Postpone death?
In memory of Peter Sjökvist, research colleague and friend
1957–2003

"Every path we take leads to fantasies about the path not taken."
HALCON$^{136}$
POSTPONE DEATH?
Nurse-physician perspectives on life-sustaining treatment and ethics rounds
ABSTRACT

The starting point of the present thesis is nurses’ reported experiences of disagreements with physicians for pushing life-sustaining treatment too far. The overall aim was to describe and compare nurses’ and physicians’ perspectives on the boundaries for life-sustaining treatment and to evaluate whether ethics rounds could promote mutual understanding and stimulate ethical reflection.

A mixed methods design with qualitative and quantitative data was used, including interviews and questionnaires. The health-professionals’ experiences/perceptions were based on known patients foremost from general wards, but also intensive care units, at four Swedish hospitals. The first two studies treated the perspective on boundaries for life-sustaining treatment and the last two evaluated philosopher-ethicist led ethics rounds. Analysis of data was performed using a phenomenological approach and content analysis as well as comparative and descriptive non-parametric statistics.

In the first study, the essence of the physicians’ decision-making process to limit life-sustaining treatment for ICU patients, was a process of principally medical considerations in discussions with other physicians. In the second study, there were more similarities than differences between nurses’ and physicians’ opinions regarding the 714 patients studied. The physicians considered limited treatment as often as the nurses did. The ethics rounds studies generated mixed experiences/perceptions. It seemed that more progress was made toward the goal of promoting mutual understanding than toward the goal of stimulating ethical reflection. Above all, the rounds seemed to meet the need for a forum for crossing over professional boundaries. The most salient finding was the insight to enhance team collaboration, that the interprofessional dialogue was sure to continue. Predominating new insights after rounds were interpreted as corresponding to a hermeneutic approach. One of nurses’ negative experiences of the ethics rounds was associated with the lack of solutions. Based on the present findings, one suggestion for improvement of the model of ethics rounds is made with regard to achieving a balance between ethical analyses, conflict resolution and problem solving.

In conclusion, the present thesis provides strong evidence that differences in opinions regarding boundaries for life-sustaining treatment are not associated with professional status. The findings support the notion of a collaborative team approach to end-of-life decision-making for patients with diminished decision-making capacity. There is an indication that stimulation of ethical reflection in relation to known patients may foremost yield psychosocial insights. This could imply that social conflicts may overshadow ethical analysis or that ethical conflicts and social conflicts are impossible to distinguish.

Keywords: Clinical ethics, life-sustaining treatment, end-of-life decisions, attitudes, nurses, physicians, inter-professional relations, ethics consultation, ethics rounds, reflective ethical practice
The present thesis is based on the following studies:


II. Svantesson M, Sjökvist P, Thorsén H, Ahlström G. Nurses’ and physicians’ opinions on aggressiveness of treatment for general ward patients. Nursing Ethics 2006 13(2):147-161


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INTRODUCTION

As a graduate nurse 20 years ago, I remember one day on the surgical ward when Tora (assumed name) was the last patient for the afternoon round. She had been an inpatient for months due to a ruptured bowel, secondary to radiation for ovarian cancer. Again, she had a high fever and the senior consultant suspected a new ruptured bowel and ordered an X-ray. He left the room, but I stayed with Tora. She started to weep and said “I don’t want to, I can’t take it any longer”. This made me run after the doctor who was just about to leave the ward. Completely out of breath I shouted, “Dr X”. Seeming a bit irritated, he stopped. I told him that Tora could not take it any more and did not want the X-ray. Furious and without a word, he turned on his heels and left the ward. Now you may think that this doctor was not very nice. On the contrary, his patients loved him and I know he wanted the best for them. Wanting the best for Tora seemed to imply pursuing life-sustaining treatment. On the other hand, maybe you think I was a naive nurse thinking short-sightedly. I also wanted the best for Tora – to relieve her suffering. This meant palliative treatment. Who was right?

This is the point of departure for my thesis: nurses in industrial countries who are frustrated with physicians for pushing life-sustaining treatment too far. When treatment only seems to extend suffering and postpone the foreseeable death, care sometimes feels demoralizing. The phenomenon under study is the disagreement over whether to continue or limit treatment. The stakeholder perspective is that of nurses’ and physicians’, parties concerned in end-of-life decision-making. The first step was to understand how physicians reason and to compare nurses’ and physicians’ opinions. The second step was to find a way to improve end-of-life decision-making.

BACKGROUND

Problems associated with stakeholders in end-of-life decision-making

Continuing or limiting life-sustaining treatment is the paramount ethical issue in hospital care. The ability to stretch the limits through technology has led to difficulties in determining when it is appropriate to accept that a patient is dying. Prognosis may be uncertain, and knowing when to stop when the benefit is no longer in prospect is difficult. The decision is not solely medical, since consideration must be taken both to the effectiveness of treatment and the meaningfulness. Effectiveness refers to measures that lead to prolonged life and meaning-
fulness to the ethical dimension, the subjective assessment that continuing treatment is meaningful. Thus, decision-making combines medical considerations with the values and beliefs of multiple stakeholders. A simple definition of life-sustaining treatment is “drugs, medical devices, or procedures that can keep individuals alive who would otherwise die within a foreseeable, but usually uncertain, time period”. Life-sustaining treatment includes mechanical ventilation and advanced cardiac life support, exclusively used in intensive care. Other life-sustaining treatments that may also be used in general wards are renal dialysis, cardio-pulmonary resuscitation, surgery, chemotherapy, antibiotics, nutritional support, hydration. Depending on the intention, a treatment can be life-sustaining or palliative, i.e. relieving symptoms to improve quality-of-life. For example, a blood transfusion can be life-sustaining, but also palliative in that it decreases symptoms of fatigue.

The patient
Although the patient is a key stakeholder in end-of-life decision-making, studies show low patient involvement. However, problems have been reported concerning patient involvement: physicians’ avoidance behavior to talk about death with the patient, patients’ lack of decision-making capacity accompanied by lack of advance directives, as well as patients’ reluctance towards involvement in end-of-life decision-making or to assume an active role in their own care. Other studies have shown that patients want to be involved in such decisions. If asked, the majority of severely ill patients want life-sustaining treatment including cardiopulmonary resuscitation (CPR). Studies also show that older people overestimate the efficacy of CPR. In connection with this, in two studies, patients’ were asked about their wishes before and after informing them of the low prognosis of survival after CPR. In one study, most of the patients then did not want CPR while those in the other study still did.

Dying a high-technology death with suffering and lack of control is frightening, but studies show that severely ill patients want life-sustaining treatment. Though there are reports of suffering and distress from former ICU patients, the majority are positive toward renewed ICU stays. In a study outside the present thesis, European co-researchers and I found that half of the former ICU patients valued life itself as a supreme value over quality-of-life and wanted renewed ICU stays, even if this only gave an extra month’s survival. The will to live is re-
ported to be strong for patients with cancer recurrence \(^{49}\) and even in the final course of the illness, \(^{183}\) but it is also reported to vary considerably. \(^{32}\) This may imply that a critical ill person and with a strong will to live may request life-sustaining treatments that the physician views as futile. \(^{48,138}\)

**Next-of-kin**

Next-of-kin or the family is also a paramount stakeholder in the decision-making process, especially when the patient has diminished decision-making capacity. There are reports that patients view the family’s role as central to decision-making, \(^{82,158}\) but complications also occur when advocating the patient’s best interests. Studies have shown that few families know the patient’s preferences regarding life-sustaining treatment \(^{40}\) and that some have inaccurate ideas about the patient’s wishes. \(^{103,143}\) Health care professionals have reported moral distress situations when families want to continue aggressive treatment \(^{118,168}\) against the patients’ wishes. \(^{148}\) When families wanted everything done, they were experienced as having too much power over decision-making \(^{167}\) and as acting solely in their own interests. \(^{135}\)

**Society: guidelines**

In Sweden, there are no laws regulating decisions concerning life-sustaining treatment, only guidelines. \(^{172,176,177}\) According to the Swedish National Board of Health and Welfare, physicians may limit life-sustaining treatment and have the sole decision-making responsibility. \(^{172}\) The focus of national and international guidelines is however not on when to limit, but on the stakeholders in the decision-making process. The physician should be guided by the patient’s wishes, or if incapacitated, by advance directives or what the next-of-kin believe to be the patient’s wishes. \(^{19,150,172,176,177,185}\) Most guidelines also stress the importance of discussion and taking into account the views of other health professionals concerned. \(^{19,172,176,185}\) In the Swedish Society of Medicine’s guidelines on CPR, \(^{176}\) allied health professionals are one of the stakeholders, but in other guidelines on withholding and withdrawing life-sustaining treatment, allied health professionals are not mentioned. \(^{177}\)

All guidelines protect the patient’s rights of autonomy, but only as *negative* rights, implying that the patient only has the right to refuse treatment. This makes the involvement of patients in decisions of CPR especially complicated. The patient cannot demand CPR, as this is limited by the physician’s clinical judgment. \(^{62,190}\)
This brings us to the problem of social justice. Ineffective treatment of a particular individual may consume resources better spent on treatment of others. The Swedish Health and Medical Services Act\textsuperscript{163} was influenced by the report of the Swedish Parliamentary Priorities Commission.\textsuperscript{141} According to the commission, three basic ethical principles guide the distribution of care. They are, in order of decreasing importance: the principle of human dignity, the principle of need and solidarity, and the principle of cost-effectiveness.\textsuperscript{141} There has been criticism, however, against ranking the principle of need before the principle of cost-effectiveness.\textsuperscript{140}

For patients with serious diseases, belonging to the group with the highest degree of urgency, this means that the higher the degree of ill health, the lower the claim on cost-effectiveness.\textsuperscript{164} This may imply that the terminally ill patient has the greatest need for life-sustaining treatment, but that the treatment may not be cost-effective, i.e. poor chances of survival or poor quality-of-life. However, guidelines only consider groups of patients, and cost-effectiveness only considers methods. There are few systematically open priorities, especially regarding life-sustaining treatment, though guidelines for recommended treatments for different groups of diseases have been put forward.\textsuperscript{171} In conclusion, societal guidelines support physicians regarding their possibility to limit life-sustaining treatment and give consideration to stakeholders, but not regarding when to limit, that is, how to apply guidelines to prioritization on the individual patient level.

**Healthcare professionals**

Stakeholders are physicians, nurses, nurse’s assistants and allied professionals. The healthcare professionals most often reported to experience ethical problems regarding end-of-life decision-making are the physicians and nurses. Traditionally, physicians are seen as the sole stakeholder in the decision-making process and nurses only as the executors of the decisions, as most studies report low nurse involvement.\textsuperscript{5,11,27,145,147,175} According to previous studies, nurses experience frustration with physicians regarding the decision-making process (Table 1). Nurse’s assistants’ experiences of ethical problems have also been described, but their stories did not concern the decision-making process, instead their relationship with patients and patients’ families.\textsuperscript{180,195}

**In summary: Problems associated with stakeholders**

Problems of patient/family involvement and lack of societal guidance concerning when to limit life-sustaining treatment seem to entail great power and responsibility for the physicians in the decision-making process, but to also affect the executors of these decisions, the nurses. There are reports of nurses’ disagreements with
physicians regarding the decision-making, and thus, it would seem to be important to study nurse-physician perspectives.

**Nurse-physician perspectives on end-of-life decision-making**

**Nurses-physician experiences in relation to each other**

Though the core ethical problem for both nurses and physicians regarding end-of-life issues is the overtreatment of dying patients, nurses seem to experience more disagreements and frustration than physicians do regarding end-of-life decision-making. Qualitative findings on nurses’ moral outrage against physicians are presented in Table 1. According to the sociologist Chambliss, this may be described as one of nursing’s systematic ethical problems, in that the same problems recur time and again in various settings and different countries. Of 230 Australian intensive care unit (ICU) nurses, 95% reported disagreements, daily to at least once a month, with physicians regarding their decisions to inappropriately initiate and continue life-sustaining treatment. In an American study of nurse-physician perspectives on the care of dying patients in ICUs, 75% of nurses experienced frustration about end-of-life communication with the physicians, whereas none of the physicians had recognized the nurses’ frustration. At the same time, harmony between nurses concerning this issue has been reported. In some studies showing nurses’ negative judgments of physicians’ behavior, nurses could nevertheless acknowledge the difficulty of the physicians’ situation and were also aware that severely ill patients occasionally survive against all odds.

Fewer studies have looked into physicians’ experiences of end-of-life decision-making, and when this has been studied, both nurses’ and physicians’ experiences are often explored. In interviews with physicians, nurses seldom appear in their stories and disagreements with nurses are hardly recognized. Physicians report more satisfaction with end-of-life decision-making processes than nurses do. In one study, physicians indicated communication with nurses regarding aggressiveness of treatment for 34% of the patients, while the nurses agreed with this in 3%. In another large study on conflicts in end-of-life decision-making, nurses experienced conflicts with the physicians, while physicians experienced conflicts with other physicians higher in the hierarchy. There are, however, reports indicating that physicians believe nurses are keener to stop treatments and sometimes feel pressured by them to stop. Physicians felt nurses lacked medical knowledge and could not remember the miracles that do occur. According
to two other studies' descriptions of physicians’ experiences, physicians felt that nurses wanted to participate in decision-making, but did not want to share the decision-making responsibility. There are reports of physicians missing communication and support, but from other physician colleagues. They experience both little room for discussion and fear of discussing ethical difficulties and uncertainties. It was perceived as easier to continue treatment, as this would save them from being criticized.

Comparing nurses’ and physicians’ experiences, nurses narrate more pessimism about prognosis than physicians do and they narrate more certainty that patients are going to die. When nurses cite problems of overly aggressive treatment, physicians are more likely to cite reflections on uncertainty about how to decide or on agonizing about whether they have made the right decision. In essence, when nurses question physicians, physicians question themselves or physicians higher in the hierarchy. Let us see in the next section how nurse/physician experiences of each other correlate with their attitudes and opinions.
### Table 1  Nurses’ experiences of end-of-life decision-making in relation to physicians

<table>
<thead>
<tr>
<th>Disagreement over too much treatment</th>
<th>Country</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiation and continuation of overly aggressive or meaningless treatment</td>
<td>Australia</td>
<td>Bucknall 1997&lt;sup&gt;22&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Norway</td>
<td>Torjuul 2006&lt;sup&gt;191&lt;/sup&gt;</td>
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<tr>
<td></td>
<td>Sweden</td>
<td>Udén 1995&lt;sup&gt;195&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>Brett 2002&lt;sup&gt;18&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Udén 1992&lt;sup&gt;194&lt;/sup&gt;</td>
</tr>
<tr>
<td>Delayed decisions</td>
<td>Canada</td>
<td>Oberle 2001&lt;sup&gt;135&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Finland</td>
<td>Kuuppelomäki 2002&lt;sup&gt;98&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Finland</td>
<td>Hildén 2004&lt;sup&gt;81&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Australia</td>
<td>Bucknall 1997&lt;sup&gt;22&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Norway</td>
<td>Bunch 2000&lt;sup&gt;23&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Norway</td>
<td>Hov 2007&lt;sup&gt;84&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Udén 1992&lt;sup&gt;194&lt;/sup&gt;</td>
</tr>
<tr>
<td>Not allowing old patients to die</td>
<td>Canada</td>
<td>Bucknall 1997&lt;sup&gt;22&lt;/sup&gt;</td>
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<tr>
<td></td>
<td>USA</td>
<td>Redman 2000&lt;sup&gt;148&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Cronqvist 2004&lt;sup&gt;43&lt;/sup&gt;</td>
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</table>

### Frustrations over physicians’ characteristics

<table>
<thead>
<tr>
<th>Fear of making end-of-life decisions</th>
<th>Finland</th>
<th>Hilden 2004&lt;sup&gt;81&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sweden</td>
<td>Silén 2008&lt;sup&gt;167&lt;/sup&gt;</td>
</tr>
<tr>
<td>Heterogeneous attitudes and contradictory orders</td>
<td>Norway</td>
<td>Torjuul 2006&lt;sup&gt;191&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Silén 2008&lt;sup&gt;167&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Udén 1995&lt;sup&gt;195&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

### Frustration over communication

<table>
<thead>
<tr>
<th>Do not listen</th>
<th>Canada</th>
<th>Oberlee 2001&lt;sup&gt;135&lt;/sup&gt;</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Sweden</td>
<td>Silén 2008&lt;sup&gt;167&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>Udén 1992&lt;sup&gt;194&lt;/sup&gt;</td>
</tr>
<tr>
<td>Lack of explanation</td>
<td>Sweden</td>
<td>Silén 2008&lt;sup&gt;167&lt;/sup&gt;</td>
</tr>
<tr>
<td>Lack of meetings</td>
<td>France</td>
<td>Ferrand 2003&lt;sup&gt;52&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Norway</td>
<td>Hov 2007&lt;sup&gt;84&lt;/sup&gt;</td>
</tr>
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</table>
Nurse-physician attitudes and opinions about aggressiveness of treatment

Most studies on this issue have focused on ICU staff’s attitudes in general or are based on hypothetical patients. In surveys on nurses’ and physicians’ attitudes toward level of aggressiveness of treatment for hypothetical patients, there were no differences associated with professional status. Findings from two studies on opinions based on real patients showed conflicting results, in one nurses were less aggressive than physicians were and in the other there were no differences between them.

Regarding attitudes and opinions influencing decisions on aggressiveness based on both hypothetical and real patients, few differences have been found between nurses and physicians. Closed-ended items most commonly used for both hypothetical and real patients were the patient’s wishes, age and quality-of-life. Studies have shown that these are the most important rationales. Medical aspects were also commonly used, but were described in other ways, such as likelihood of survival, premorbid illnesses, futility and prognosis.

In summary: Nurse-physician perspectives

Few studies have gone beyond nurses’ and physicians’ experiences to exploring their reasoning and opinions in actual clinical practice with real patients. Physicians’ reasoning has been less explored than nurses’ has, and to my knowledge no study has explored physicians’ reasoning regarding actual end-of-life decisions. Few studies have compared nurses’ and physicians’ opinions regarding aggressiveness of treatment, especially for general ward patients, and the findings show conflicting results. Furthermore, nurses’ reported disagreements with physicians seem to be closely connected with feelings of frustration, especially over lack of communication.

How to improve end-of-life communication between nurses and physicians

Promoting mutual understanding

Starting from nurses’ experiences of disagreement over too much treatment and frustration over communication with physicians, a limited understanding of each other’s role and lack of communication are seen as major causes for conflicts regarding life-sustaining treatment. A collaborative team approach is called for and advocated with regard to end-of-life decision-making. Katzenbach and Smith defined a team as “a small number of people with complementary skills who are committed to a common purpose, perform-
ance goals, and approach for which they hold themselves mutually accountable”.

Compared to other areas such as psychiatry, which has a well-established system of interprofessional teamwork, teamwork in the care of critically ill hospital patients does not seem to be generally established. Several studies have shown that collaboration in interprofessional teams generally lead to more efficient work, timesaving and reduced costs compared to efforts from a lone profession. However, objective valid outcome measures are difficult to find, and in one review study, only 11 of 2000 studies qualified as good research. Thylefors concluded that the superiority of interprofessional teams has not been proven. In a scientific report on interprofessional teamwork, Blomqvist also found studies that do not support teamwork. Teamwork may lead to more conflicts due to profession-related differences and to overly time-consuming decision-making processes.

Improved communication through use of daily goals for care in ICUs led to decreased length of stay. Within the area of end-of-life decision-making, some studies support the notions that improved physician-nurse collaboration leads to improved quality of care and earlier transition to palliative care. Bunch found that in situations where team organizations were established, nurses and physicians made consensus agreements on limiting treatment. In more hierarchical places of work, physicians made decisions themselves, which nurses sometimes felt was not the most ethical decisions.

One Swedish study evaluated an intervention involving ethical discussion groups intended to improve the climate in interprofessional work between social and nursing staff in special houses for elderly and disabled people. The goal of the discussions was to promote mutual understanding between the professional groups. Scales of job satisfaction, sense of coherence and burn-out were used for the intervention and control group as well as qualitative interviews about their experiences. The only findings showing positive changes of the intervention were those from the qualitative part. The interviews revealed that the discussion groups had helped the staff groups come closer, and subtle changes were seen in their attempts to understand colleagues’ perspectives and to view them as less of a hindrance.
Therefore, together with nurses’ experiences of overtreatment and lack of communication, there appears to be an incentive to improve end-of-life decision-making by creating an arena for dialogue concerning severely ill patients. An important intermediate goal to improve decision-making would be to promote mutual understanding between nurses and physicians.

**Stimulating ethical reflections**

Improving dialogue alone may not improve end-of-life decision-making, as there still remain the difficulties of determining when and how to limit life-sustaining treatment. Kälvemark referred to previous research on health staffs’ lack of support to deal with ethical problems.

**Ethics consultation**

In North America, dealing with clinical ethical problems through ethics consulting (EC) has been in practice since the 1970s and is offered in most hospitals today. A consensus conference in Chicago 1995 led to following definition: “Ethics consultation is a service provided by an individual consultant, team, or committee to address the ethical issues involved in a specific clinical case. Its central purpose is to improve the process and outcomes of patient care by helping to identify, analyse, and resolve ethical problems”.

There are, however, reports on the high degree of variability in EC services and its tasks, goals and effects are a source of ongoing debate. A recent major survey exploring EC goals in hospitals throughout the U.S. showed that the most common goals are to protect patient rights, improve care and resolve conflicts. A less common goal is to educate staff about ethical issues. The majority of consultations are one-to-one discussions with health care staff or the patient/family, resulting in recommended courses of action. The main reason for contacting EC services is end-of-life decision-making.

North American ethics consultants, so-called ethicists and foremost members of clinical ethics committees, come from a variety of professional backgrounds: They are physicians, nurses, priests, lawyers, social workers or philosophers. However, in a recent study of EC practices, ethicists were primarily clinicians without formal ethics education and less than 5% of them were philosophers. The authors saw the lack of ethics education as a cause for concern. Meyers defended the philosopher as ethicist, arguing that they have skills of reasoned arguing and that there is an expectance of impartiality. No study has examined the
role of only using philosophers as ethicists. Furthermore, there is also disagree-
ment over the role of ethicists, concerning whether they should only clarify the
circumstances or give recommendations,\footnote{192} i.e. whether they should assume a fa-
cilitative\footnote{2} or authoritative\footnote{122} role.

Subjective evaluations of ethics consultation have shown high staff satisfaction,
also among physicians, regarding help in identifying, analyzing and solving ethical
problems as well as issues of ethics education.\footnote{119,160} Objective evaluations of EC in
intensive care have shown positive outcomes of reduction in non-beneficial treat-
ment and costs, through earlier decisions to limit life-sustaining treatment com-
pared to the control group.\footnote{46,65,159,160} One of these studies involved 550 patients at
seven hospitals.\footnote{160} The EC went through the following steps in this study: review-
ing medical records, interviewing those involved in the patient’s care, formulating
an ethical diagnosis, improving communication between those involved from team
meetings to formal conferences involving an ethics committee, facilitating resolu-
tion and follow-up support.\footnote{160}

In Europe, EC similar to those in the American model have been reported,\footnote{55,56,88,
170} but Reiter-Tell et al. conclude that empirical research of this topic remains un-
derdeveloped.\footnote{149}

In Sweden, the moral philosopher Brülde\footnote{20} introduced a form of ethics consulta-
tion in clinical practice as a non-scientific project during 2002, on commission by
the Swedish Association of Local Authorities and Regions. Thereafter, a national
network of philosophers was established, assisting health care professionals with
clinical ethical problems. Brülde found that the staff wanted help in identifying
and analyzing ethical problems, but not help with solving them.\footnote{20} Some skepticism
has been expressed about using ‘expert’ help to solve ethical problems.\footnote{41,109, 137}
Pellegrino\footnote{137} pointed out the risk that an outside expert could remove responsibil-
ity from the person formally in charge of decision-making. Contrary to American
ethics consultation, the European literature seems to show that support for health
care teams in dealing with ethical problems through reflective practice is more
commonly advocated\footnote{51,71,75,125,198} and practiced.\footnote{77,125,198} Thus, it would seem ap-
propriate to support Swedish staff by stimulating ethical reflection, that is by
helping them identify and analyze ethical problems, but not by helping them to
solve such problems. This stimulation may prepare staff for solving ethical prob-
lems on their own in the future.
Models of ethics rounds

Stimulating ethical reflection involves a pedagogic component. WHO advocates shared learning between different professional groups in healthcare, which implies learning with, from and about each other to improve collaboration and the quality of care. Regarding ethics education, there is a gap between theory and practice and case-based teaching is advocated. One pedagogical challenge is to discuss patients known to the participants. The social context is taken into account, which brings realistic complexity into the discussion, preventing simple solutions, as compared to hypothetical scenarios. Furthermore, as regards using the case method, studies show more effective learning when an actual critical situation from clinical practice is involved.

One form of reflective ethical practice is ‘ethics rounds’. The term has been previously mentioned in North American literature, usually in association with the teaching of medical ethics to students and practicing professionals by means of case discussions. No scientific evaluation has been found. In a Swedish model initiated by Hansson, an ethicist leads discussions with staff concerning a particular patient case. The ethicist’s role is to facilitate a democratic dialogue. No one is an expert, and the ethicist helps to bridge any gaps and alleviate tensions due to workplace hierarchies so as to focus on the matter on hand. By listening to each other’s perspectives, participants can become aware of alternative perspectives and multiple values related to clinical practice. Hansson stressed that the ethicist may give valuable input with regard to the weighing of values at stake for the patient, but the moral responsibility for decision-making still rests with the staff.

One study evaluating the above-mentioned ethics rounds model, using scales of moral distress to indicate improved ethical competence and another evaluating ‘moral case deliberation’ using responsive evaluation were published after the present research project had been finished.

In summary: How to improve end-of-life communication

To help nurses, physicians and allied health professionals improve end-of-life communication, it seems important to promote mutual understanding and to stimulate ethical reflections using a model of ethics rounds. To my knowledge, no study illuminating and evaluating reflective ethical practice regarding known patients has been published at this stage.
AIMS OF THE THESIS

The overall aim of the present thesis was to describe and compare nurses’ and physicians’ perspectives on the boundaries for life-sustaining treatment and to evaluate whether ethics rounds could promote mutual understanding and stimulate ethical reflection.

This is presented in four studies with the following specific aims:

I. To explore how admitting-department physicians reason when they make end-of-life decisions for ICU patients.

II. To describe and compare nurses’ and physicians’ opinions regarding level of life-sustaining treatment for their patients and the rationales on which their opinions were based.

III. To describe and evaluate one ethics rounds model, by describing nurses’ and physicians’ experiences from the rounds. An additional aim was to describe their opinions of how ethical discussion should be conducted.

IV. To describe and evaluate whether the ethics rounds stimulated ethical reflection.

With respect to the aims of the studies, the term evaluate is used in the sense of ‘formative evaluation’. It provides description of patterns of strengths and weaknesses so that improvements can be recommended. Guba and Lincoln referred to this as second-generation evaluation as opposed to first-generation, which determines effectiveness through measurement. The studies exist in a context and attention is paid to the local situation, without the possibility to control conditions.
METHOD

Design
The present research project had a mixed methods design including both qualitative and quantitative data. The nature of the research questions, accompanied by pragmatic assumptions about the different methods’ strengths in terms of data collection and analysis, has guided the choice of methods rather than any philosophical assumptions.21,136 Greater weight has been given to the qualitative approach, as it is useful when the subject under study is relatively unexplored and when investigating individual experiences136 as well as in capturing complex social processes. Two of the studies (Study I and III) were exclusively qualitative, whereas the two others involved mixed methods (Table 2). The three first studies had an inductive approach and the last a deductive approach, as patterns started to emerge in the inquiry.136

Setting
The setting was intensive care units (Study I) and general wards (Study II-IV) at four Swedish hospitals (Table 2).

In Study III and IV, a model of ethics rounds was applied that was inspired by the ethics rounds model by Hansson77,99 in combination with the goal established by the American Task Force on Standards for Bioethics Consultation, to identify and analyze the ethical problem, excluding the solving component.53,165 Four philosopher-ethicists, rotating between departments, led interprofessional care conferences regarding particular dialysis patients. The philosophers were recruited from the recently established national network. They held different ethical theories – consequentialist, realist, particularist and the fourth held no particular theory. The goals of the rounds were to promote mutual understanding and stimulate ethical reflection. The rounds were held regularly every other month, in total four times at each hospital, and each session lasted one and a half hours. The head nurse chose the patient to be the subject of the ethics rounds, in accordance with the advice of the nurses and in consultation with the physicians. It was the most moving cases that were chosen. See further description in Study III and IV.
<table>
<thead>
<tr>
<th>Table 2: Methods Study I - IV</th>
<th>Design</th>
<th>Source</th>
<th>Setting</th>
<th>Selection</th>
<th>Participants</th>
<th>Drop-out</th>
<th>Data Collection</th>
<th>Analysis</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative</td>
<td>Descriptive</td>
<td>Settings</td>
<td>Selection</td>
<td>Patients as source for data collection</td>
<td>Drop-out</td>
<td>Data collection</td>
<td>Analysis</td>
<td>Methods</td>
</tr>
<tr>
<td>II</td>
<td>Quantitative/Qualitative</td>
<td>Descriptive</td>
<td>Settings</td>
<td>Selection</td>
<td>Patients as source for data collection</td>
<td>Drop-out</td>
<td>Data collection</td>
<td>Analysis</td>
<td>Methods</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative</td>
<td>Descriptive</td>
<td>Evaluative</td>
<td>Selection</td>
<td>Patients as source for data collection</td>
<td>Drop-out</td>
<td>Data collection</td>
<td>Analysis</td>
<td>Methods</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative/Quantitative</td>
<td>Descriptive</td>
<td>Evaluative</td>
<td>Selection</td>
<td>Patients as source for data collection</td>
<td>Drop-out</td>
<td>Data collection</td>
<td>Analysis</td>
<td>Methods</td>
</tr>
</tbody>
</table>
**Participants**

Of the stakeholders in end-of-life decision-making, the present perspective was mainly limited to the nurse-physician perspective (Study I-IV) (Table 2). Most of the participants were female nurses and male physicians. Other professionals such as nurse’s assistants, social workers, physio- and occupational therapists participated in one of the studies (Study IV), but their part will not be separately analyzed. Different selection strategies were used in the studies (Table 2).

**Data collection**

All data collection was based on patients, where the majority were general ward patients (Study II-IV) in current treatment and the minority ICU patients (Study I) (Table 2).

**Interviews**

In Study I, the interviews with physicians applied a phenomenological approach with one single question (Table 3) and without interrupting the physicians. In Study II, two research nurses and I asked nurses and physicians structured questions (Table 3) and an open-ended question. When answers seemed unclear, the interviewers asked for clarification. In Study III, a co-researcher who is a physician interviewed the physicians and I as a nurse interviewed the nurses (Table 3).

**Questionnaires**

In Study IV, a self-reporting pre-/post-questionnaire for the ethics rounds was used (Table 3). Inspiration in formulating the questions was derived from Thorsén’s decision model of ethical problems and from Schneiderman et al.’s follow-up questions regarding helpfulness of ethics consultation. In the pilot test of the first questionnaire, staff answered on the basis of ethically problematic patient situations. All answers were rich and no misunderstanding was detected. In the second pilot test, including both questionnaires, a philosopher led an ethics round at another nephrology department. The answers after the rounds were less rich than the answers before rounds. A discussion afterwards with the participants resulted in reformulations into simpler language.
Table 3 Questions in the interviews and the questionnaires

<table>
<thead>
<tr>
<th>Study I (interview with phenomenological approach)</th>
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<tbody>
<tr>
<td>Can you give a description of the time when you first learned of the patient to when the decision was made to forego life-sustaining treatment?</td>
<td>Open-ended question</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Study II (structured interview)</th>
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</thead>
<tbody>
<tr>
<td>Expectation of survival for your patient?</td>
<td>Closed -ended question*</td>
</tr>
<tr>
<td>In your opinion, what level of life-sustaining treatment is appropriate for your patient?</td>
<td>Closed -ended question**</td>
</tr>
<tr>
<td>The rationale for your opinion?</td>
<td>Open-ended question</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study III (semi-structured interview)</th>
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</thead>
<tbody>
<tr>
<td>Please, describe how you experienced the ethics rounds.</td>
<td>Open-ended question</td>
</tr>
<tr>
<td>How would you like discussions about ethical problems at your workplace to be conducted in the future?</td>
<td>Open-ended question</td>
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</table>

<table>
<thead>
<tr>
<th>Study IV (questionnaire)</th>
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</thead>
<tbody>
<tr>
<td><strong>Questions before the ethics rounds</strong></td>
<td></td>
</tr>
<tr>
<td>1. Do you believe that an ethicist can help give you insights into the ethical problems in the care of the patient in question?</td>
<td>Closed-ended question***</td>
</tr>
<tr>
<td>2. Describe the ethical problems that you perceive in the care of the patient in question.</td>
<td>Open-ended question</td>
</tr>
<tr>
<td>3. Describe how you think the team should try to solve the ethical problems.</td>
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</table>

<table>
<thead>
<tr>
<th>Questions after the ethics rounds</th>
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</thead>
<tbody>
<tr>
<td>4. Have you gained any insights during the ethics round regarding what the ethical problems are in the care of the patient in question?</td>
<td>Closed -ended question***</td>
</tr>
<tr>
<td>5. Have you gained any insights into how the team should try to solve the ethical problems?</td>
<td>Open-ended question</td>
</tr>
<tr>
<td>6. Follow-up question from 4 and 5: If you experienced gaining new insights regarding the care of the patient in question, please describe these insights.</td>
<td>Open-ended question</td>
</tr>
<tr>
<td>7. If you answered “None” or “Low level” on Question 4 or 5, please describe what the reasons might be.</td>
<td></td>
</tr>
<tr>
<td>8. Indicate to what level the ethicist facilitated your insights.</td>
<td>Closed-ended question***</td>
</tr>
<tr>
<td>9. Indicate to what level the participating staff facilitated your insights.</td>
<td></td>
</tr>
</tbody>
</table>

* Alternatives: Less than one month, less than one year, greater than one year or not predictable
**Alternatives: Full life-sustaining treatment, limited life-sustaining treatment or uncertain about level of aggressiveness.
*** Adjective scale: none (1), low (2), moderate (3), rather high (4) and high (5).
Qualitative analysis

Phenomenology
In Study I, phenomenology was chosen to minimize my influence on the informants and the analysis, owing to preconceptions about end-of-life decision-making. A descriptive phenomenological approach by Giorgi was implemented (Table 2). The phenomenologist’s purpose is to discover the essence of and variation in a phenomenon, as given by the subjects. Using the phenomenological method entails as strong an effort as possible to disregard preconceived ideas that might prevent researchers from participating in experiences of the subjects – experiences that are the subjects’ preferential rights. The analysis proceeded in four steps:
1. Reading through the whole experience several times to get a grasp of the whole.
2. Breaking the text down into meaning units, which seem to be connected in meaning, focusing on the phenomenon of the decision-making process.
3. Analyzing every meaning unit separately through a process of reflection and “imaginative variation” with emphasis on the phenomenon, without changing the meaning.
4. Synthesizing the transformed meaning units into a consistent statement about the structure of the phenomenon, including its essence and variations.

Content analysis
Content analysis was chosen to facilitate utilization of descriptions on both the manifest (the visible and obvious) and the latent level (the underlying meaning). The theoretical assumptions are based on communication theory and structuralism, but are scarcely described in papers. Choice of the content analysis method depended on how comprehensive and deep the available data were: almost manifest level (Study II), more manifest than latent (IV) and more latent than manifest (Study III) (Table 2). Although there were different levels of depth, the analysis process followed similar systematic steps. Each step was scrutinized and discussed by all the co-researchers, especially in Study II and IV:
1. All data were read several times to obtain a sense of the whole.
2. The text was divided into meaning units and thereafter condensed and more or less abstracted depending on the depth of data (less in II).
3. Similar abstracted meaning units were grouped together and labeled as preliminary subcategories/subthemes. The text for each subcategory/subtheme was read again and the label was refined in light of the whole dataset.
4. The subcategories/subthemes were then compared with each other, and those that shared similar meaning were collapsed, sorted and abstracted into main categories/themes/dimensions/approaches.

In Study IV, the content analysis was carried out using the software NVivo to facilitate sorting. After the inductive steps described above, this analysis was transformed into a deductive ‘Directed content analysis’, because of the discovery of a pattern in the answers. This pattern seemed to be in line with a theoretical framework presented in a guide for practical ethical analysis by Boyd. This implied using Boyd’s principles, persons and perspectives approaches (see beneath) as coding categories. The approaches were used as operational definitions for each category. Step 4 above was repeated, with new categorization and sorting into these three approaches. This involved a comprehensive process of moving between the empirical data and the framework in a continuous process of refining categories and sorting data.

**Principles, persons, perspectives**

- **Principles approach:** principle-based, primarily deontological and teleological ethics, including the four principles of respect for autonomy, nonmaleficence, beneficence and justice.

- **Persons approach:** focus on the moral agent. It is referred to as virtue ethics, which is concerned with the best kind of person to be.

- **Perspectives approach:** focus on the case, which implies understanding of a problematic situation and being context sensitive. It is referred to as a hermeneutic approach, which considers multiple contexts, such as psychological and social. This approach seeks to highlight complexities and implies interpretation through openness to different perspectives, which may lead to awareness of one’s prejudices and a new shared perspective among individuals.

**Statistical analysis**

The data were ordinal and analyzed using descriptive and comparative nonparametric statistics in Study II and IV. For the answers from the closed-ended questions in Study II, comparisons regarding agreement for level of aggressiveness were calculated as the difference between paired proportions. In Study IV, for the comparison between expectation of gaining insights about ethical problems and
reported new insights, the Sign test was calculated.\textsuperscript{1} The qualitative categorizations of answers from the open-ended questions in Study II and IV were quantified. In Study II, the rationales for aggressiveness were then compared by calculating the difference between two independent proportions.\textsuperscript{130} For the comparison between nurses and physicians regarding the rationales, confidence intervals for the difference between two independent proportions were calculated.\textsuperscript{130}

Subgroup analyses were performed in both Study II and IV. In Study II, nurses’ and physicians’ uncertain answers and patients with an expected survival of more than a year were treated separately. This was done because being uncertain was not considered as disagreement with full or limited treatment, and because some patients were not ill enough to elicit the question of need for limited life support. In Study IV, a subgroup analysis was made with random selection of all participants from a collective list of all ethics rounds to detect any effect of respondents attending more than one ethics round. From this subgroup, factors of profession, department and philosopher thought to affect perceived insights were tested using Kruskal-Wallis and then Mann-Whitney tests.\textsuperscript{1}

**Ethical considerations**

Research Ethics Committees approved all research projects, except Study I for which approval not was sought. In Study I, the interviewed physicians were not in a state of dependence on me as a subordinate nurse. The interviews took place after the decisions about limiting life-sustaining treatment had already been made and therefore could not affect patient care. However, at the time of the interviews (1997-1998), the issue of limiting life-sustaining treatment seemed tense, which I experienced from some of the physicians. In one interview a colleague physician participated as support, but none of the physicians seemed upset after the interviews.

The research participants were informed that confidentiality was guaranteed. Informed consent was based on written information regarding the study and voluntary participation. In Study II, the head of the departments approved of the study well in advance. The participants, however, did not receive information until the day of participation, which implied less time for consideration of consent. This did not seem to pressure the participants, although a few physicians did show some distress over being asked about their rationales for their opinions about *full* life-sustaining treatment.
Two major ethical issues in Study III and IV were considered. One issue in the ethics rounds was the non-participation of patients, most of whom were not informed about being the subject for the rounds. Excluding patients as participants was not considered ethically wrong, as ethical problems were not to be solved during the rounds. As the ethics rounds constituted a sort of supervision, the tradition in Swedish healthcare is to discuss patient cases without their presence. The other ethical issue was the emotionally charged issue of end-of-life, which may cause distress for staff during and after the ethics rounds. Regarding the potential distress for these participants, the head nurses were prepared to arrange psychological help if needed. Emotional distress was noticed in one of the participants especially. The interview situation afterwards seemed to provide some relief, and I also followed up the contact.
KEY FINDINGS

Only the key findings for each study will be presented in this section, and in the next, the findings will be expanded in connection with considerations.

Study I

End-of-life decisions in the ICU: How do physicians from the admitting department reason?
The physicians’ reasoning during the decision-making process to limit life-sustaining treatment for ICU patients involved great individual variation in attitudes. However, two major approaches were found. One approach was focused on saving life and considering limiting life-sustaining treatment only after realizing that the patient was going to die even with treatment. The other approach was also about saving life, but at the same time keeping in mind the option of limiting treatment. A pattern of five phases in the process emerged: defining role and contact with the patient, knowledge of the patient, evaluation and action, turning point and decision-making. The essence of the physicians’ decision-making process consisted principally of medical considerations in discussions with other physicians. Patients, next-of-kin and nurses did not seem to play an important role as stakeholders.

Study II

Nurses’ and physicians’ opinions regarding aggressiveness of treatment for general ward patients
There were more similarities than differences between nurses’ and physicians’ opinions about the 714 patients studied. There was 86 % agreement between their opinions regarding full or limited treatment. Agreement was lower for patients with a life expectancy of less than one year (78 %), but the disagreement was not associated with professional status. The hypothesis that nurses would consider limited treatment for a greater number of patients than would physicians was not verified. The physicians considered limiting life-sustaining treatment as often as the nurses did (support for similarity 95 % CI -3 to 3 %). For the majority of patients, medical rationales were used, and age was important in one-third of the patients. When considering full treatment, nurses used quality-of-life rationales for 42 % of the patients compared to physicians’ 24 % (99 % CI 11 to 26 %). Respect for patient’s wishes was mentioned for few patients.
Study III

Learning a way through ethical problems – Swedish nurses’ and doctors’ experiences from one model of ethics rounds

The nurses and physicians described mixed experiences from the ethics rounds. The goals of the ethics rounds – to promote mutual understanding and stimulate ethical reflection – seemed to be partially achieved. Positive experiences included stimulation to broadened thinking, a sense of connecting between nurses and physicians, strengthened confidence to act, insight of moral responsibility and emotional relief. Negative experiences were associated with a sense of unconcern and resignation that change is not possible. Nurses were frustrated with the lack of solutions. In some rounds, there were also experiences of a sense of alienation between nurses and physicians as well as in relation to the philosopher. The main response to the additional question about how ethics discussions should be conducted in the future was that interprofessional team conferences were sure to continue, as this was more important than continued ethics rounds.

Study IV

Interprofessional ethics rounds concerning dialysis patients: Staff’s ethical reflections before and after rounds

The goal evaluated here, to stimulate ethical reflection, was not completely achieved. Seventy-six percent of the respondents reported a moderate to high rating regarding new insights into the ethical problems. But the ethics rounds did not stimulate the ethical reflection that respondents had expected \((p < 0.001)\). Two major issues were experienced with regard to the selected patients; end-of-life issues and non-compliance to medical treatment. The pattern discerned in the answers concerning perceptions of ethical problems before rounds and insights gained after could be sorted into the principles, persons and perspectives approaches (see p.30). The ethical problems described before the rounds were foremost sorted into the principles approach (74 % of the meaning units): problematic patient participation and exposing for suffering. The most prevalent insights concerning identification of ethical problems after rounds were sorted into the perspectives approach (72 %). This was illustrated by an extended perspective on the patient and increased awareness of relations to other professions. Regarding the persons approach, some answers both before and after rounds concerned reflections over personal responsibility. Concerning the insights into how to solve the ethical problems, the request to enhance team collaboration including reaching a consensus for care and further inter-professional dialogue predominated.
EXPANDED FINDINGS WITH CONSIDERATIONS

The phenomenon under study in the present thesis – disagreement over whether to continue or limit treatment – unfolded to an understanding of physicians’ difficult role in end-of-life decision-making, but also their shared opinions with nurses. This led to the realization that nurses and physicians should be brought together to share both their experiences of disagreement and their similar opinions. Ethics rounds were applied in order to promote mutual understanding and stimulate ethical reflection. These goals seemed to be only partially achieved. The findings suggest that the rounds primarily met the need for a forum for crossing over professional boundaries, but did not stimulate the kind of ethical reflection that was expected. The negative findings led to considerations about improvement of the ethics rounds model. Finally, considerations emerged over what kind of insights may be gained from ethical analysis concerning known patients. The four following sections illustrate further the findings in the present thesis.

Physicians’ perspective compared with nurses’
This section will focus on findings from Study I and II. According to the physicians in Study I, they were the key stakeholders in the decision-making process to limit life-sustaining treatment. Nurses were not described as stakeholders. The only time they were mentioned was in connection with patient care conferences, which however the participating physicians expressed great appreciation for.

Physicians’ professional behavior and personal beliefs
Although Study I concerned the decision-making process to limit life-sustaining treatment, the physicians’ reasoning was about continuing treatment until reaching the point of no return. The focus was on medical considerations, predicting the prognosis and survival. In Study II, when asking about opinions of aggressiveness of treatment, these physicians used similar reasons as the nurses did, medical and quality-of-life reasons, as also shown in previous studies. They also considered limited treatment for the same number of patients as the nurses did. This agreement is supported by one small American study on real patients and others on hypothetical patients.

To understand the discrepancy between previously reported disagreement over too much treatment (Table 1) and shared opinions about aggressiveness of treatment (Study II), the findings may be viewed from the physicians’ perspective –
their professional behavior and personal beliefs. This reasoning is partly based on Udén et al.’s\textsuperscript{194} and Lindseth et al.’s\textsuperscript{110} papers on nurses’ and physicians’ narratives about ethically difficult end-of-life care episodes. The nurses and physicians were interviewed twice. First, the physicians narrated about scientific knowledge and preserving life, emphasizing atomism, while nurses emphasized holism.\textsuperscript{194} In the following interview, the physicians and nurses reflected on their previous narratives and then the physicians narrated about similar experiences as the nurses did – experiences of meeting death and seeing care as holistic. The physicians’ first narration was interpreted as their professional experiences and the subsequent narration as their personal experiences.\textsuperscript{110} Transferring this to Study I, the physicians seemed to narrate based on their professional behavior, in their role as decision-maker and their assumed responsibility for saving lives. In Study II, not being in the decision-making role when answering the questions, some of the physicians might have responded based on their personal beliefs, not based on how they would act. Thus, with regard to the discrepancy between nurses’ previously reported disagreement over too much treatment and physicians’ reported willingness to consider limited treatment to the same extent as the nurses in Study II, there seems to be a discrepancy in what some physicians actually do and what they believe should be done. This is confirmed by an unpublished finding in Study II, showing that 49\% (95\% CI, 41 to 56\%) of patients for whom physicians considered limited treatment did not have a limitation order. This is also supported by a previous survey in which 80\% of European ICU physicians felt that do-not-resuscitate orders should be applied, but only 58\% reported using such orders.\textsuperscript{199} In another study, physicians reported having acted against their conscience in providing overtreatment for their patients.\textsuperscript{173}

**Physicians’ individual attitudes toward limiting treatment**

The findings, however, showed discrepancies in opinions about aggressiveness of treatment, though this was not associated with professional status. The reported agreement of 78\% in Study II for patients with a life expectancy of less than one year held for the answers ‘full’ or ‘limited’ treatment. When also including the answer ‘uncertain’, meaning disagreement between uncertain and full or limited treatment, the agreement was only 63\% between nurses and physicians. There was still no association with professional status. The different choices seemed rather to be associated with individual differences, which is supported by a previous study.\textsuperscript{36} This may illustrate how incredibly difficult end-of-life decisions are and how both individual nurses and physicians have different attitudes toward aggressiveness. The physicians in Study I also revealed different attitudes regard-
ing willingness to limit treatment. This may primarily suggest that nurses’ frustrations are related to individual physicians’ reluctance to limit treatment. This may be one explanation of nurses’ previously reported frustrations over physicians’ heterogeneous attitudes toward aggressiveness of treatment (Table 1). This heterogeneity is also supported by previous studies revealing arbitrary end-of-life decision-making processes, based on physicians’ own biases and values. 

In summary: Physicians’ perspective compared with nurses’

The present findings suggest that physicians share opinions with nurses concerning the boundaries for life-sustaining treatment, when physicians are not in the decision-making role. The difference between physicians’ and nurses’ perspective seems to be physicians’ burden of having to make the decisions to limit treatment and nurses’ burden of living with the fact that the decisions are not made. This suggests that physicians and nurses both need support in the decision-making process.

Partially achieved goals of ethics rounds

The focus will now be on the findings from Study III and IV.

The goal of promoting mutual understanding

This goal seemed to be achieved to a greater extent than the goal of stimulating ethical reflections and focus is here on the positive experiences from the rounds. The findings cannot confirm conclusively that mutual understanding was achieved, but they do suggest that the ethics rounds primarily met the need for a forum for crossing over professional boundaries. Experiences of connecting (Study III) and increased awareness of relations to other professions (Study IV) confirm this. The most salient finding from both studies was the insight to enhance team collaboration and that interprofessional dialogue was sure to continue. The nurses felt the physicians listened to them, something the same nurses reported was lacking when they were interviewed before the ethics rounds; lack of listening was also reported in another study. But according to the physicians, the rounds seemed to mainly serve the purpose of defending and explaining their rationales for continuing life-sustaining treatment (Study III).

Attempts at mutual understanding could be seen in the expressed understanding for the difficulties inherent in each other’s professional role. The nurses expressed
an understanding of the physicians’ loneliness and sense of powerlessness in making the right decision (Study III and IV). This may have contributed to improved understanding concerning the delayed decisions previously reported (Table 1). Likewise, the physicians expressed understanding for nurses’ feelings of being bound by their closeness to long-term patients (Study III and IV) and for how frustrating physicians’ heterogeneous attitudes toward life-sustaining treatment could be (Study III).

The findings showing crossing over of professional boundaries, including attempts at mutual understanding, correspond with previous evaluations of reflective ethical practice, such as coming closer to each other, understanding each other’s perspective better and changing attitudes toward each other. This is also in agreement with a large evaluation of interprofessional education interventions, mostly involving nurses and physicians. Major positive outcomes of the studies were changes in attitudes/perceptions toward other professions and improved understanding of their roles and responsibilities.

The philosopher-ethicists seemed to have an important role in promoting the crossing over of professional boundaries. They were described as facilitating an open climate (Study III and IV) when they actively led the discussions, distributing speaking time fairly and promoting mutual understanding by turning accusations into ways of seeing things from a different perspective (Study III).

**The goal of stimulating ethical reflections**

In Study III, there were experiences of stimulation to broadened thinking, which was very much connected with the role of the philosopher-ethicists. This emerged foremost in Study III, but also as additional findings in Study IV. The philosopher-ethicists were appreciated for giving clarifications (Study III and IV), stimulating to brake from habitual ways of thinking (Study III) and seeing things from different perspectives (Study III and IV). However, the quantitative part of Study IV revealed that the ethics rounds did not stimulate the ethical reflection that the respondents had expected. This corresponds with the results from an evaluation questionnaire of a Dutch project, in that the expectations of the goal of moral deliberation were higher than the goal perceived to be reached. The participants in present project may have expected to gain principle-based insights into the reported problems of patient participation and suffering. Instead they gained insights that did not fit into traditional ethics (often referred to as principle-based ethics, but also virtue ethics), and these insights were interpreted as corresponding
to a hermeneutic approach. This was illustrated as an extended perspective on the patient, gained from others’ perspectives and knowledge, finding the problems more complex, but also as gaining an increased understanding of the patient. There were also descriptions of increased awareness of relations to other professions, which was also one of the main findings of Study III, as described above. Leder\textsuperscript{104} pointed out that the hermeneutic approach opens up for interpretations, but does not distinguish between right and wrong. Thus, hermeneutic approach cannot provide quick solutions to problems, which are what clinical practice seems to demand. Further ideas about what kind of insights may be gained are discussed under 'Theoretical considerations of ethical analysis concerning known patients'.

Aspects that obstruct mutual understanding and ethical reflection

Compared to the positive remarks in Study III and IV, the negative remarks in the interviews and questionnaires were fewer in number, but not lower in intensity. Negative findings are important to report, because there is a lack of negative qualitative descriptions in previous studies on reflective ethical practice\textsuperscript{100,125} and interprofessional education.\textsuperscript{10} The findings of nurses’ frustration with the lack of solutions will be discussed later. Some of the other negative experiences were described as conditions outside the rounds, such as lack of time for further reflection and discouragement of colleagues’ lack of commitment. A large part of the negative findings, however, seemed to be associated with individual- and group-related aspects during the rounds. A new categorization of subthemes from Study III and subcategories from Study IV will illustrate this as in Figure 1:

\textbf{The group of professionals:} Relationships between workmates seemed to influence experiences to a great extent. A deadlock between nurses and physicians was experienced when nurses felt that physicians did not listen to or understand them, and the physicians felt criticized (Study III). In Study IV, a gap between the professionals was perceived, which confirmed their pre-understanding of how far physicians and nurses stand from each other. Some lacked new input from workmates; they felt they had already heard it all before.

\textbf{The philosopher-ethicist:} The philosopher seemed also to have a great influence on experiences. When the philosopher was too passive, participants could experience the rounds as polemical and filled with unleashed emotions. Worthless input was associated with failure to make the knowledge applicable to the real world. A few participants also experienced that the philosopher influenced the round too
much with his own opinions, and they found this coercive and that it inhibited the discussion.

The patient: Unmoving patient cases were experienced as negatively affecting the overall feeling. This could occur when the patient was unknown or the problem was perceived as being neither emotionally moving nor ethically relevant.

The individual professional: Perceptions of already knowing the answers and being morally secure about values, possible actions and the solving of the problem gave feelings of indifference. There was also a feeling of insoluble classical problems, such as nurses feeling it is impossible to influence physicians and physicians believing that nurses will never understand the difficulties connected with the decision-making responsibility.

Figure 1 Group- and individual aspects contributing to negative experiences/perceptions during the ethics rounds

The group of professionals
Deadlock between nurses and physicians (III)
Gap between the professionals (IV)
Already heard it all before from other staff members (IV)

The individual professional
Already morally secure (III)
Already knowing the answers (IV)
Resignation of insoluble classical problem (III)
Powerless to affect decisions (IV)

The philosopher-ethicist
Too passive (IV)
Worthless input (III)
Inflicted value judgments (III)

The patient as subject for the round
Unmoving patient cases (III)
Not familiar with the patient (IV)
Several of the aspects that seemed to obstruct mutual understanding and ethical reflection are in line with Sarvimäki and Stenbock-Hult’s descriptions of hindrances to ethical dialogue, such as lack of time, perception of ethical problems as insoluble, other’s predominating attitude and leaving decision-making to others.

In summary: Partially achieved goals of ethics rounds
It seemed that the goal of promoting mutual understanding was achieved to a greater extent than the goal of stimulating ethical reflection. Insights into ethical problems did not fit into traditional ethics, but could rather be interpreted as corresponding to a hermeneutic approach. The findings support the notion of a collaborative team approach to treating severely ill patients. However, individual- and group-related aspects should be taken into consideration as possible hindrances to mutual understanding and ethical reflection.

Improvement of the model of ethics round

Critical considerations of the model
There are at least four concerns regarding the model of ethics rounds in the present thesis: the leadership of the rounds, the timing of them, the selected patients and the goals. Because it is unusual for Swedish philosophers to be involved in everyday clinical practice, only two of the four philosopher-ethicists had experience of ethics discussions in connection with clinical practice. A series of pilot rounds may have been beneficial for the inexperienced philosophers. Reported reasons for the lack of moving cases were the scheduled ethics rounds and the criterion that staff members from both the dialysis unit and the ward were to be familiar with the patient. Additionally, at least five of the patients’ problems were of long duration and seemed difficult to solve. This may indicate the need for ethics rounds proactively, i.e. to anticipate ethical problems before they become severe and to be able to arrange ethics rounds in critical situations. The fourth concern, the expectation of solving the ethical problems is dealt with in the next section.

Adding solving to the model
When deciding about the goals of the ethics rounds in the present thesis, the decision was taken to exclude the idea of finding solutions of the ethical problems. This decision was based on European ethical literature, which advocates supporting healthcare teams through reflective ethical practice rather than through expert solutions. This, however, must be reconsidered. The negative findings
from Study III and IV revealed that nurses expected solutions to the ethical problems, lacking a formal decision that would direct future actions. Some wished for an answer book and became impatient when theoretical reflections were discussed instead of practical solutions. Also in the Dutch study of moral case deliberation, respondents missed concrete suggestions and consensus for solving.\textsuperscript{126}

In a few of the present rounds, however, alternatives of action were offered, which was appreciated by the nurses (Study III). The approach these philosopher-ethicists used in present project appears to be similar to the facilitation approach used in American ethics consultations, where attempts are made to facilitate consensus building among health-care professionals. Schneiderman et al.\textsuperscript{160} showed that the help ethics consultants provide with identifying and analyzing ethical problems yielded high staff satisfaction. This may be due to the simultaneous help with problem-solving, which also was ranked high.\textsuperscript{160}

The nurses’ frustration should be taken into consideration. This would imply adding a further goal to the ethics rounds: to promote solving ethical problems. See Figure 2 for the proposed model. In this model, the addition entails letting the ethicist help the participants in the rounds in their analysis of different courses of action and, after the rounds, arranging an interprofessional team conference aimed at solving the problems at hand. One should keep in mind here the importance of allotting sufficient time to analyzing what the ethical problems actually are.

Because the goal of the ethics rounds in the present thesis did not include solving ethical problems during the rounds, it was not considered ethically wrong to exclude the patients as participants. But adding the goal of promoting problem-solving, there is a major ethical concern about the non-participation of patients and next-of-kin. It could be argued that the proposed model further strengthens the powerful group of health professionals in relation to the already weak group of patients and next-of-kin. Let us analyze the lack of patient autonomy in end-of-life decision-making and how interprofessional team conferences or ethics rounds may serve as a source of trust for the patient.
Figure 2 From Study III. A model based on findings illustrating one possible way of dealing with ethical problems in patient care

A model of interprofessional team dialogue about the care of the severely ill patient

Interprofessional team conference

Health-care staff engaging in a dialogue about the goal of the care

Awareness of an ethically complicated situation

Consensus about the goal and what course of action to take, followed by patient/family involvement

Ethics rounds with an ethicist

First phase: Ethicist helps staff to identify and analyse the ethical problem as well as to deal with any relational conflicts

Second phase: Ethicist facilitates problem solving by helping to analyse different courses of action

Interprofessional team conference

Only health-care staff engaging in a dialogue with the aim to suggest what course of action to take

Decision together with patient/family
Ethics rounds serving as a source of trust for patients with diminished decision-making capacity

Although respect for autonomy, in addition to human dignity, appears to be the paramount ethical principle in health-care, Study I and II confirm the results from previous studies showing low patient involvement in end-of-life decision-making. Compared to previous survey results revealing that healthcare professionals view patients’ wishes as important, this was rarely mentioned in Study II. In previous studies, patients’ wishes may have been a socially desirable option, being one of several closed-ended options in contrast to the open-ended question in the present study.

For patients with decision-making capacity, refusing treatment does not seem to be controversial. Yet even if measures are taken to improve patient involvement, there will still be quite a few patients with lack or fluctuating capacity to make rational choices. In Study IV, the predominating perceived ethical problem for the patients as subjects for the ethics rounds was problematic patient participation. The respondents felt that several of the severely ill and non-compliant patients lacked decision-making capacity.

For patients who have diminished decision-making capacity of various origins, who have not given advance directives and who have no sensible next-of-kin, the physicians have great moral responsibility to determine what is best for the patient. They must, besides determining the effectiveness of the treatment, also make a subjective assessment of the meaningfulness. I am aware that most of the physicians in the present thesis did not explicitly ask for support in decision-making. Rather they realized that the interprofessional dialogue should be continued in order to meet the need of the nurses. However, adding a problem-solving part to the ethics rounds model implies a team approach to the assessment of meaningfulness in end-of-life decision-making. Interprofessional team conferences or ethics rounds may serve as a support and basis for the physician’s decision, by providing the perspectives of several professions and a more integrated and holistic view of the patient, as shown in Study III and IV. Together with help from an ethicist in analyzing the problem and courses of action (still without giving recommendations), this may lead to better ethical decision-making, preventing reported arbitrary decision-making.

Competent patients who do not wish to assume an active role in their own care or be involved in end-of-life decision-making and patients who do not
have a physician they trust may leave their autonomy in the hands of ethics rounds, which then may serve as their source of trust. Trust has been defined as “the reliance on others’ competence and willingness to look after rather than harm things one cares about which are entrusted to their care”. This, however, presupposes continuity in care by nurses and allied healthcare professionals.

In summary: Improvement of the model of ethics rounds
Findings from Study III and IV show the need for short-term help in solving ethical problems. This may be possible in patient team conferences or ethic rounds regarding patients with diminished decision-making capacity or competent patients who entrust their autonomy to the team. A balance should be found between ethical analyses, conflict resolution and problem-solving.

Theoretical considerations on ethical analysis concerning known patients
The mixed findings in Study III and IV concerning whether the ethics rounds stimulated ethical reflections caused me to reflect further on what kind of insights may be gained from reflective ethical practice regarding known patients. The insights gained here suggest that these kinds of insights are different from those expected when analyzing hypothetical or disguised patient cases with insufficient context, which is most commonly the case in traditional ethics teaching.

Is it possible to distinguish between ethical and psychosocial reflections?
It seems difficult to distinguish pure ethical reflections from psychosocial reflections. At first glance at the questionnaire answers in Study IV, most perceived insights after rounds concerning identification of the ethical problems appeared to be psychosocial reflections about communication and how the dialogue of the ethics rounds worked, and could be argued not to be ethical reflections. The request to the respondents in Study III to describe experiences of the ethics rounds revealed answers of a cognitive, social and psychological nature. The respondents in Study IV may have answered based on their broader experience of ethics rounds and not based on the apparently narrow question of insights into the identification of the ethical problems. On the other hand, the respondents may not have been clear about what is meant by ethical reflections. In Study III, experiences of the philosopher-ethicists’ structuring of the thinking into steps were appreciated, but only one of the respondents could explicitly describe insights into this. Previous studies have also reported that nurses did not articulate traditional ethical concepts and were unable to give examples of ethical situations.
Contemplating how to analyze the questionnaire answers in Study IV, my co-researchers and I decided at last to give the respondents the preferential right to define ethical problems and insights. The pattern that emerged in the answers led to Boyd’s\(^{15}\) three approaches to practical ethical analysis, where the hermeneutic approach was added to principles and virtue ethics.

**Hermeneutic approach in relation to other context-sensitive approaches**

In philosophical literature, discussions about which theories/approaches are appropriate to use in ethical analysis appear to be blurred with the actual method of analysis, such as a Democratic, Socratic dialogue or Moral case deliberation. Two different accounts of approaches to ethics appear. One emanates from general principles for seeking answers in the particular ethical case. The other emanates from the particular ethical case or situation and pays close attention to the rich complexity that exists, so-called context-sensitive theories.\(^{104,129,186}\) These may either deny the significance of principles or view context-sensitive knowledge as a complement to principles.\(^{156}\) Because ethics rounds constitute a kind of method of analyzing a particular case, you may regard this as circular reasoning, ending up in the context-sensitive hermeneutic approach. As a comparison, however, there are other context-sensitive theories such as casuistry,\(^90\) moral particularism,\(^{189}\) narrative ethics,\(^{77,125}\) situation ethics\(^{186}\) and imaginative ethics.\(^{77}\) They all share with the hermeneutic approach a focus on details, interpretation and self-reflectiveness in the situation.\(^{104}\) However, these approaches do not seem to deal with the prejudices, social structures and behaviors of those involved in the communicative act. Imaginative ethics appears to best resemble the hermeneutic approach, formulated by Hansson\(^{77}\) and based on his experience as an ethicist in ethics rounds (the model of inspiration in the present thesis). Imaginative ethics deals with the diversity of perspectives on the case. By listening to other perspectives, alternative perspectives and multiple values may be imagined. The focus appears to be on the values at stake, but Hansson\(^{77}\) acknowledged that he had no scientific basis for the nature of ethical reflection during rounds. As a comparison, in Study III and IV, one of the main features of the ethics rounds was the connecting that occurred between nurses and physicians, who were trying to understand each other’s perspective. According to Leder\(^{104}\), ethical problems do not arise only from the complex details of the situation. The diverging perspectives of stakeholders may provoke “interpretive” conflicts.
Is it possible to distinguish between ethical conflicts and social conflicts?

When analyzing the case of a known patient, the question is whether it is possible to distinguish between ethical and social conflicts? In two previous studies evaluating ethics consultation qualitatively, the conclusion was that what appeared to be ethical problems were instead interpreted as a breakdown in communication and relational problems.56,93 Kelly et al.93 found that traditional ethical concepts were not relevant, instead there appeared to be interpersonal, cultural and professional factors involved, such as differences in the professional cultures of medicine and nursing. In Study III, it was expressed that the ethical analysis was overshadowed by relational conflicts. The sociologist Chambliss meant that ethical problems in healthcare are an expression of interest group conflicts, such as professional clashes between nurses and physicians.31 Thus, an ethical conflict may not only be a conflict between values, but also between different stakeholders. According to Leder104, an ethical dilemma can be recognized when consensus breaks down. In this respect, a breakdown in communication could be interpreted as a type of ethical problem. A major portion of American ethics consultation seems to deal with mediating social conflicts in healthcare.59

In conclusion, there is an indication that a major part of clinical ethical analysis regarding known patients concerns the social and the communicative act. Therefore, it seems difficult to distinguish ethical reflections from psychosocial reflections as well as to distinguish ethical conflicts from social conflicts. Yet, the ethical inquiry still remains: What is it one ought to do?

Philosophers as ethicists

The choice of ethicists for the present ethics rounds fell on philosophers, due to my preunderstanding that ethical analysis constitutes analyses of the values at stake, conflicts of interest and the weighing of pros and cons. Based on the insights described after the ethics rounds (Study IV), one might not assume that the ethicists were philosophers. If the ethicists in the present thesis had been chosen from professional groups such as nurses, physicians or social workers, as suggested by research colleagues, it may have been more natural to interpret the insights gained after the rounds as solely psychosocial.

Owing to both the study design and the findings of the present thesis, support for choosing philosophers as ethicists in clinical practice cannot be offered. The interviewees in Study III had little to say regarding from which profession the ethicists in future rounds should be drawn, being more concerned with the ethicists’ char-
acter and competence. This is in accordance with the American Task Force on Standards for Bioethics Consultation.\textsuperscript{2,165}

The philosopher-ethicists in the present thesis appeared to have different abilities in group-process skills, such as handling the power balance between the nurses and the physicians. Maintaining control over the discussions seemed important to the respondents (Study III). Given the value-laden subject of end-of-life, losing control over the discussion seemed dangerous. In Kelly et al.’s\textsuperscript{93} ethnographic study of ethics consultation, in contrast to the physician-ethicists, the philosophers and social workers distributed the time more equally and stimulated more discussion. The role of the philosopher and social worker as ethicist should be further studied.

Finally, connecting the ethicist’s role with the hermeneutic approach, Leder\textsuperscript{104} proposed that from being an “answer” person, the ethicist may instead become a facilitator; “fostering mutual understanding and respect” as opposed to pro and con perspectives. Boyd\textsuperscript{15} considered that the ethicist may help by asking relevant questions, but the answers need to come from the participants.

\textbf{In summary: Theoretical considerations on ethical analysis}

Analyzing ethical problems in relation to known patients seems to produce psychosocial insights. This could imply that social conflicts may overshadow ethical analysis or that ethical conflicts and social conflicts are impossible to distinguish.
CRITICAL METHODOLOGICAL CONSIDERATIONS

In analyzing and measuring how well the design, data and analysis processes have addressed the intended focus, credibility and dependability as well as internal validity and reliability will be described below. They are described together because they are intertwined: There can be no dependability without credibility and no internal validity without reliability. But first some considerations of the difficulties of designing the studies III and IV.

Designing the ethics rounds studies

The initial ambition was to evaluate the goals of promoting mutual understanding and stimulating ethical reflections by measuring impact and outcomes according to Gubas and Lincoln’s term ‘first generation evaluation’. To my knowledge, no previous study has evaluated these goals in reflective ethical practice, and consequently no validated instrument was found. Furthermore, previous studies using instruments with control groups to evaluate reflective ethical practice could not detect any long-term impact. In one of the research projects, only positive changes of the intervention emerged from the qualitative findings, and there were methodological reflections over the quantitative design’s inability to measure complex social processes. When purely quantitative designs are used to study psychosocial processes, there seems to be a problem of excluding the contextual perspective and of controlling conditions. As it appears, when interventions are aimed at a long-term instead of short-term impact, such as solving ethical problems for particular patient situations (American ethics consultation), valid outcome measures are difficult to find.

Thus, in the present thesis, the most realistic approach was to illuminate how ethics rounds were conducted as well as to evaluate the strengths and weaknesses of both goals with a view to improvement. Guba and Lincoln described this as ‘second generation evaluation’. Looking back at this point, ‘responsive evaluation’ may have been a better alternative for finding evaluation criteria and for better understanding of the weaknesses and strengths of conducting the rounds. Guba and Lincoln described this as ‘fourth generation of evaluation’. Responsive evaluation was used in a Dutch 4-year moral deliberation project, which was published after the present research project had been finished. The Dutch project implied that the evaluation criteria were derived from the stakeholders such as the management’s and staff members’ expectations of moral deliberation. They became active and equal partners in the research process and also the researchers
participated themselves as ethicists and in regular work activities. Mixed methods were used to gather information on group dynamics and the actual learning process, as well as the implementation process.\textsuperscript{125,126} Regarding implementation, none of the departments in the present research project and in the other ethics rounds study\textsuperscript{99} have continued with the reflective ethical practice. Kälvemark concluded: “A deeper understanding is needed of why methods such as this are not put into practice after the enthusiastic first phase”.\textsuperscript{99 p.50} In light of the above, in the present research project, management and staff members should have been involved regarding the expectations of the ethics rounds. The present research project cannot offer support for the superiority of ethics rounds in promoting mutual understanding and stimulating ethical reflection. But the findings from the mixed-method approach have provided a broad spectrum of strengths and weaknesses serving as a knowledge base for improvement of reflective ethical practice. Several findings from Study III and IV confirm each other, and the combination of different data collection methods may be seen as representing a triangulation approach,\textsuperscript{42,108} which strengthens the trustworthiness.

**Credibility and dependability in the qualitative parts**

**Data collection**

The appropriateness of the inquiry in Study I may be challenged. The question posed to the physicians may not have completely captured the decision-making process in a phenomenological sense: “Can you give a description of the time from when you first learned of the patient to when the decision was made to forego life-sustaining treatment?” A more phenomenological question for capturing the lived experience might have been “Can you give a description of the experience to be in the decision-making process?” Owing to weakened credibility, the phases may not have captured the essence of the decision-making process, but rather represented a reconstruction of memories of the process. However, the physicians were interviewed without interruption, giving them the preferential right to decide what they considered as important in the decision-making process.

Using two interviewers in Study III may have constituted a threat to dependability. My co-researcher and I used somewhat different interview techniques, a conversational style as opposed to a probing technique.\textsuperscript{136} I may have been too focused on the research questions, thereby keeping the nurses from offering new ideas. My co-researcher did not follow up some interesting reasoning, but the relaxed interview atmosphere may have encouraged the physicians to be more open. This,
however, was taken into consideration, as both manifest and latent analysis were performed, depending on the nature of the statements.

It could be argued that the question in Study IV regarding description of new insights into the ethical problems (Table 3) may not have captured ethical reflections, as discussed above. Using a questionnaire for these kind of questions may have been a too superficial method. There could also be difficulties in formulating insights immediately after the rounds. However, the broad question of experiences of ethics rounds in Study III, when rounds were distant in time, also did not capture ethical reflections in the traditional sense. Another consideration is whether the other goal, to promote mutual understanding, influenced the answers regarding insights.

Analysis
In establishing credibility, the data have been subject to co-assessment from co-authors and peer debriefing during seminars, which helped me be “honest” when co-authors and seminar participants played the devil’s advocates. Biases have been proved and the basis for interpretation clarified. However, the different levels of data in the present thesis have made this varyingly possible. For the data consisting of short answers (Study II and IV), the strength was the rigorous co-assessment. But the interpretation and categorization were sometimes difficult, involving struggling with what the informants actually meant owing to the lack of rich description. Contrary to the studies with short answers, the longer descriptions from the respondents (Study I and III) made deeper interpretation possible, owing to the rich context. However, co-assessment seemed more problematic due to the co-researchers’ reduced possibility to obtain a sense of the whole data, a problem pointed out in the literature.
Internal validity and reliability in the quantitative parts

Data collection
The confidence of the finding in Study II showing that nurses and physicians considered limited treatment for the same number of patients is high. This due to the large sample size, and the difference was only 0.5 % with a narrow 95 % confidence interval around 0 (-3 to 3 %). The reliability of this finding seems high, as the data were collected during separate years, with no differences detected between the time periods. The sample size in Study IV may seem inadequate, because there were few possibilities to perform extensive statistical calculations and subgroup analysis, especially of different professional groups. The goal of the quantitative data collection was, however, to capture the group of participants’ subjective evaluation of the stimulation of ethical reflection, not to find causal explanations.

Analysis
When comparing possible differences between the nurses and physicians, it could be argued that consideration of gender is important. One limitation, especially in Study II, was that it was impossible to separate the professional role from gender, as the majority of nurses were female and the majority of physicians male. Chambliss considered that it is impossible to distinguish the effect of gender (female) from profession (nursing), because they are so highly correlated. According to him, comparing male and female nurses is like comparing unconventional men with quite conventional women.

It may be argued that the Sign test should not have been chosen in Study IV to compare the expectation of gaining insights into ethical problems with reported new insights. This is because the questions posed before and after the rounds were not worded identically, one concerning expectations of whether an ethicist could provide insights and the other concerning any insights gained after the rounds (Table 4). However, there was also a question about insights that came specifically from the ethicist, and this result did not differ from overall insights gained.

External validity/transferability
The finding of physicians considering limited treatment as often as the nurses did (Study II) may be generalized to hospital ward settings in Western Europe and North America. This because respondents and patients were included from differ-
ent wards, and because of the total selection criteria, low attrition (Table 2) and narrow statistical confidence limit. Despite naturalistic inquiry, the essence of physicians’ decision-making process in Study I, which entailed medical considerations in discussions with other physicians, may be transferable to other ICU settings in Western Europe. This due to the manifest findings, consecutive nature of selection and because the study comprised half of the decisions made during one year in each hospital. The findings in Study III and IV are context specific, owing to the model of ethics rounds, workgroup cultures and the fact that there were only 12 patients as subjects for the ethics rounds. Therefore, thorough descriptions are presented to enable the readers to judge the transferability.
CONCLUSIONS AND IMPLICATIONS

First, the present thesis provides strong evidence that differences in opinions regarding boundaries for life-sustaining treatment are not associated with type of profession. Physicians want to limit life-sustaining treatment as often as nurses do, and there is an indication that some physicians want to limit treatment for more patients than they actually do. Accordingly, this suggests that some physicians need support regarding when to limit. Furthermore, the findings on shared opinions may contribute to improved understanding and collaboration between nurses and physicians regarding end-of-life decision-making.

Second, several of the findings support a collaborative interprofessional team approach to end-of-life decision-making. Using a team approach may be seen as self-evident, but not for the Swedish Society of Medicine. Their guidelines regarding withholding and withdrawing life-sustaining treatment,177 seem to indicate that this is an affair between physicians and the patient/family only. One suggestion here is to add to the guidelines a recommendation for the team approach for patients with diminished decision-making capacity. The Swedish National Board of Health and Welfare may also wish to emphasize this further when revising their old guidelines.172

Third, the present thesis indicates that stimulation of ethical reflection in connection with known patients may yield other insights than those gained from traditional ethics reflections. These insights may be interpreted as corresponding to a hermeneutic approach. The kind of ethical analysis that is most beneficial to clinical practice concerning particular patient cases should be furthered explored. Furthermore, it would be interesting to capture the learning process associated with the kind of ethics that is beneficial to everyday clinical practice.
SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

"Uppskjuta döden? Sköterske- och läkarperspektiv på livsuppehållande behandling och etikronder"

Utgångspunkten för denna avhandling är sjuksköterskors upplevelser av att livsuppehållande behandling drivs för långt. Syftet var att beskriva och jämföra sjuksköterskors och läkares perspektiv på gränsdragning för livsuppehållande behandling och att utvärdera om etikronder kunde främja ömsesidig förståelse och stimulera etisk reflektion. Både kvalitativa och kvantitativa metoder har använts, i form av intervjuer och enkäter. För analys av resultaten har fenomenologi, innehållsanalys samt statistik använts.


Studie II: I jämförelsen mellan sjuksköterskors och läkares åsikter om nivån på livsuppehållande behandling fanns fler likheter än skillnader för de 714 patienterna i studien. Samstämmigheten var 86 % avseende full eller begränsad behandling. För patienterna med en förväntad överlevnadstid under 1 år var samstämmigheten lägre, 78 %, men oenigheterna hade inte något samband med yrkestillhörighet. Hypotesen att sjuksköterskorna skulle vilja begränsa behandling för fler patienter än läkarna verifierades alltså inte. Sjuksköterskorna och läkarna motiverade sina åsikter om att begränsa eller fortsätta behandling på liknande sätt. De anförde medicinska skäl för majoriteten av patienterna, därefter livskvalitetsskäl, för en tredjedel åldersskäl och hänsyn till patientens vilja för en minoritet.

Studie III och IV: För de två sista studierna anordnades 12 etikronder på tre njursektioner. Det innebar att filosofer ledde vårdkonferenser angående etiska problem i vården av särskilda dialytpatienter, där främst sjuksköterskor, läkare ochundersköterskor deltog. Målet för ronderna var att främja ömsesidig förståelse mellan yrkeskategorierna och att stimulera etisk reflektion. Filosofernas uppgift var att hjälpa vårdpersonalen att identifiera och analysera de etiska problemen, men inte ge förslag på lösning. Utvärdering skedde dels genom intervjuer om upp-
levelserna av ronderna och dels genom enkäter om uppfattningar om de etiska problemen före rond och eventuella nya insikter efter rond.


Slutsatser: Resultaten från de två första studierna tyder på att läkares och sjuksköterskers åsikter om gränsen för livsuppehållande behandling är lika, när läkarna inte har den beslutsfattande rollen. Skillnad i inställning beror inte på yrkestillhörighet. Resultaten från de två sista studierna styrker uppfattningen om en mångprofessionell teambaserad inriktning till beslutsfattande i livets slutskede. Etisk reflektion kring en patient som är känd för personalen verkar ge andra insikter än vid traditionell etikundervisning. Reflektionen verkar främst ge psykosociala insikter, vilket antingen kan betyda att sociala konflikter överskuggar den etiska analysen eller att det helt enkelt inte går att skilja mellan etiska och sociala konflikter. Sjuksköterskornas frustration över utebliven lösning i etikronderna har givit anledning till ett förslag att ändra modellen, för att hitta en balans mellan etisk analys, konflikt- och problemlösning (Figur 2).
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