freely, and other questions concerned specific aspects of the DNR situation (Table 5).

Table 5. Interview questions Study II

Main questions

Can you describe a situation you experienced when a DNR order was made?

Can you describe a situation when you informed a patient/relative about a DNR decision?

Have you experienced problems associated with DNR decisions?

How do you feel about including patients and/or relatives in the discussion about DNR?

Do you have a clear discussion with patients on the shift of treatment from curative to palliative care? Why or why not?

What do you feel about informing patients/relatives about DNR decisions?

What can be ethically difficult when deciding if a patient should have a DNR order or not?

How do you define the term do-not-resuscitate order?

What can be ethically difficult when deciding whether a patient should have a DNR order or not?

Is it important to have DNR orders? Why or why not?

Can you describe a situation where there were disagreements about the decision that was made?

What reasons do you have for deciding to perform CPR in case of a cardiac arrest?

Do you think that DNR orders affect the nursing situation for the patient or the behavior towards the patient's relatives? Why or why not?

How are DNR orders documented in the department?

In addition, the physicians were questioned about the concept of ethical competence and how ethical competence can be developed. However, the answers to these questions were analyzed and reported in Study III. Probing questions were asked when needed to clarify the question and/or elicit a deeper answer. A few questions arose during the first interviews, and they were added to the probing questions of the interview guide (whether the physicians had clear breakpoint discussions or not, if there were situations where patients and/or their relatives were not informed about the DNR decision and if there were different views on the definition of DNR). The interviews took place in a room near the ward or at the physician's office. They lasted between 32 and 67 minutes. They were recorded and transcribed verbatim.

Data collection Study III

The data in Study III consisted of the same interviews as in Study I and Study II. The questions asked were a part of the interview guides used for Study I and Study II.

The topics of the interview questions for Study III concerned ethical competence and guidelines (Table 6).

Table 6. Topics of the interview questions from Study I ad Study II, analyzed in Study III.

Topics

Knowledge of guidelines

Content of guidelines

Understanding of ethical competence

Need for ethical competence in DNR decisions

Development of ethical competence (*added for physicians*)

Some nurses mentioned the development of ethical competence during their interviews. Thus, the topic *Development of ethical competence* was added to the interviews with the physicians.

Probing questions were asked when the participants needed clarification and/or their answers needed further development.

Data collection Study IV

For Study IV, the authors developed a study-specific web survey. The survey was based on aspects of DNR decisions that are regulated in Swedish law [7, 8] and on findings from previous studies [21, 30, 41, 57, 59], such as participation in DNR decisions and information about and documentation of DNR decisions. The Survey Monkey tool was used to design the web survey. The respondents were asked to fill in the following three sections:

- Background data (Table 3), including a choice of specialty – oncology or hematology. Based on this choice, a fictitious patient case in oncology or

hematology was presented as a short vignette (Table 7a and Table 7b). The vignettes were presented to represent the conditions surrounding a typical DNR decision, including typical history of and progress of an illness found in their wards [60].

- Questions that respondents answered using a Likert scale from 1 (not important/likely) to 6 (very important/likely). Referring to the scenario presented in the vignette, the participants answered questions about how *important* an aspect of the DNR decision process was, and in the next question how *likely* this was to happen at their work. The questions were phrased as follows:
 - How important/How likely do you think it is that a DNR decision is made after dialogue with the patient/relative?
 - How important/How likely do you think it is that a DNR decision is made in consultation with another physician/nurse?
 - How important/How likely do you think it is that the patient/relative/care team is informed about the DNR decision?
 - How important/How likely do you think it is that a DNR decision is clearly documented?
- Choosing the three (out of eight) most important attributes in relation to DNR decisions. The choices were based on the outcome of interview questions about ethical competence with nurses and physicians as reported in Study III:
 - survival and quality of life after resuscitation,
 - medical prognosis,
 - the right to a peaceful death,
 - patient autonomy,
 - principle of non-maleficence,
 - principle of beneficence,
 - patient age, and
 - opinions of relatives.

The participants had the opportunity to write text comments at the end of each topic in the questionnaire and to write free comments at the end of the questionnaire.

Table 7a. Vignette hematology

Erik Larsson, 75 years. Married, two adult children

Previous Diseases:

Chronic Obstructive Pulmonary Disease (COPD) diagnosed 5 years ago. Smoking cessation and local treatment.

Myocardial infarction 3 years ago. Angina pectoris occasionally.

Diagnosed with multiple myeloma six years ago. Treatment was discussed and autologous stem cell transplant was not chosen due to age and concurrent diseases. Received custom first-line treatment according to national care program. Transfusions initially for anemia and thrombocytopenia. Plateau phase was reached after 9 months.

Relapse after four years and new treatment began with second-line treatment according to the care program. Back pain was treated with long-acting morphine. Two spontaneous fractures (arm and shoulder) were irradiated with good results and plateau phase was reached again after 11 months of treatment. During treatment, repeated pulmonary infections. COPD follow-up showed 50% lung capacity.

Six months after the second treatment, Erik returns to the emergency room with pneumonia, increasing cough and breathing difficulties. He is exhausted, but awake and cognitively unaffected. Erik is admitted to your ward. Relatives visit every day, and they are very concerned about Erik's worsening condition. The back pain is worse and blood tests show anemia and increased infection rates. Discussion about a DNR decision is pertinent.

**Definition of DNR in this document: a decision not to perform basic CPR (chest compression and assisted breathing) or advanced CPR (defibrillator or medical drugs).*

Table 7b. Vignette oncology

Erik Larsson, 75 years. Married, two adult children

Previous Diseases:

Chronic Obstructive Pulmonary Disease (COPD) diagnosed 5 years ago. Smoking cessation and local treatment.

Myocardial infarction 3 years ago. Angina pectoris occasionally.

Heredity for prostate cancer (father and brother).

High PSA values were detected through screening, leading to the start of oral hormone treatment. After one year, PSA increased further, and transition to hormone injections started, given every third month. Irradiation toward the prostate was given a total of 35 times.

Two years later, lymph glands were detected in the lower abdomen. These were successfully irradiated, in a total of 25 events. Subsequent problems with swollen legs and pain, which were well treated with compression stocking and pain relief.

After another two years, new relapse treated with chemotherapy. A total of 5 occasions were planned, but after the fourth occasion, Erik had a bone marrow failure. Pneumonia was also detected. Treatment started with antibiotics and transfusion support during a two-week placement. The pain increased in the back and suspicion of skeletal metastases were confirmed in a skeletal scintigraphy. Follow-up of COPD showed 50% lung capacity.

A month later, Erik suffers from new pneumonia, with increasing cough and breathing difficulties. He is exhausted, but awake and cognitively unaffected. Erik is admitted to your ward. Relatives visit every day, and they are very concerned about Erik's worsening condition. The PSA value has risen again since the chemotherapy treatment ended. Discussion about a DNR decision is pertinent.

**Definition of DNR in this document: a decision not to perform basic CPR (chest compression and assisted breathing) or advanced CPR (defibrillator or medical drugs).*

Procedure Study I

Study I was conducted in the hematology and oncology departments at four hospitals in central Sweden. Approval was given by the head of each department at participating hospitals to include both nurses and physicians. Nursing unit managers of the respective departments were contacted and informed, and they assisted in contacting nurses eligible for the study. They were asked to recruit both male and female participants of different ages and work experience.

The first author contacted most nurses that preliminary accepted participation, but some nurses contacted the first author themselves. On this occasion, they

received verbal information about the study, and before the interview, they received written information about the study and signed an informed consent form. All contacted nurses accepted participation and were included in the study except one, who accepted but was unable to be interviewed due to family reasons. Another nurse from the same department, the same gender, and approximately the same age, participated instead. The inclusion was ongoing until saturation of the material was obtained. Data were collected between April 2011 and June 2011.

Procedure Study II

Study II was conducted in the hematology and oncology departments at seven hospitals in central Sweden. Data were collected between September 2012 and March 2013. The unit managers of the respective departments were contacted, and after information they assisted in contacting the physicians eligible for the study. Several physicians contacted the first author to make appointments for interviews. To increase the number of participants in the study, a resource person in the research team (hematologist) sent a request to professional contacts at hospitals in the region including information about the study, and then more physicians contacted the first author about the study. To get the head of departments' approval and still preserve confidentiality, the first author contacted the head of departments and received verbal authorization that one or more physicians participated in the study. The interested physicians contacted the first author to make appointments for the interview. They were given verbal information about the study at the time, and before the interview, they received written information and signed an informed consent form.

Procedure Study III

Study III was performed using parts of the data from the interviews with nurses in Study I and with physicians in Study II; the parts that concerned ethical competence and guidelines in relation to DNR decisions. Thus, the procedure was the same as in Study I and II.

Procedure Study IV

For Study IV, ward manager or other coordinators (physicians and administrators) provided e-mail addresses of physicians and nurses who had worked in hematology and/or oncology wards for at least six months. An e-mail with

information about the study and a link to the web survey was sent to the provided e-mail addresses. All presumptive participants received at least two reminders since the web survey was anonymous. The first author visited several wards and provided brief information about the study. Prepaid envelopes and paper surveys were distributed at the wards during the visit to those who preferred to complete the survey that way. Data were collected from February to October 2017.

Data analysis Study I

The data analysis in Study I was made using thematic content analysis as described by Burnard et al. [61]. The first author read through all the transcripts, writing significant words or phrases in the margin as a first encoding of the content. Margin words (codes) were listed and duplicates or similar words were removed. The meaning units for each code were sorted under the appropriate code. The codes were then placed into groups that became subcategories and categories. The meaning units became quotations to illustrate the analysis for each category and subcategory. The co-authors listened to randomly selected interviews and read randomly selected transcripts. Categorization was made by all three authors and the final version of the analysis was made in consensus.

Data analysis Study II

The data analysis in Study II was made using Systematic Text Condensation as described by Malterud [62]. To gain an overview of the material, the first author read through all the transcripts. Previous preconceptions were bracketed. Meaning units (quotations) representing the experience of DNR decisions were identified and coded. The content of each code group was condensed, first as subjective story as told by one person and then as synthesized version to generalize the descriptions and concepts illustrating the research questions, which were presented in a narrative. Quotations were chosen to illustrate the narrative for each theme/category. The co-authors listened to randomly selected interviews and read randomly selected transcripts. Categorizations were made by all three authors and the final version of the analysis was made in consensus.

Data analysis Study III

The data analysis in Study III was made using the same method as Study I – thematic content analysis as described by Burnard et al. [61]. The first author read through all the transcripts and made a first encoding of the content by writing words or phrases in the margins. Margin words (codes) were listed and duplicates were removed. Meaning units for each code were then sorted under the suitable code. Subcategories and categories were made by matching groups of codes. Meaning units became quotations to illustrate each category and subcategory. All three authors participated in the categorization and agreed to the final version of the analysis.

Data analysis Study IV

The data analyses in Study IV were made in Statistical Packages for the Social Sciences [SPSS], version 24. Data were presented descriptively as numbers, percentages, and measures for central tendency and ranges. The answers to questions about importance and likelihood rated on a Likert scale were grouped as follows: 1-2 as “unimportant/unlikely”; 3-4 as “neither important/likely nor unimportant/unlikely”; and 5-6 as “important/likely”. Mann-Whitney U test was used to analyze ordinal data and a Chi-Square test was used to analyze categorical data. To reduce the risk of Type 1 errors, alpha was set after Bonferroni correction ($0.05/16 = 0.003$ for important/likely ratings and $0.05/8 = 0.006$ for attributes).

In response to the question about the three most important attributes in relation to DNR decisions, six participants made one or two choices instead of three. These answers were included in the analysis. Ten participants made no choice, and one participant made four. These answers were not included in the analysis.

Ethical considerations

According to Swedish legislation [63, 64], no formal approval from the Regional Ethics Review Board was needed for Study I, II, and III, as these studies did not deal with sensitive personal data or risked impacting the participants physically or psychologically. On the contrary, it can be helpful for the informants to talk and reflect about their experiences in a calm situation. All steps of this work followed the ethics guidelines as outlined in the Declaration of Helsinki [65]. The informants were included after informed consent. They were informed that participation was voluntary and that they were free

to withdraw at any time. The information also emphasized that data would be handled confidentially and that the reporting of results would not make identification of the informants possible.

For Study IV, approval from the Regional Ethics Review Board was sought (Dnr 2016/484), but the Board found that no approval was needed. In addition, this work followed the ethical guidelines as outlined in the Declaration of Helsinki [65]. The participants in the survey study received information about the study in the e-mail invitation. It included information about anonymous answers of the survey resulting in reminders for all participants at all times and that answering and sending the survey was equal to consenting to publishing the results analyzed on group levels in a scientific paper.

Summary of findings

Study I

The analysis of the interviews with the participating nurses in Study I revealed two categories and seven subcategories:

- Specifics of nursing care in relation to DNR orders:
 - Closeness to the patient
 - Levels of nursing
 - Important values

- Hindrances to good nursing care in relation to DNR orders:
 - Partial and/or unclear DNR orders
 - Uninformed patients and relatives
 - Disagreements among caregivers and/or family
 - Inadequate documentation and reporting

The nurses in this study described how they often had a close relationship with their patients. Due to this closeness, they experienced that they could see early on when their patients' health and well-being changed. Therefore, they often initiated discussions about DNR.

The nurses also expressed that they could provide better care when their patient and their family were informed about the DNR decision and the transition to palliative care. They stated that they could then talk openly with the patient and family and be supportive of their acceptance of the situation. With a clear transition to palliative care, sometimes including a DNR decision, the nurses also believed that the nursing care improved as the care tended to be calmer and more focused on good care instead of on the technical medical details.

The nurses expressed that they depended on a clear DNR decision reported and documented in a safe manner. Otherwise, their ability to provide the best care possible was jeopardized, as patients risked receiving unwanted CPR. Disagreements around DNR orders could occur when family members and patients had different wishes concerning end-of-life care or when nurses and

physicians disagreed on the level of care for the patient, including whether DNR was appropriate.

Study II

The analysis of the interviews with the participating physicians in Study II revealed two parts. One part described the physicians' different roles in relation to DNR decisions and one part described experiences of ethically challenging decisions regarding DNR. Both parts included several aspects:

- The physicians' different roles in relation to decisions about DNR
 - Decision-maker
 - Patient advocate and mediator for relatives
 - Team member

- Experiences of ethically challenging decisions about DNR
 - The transition to palliative care
 - Differences between oncology and hematology
 - Definitions of DNR
 - Important values

This study identified three roles for physicians. As a *decision-maker*, the physician was responsible for DNR decisions, which for some were perceived as a significant decision and for some a less significant part of their responsibilities in a larger context of whether they should receive treatment or not. As an *advocate for the patient and a mediator of relatives*, the physician should act in the patient's best interests, but family members might need information and support, and sometimes conflicts might arise when a physician makes a decision or mediates a conflict. The decision to inform about a DNR order or not was individualized according to each patient and/or family and assessed whether the information would be beneficial or harmful. As a *team member*, the physician was part of a collaborative medical team responsible for providing information, collaboration, and supervision.

The physicians made the decisions about the transition from curative to palliative care and DNR mainly on medical grounds with regards to the prognosis of the disease, expected survival of cardiac arrest, expected quality of life, and age. However, they also reflected on the ethical aspects of the decision, weighing maleficence and beneficence.

The physicians in this study experienced differences in how decisions about end-of-life care were made in oncology and hematology. Oncology patients could have a long palliative phase, where it was known that the disease was not curable, but the patient could still feel quite well in the meantime. Hematology patients, on the other hand, could become seriously ill from the treatment, which could last for a long time, but the disease could still be considered curative. The active treatment could continue for a long time, and the palliative phase could be as short as a few days.

Study III

In the analysis of data from all interviews with the participating nurses and physicians, one theme was elaborated in Study III:

Ethical competence in relation to DNR decisions.

Under this theme, three categories and eight subcategories were grouped together:

- Understandings of ethical competence
 - Applying knowledge
 - Individual virtues
- Learning and developing ethical competence
 - Education and courses
 - Experience
 - Self-reflection
 - Working climate
- The role of guidelines
 - Support and safety
 - Obstacle

The results showed that both physicians and nurses were able to reflect on their ethical competence in relation to DNR decisions as well as on what it should comprise. The participants' descriptions of ethical competence in relation to DNR decisions corresponded to the description of ethical competence as *being, doing, and knowing* – i.e., to have appropriate virtues for your role as a nurse or a physician, to have the ability to act on the ethical judgments you have made, and to have knowledge of ethical theories and relevant clinical guidelines. To make ethically sound DNR decisions in oncology and hema-

tology care, physicians and nurses need all three aspects of ethical competence, which the respondents' reflections showed in this study. They reflected on their work and they made thorough ethical considerations if they felt they needed to deviate from guidelines in relation to DNR decisions. However, the respondents also described the need for the workplace to provide an environment with opportunities for reflection on ethics regarding end-of-life care, in order to keep their ethical competence on a high level.

Study IV

The first part of the result in Study IV presented the respondents' answers to how important, and how likely to happen at their workplace, they considered various aspects of the DNR decision process in relation to the patient in the presented vignette. Most respondents thought it was important to make a DNR decision after discussions with the patient and his relatives and in consultation with nurses, but they also thought that it was unlikely that this would happen at their place of work. The majority also thought it was important to inform the patient (57%) and his relatives (69%) of the DNR decision, but fewer thought it was likely to happen (21% and 36%, respectively). Twenty-one percent reported it unimportant to inform the patient about the DNR decision. A majority thought it both important and likely for the care team to be informed of the decision (97% and 84%) as well as for the decision to be documented clearly (98% and 87%).

Nurses rated the importance of making the DNR decision after discussion with patients and relatives higher than the physicians did. Nurses also rated the importance of informing patients and relatives of the decision higher than physicians did. Nurses rated clear documentation of the decision less likely to happen than the physicians did.

In the second part of the results for Study IV, the participants indicated the three (out of eight) most important attributes in relation to DNR decisions. For both nurses and physicians, the top three attributes overall were survival and quality of life after resuscitation, medical prognosis, and patient's right to a peaceful death. However, after the top three, nurses chose patient autonomy more often than physicians did, whereas physicians chose non-maleficence more often than nurses did.

Methodological considerations

Studies I-III

The nurses and physicians in the interview studies appeared to be interested in the subject and talked easily about DNR decisions. The interviews may have been facilitated by the fact that the interviewer is a nurse who is familiar with oncology and hematology care. There was no difficulty in understanding context and vocabulary for the interviewer or for the informants. The interviews were characterized by collegiality, but at the same time, the interviewer was aware of her pre-understanding, so she tried to be as neutral as possible to avoid affecting the informants' answers or the analysis. While the information gathered in Study I was mainly perceived as a confirmation of the interviewers pre-understanding of being a nurse participating in DNR decisions in cancer care, Study II gave insight in unknown and different perspectives through the interviews with the physicians. A strength of the studies is that several of the interviewed nurses and physicians worked in the same departments, allowing interconnections in the results. However, there is a risk of selection bias: the physicians and nurses who chose to participate in a study might be interested in the topic and may have spent time thinking about the topic.

The construction of the interview guide in Study I was partly based on Virginia Henderson's theory of nursing [51], medical ethics [47], and communicative ethics [52]. The data collection in Study II was based on the interview guide in Study I, with the questions adjusted for the profession. Hence, the construction of the interview guides for Study I and Study II could be said to have a deductive approach. The analyses in both Studies I and II, however, were made without using predetermined categories. Some of the interviews in Study II were made close to the release of Ethical Guidelines for CPR [3] and some physicians already had knowledge of the guidelines. This could have made them more likely to participate in the study and to give more elaborated answers to the questions.

As mentioned earlier, the physicians in study II were questioned about the concept of ethical competence and how ethical competence can be developed. The answers to these questions were analyzed and reported in Study III. In

addition, a secondary analysis of the interviews from Study I was performed, from the view of research questions about ethical competence and the role of guidelines. In a secondary analysis, existing data from a previous study can be used to answer questions that was not initially envisioned [60]. The analysis was primarily inductively made from the research questions; however, the results were discussed from the theoretical framework of Eriksson et al. [55]. The framework was chosen since virtues (being ethical) and acting ethically (doing) are represented in several descriptions of ethical competence [66, 67], but Eriksson et al. [55] also add knowledge about ethics (knowing) as an aspect of ethical competence, which seemed suitable for our study.

The analyses in Studies I and III were made with content analysis according to Burnard et al. [61]. The analysis in Study II was made with Systematic Text Condensation as outlined by Malterud [62]. The analyses in these two methods are structured differently and the steps in the analyses are made in a different order: meaning unit – code – condensation – synthesizing – category according to Malterud [62] and code – meaning unit – category according to Burnard et al. [61]. However, the methods were similar in terms of handling the data and it is reasonable to believe that the outcome of the analysis in Study II would have been similar using content analysis according to Burnard et al. [61] as using Malterud [62], providing that the research questions were the same. However, the analysis in Study III was again made according to Burnard et al. [61].

Trustworthiness

The recruitment of informants continued until saturation of the material was considered achieved [60]. Credibility was strengthened in that none of the informants had difficulties understanding the questions, and the interviewer confirmed the informants' answers and asked probing questions when needed [68]. Confirmability was supported by the fact that the interviewer was well aware of her pre-understandings as a nurse [68], and that all authors participated in the analysis process, in which the final versions of categorization were made in consensus [69]. Dependability was assured through the use of interview guides in both studies and all informants answered the same questions. All interviews were made by the same person [69]. Concerning *transferability*; although these studies were made in hematology and oncology settings, the results may be transferable to other settings in which terminally ill patients receive care, such as internal medicine or surgery [68, 69].

Study IV

In Study IV, seven local hospitals were enrolled. These hospitals are larger county hospitals and university hospitals in cities of various sizes with both rural and urban catchment areas. Sixteen wards were included in the study. They were also of different sizes. Some offered hematology or oncology care, some were mixed with another specialty (medicine or surgery), and one had both hematology and oncology. This variety could contribute to the generalizability of the findings.

Information about Study IV, including a link to the web survey, was sent to all presumptive participants. Some e-mails bounced due to server errors and in some cases an auto responder announced absence. The response rate (43%) could, therefore, be higher, but not lower than reported. In addition, more respondents answered the question at the beginning of the survey and less in the latter part. When discussing participation in surveys during the personal visits at some wards, staff representatives agreed to the importance of the topic. However, they referred to a lack of time as the main reason not to participate in the study. Baruch and Holtom [70] found decreasing response rates since the 1970s, and low response rates are not unusual in recent internet-based health care research. Several studies report response rates at 10-40% [71-74]. The main reasons for non-response were high survey burden and lack of time.

Content validity in Study IV was supported by a survey on the aspects of DNR decisions regulated by Swedish law and guidelines [3, 7, 8] and on previous qualitative interviews with both nurses and physicians [57, 59]. A vignette was provided so the respondents could imagine a scenario where they would have to make or participate in a DNR decision, and the respondents' perceptions of such a situation could be collected [60]. The patient cases in the vignettes were reviewed in consultation with a physician, a specialist in hematology. Two nurses working in hematology reviewed the questions for the survey and the final web survey was tested on 15 nurses who teach at the nursing program at Uppsala University. They reported no difficulties in understanding the questions or survey web tool, but they provided comments that led to minor adjustments in phrasing and layout.

The Bonferroni correction to protect against the risk of Type I errors caused by multiple comparisons has been criticized for causing a substantial reduction in the statistical power of rejecting an incorrect H_0 in each test – i.e., increasing the risk of Type II errors [75]. Nevertheless, the procedure seemed reasonable as the statistically significant results are supported by results from an earlier qualitative study [57] and appear to be clinically significant in terms of mean differences.

More female than male nurses (94/6%) participated in Study IV, which seems reasonable as only 7% of the nurses who received the survey were male. Moreover, according to the National Board of Health and Welfare [76], 12% of registered nurses in Sweden in 2015 were male. Thus, it is likely that 7% represents the number for hematology and oncology wards, as male nurses to a higher extent work in emergency care, anesthetics/intensive care, and psychiatry [77].

Limitations

The present work concerns the experience of DNR decisions among nurses and physicians working in hematology and oncology. The perspectives of patients or relatives in cancer care are not examined, although that perspective also would have been highly relevant to investigate.

Discussion

The present project brings together empirical knowledge of DNR decisions in oncology and hematology care and theoretical discussions on the ethical aspects of such decisions and the competence that is needed to make such decisions. Two central concepts have emerged during the work, namely *competence* and *communication*. In the following, these aspects are discussed in light of the results from the separate studies.

Dilemmas in DNR decisions in cancer care

Study I found that the nurses strived for good nursing care in relation to DNR orders. To provide good nursing care, they needed clear and well-documented decisions on DNR, and they wanted patients and families to be informed about DNR decisions and palliative care. The opposite was perceived as a hindrance to providing good care. If DNR is not discussed at all, the nurses can become unsure whether CPR should be performed. To start CPR on a patient who would not benefit from it was perceived as an undignified end for the patient and not compatible with good nursing care. This also applied to patients where the decision was not documented and reported in a clear and secure manner.

This reasoning is in line with Henderson's theory on nursing for the dying patient [51], and the nurses' attitude about these questions have been reported in other studies [38-40, 78]. However, one of the physicians in Study II suggested the possibility that the patient's suffering would not increase by having CPR performed, but rather performing CPR would increase the family's understanding and facilitate the grieving process when they saw that the medical team really tried everything. Another physician mentioned that they made the decisions based on the information they had at the moment, and, in retrospect, it was easy to say that one could have acted differently. When uncertain, the physicians always had to decide CPR, not DNR. This reasoning is in line with the Swedish ethical guidelines for DNR orders [3].

In Study II, several physicians mentioned that there were differences between hematology and oncology regarding end-of-life care. For oncology patients, it could be easier to know when the disease was no longer curable. The palliative

phase could thereby be long, sometimes several years, but the patient could often feel quite well during that period. Regarding the hematological patients, they often became severely ill from the treatment and might even need care in the ICU. Nevertheless, they were still in a curative treatment. The treatments were repeated until no more options were available, and then the palliative phase could become very short. However, several nurses in Study I mentioned that they thought physicians had difficulties finishing curative treatment and shift to palliative care. As the nurses spent a great deal of time with their patients, they witnessed their patients' suffering in different ways and degrees than the physicians. The significance of this closeness has been argued for in other studies [79, 80] and can be interpreted in light of Henderson's theory on nursing [51], which also emphasizes the need for nurses to be close to their patients as this closeness helps them anticipate their patient's needs. The nurses in Study I mentioned that the physicians had the necessary medical knowledge, and the physicians in Study II emphasized that they also saw examples of when the treatments had finally succeeded as they met healthy patients on revisits at the open clinic.

The nurses in Study I expressed a concern about when relatives and patients were not informed about palliative care or DNR. They expressed how they then could not talk openly about this and that patients and relatives might not receive good nursing care, comfort, and support in that extraordinary difficult situation. This was also supported in Study IV. Here the nurses, compared to the physicians, more often reported that it was more important for patients and relatives to participate in DNR decisions and to be informed about the DNR decision. Previous studies have shown that involved family members can be helped to accept the end-of-life situation, which nurses found satisfying [38-40]. This finding is also consistent with Henderson's theory on nursing [51]. However, the physicians (Studies II and III) provided reasons for why they sometimes made decisions about DNR without informing the patient or relatives. Some physicians stated that they sometimes withheld information after ethical considerations because, for example, they believed the information would do more harm than good. Some of them described how they did talk to the patient, but without mentioning the word DNR. Instead, they talked about what they would do – not transfer the patient to ICU, relieve pain, stay on the ward, and provide good care. In several cases, the physicians mentioned that the patient understood that CPR was not to be performed, although it was not expressed. This was assumed as families seldom questioned why no attempts were made to restart the heart when the patient died. Another possible explanation could be that the patient had become so weak that relatives understood that death was inevitable.

When the physicians' decision to inform or not are made after ethical consideration, it is in accordance with guidelines [3] as well as ethical principles [47]. However, according to Swedish regulation, patient participation and information to patient and/or relatives are crucial, and deviations from participation and information should be documented in the medical record [8]. Some of the physicians in Study III expressed that they felt guilty for deviating from the regulations when not informing their patients about a DNR decision even though they might have withheld DNR information because they believed the information would do more harm than good. Thus, the regulation may be perceived as more compulsory than the guidelines. Nevertheless, 45% of the participants in Study IV reported it not likely that the patient should be involved in a DNR decision, and 21% reported it unimportant to inform the patient about a DNR decision. In addition, 57% of the participants found it important to inform the patient, but only 21% reported it likely to happen at their place of work.

Despite the reasons for not informing (insecurity or discomfort [10, 41, 81] or ethical consideration and risk of harm [41-43, 82]), physicians today face the challenge of meeting patients and relatives who have researched their medical record on the Internet. This means that if the physician does not inform patients or relatives about a DNR decision or other limitations of treatment, there is a risk that they will find the information in another way. This situation can cause even more harm than if the physician had provided the DNR information in the first place.

Nurses in Study IV reported it more important for patients and relatives to participate in DNR decisions and to receive information about the decision than physicians did. In addition, nurses chose Patient autonomy as the fourth (out of eight) most important attribute in relation to DNR decisions. These differences may reflect the nurses' closeness to the patient as reported in Study I. Physicians chose the Principle of non-maleficence as the fourth most important attribute, which is also stated in the physicians' Hippocratic Oath [83]. In Studies II and III, several physicians expressed that DNR decisions primarily were made on medical grounds and required medical knowledge. However, they also stressed that ethical competence was needed. According to Swedish law, a patient cannot choose CPR if the physician concludes that CPR will provide no medical benefit [4]. In addition, physicians in Study II mentioned how important it is that relatives understand that the decision on DNR is the physician's responsibility, not the relatives. This view could explain the lower rating in importance of participation from the physicians in Study IV.

Communicative ethics in end-of-life care

Nurses and physicians have different perspectives on DNR decisions, some as the result of different responsibilities in the decision-making as regulated by laws and guidelines. Therefore, there can be an imbalance in these situations, where the nurses have less possibility to influence the decision. This imbalance can increase the risk for moral distress among nurses [77]. According to Jameton [84], moral distress in nursing can be defined as a challenge in which a caregiver's moral or ethical judgment about care is in contrast to the judgment of those who are in charge. Young et al. [85] found that nursing staff experienced moral distress when they were unable to influence a patient's end-of-life care in the way that they felt was right. The moral distress resulted from a feeling of powerlessness and an inability to do the right thing. In Prentice et al. [86], nurses and physicians described moral distress not only when experiencing that patients suffered during their care, but also when acting against their conscience or when forced to choose between competing ethical principles or when unable to act in the patient's best interest due to things they could not control.

A Moral Distress Scale for measuring moral distress is described by Corley et al. [87]. High scores on a Likert scale for a 32-item statement indicated risk for moral distress. Examples of statements in the scale for nurses were: "Follow the physician's request not to discuss Code status with patients", and "Follow the family's wishes to continue life support even though it is not in the best interest of the patient" [87]. In line with the results in Study IV, these examples indicate that moral distress can occur in relation to DNR decisions in cancer care. This is also supported by Mehlis et al. [88].

However, ethical conflicts are highly connected to DNR decisions. For example, Källemark et al. [89] found that all categories of health care professionals have an increased risk for moral distress related to the context of ethical conflicts, and in study II, some physicians expressed that making a DNR decision was ethically difficult and that they felt like making themselves God. Hence, also physicians have an increased risk of experiencing moral distress in relation to DNR decisions.

The results from Study I were analyzed with democratic dialogue [52] as a guide for improved communication between nurses and physicians. A democratic dialogue implies that it is the strength of the argument that is important, not the person who delivers the argument. Everyone who experiences difficult situations can add them to the agenda. The goal is to reach consensus so that the practical work can continue. However, as shown in the studies in this project, a consensus might not be reached due to the

different perspectives and the imbalance in responsibility between physicians and nurses. Therefore, more relevant in this setting with DNR decisions is Benhabib's [90] theory of communicative ethics. Benhabib argues that the goal of the ethical dialogue is not consensus, but to seek understanding of each other's perspectives and to be able to continue the discussion, despite possible disagreements. Such communication, for example, could be reached in ethics rounds with interdisciplinary participation as suggested by Källemark et al. [89]. As argued by Eriksson et al. [55], such ethics rounds could also be a way to enhance ethical competence among nurses and physicians in that the democratic dialogue can improve competence concerning both ethical knowledge and character. Such improved competence and communication among nurses and physicians can contribute to safer and better care for patients in severe cancer treatments in their end of life.

Conclusions and clinical implications

DNR decisions in cancer care can be associated with ethical conflicts of interest, and nurses and physicians have different perspectives of DNR decisions which they need to share. Competence in ethics and inter-professional communication are central concepts for nurses and physicians participating in such decisions.

In order to provide safe and good care for patients in end-of-life situations, nurses need DNR decisions to be clear and well documented. Nurses also need patients and relatives to be informed about the DNR decision so they can provide additional support in relation to the decision. Physicians make decisions on DNR primarily on medical grounds such as prognosis or expected survival after resuscitation. They also include ethical considerations, such as weighing benefit against harm, and whether to inform patients and/or relatives of the decision. The DNR decision could be seen as a minor part of a greater decision about life-sustaining treatment and limitations of treatment as well as a major decision, deciding over life and death. In order to make or participate in DNR decisions, nurses and physicians need ethical competence. Hence, they need to develop virtues appropriate for their profession, and they need to enhance their knowledge about ethics. Furthermore, in ethically difficult situations, they need to act according to the ethical judgments they make. Nurses and physicians rated it more important that patients and relatives should be involved in, and informed of, DNR decisions higher than they rated this likely to happen at their place of work. Both professions need to be aware of that what they believe important is not always likely to happen, but especially nurses, who rated the importance of participation and information higher, and the likelihood lower, than the physicians did.

From these conclusions, the following implications for practice are made: Nurses and physicians need to be aware of the fact that they have different perspectives about DNR decisions in cancer care. They also need to be aware of the fact that there will always be a power imbalance between them when it comes to DNR decisions, as regulations determine that the physician is ultimately responsible for making medical decisions and providing information to patients and/or relatives. If the physician withholds information about a

DNR decision due to risk of harming the patient, he/she must be aware of the risk that the patient receives the information through, e.g., Internet access of medical record. In order to reduce conflicts around DNR decisions and to protect all involved parties from the increased risk of moral distress due to ethical conflicts, it is important to improve both ethical competence and the communication in the wards. Health care organizations need to facilitate the communication and give time and space for ethical dialogues. Communication training for nurses and physicians needs to start during their education, for example, through inter-professional classes in ethics. All communication needs to be according to the principle of democratic dialogue, and the participants need to be able to continue the discussion and work together, even if consensus is not reached. This could be achieved, for example, through ethics rounds, which could also contribute to enhanced ethical competence in nurses and physicians working in cancer care. Nurses and physicians have a shared responsibility to inform each other of their different perspectives in relation to DNR decisions in order to reach a mutual understanding that would help ensure a safe care to patients in the end of life. Furthermore, patients and relatives will benefit from receiving the same information from nurses and physicians.

Future work

The first step in our future work is to report the results of this thesis to the participating nurses and physicians. An extended Summary in Swedish will be printed in a brochure and delivered to all participating hospital wards. A short oral presentation will also be offered to the participating clinics.

Furthermore, a fifth study is planned within the project. In Study IV, the participants had the possibility to leave comments after every set of questions and at the end of the survey. This resulted in 89 participants leaving a total of 287 comments. These comments need to be analyzed and presented. One focus of this planned study will be on the concept of Allow Natural Death (AND), as this was mentioned in some of the comments. In addition, ethical perspectives on different aspects of the DNR decision process will be highlighted in this planned study.

Finally, the perspectives of relatives would also be interesting to investigate. During the finalization of the fourth study and during presentations and meetings, several people shared with me their personal experiences of participating closely at the death of relatives. A few of them had the experience that the decisions about DNR or CPR or other treatment limitations were in fact theirs, as relatives. Therefore, it would be interesting to explore the relatives' understandings of information concerning treatment limitations and DNR decisions.

Svensk sammanfattning (Swedish summary)

Beslut om Ej HLR fattas ofta i cancervård, då hjärt-lungräddning (HLR) bedöms som utsiktslöst. Patienten kan ha en dålig prognos i sin grundsjukdom, eller små chanser att överleva ett hjärtstopp med god livskvalitet. Patienten kan också själv ha uttryckt en önskan om att inte återupplivas i händelse av hjärtstopp. Om en patient inte har ett beslut om Ej HLR, ska hjärt-lungräddning inledas inom 60 sekunder efter ett hjärtstopp, och defibrillering ska ske inom tre minuter.

Socialstyrelsens föreskrifter och allmänna råd om livsuppehållande behandling gör klart att ansvarig läkare ska fatta beslut om Ej HLR i samråd med annan legitimerad yrkesutövare, och helst i samråd med patient och andra i vårdteamet. Där beskrivs också hur beslut och information ska dokumenteras. Patientlagen reglerar patientens rätt till information om sjukdom och behandling. Om patienten inte kan ta emot information, ska den om möjligt ges till anhöriga istället.

Enligt Socialstyrelsen har en patient i Sverige inte rätt att välja behandlingsalternativ som inte är förenligt med vetenskap och beprövad erfarenhet. Det innebär att om läkaren inte anser att en behandling är till nytta för en patient, kan patienten inte kräva den behandlingen. Det gäller även hjärt-lungräddning och andra livsuppehållande behandlingar. En patient kan däremot alltid avsäga sig behandling, och det är ett beslut som måste respekteras av läkare och vårdpersonal. Svenska Läkaresällskapet, Svensk sjuksköterskeförening och Svenska Rådet för Hjärt-lungräddning har gett ut Etiska riktlinjer för hjärt-lungräddning. Där ges även råd för beslut om Ej HLR.

I samband med Ej HLR-beslut har många studier i olika delar av världen och inom många olika specialiteter rapporterat om liknande problem, t.ex. att patienter riskerar oönskad hjärt-lungräddning för att besluten om Ej HLR är otydliga och dokumenteras otydligt. Begreppet Ej HLR tolkas ibland också olika. Ofta är det svårt att besluta om Ej HLR, vilket gör att besluten fattas sent i patientens sjukdomsförlopp, ofta samma dag som patienten avlider. Det är vanligt med etiska konflikter kring besluten, ofta på grund av att professionerna i vårdteamet tycker olika, eller på grund av att patient och anhöriga

tycker olika. Dessa konflikter kan handla om vilken tidpunkt Ej HLR-beslutet ska fattas, om patient och/eller anhöriga ska få vara delaktiga i beslutet och om de ska få information. En del läkare tar med andra vårdgivare i diskussionen om Ej HLR-beslut, medan andra fattar besluten själva eller tillsammans med andra läkare.

Det övergripande syftet med avhandlingen var att undersöka kliniska och etiska aspekter av Ej HLR-beslut hos sjuksköterskor och läkare verksamma inom hematologisk och onkologisk vård. Etiska teorier, principer och modeller har använts för att planera studier, utveckla intervjufrågor och förklara resultat i studiernas diskussioner.

Syftet med studie I var att undersöka sjuksköterskors upplevelser och erfarenheter av Ej HLR-beslut, för att få en djupare förståelse för sjuksköterskans specifika roll i dessa beslut. Femton sjuksköterskor på åtta hematologi- och onkologiavdelningar i Uppsala-Örebroregionen intervjuades. Intervjuerna analyserades med tematisk innehållsanalys, och resulterade i två kategorier och sju subkategorier. Sjuksköterskorna beskrev hur de snabbt kunde se förändringar i patientens tillstånd, då de arbetade så nära patienten under långa arbetspass. Ofta tog de initiativ till en diskussion om Ej HLR-beslut med läkaren. Sjuksköterskorna ville gärna att patienter och anhöriga skulle få information om Ej HLR-beslut, eller övergång från kurativ till palliativ behandling, för då kunde de prata öppet om det med patienter och anhöriga som ville det och ge extra stöd. Sjuksköterskorna ansåg inte att Ej HLR-beslut påverkade patientens vård, men det kunde bli lugnare och vården inriktas mer på god omvårdnad än på medicinsktekniska moment när ett beslut var taget. Sjuksköterskorna uttryckte även att de behövde tydliga Ej HLR-beslut och klar och enhetlig dokumentation av besluten för att patienten inte skulle riskera att få oönskad HLR.

Syftet med studie II var att undersöka läkares upplevelser och erfarenheter av Ej HLR-beslut inom onkologi och hematologi, för att få en djupare förståelse för deras specifika roll i beslutsprocessen, med fokus på de etiska aspekterna av beslutet. 16 läkare på sju sjukhus intervjuades. Intervjuerna analyserades med systematisk textkondensering. Läkarna upplevde sin roll som beslutsfattare på olika sätt. En del såg Ej HLR som ett mindre beslut i en större kontext av att besluta om avslutande av kurativ behandling, övergång till palliativ vård och andra beslut om behandlingsbegränsningar. Andra såg det som ett stort beslut där de gjorde sig själva till Gud och bestämde över liv och död. Besluten om Ej HLR fattades till största delen på medicinska grunder, men läkarna gjorde också etiska bedömningar om vad som var bäst för varje patient och om information till patient och/eller anhöriga kunde skada eller göra nytta.

Några läkare nämnde olikheterna mellan hematologi och onkologi, där onkologipatienter under en lång period kunde vara palliativa och inte kunde botas, men ändå må ganska bra, medan hematologipatienter ofta blev livshotande sjuka av behandlingen men ändå hade fulla åtgärder eftersom det fortfarande var kurativ behandling som kunde pågå under lång tid, så att patienten fick en mycket kort palliativ fas.

Syftet med studie III var att undersöka hur läkare och sjuksköterskor i onkologi och hematologi förstod begreppet etisk kompetens för att fatta eller vara delaktiga i Ej HLR-beslut, och hur sådan kompetens kan läras och utvecklas. Ett ytterligare syfte var att undersöka riktlinjers roll i relation till utveckling av etisk kompetens i Ej HLR-beslut. I intervjuerna med sjuksköterskorna nämnde några av dem etiska ronder, och därför fick intervjuguiden för läkare en fråga om hur etisk kompetens kan utvecklas. En sekundär analys av intervjuerna från studie I och studie II gjordes, på de delar som handlade om etisk kompetens och riktlinjer i samband med Ej HLR-beslut. Analysen gjordes med tematisk innehållsanalys. I analysen framkom tre kategorier och åtta subkategorier. Läkarnas och sjuksköterskornas förståelse av etisk kompetens kunde relateras till beskrivningen av etisk kompetens som *being*, *doing* och *knowing*. Flera deltagare nämnde etisk kompetens som *being* - att vara en etisk person, dvs. att utveckla dygder specifika för sin yrkeskompetens, såsom t.ex. mod, ödmjukhet, medkänsla och empati. Flera pratade även om *doing* – att ha förmåga att i situationer handla utifrån etiska bedömningar. Även *knowing* nämndes – att ha kunskap om etiska begrepp och teorier, men också en medicinsk kunskap om kontexten kring sjukdomen, för att kunna göra etiskt korrekta bedömningar. För att utveckla etisk kompetens behövdes utbildning och kurser, men framför allt erfarenhet, goda förebilder och självreflektion. Det behövdes även ett arbetsklimat som tillät detta.

Syftet med studie IV var att undersöka sjuksköterskors och läkares uppfattning om hur viktiga olika aspekter av ett Ej HLR-beslut är, och hur troligt det är att dessa aspekter beaktas på deras arbetsplats. Vidare undersöktes vilka attribut de såg som viktigast i samband med Ej HLR-beslut. En webbenkät skickades ut till samtliga sjuksköterskor och läkare verksamma inom onkologi och hematologi i Uppsala-Örebroregionen. Svarsfrekvensen var 43%, 132 sjuksköterskor och 84 läkare. I bakgrundsfrågorna fick de välja om de hörde till hematologi eller onkologi, och då slussades de till en vinjett, i form av ett fiktivt patientfall för den specialiteten. Därefter följde frågor där de rankade på en Likertskala från 1 till 6 hur viktigt de tyckte att vissa aspekter av processen kring Ej HLR-beslut var, samt hur troligt de trodde att det var att aspekterna skulle beaktas där de arbetade. Majoriteten av de svarande tyckte att det var viktigt att patient och/eller anhöriga var delaktiga i besluten om Ej HLR och

att de fick information om beslutet, men färre trodde att det var troligt att detta skulle hända på deras arbetsplatser. Sjuksköterskor rankade detta som viktigare än läkarna. Deltagarna fick också markera de tre viktigaste attributen (från en skala med åtta attribut) i relation till Ej HLR-beslut. De tre viktigaste attributen var överlevnad och livskvalitet efter hjärt-lungräddning, medicinsk prognos och patientens rätt till en fridfull död. På fjärde plats valde sjuksköterskorna patientens autonomi, medan läkarna valde principen att inte skada.

Sjuksköterskor och läkare behöver vara medvetna om att de har olika perspektiv i relation till Ej HLR-beslut. Det kommer alltid att vara en maktobalans mellan dem, beroende på att läkarna är de som fattar beslutet om Ej HLR, och även är de som beslutar om delaktighet av patienter/anhöriga samt information till dem. Om läkare inte informerar om ett Ej HLR-beslut måste de vara medvetna om risken att patient eller anhöriga får veta det på annat sätt, t.ex. genom att titta på sin journal på Internet. Kommunikation och etisk kompetens är centrala begrepp för sjuksköterskor och läkare i beslut om Ej HLR. För att minska riskerna för moralisk stress på grund av etiska konflikter och maktobalans är det viktigt att öka den etiska kompetensen och ge möjlighet till dialog och god kommunikation på avdelningarna. Träning i demokratisk dialog, där innebörden av vad som sägs är viktigare än vem som säger det, behöver börja redan i utbildningarna, förslagsvis genom interprofessionell undervisning i etik. Sjuksköterskor och läkare har ett gemensamt ansvar att delge varandra sina olika perspektiv i beslut om Ej HLR, för en gemensam förståelse och för att patienter ska få samma information från både sjuksköterskor och läkare, samt få en säkrare vård i livets slut.

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