The ethics of bedside priorities in intensive care
Value choices and considerations

A qualitative study

Kristin Halvorsen
Section for Medical Ethics
Faculty of Medicine
University of Oslo
2009

ABSTRACT

Background: The Lønning II white paper asks for more knowledge on clinical priorities in different areas of health care. This in particular goes for resources used in intensive care units. Thanks to improvements in medical and technological knowledge and a greater proportion of older patients with complex diseases intensive care units face serious challenges regarding bedside priorities. Which patients and what kind of treatment should be prioritised?

Aim: The aim of this research has been to shed light on the values and considerations that affect the priority decisions with regard to limitation of intensive care treatment in intensive care. Further it was to illuminate if and how resource restrictions were followed by specific limitations in medical and nursing care.

Method: This research is based on qualitative method through field observations and in-depth interviews with intensive care physicians and intensive care nurses in three intensive care units in Norwegian University Hospitals. Emphasis was on eliciting the underlying rationale for prioritisations in clinical intensive care with particular focus on clinicians' value considerations when limiting intensive care treatment.

Findings: Informants perceived that provision of treatment that was not found to be meaningful represented an increasing dilemma in intensive care. One possible explanation could be that the basis for decision-making was uncertain, complex and contradictory. The informants claimed that those who were responsible for making decisions on the admitting ward wished to prolong futile treatment because of feelings of guilt or responsibility for something that had gone wrong during the course of treatment.

The assessments of the patient's situation that were made by physicians from the admitting ward were often more organ-oriented, and their expectations tended to be less realistic than those of the clinicians in the ICU, who frequently had a more balanced perspective on the patient's total condition.

Aspects such as the personality and the specialisation of those involved, the culture of the unit and the degree of interdisciplinary cooperation constituted important issues in the decision-making processes.

Significant others could cause unintentional discrimination of ICU patients. Family members who were demanding could receive more time and attention to the patient as well as for themselves.

The status and position of patients and next of kin and /- or an interesting medical diagnosis appeared to govern the clinicians' priorities with regard to patients and families – consciously as well as unconsciously.

Scarcity of resources in the ICUs regularly gave rise to suboptimal professional standards of medical treatment and nursing care. The clinicians rarely referred to national priority criteria as a rationale for bedside priorities. Because prioritisations were undertaken implicitly and most likely partly without the clinician being aware of it, essential patient rights, such as justice and equality, could be at risk.

Conclusion: Under-communicated value considerations jeopardise the principle of justice in intensive care. If intensive care patients are to be ensured equal treatment, strategies for interdisciplinary, transparent and appropriate decision-making processes must be developed, in which open and hidden values are rendered visible, power structures are revealed, employees are respected and the various perspectives on the treatment are awarded legitimate attention.

ACKNOWLEDGEMENTS

First and foremost I am very grateful to Akershus University College, the Faculty of Nursing Education for funding this PhD project. Without this financial support I could not have undertaken this work. A special thanks also goes to the Ethics Programme at the University of Oslo, which financed the pre-qualifying work for this project.

I wish to express my sincere gratitude to the nurses and physicians in all three intensive care units for letting me enter their routine workday, and for sharing their thoughts and experiences with me with openness and honesty. Without their open-heartedness and generosity this project would not have been possible. I also wish to thank the heads of departments who granted me access to the hospitals and the intensive care units.

I owe a particular debt of gratitude to Professor Per Nortvedt and Professor Reidun Førde at the Section for Medical Ethics, UiO, my supervisors, who have generously shared their knowledge and provided continuous support and constructive criticism throughout the whole project. Drawing on their involvement in clinical ethics and prioritisations in the medical field, they have engaged me in rewarding discussions and showed me their unfailing confidence, and their commitment to and concern for the study have been of invaluable help in the research process. They have supported me in believing that I could pull this project through, even in times when it appeared too difficult.

Many thanks also to Professor Jan Helge Solbakk, who in 2003 in his position as leader of the Section for Medical Ethics, admitted me as a pre-qualifying student. I am also grateful for his numerous knowledgeable contributions throughout the PhD project.

I will give a special thanks to Professor Knut Erik Tranøy who read my manuscript in an early phase of this project. Thanks for your wisdom and generosity.

I also want to thank the dean, all my colleagues and research fellows at Akershus University College, the Faculty of Nursing Education and the Section for Medical Ethics, for their collegial support and good times! You have all been of great significance to me!

A special appreciation to Kristine Johaug and Nils Smith Erichsen, my employers at the intensive care unit, Akershus University Hospital for being such good leaders and for your valuable support, from starting my master’s degree studies and throughout my doctoral work.

Many thanks to Marianne Bahus, Berit Støre Brinchmann, Heidi Jerpseth, Anne Cathrine Næss, Terje Takle and André Sjåvåg for reading my manuscripts and sharing their knowledge on legal, nursing, medical, methodological and linguistic matters. Also many thanks for good moments and much laughter.

Thanks to Svanhild Storbråten and her staff Erik Hansen, Ruth Johnson and Karin Lillehei in Akasie kurs og Veiledning for translation and proofreading of manuscripts.

Throughout these years on our many common walks with our beautiful dogs, my good friend Cecile Bjørgo, has inspired me with her interest in my project, with rewarding discussions, insistent questions, reflections and friendship. Thank you for your important contributions.

A big thank you to those close important persons and friends in my everyday life, who make my days bright!

And finally, my very special gratitude and appreciation go to my three children: Ingvild, Guro and Bendik, who are always by my side. What would I have done without you! A special thanks to Bendik, who is irreplaceable when it comes to technological matters! The warmest gratitude of all goes to my mother Reidun, who has always been there for me.

LIST OF ARTICLES

I Halvorsen K, Førde R, Nortvedt P. Professional Challenges of Bedside Rationing in Intensive Care. *Nursing Ethics* 2008; 15; 715-727.

II Halvorsen K, Førde R, Nortvedt P. Value choices and considerations when limiting intensive care treatment: a qualitative study. *Acta Anaesthesiologica Scandinavia* 2009; 53; 10-17.

III Halvorsen K, Førde R, Nortvedt P. The principle of justice in patient priorities in the intensive care unit: the role of significant others. Accepted for publication, May 2009, in *Journal of Medical Ethics***.**

Attachments

Attachment 1: Information to the ICU units
Attachment 2: Information to families and others
Attachment 3: Information to respondents.
Attachment 4: Informed Consent sheet (in Norwegian and English).
Attachment 5: Observation guide
Attachment 6: Interview guide; ICU physicians.
Attachment 7: Interview guide; ICU nurses

Abbreviations

In this summary I have used the expressions of both 'intensive care' and 'ICU', when talking about nurses, physicians, units and patients coupled to the ICU / intensive care. I have used the concept of ICU physician, and not anaesthesiologist, as done in the articles. All physicians in this study were anaesthesiologist, but had decision-making responsibilities in the ICUs. Nurses / ICU nurses are as well described without differentiate between them.

1 INTRODUCTION

> “In intensive care, the question arises after a while: what’s the use? What are we doing for the patient? What can the outcome be for the patient – in the best case? Is it more a question, say, of prolonging death rather than bringing life for some patients? And as things progress for some of them in general – the development of disease, aging and so on – the question just gets bigger: How far should we push the treatment with each individual patient? To what extent do we actually help the patients? That’s in a way the greatest challenge, more than the pure medical aspects. When should we say ‘stop’, or what should we even not start?” (Interview; intensive care physician)

To a large extent this physician sets the agenda for this project and highlights the dilemmas that physicians and their collaborating decision-makers, e.g. physicians from the patients’ “home wards” and nurses in intensive care units (ICU), have to deal with in everyday practice. Intensive care’s prime value is to give life to people, to bring patients through serious medical crises. Although advanced technology, medicine and nursing have made this possible, in an everyday context the clinicians in intensive care have to ask the difficult questions and make the tough priorities about whether patient treatment is meaningful or futile. These are value-laden decisions, involving so much more than “pure” medicine. And along with these complex deliberations they have to consider and struggle with how resources are put to use – both for their current patients and for those of the future. What considerations and value choices influence decisions when intensive care treatment is to be limited? What shapes the basis of the clinicians’ decision-making? Which criteria and values count, and to what degree are these values explicit? To what extent do resources create a dilemma and give grounds for concerns and worries in an everyday intensive care practice? These questions constitute the main issues of this dissertation.

1.1 Aim of the study

The aim of this study is to undertake empirical research to obtain better knowledge of the priority considerations and value choices that are prominent in clinical prioritisations in intensive care practice, with particular focus on the limitation of ICU treatment.

To complete the aim, intensive care physicians and intensive care nurses are included in the study. Even though the physician is responsible for making the medical decisions, the medical and nursing needs of the patient belong to the same context and are closely connected. However, prioritisation at the bedside may give rise to different dilemmas for nurses than those facing physicians (and vice versa). Implementing this study by focusing only on the experiences of physicians or only those of nurses with regard to the priority considerations that they perceived as most prominent would have yielded a strongly incomplete impression of the problems related to prioritisation in the context of intensive care.

1.1.1 The engagement of the study

This study has been prepared on the basis of my engagement with intensive care medicine and intensive care nursing, being a trained intensive care nurse. This has been a meaningful job, where I often witnessed how intensive care made a difference to people. Everyday life in the ICU consisted of meetings with people in some of life’s most vulnerable situations. These encounters involved grief, hope and joy in an everyday situation where life and death were often only a hair’s breadth apart. On the other hand, they also involved experiencing the sad fates of some families, giving rise to feelings of helplessness and a sense of the futility of the help provided.

During my final years in the ICU I experienced how workdays gradually grew busier and the resources became increasingly scarce. At the same time, the boundaries of intensive care medicine were shifted. New forms of treatment emerged; giving rise to new opportunities and difficult ethical issues that had to be addressed. Some patients on the ward were often extremely ill, quite a few were elderly; some had multiple and chronic illnesses with complex clinical pictures. The conversations between colleagues centred more frequently on what was perceived as right or wrong, worthy or undignified in the treatment of some of the intensive care patients. Spurred by this development, I decided to investigate the priority considerations and the value choices of physicians and nurses in the context of limiting intensive care – both in relation to the withdrawal of intensive treatment that no longer appeared meaningful and to the limitations imposed by scarcity of resources.

With the medical ethicists Per Nortvedt and Reidun Førde as supervisors and active partners, the project gradually took shape. The topic is a comprehensive one. Now, at “the end of the dissertation journey”, I am grateful for all that I have learned and experienced, and not least for the insights that skilled ICU clinicians have shared with me throughout this work.

1.2 Structure of the dissertation

This dissertation is based on a large, qualitative empirical study in which focus has been placed on acquiring insights into considerations for decisions and value choices concerning limiting treatment within ICU medicine and ICU nursing from the perspective of how priorities are formed. The dissertation comprises three scientific articles (1-3) as well as this summary. The articles concentrate on key elements of the empirical findings of the study, while the summary comprises “a journey through the work” and provides a more thorough description of the theoretical and methodological basis of this research, as well as a more comprehensive discussion. This introductory chapter presents the aim and background for the study, research problem and research issues, as well as key definitions. Chapter 2 elucidates the theoretical perspectives. The next chapters, 3 and 4, provide a description of the basis of this dissertation in theory of science as well as its empirical methods. Chapter 5 describes the empirical findings generated by the three articles that comprise the dissertation, and Chapter 6 gives a critical review of the methodology. A further discussion of the findings is provided in Chapter 7, while chapter 8 summarises the most prominent consequences of the findings and outlines some perspectives for further research. Chapter 9 lists the references.

.

1.3 Background

Medical progress places great demands on the prioritisation of health services. In the mid-1980s, Norway was one of the first countries in the world to place priorities regarding health care on the political agenda through the first “Lønning Commission” (4). Norway has been characterized as one of the best countries in the world to live in. We spend considerably more of our GDP[1] on health than other comparable OECD[2] countries do. In spite of this early and continuing focus on the prioritisation of health services, as a nation we still encounter considerable difficulties in distributing the resources of the health sector in a fair, equitable and appropriate manner. There is an incongruity between what is medically feasible, the available resources and the expectations of the public in terms of what can possibly be achieved by way of medical services (5-8).

1.3.1 An introduction to priorities of health care

Prioritisation of health services takes place at several levels, from the 1st ordinate healthcare-policy level (macro level) to the patient's immediate environment, the 2nd ordinate level (micro level), which is the focus in this study.[3] The 2nd ordinate level also consist of a level where medical communities prioritise group of patients, diagnoses and other relevant criteria on behalf of their medical discipline (6).

It was determined by the Lønning II Commision that guidelines for priorities with regard to diagnoses and groups of patients on a 2nd ordinate level, but still "one step" away from the patient, would be of great support for the clinicians in their prioritisation among individual patients. It would also ensure a more fair allocation of available resources at the clinical level (6). However, there has been resistance in the medical communities to establish these priority-guidelines at the 2nd ordinate level. Recently, more than ten years later, several medical communities have started this extensive work and guidelines from various communities are in place and available online for clinicians working bedside[4] .

The most recent Official Norwegian Report on the prioritisation of healthcare services in Norway emphasises a "bottoms-up" approach to priorities (6, 9). The prioritisation of healthcare services for the individual patient should be rooted in the medical community and the healthcare personnel. Since the actual specific clinical priorities are made by healthcare

---

[1] BNP – Brutto Nasjonal Produkt

[2] OECD - Organization for Economic Co-Operation and Developement

[3] In political theory, the superordinate level, corresponding to the level of health policy, is often referred to as the *macro level*. The level in the patient's immediate environment, at the individual level, is correspondingly referred to as the *micro level*. Between these levels there is an intermediate level, a *meso level*, that represents the employer's level at an intermediate stage between the macro and micro levels (Norheim 2003).

[4] www.shdir.no/veiledere/ assessed June 25th -2009.

personnel. The hard choices are made "bedside", where medical treatment and nursing care in various ways need to be prioritised and rationed – choices that need to take account of resources and /-or prioritisations that are made on the basis of medical and ethical considerations (5-9). The second report from the Lønning Commission requested more knowledge on the priorities that are made by clinicians by way of reports from the various medical communities and through research that elucidates priorities at the clinical level (6). This study focuses on some of the aspects requested by the Lønning II Commission through its investigation of priority considerations among intensive care physicians and intensive care nurses at the clinical level, in particular related to limiting the medical treatment and nursing of adult intensive care patients.

1.3.2 Intensive care – looking back

The origin of intensive care medicine dates back more than 200 years. Internationally, in England[5], the monitoring of exceptionally ill patients was described as early as 1801 (10). Florence Nightingale was an intensive care nursing pioneer. Through practical efforts and statistics, she demonstrated that good ventilation, a comfortable bed and proper hygiene resulted in drastic reductions in mortality among soldiers wounded in the Crimean War[6] (11). In the Nordic context, intensive care medicine and nursing remains a fairly young discipline, and made its real entry into Scandinavia and Norway only in the context of the polio epidemic in the 1940s and 1950s. At that time tracheotomies started to be performed on patients suffering from polio to provide treatment that could facilitate respiration (10).

Technological and medical development accelerated during the 1960s, and the therapeutic opportunities for the critically ill continued to improve. In his dissertation "A discipline on pillars"[7], Kjell Erik Strømskag (10, p. 213) describes these in the following manner[8]:

> "Technological development provided modern respirators and dialysis machines, allowing many patients who previously would have had died at an early stage of the illness to remain in hospital, and many could be discharged after a period that required substantial resources in all senses. Not least, the therapeutic attitude among the

---

[5] Newcastle upon Tyne

[6] Crimean War 1853-1856. http://no.wikipedia.org/wiki/Krimkrigen (accessed 11 April 2009).

[7] "Et fag på søyler"

[8] My translation

> physicians and the health authorities became more assertive. It became legitimate and ethically acceptable to treat patients who had previously been perceived to be beyond the possibilities of therapy."

During the 1950s and 1960s Norwegian hospitals established a number of recovery units for monitoring patients after surgery. In the latter half of the 1960s, most Norwegian hospitals established ICUs. The development of intensive care medicine from the very beginning and until today has been characterised by the introduction of increasingly sophisticated technology, closer monitoring and aggressive treatment of very ill patients (ibid.).

1.3.3 Intensive care – advanced medical and nursing care

Currently, intensive care medicine represents some of the most advanced services within the health sector, and the intensive care patients reflect the demographic changes that have occurred in society as a whole. This implies that present-day intensive care patients to a larger extent than previously, are elderly and may suffer from several associated illnesses, chronic diseases and comply complex clinical pictures (12, 13).

Intensive care medicine has the marvellous ability to help a number of people through serious medical crises, but unfortunately there are also a fair number of situations where intensive care is unable to save the patient and the treatment must be limited by being withdrawn or withheld. It is not given that all patients who suffer from life-threatening conditions should receive intensive care, but should be given other proper medical and nursing care at the end-of-life (14). A basic principle for intensive care is that the life-threatening condition of the patient must be reversible by the provision of intensive care (15). At the same time, the prioritisation of ICU treatment shall also be undertaken in accordance with principles and values for the prioritisation of health services in general. The seriousness of the illnesses must be assessed in relation to the benefits and costs of the treatment (6). These priorities give rise to some of the hardest medical-ethical assessments and decisions that are made on a daily basis in ICUs. Decisions to limit ICU treatment entail major consequences for the individual patient as well as for a just and appropriate distribution of resources (16, 17). This division of medicine represents some of the most prominent dilemmas of modern medicine as such. ICU nurses and physicians are key actors in this context, and we need to obtain renewed knowledge of how they form their priorities at the clinical level and how they perceive the difficult task of exercising these priorities in their intensive care practice. In the following is a review on relevant research for the study.

1.3.4 The intensive care context

Musschenga emphasises that empirical ethical research is context-sensitive, and the quality of such research depends on understanding and illuminating different sides of the practice within the research (18). I believe it is important to give a short glimpse into the environment of intensive care and the context in which priority decisions are often made.

The context of intensive care is designed to save the lives of the sickest patients. This ward includes nurses and physicians on 24-hour shifts who provide constant care for critically ill patients. These wards are characterised by high technology, e.g. respirators, dialysis machines, medication pumps, intravenous fluids, etc., surrounding the patients. One could say that the ICU is characterised by both high tech and noise, but at the same time there is a confident and competent atmosphere that reflects that those patients are being cared for safely (19, 20).

Something very particular to the intensive care context is the “many stakeholders” of the patients, as ICU clinicians describe it themselves. This entails doctors from the “home ward” who “own” the patients. The home ward is the ward where the patient belonged before he or she was transferred to intensive care, or belongs to even if he or she was admitted directly to the ICU. Even though intensive care wards are organized in slightly different ways in different hospitals, something that they have in common is that physicians who specialise or are involved in the diagnosis the patient is admitted for bear a particular medical responsibility for the patient. These physicians play an important role in the medical decisions. How decision-making processes are organised within this context influences how priority decisions are made. Musschenga quotes Zussmann where he claims that research shows that the actual processes involved in intensive care decision-making are clarified only to a limited extent (18). When these contexts are excluded, the research contributions elucidate to a greater degree how decision-making should be and not how it actually is (ibid.). In this study the goal was to obtain insight in the actual priority decisions and not a normative evaluation regarding how these decisions ought to be.

1.3.5 Relevant research

The focus on resource issues in ICU medicine is not a new phenomenon. During the 1980s the naesthetists Øyvind Løes and Nils Smith Erichsen undertook a study of resource use at the ICU at Akershus Central Hospital.[9] At Ullevål Hospital the physicians Svein Sunde, Andreas Skulberg and Petter Andreas Steen undertook a similar analysis.[10] Both these works documented the benefits of intensive care medicine, and the debate over resource use abated[11] (10). However, the debate over how the resources of intensive care medicine shall and ought to be used must nevertheless be kept alive. In an editorial from 1999 D. Cook and M. Giacomini claimed that rationing resources for critically ill patients was "The sound of silence" (21). From the little amount of research on the rationing area in intensive care it still may be this way.

1.3.5.1 Search methods and key-words

Identification of research with relevance for this study has been done through regular searches over the past five years mainly in Medline, Cinahl, Ovid, Cochrane, PubMed, The Health Library and direct searches in several journals.[12] I have used the following keywords in different sequences and combinations: priority setting, resource allocation, rationing, justice, fairness, intensive care nursing, intensive care medicine, critical care, ethics, ethical dilemmas, withholding and withdrawing ICU treatment, limitation of treatment, end-of-life, decision-making, age, gender, race, families, relatives, next of kin, qualitative method, observational studies, interviews, field research, research ethics in ICU and informed consent. I have tried to cover the relevant research to the best of my knowledge, but the field is extensive and an exhaustive coverage is impossible.

---

[9] Akershus Central Hospital currently bears the name Akershus University Hospital.

[10] The work of Løes and Smith Erichsen was published in Acta Anaesthesiologica Scandinavia 1987. The work of Sunde, Skuldberg and Steen had the title "Omkostninger og resultat ("Costs and results") (10)

[11] This work was honoured with the Royal Medal of Merit (10)

[12] These were in particular, Acta Anaesthesiologica Scandinavia, Intensive Care Medicine, Critical Care Medicine, Journal of Medical Ethics, Medicine Healthcare & Philosophy, and several Nursing Journals such as Nursing Ethics, Journal of Advanced Nursing, Nursing Philosophy and Intensive Care Nursing.

1.3.5.2 Research on prioritisation and resource issues in intensive care

In a systematic review on rationing in intensive care Sinuff et al. found that the most common reason for refusing ICU admission was low expected benefit of treatment, which also corresponds to death of patients. Factors such as bed availability, severity of illness, medical diagnoses and age were used as triage tools. The relative importance of the factors, however, was uncertain (17). Several studies indicate that available resources have an impact on priority decisions and ICU outcomes (22-26). Weekend admission is associated with increased mortality and increased risk of readmission (23, 24). Garland et al. demonstrated that the mortality rate does not decrease with higher resource use in ICUs (27). In a British study, Wunch et al. found that hospital mortality was not significantly associated with day and time of admission to the ICU (28). A Canadian study, however, found that discharge in the night-time resulted in a higher mortality rate (29). Late admission to an ICU is also related to higher mortality (25). Workload and personal stability appear to have an impact on early discharge and readmission (26, 27). To avoid premature discharge and prevent readmission and possible admission, transfer to high dependency units (intermediary units / step down units) are often suggested, since these provide the necessary monitoring, medical and nursing care, but with lower costs than ICU (30, 31).

1.3.5.3 Research on values issues associated with limiting intensive care treatment.

Withholding and /-or withdrawal of intensive care are seen as priority determinants in ICUs, and the differences in how these are emphasised constitute a threat to equitable priorities (32, 33). Research on what is affecting end-of-life decisions is from this point of view of significance for this study.

Research indicates that futility is an ethical dilemma in intensive care, and that clinicians in some cases provide futile care and futility is as well a resource problem because a vast amount on the resources devoted to ICU treatment is spent within the last few days of the patient’s life (34-36). It is also a dilemma for provision of care when the attempt to defeat death obstructs the transition of care from taking place at the right time (14, 37-39). Research has focused on how treatment is sustained when the actual decisions are made, because this in itself involves ethically difficult actions for clinicians. In particular, this appears to be associated with withdrawal of mechanical ventilation, a situation that could be explained as involving an experience of more active withdrawal of treatment and therefore more difficult to undertake (40, 41).

Research sheds light on variations in the basis for decision-making with regard to end-of-life issues, in terms of how these are handled, documented and communicated. Variations that could lead to prolonging as well has hastening of patients death. Differences could be found between professionals, among countries and within countries, as well as between and within hospitals. Cultural, religious, professional and personal values influence decision-making processes and end-of-life decisions (36, 42-50).

Several studies indicate differences in whether and to what extent patients' preferences and autonomy are taken into consideration in decision-making concerning treatment at the end of life. In Europe less attention is paid to patient autonomy, whereas patient autonomy and advanced directives are more prominent issues in the US (16, 42, 46, 47, 51). Recent studies from Europe place emphasise strengthening the patients' perspective and autonomy in decision-making (16, 42). Attention with regard to patients' preferences is also drawn to the importance of good care, dialogue and information with the next of kin as the patients' guardians, but also to different views on the role and the decision-making capacity of the families (51, 63).

Research emphasises that end-of-life decision-making must be a multi-professional process, that includes all perspectives. Several studies indicate that physicians and nurses in ICUs have different perspectives on end-of-life issues, as well as on the point when treatment ought to be assessed as futile. Conflict of care sometimes occurs within the treatment team and between the team and the patients' families. The nurses' involvement or non-involvement in the decision-making is also an issue. Conflicts may lead to dilemmas and moral distress for involved parties. Insufficient communication between physicians and nurses with regard to these issues also creates obstacles to good patient care (35, 68-73).

The perspectives and challenges involved in treatment of more patients in advanced age groups have been discussed in several studies and articles, and the outcomes have been made more evident (13, 74-76). Issues of ageism are also at stake in other parts of the health care system and require collaborative work among professionals (77, 78). Research also indicates that age, gender, race and educational status, among others, contribute to unjustified decisions concerning patients or groups of patients in Europe as well as in the US. It is not proven that the outcome of actual medical and nursing care is worse (78-81). Furthermore, research indicates that knowledge of the different cultures present in multicultural societies needs to be strengthened in order to ensure that proper medical treatment and nursing care is provided at the end of life (82).

1.4 Research problem and research issues of the study

As shown few studies of decisions to limit ICU treatment have been undertaken with a particular view to bedside priorities. However a number of studies involve ICU decision-making with priority consequences. Therefore, this study contributes some new aspects since it elucidates how resource scarcity results in quite specific limitations in medical and nursing care of intensive care patients. It as well shed light on considerations about forgoing intensive care treatment from a priority perspective. The angle on priorities also includes the societal mandate of clinicians in relation to a just distribution of available resources to and between individual patients in the ICU as well as other patients in the health service in general.

In a systematic review from 2004, Sinuff et al. call for studies that assume a perspective on priorities to obtain knowledge of considerations pertaining to the limitation of ICU treatment (17). In the same article, but also in another publication, Sinuff et al. call for knowledge on clinical prioritisations from qualitative studies in order to obtain deeper insights into the grounds for taking such decisions (17, 83).

Two principal assumptions and perceptions formed the basis of the entire study.

1) Intensive care nurses and intensive care physicians must enact limitations in medical treatment and nursing care on the basis of resource scarcity.

2) In some cases, intensive care treatment is prolonged further than that which appears to be dignified in relation to the patient.

On the basis of these pre-assumptions, the following research theme emerged:

1. The ethics of bedside priorities in intensive care – value choices and considerations.

The research issues are derived from the research problem:

a) To what extent and in what manner are national prioritisation criteria used for setting priorities in intensive care treatment?

b) To what extent and in what manner is it possible in a resource perspective to assign priority to the comprehensive medical and nursing needs of the intensive care patient?

c) What value choices and considerations are prominent in clinicians' decisions to limit intensive care treatment?

Research issues a) and b) are reflected in Article I, "*Professional Challenges of Bedside Rationing in Intensive Care*" (1). Research issue c) is reflected in the two remaining articles, article II "*Value choices and considerations when limiting intensive care treatment: a qualitative study*" and article III, "*The principle of justice in patient priorities in the intensive care unit: the role of significant others*" (2, 3).

Article III has been through final proof reading. The comment sheet from the editor is attached to the article. These comments did not make any difference for the content or conclusions of the Article. In this version a heading on research ethics is not present.

1.5 Clarifications of concepts and delimitations of the study

The major concepts in use, and how they are used, will be clarified in this chapter. Important delimitations with regard to relevant issues that were not included in the study will be illuminated as well.

1.5.1 Prioritisation of health care – clarification of concept

Prioritisation of health care is mainly described in terms of “saying no”.
Ruyter et al. (7, p. 240) claims that:

> ‘priorities of health care in most peoples’ consciousness is understood as deciding about delivery of resources among different patient groups, based on criteria connected to the patient and to the necessity of the intervention […] prioritisation means to set something that is useful in advance to something else that is also useful. Prioritisation entails, inter alia, finding ethical, acceptable ways of saying no to patients in need of well-considered medical care, because other patients’ needs have to be preferred.’[13]

In addition Ole F. Norheim describes prioritisations as deliberate and unconscious decisions (84, p.1).

Prioritisation of health care is a concept of many dimensions and is often used in regard to delivering resources among different patient groups (6). The Lønning II Commission described these different dimensions of prioritisation as (6, p. 25-26): 1) *Balancing* between main categories of treatment measures, e.g. acute care and rehabilitation. 2) *Rationing* services, e.g. delaying tasks and services, diluting quality of services, deterring services by constructing barriers for patients’ requirements, and denying different services. 3) *Ranking* different tasks or services, e.g. priority for diagnoses and the degree of urgency of need for treatment.

In this project it was also important to gain knowledge of how nurses and physicians prioritised, and why they prioritised as they did with regard to limiting medical and nursing care. Prioritisation is in this study as much connected to reasons for *saying yes* as for *saying no* to actual treatment at the clinical level. When the respondents where interviewed they *were not* made familiar with definitions of prioritisation that constitutes the understanding for the concept in this study.

---

[13] My translation

1.5.2 Limitation of intensive care treatment

Limitation of treatment in this study includes both withholding and withdrawing treatment from a viewpoint of what influences the priority decisions when medical and nursing care are limited.

Withholding and withdrawing intensive care treatment are based on thorough medical and ethical judgements of clinicians who conclude that treatment is futile and not in the patients' interest. These difficult assessments have to be carried out by clinicians in ICUs regularly (85). In the literature withdrawing treatment is understood as ending ongoing, vital intensive care treatment, e.g. stop inotropic medication for circulatory functioning. Withholding treatment is understood as not initiating intensive care treatment on patients with life threatening illnesses, or “freezing” ongoing treatment, e.g. not putting the patient back on the respirator if his lung functions collapse after extubation, but providing adequate palliative care (86).

Limitation of intensive care treatment is in this study also seen as the rationing of medical treatment and nursing care due to resource scarcity, e.g. reducing quality of care, different medical and nursing tasks, or exclusion of medical and nursing care.

With this perspective on the limitation of treatment there will be different ethical issues regarding the phenomenon at stake that are *not* given in-depth deliberations, e.g. patients' autonomy, specific care for the dying patient in intensive care, care for next of kin, etc. Some issues have been briefly examined from a priority perspective, as part of the findings, but not as the sole ethical issues in intensive care.

1.5.3 Meaningless or futile treatment

In this study the respondents have used the concept of meaningless treatment or futile treatment. It is important to emphasise that I have not gone in to any degree and evaluated whether the treatments they label meaningless are actually meaningless or not. I have been concerned about understanding the clinicians' point of view through observations and interviews and focused on describing their experiences in this respect.

Futility of treatment is by all means a very complex phenomenon in which no agreements are reached conclusively. There are cultural and personal differences about futility. Some define futility as purely medical futility, and others prefer to propose the inclusion of qualitative as well as quantitative futility, in particular by connecting qualitative futility with cognitive functioning (87-90).

1.5.4 Moral dilemma and ethical issues

In this dissertation the concepts of ethical dilemma, moral dilemma, and ethical problem is used inconsistently. I have not defined the concept of moral dilemma to the respondents. It was the respondents' experiences of what is perceived as ethically problematic, according to priority decision-making when limiting intensive care treatment that was in focus. This implies that respondents may encounter issues as dilemmas that are not compatible with the definition, and they might find some that are consistent with it.

A moral dilemma is described by Beauchamp and Childress as (91, p. 10):

> "Moral dilemmas are circumstances in which moral obligations demand or appear to demand that a person adopt each of two (or more) alternative actions, yet the person cannot perform all the required alternatives. Theses dilemmas occur in at least two forms. 1) some evidence or argument indicates that an act is morally right, and some evidence or argument indicates that it is morally wrong […]. 2) An agent believes that on moral grounds he or she is obliged to perform two (or more) mutually exclusive actions. In a moral dilemma on this form one or more moral norms obligate the agent to do x and one or more moral norms obligate the agent to do y, but the agent cannot do both in the same circumstance."

Grady illuminates moral problems in several ways: 1) *moral uncertainty,* where one is unable to clearly identify the moral conflict; 2) *moral dilemma,* where two or more conflicting principles or alternatives exist and by choosing one, the other has to be violated; and 3) *moral distress,* when one can clearly identify the moral conflict and how to resolve it, but disagreements prevent one from appropriate action (86, p. 77). Grady's characterisation of moral issues or problems *does* include a broader perspective of how everyday moral problems can be perceived and supplement the understanding of how moral problems are understood in this dissertation.

1.5.5 Delimiting the gender perspective

This study involves men and women. The gender perspective is however not taken into account. The gender issue was not primarily at interest and the material is too small to make any kind of conclusion related to gender differences. In presentation of the sample different genders are made transparent.

2 THEORETICAL PERSPECTIVES

In this chapter I will give an account of the theoretical basis of the study, which draws on prioritisation theory and the Norwegian health care priorities. Within the perspective of prioritisation theory I will give an account of different relevant principles, values and ethical perspectives. Further, I will describe relevant existing research within the context of intensive care and patient priorities.

2.1 Health care priorities in Norway – principles, values and ethical aspects

Even with all the contemporary medical and technological advances there will always be a discrepancy between the need for, and the availability of, health care resources. The guidelines for health care priorities in Norway state that *"The technological interventions of yesterday create the priority problems of tomorrow"* (6 p. 31). This quotation accurately portrays the reality of intensive care, which over the last three decades more or less continuously has been supplied with increasingly sophisticated technology, e.g. dialysis to patients with acute renal failure (ARF) , ECMO,[14] or advanced respirator support for severe respiratory failure, induced hypothermia treatment after out-of-hospital cardiac arrest, to mention only a few. These developments provide new possibilities for patients to survive critical illness, but they also give rise to moral dilemmas, priority considerations and questions of resource use.

The allocation of health care resources in Norway is based on principles and values embodied in international human rights as well as on principles and values cherished by the Norwegian society (6-8). Health care systems in all Scandinavian countries are to a large degree public founded, based on basic principles of equality and solidarity (92). Norman Daniels claims that health care is a social good (93)[15]. These health care goods must be provided in an equitable

---

[14] Extra Corporal Membrane Oxygenation

[15] In a more global perspective health care is not a matter of course. The global perspective will not be taken into account in this study and therefore not followed further. However, it is of course a moral question with regard to

manner with regard to patients' needs (6, 8, 93). Guidelines, rules and regulations have been published to ensure fair provisions of health care services. These include the Lønning II Commission White Paper from 1997, the Prioritisation Regulations in the Healthcare Services[16], the Patients' Rights Act and the Health Personnel Act (6, 94-96). These regulations establish that the patients' medical needs should constitute the foundation for medical and ethical decisions to give certain groups of patients or specific patients priority over other patients (6). To put health care issues even more firmly on the agenda, a National Advisory Board[17] for health care priorities was established in 2000 (7). However, there are other forces, conscious as well as unconscious, that regulate and influence priorities at the bedside, such as academic and personal preferences and values, as has been elucidated in theory and research (5, 7, 84, 97, 98). In a systematic review of qualitative studies Strech et al. found that several sociological and psychological factors were related to bedside rationing i.e. the context of the situation, the attitudes of the physicians and the characteristics' of the patient (97).

2.1.1 Priorities based on needs

The prioritisation guidelines distinguish between different levels of patients' needs, with *basic health care needs* as the first priority (6). The Norwegian population should be able to receive health care services to support their basic health care needs; these are referred to as '*shall'* services by Ruyter et al. (7). The second level of priority is given to supplementary health care services, to '*ought to'* services. The third level of needs is associated with a lower priority group, described as '*may'* services. The lowest level is associated with *needs that fall outside of public obligations* related to health care, i.e. treatment that falls outside common perceptions of what can be categorized as illness, treatment that will not make any difference in terms of survival or functional status, and finally treatment involving extreme cost in relation to benefit, certain high-risk forms of treatment and treatment perceived as unethical (6, 7). Doubtlessly, intensive care must be considered as belonging to the category *basic health care needs*, but some possible interventions within intensive care may also incur extreme costs or involve high risk and marginal benefits, and may or should therefore not be

---

all the resources used in very advanced medicine that only help a few compared to the same resources spent on health services in developed countries.

[16] Prioriteringsforskriften

[17] Nasjonalt prioriteringsråd

recommended. These deliberations may be very sensitive and difficult for ICU clinicians. However, patients to whom intensive care is denied will be entitled to basic health care treatment and nursing care because of the severity of their illness, although possibly in the form of other types of medical and nursing care and /-or palliative care. The importance of maintaining nursing and care whenever needed, although the condition in itself cannot be cured, is emphasised in the guidelines and regulations for health care services in Norway (6, 94, 95)

2.1.1.1 Three criteria

The concept of needs is not straightforward, and it is difficult to define even with explicit criteria (99). According to John Harris, the degree of health care needs includes at least three dimensions, associated with 1) the urgency of these needs, 2) the amount of whatever is needed, and 3) the capacity for the individual to benefit from what he or she needs (99, p. 294). John Harris argues that in micro-allocation it is essential to decide which dimensions of these needs indicate a more pressing necessity for treatment or have a more compelling claim on the available health care resources (99, p. 295). To be able to prioritise between the needs of patients and groups of patients the Lønning II Commission focused on three main criteria: 1) *severity of illness*, 2) *benefits of treatment* and 3) *cost-effectiveness of treatment*. These criteria have to be evaluated in relation to each other, which often entails striking a balance between values that pull in different directions (6, 7).

Severity of the illness is associated with diagnosis and conditions which, if left untreated, represent a loss of prognosis corresponding to risk of death in excess of 5-10% over a five-year period (6). Intensive care treatment could almost without exception satisfy this part of the criterion in one way or another, because the risk of death or severe loss of capacity is extensive for patients with acute life-threatening conditions (17). However, there is no obligation to initiate intensive care treatment which is considered medically wrong or futile (100). *Severity of illness* is further associated with reduced physical and psychological functionality, including permanent and severe loss of capacity to regularly perform daily activities that are normal within this patient’s age group. In addition, it is associated with invalidating pain that cannot be reduced with the aid of prescription-free medication (6, 7).

The Lønning II Commission takes for granted that there is agreement within the medical communities that severity of illness in itself does not constitute an isolated priority criterion with regard to treatment, if this treatment will benefit the patient or a group of patients only marginally, or not at all (6). Severity of illness is a necessary but not an exclusive criterion, except with regard to provision of nursing and care (ibid), which means that the patients' needs for nursing and care shall never be rationed irrespective of whether the patient can be helped with intensive care treatment or not. This point is emphasised in several research contributions about the end of life and is important in an ethical and priority perspective that implies a transition of care, not a denial of treatment (14)[18].

The White Paper of the Lønning II Commission states the following with regard to severity of illness (6, p. 86): *"The concept of severity fills many dimensions. Among them are the risk of death, the risk of permanent afflictions, the scope of possible permanent disability, the strength of pain and the loss of self-reliance of the ill person"*[19]. These dimensions are not measurable, and assessing them in terms of the benefits of treatment is a complicated issue.

Benefits of treatment must be considered jointly with the severity of illness and the *cost-effectiveness of treatment*. The expected benefits of treatment must be equal to the improvements foreseen by the conditions described in relation to intensity of treatment,[20] within the limits of reasonable costs. Expected benefit is also associated with secure nutrition and daily functioning with regard to hygiene, getting dressed and ability to function socially (6, 7). Priorities based on expected benefit is based on the view that treatment with large benefits should have priority over treatment with lower benefits (6), which in the ICU setting implies that individual patients' benefits of treatment have to be weighed against each other. This has proven to be problematic in intensive care as well as in other parts of health care (16, 46, 97).

The Lønning II Commission emphasised the importance of clarifying the relationship between medical effect and benefit of treatment. Medical effect is associated with increased probability

---

[18] The Standard for Norwegian intensive care treatment also emphasises that there should be good reasons for discharging patients from an ICU when treatment is limited if the patient is expected to die within a short period of time. Palliative nursing and medical care should as far as possible be provided in the ICU, where the patient and the next of kin are familiar with the staff and the ICU context.

[19] My translation

[20] Expected probable survival more than 5-10% within the next five years or improvement of physical or psychological conditions, whole or partly restoration of previous health or reduction of invalidating pain.

for survival, increased functional ability, physically and / - or psychologically, and a reduction of pain and / -or a decrease in the level of physical and psychological affliction. The value of treatment results can be described as equal to the benefit of treatment. However, how the effect of treatment should be valued, or in fact is valued, is not obvious (6, p. 87). Research undertaken in ICUs elucidates how patients, the public and health care personnel value ICU treatment differently. Research from other parts of the health care system also emphasises these differences (101- 104).

The benefit of treatment is closely connected to the prognosis. Substantial work has been undertaken to estimate the prognosis of ICU patients (105-110). A research review (111) illustrates that survival rates are higher than what the prognosis of condition reflects, although the prognosis decreases rapidly when the patient’s condition is aggravated (111). Long term survival after intensive care seem however to be worse than the general population (109, 110).

In Norwegian and international ICUs a scoring system, called SAPS II,[21] is used to guide ICU physicians in estimating a prognosis, resource use, severity of the condition and the benefits of treatment as well as to provide decision-making support in clinical and priority decisions of whether to limit intensive care treatment or not (113, 114). A review of studies illuminated however that physicians discriminate between survivors and non-survivors more accurate than the scoring systems (111).

In intensive care *cost-effectiveness* constitutes a difficult criterion, since intensive care in itself is cost-intensive, compared to other parts of health care, and these costs only concern a small number of patients (110). This does not mean however that the cost-effectiveness of treatment should not be part of the priority decisions at the clinical level as well. Attempts have been made to evaluate when intensive care treatment is cost effective (115). Cost of Norwegian intensive care is investigated in one study over a period of two years (1997-1999), where they found that 60, 9 % of the patients survived more than 18 months after the ICU stay, however reported reduced quality of life. The conclusion of this study was that costs providing intensive care were low compared to what intensive care could achieve for patients (116).

---

[21] SAPS II is a classification system for severity of disease in intensive care and is an abbreviation of "Simplified Acute Physiology Score". SAPS II is one of several ICU scoring systems.

The Lønning II Commission White Paper states that the evaluations of costs against benefits in a situation with resource scarcity involves saying no to one patient, but saying yes to another patient who will benefit more (6). This may be a very difficult decision from an ethical and medical viewpoint in clinical intensive care, literally having to weigh one patient's life against that of another (46). Saying no is proven to be problematic in other parts of health care due to values and interests pointing in different directions (117).

2.1.1.2 Other legitimate and not legitimate criteria

Based on an assessment of these three criteria, and supported by the guidelines for the medical communities, health care services are foreseen to be delivered fairly, bedside as well as on a macro level, based on the principle of justice and equality. There is no legitimacy for discrimination of patients because of their social background and status, i.e. education and personal economy, or with regard to other factors such as ethnicity, religion, geography, age or self-inflicted illness (6). Age may be considered, but only if the risk of treatment overrides the benefit of treatment. No matter how strongly this value is emphasised in the priority regulations, there is evidence indicating that discrimination on the basis of age does occur in the Norwegian health care services (98, 118, 119). A self-inflicted illness should never by itself be used as a criterion, although the physiological damages are occasionally so severe that treatments options are limited. The Norwegian health care priorities embrace the general value that priorities shall not be made on the basis of any moral judgment of patients 5, 6). However, this issue could constitute a challenge, in particular in light of current developments, as people tend to have lifestyles that might be negative for their health (5). There are sometimes very subtle distinctions between moral judgment of persons and medical judgement when priorities are being made, and this only underscores the need for transparency in prioritisations.

2.1.2 Priority criteria pulling in different ethical directions

A problem that was emphasised in the guidelines from the Lønning II Commission was the observation that the priority criteria were pulling in different ethical directions. While the severity of illness is closely associated with the deontological and a duty-based ethical tradition, emphasising how principles and norms should guide the right actions, the benefit of treatment is associated with the utilitarian tradition, which emphasises how the correctness of actions should be assessed from its consequences (6, 7).

2.1.2.1 Duties and principles

Deontological or duty-based ethics as a normative theory of ethics is derived from the German philosopher Immanuel Kant.[22] Kant's moral philosophy was influenced by the medieval theologian Thomas Aquinas,[23] even though ethical principles to guide medical practice saw the light of day centuries earlier, in the tradition of Hippocrates in antiquity.[24] In the deontological tradition of Kant, to act morally is to act according to principles that are a priori to other principles and norms.[25] Kant's approach to moral principles guiding moral actions comprised the categorical imperative and universalism, which implied that these principles should be considered to constitute a universal law and that no action should only count as a means to an end, but also as an end in itself (91, 120, 121). An essential element in Kant's philosophy is the fundamental respect for life and human autonomy, principles that resonate within the professional ethics of nurses and physicians and in medical ethics in general (120. 22, 123). Autonomy is also one of the four basic principles presented by Beauchamp and Childress (91). However, to enact a principle as though it constitutes a universal law, as prescribed by deontological ethics, is not possible in medicine and nursing. Many situations require different principles and values to be weighed against each other, and priority must be given to the principle that in the given situation is considered as the "most morally right", and considered as the *prima facie* principle, as a principle with precedence to other principles (91, 120).

One of the basic principles in medicine (and nursing) is to prevent premature death and suffering due to illness and to save lives. To *cure, care and comfort* is stated in ethical rules for doctors (122), which implies that care, mercy and human compassion should accompany all medical and nursing activities, whether the patient's life can be saved or not. Sometimes a cure is not possible, and care and comfort have to take priority over life-saving actions. These values and virtues are grounded in the Hippocratic principle of first and foremost to do no

---

[22] Immanuel Kant lived and died 1724-1804 (51).

[23] Thomas Aquinas lived and died 1224-1275 AC (51).

[24] Ca. 460- ca. 370 BC http://en.wikipedia.org/wiki/Hippocrates (assessed June 13, 2009).

[25] Beauchamp and Childress (2002) make distinctions between principles and norms and state that principles have a more rule and regulation approach, and therefore mostly are to be considered as prima facie related to norms.

harm (primum non nocere) (120, p 83), later known as *the principle of non–maleficence* in the principle-based ethics developed by Beauchamp and Childress (91). Giving priority to the severity of illness has its moral ground in the principle of saving lives and doing no harm.

2.1.2.2 Utilitarianism – benefits and consequences of actions

Utilitarianism or consequentialism is derived from the English philosopher Jeremy Bentham,[26] and is basically associated with one core principle – benefit, where the good consequences of an action give moral precedence to this action (7, 121). The right action is the action that provides for the largest total benefit for most people, and an action is right only if it provides for the best consequences for most people. Benefit is perceived as well-being. There are several versions of utilitarianism, depending on the perception of benefit and how well-being is understood and defined. To simplify, the traditional utilitarianism as described by J. Bentham and J.S Mill[27] conceives of well-being as *happiness and satisfaction* as opposed to unhappiness and pain. In the more modern versions of utilitarianism derived from R.M. Hare[28] and P. Singer,[29] well-being is measured according to *persons' preferences of quality of life.* The English philosopher G.E. Moore associates well-being with *universal goods*[30] (7). As I understand it, the notion of benefit in the Norwegian health care priorities appears to include all three conceptions of well-being. Concerns about satisfaction, happiness and quality of life are all embodied in the notion that health care services should support people in their experience of good health, if possible, based on quality of life. The notion that benefit of treatment should serve as a criterion for health care priorities includes the perspective that health care is a universal good that should be distributed fairly.

---

[26] Jeremy Bentham, (1748-1832). In addition to being the "first utilitarian", was a fighter for individual freedom of men and fought for important rights such as freedom of expression and equal rights of women. He also made distinct contributions through his critique of the death penalty (51).

[27] John Stuart Mill, (1806-18 73). An influential English philosopher who followed closely in Bentham's footsteps as one of his students (51).

[28] Richard Mervyn Hare (1909-2202) English philosopher. He believed that formal features of moral discourse could be used to show that correct moral reasoning will lead most agents to a form of preference utilitarianism (http://en.wikipedia.org/wiki/R._M._Hare)(assessed June 13, 2009).

[29] Peter Singer (1946-). Well-known Australian moral philosopher and utilitarian. Concerned with global justice and utilitarianism (Singer 2002; One community I: One world). Is also known for controversial viewpoints on topics such as defending euthanasia. (NB! Is the I: above correct?)

[30] Utilitarianism may be action-oriented or rule-oriented. Roughly one can say that action-oriented utilitarianism views the action that performs the most benefit to most affected parts as morally preferable. The rule-oriented version views the action that follows certain rules as morally preferable. In this manner rule utilitarianism has some comparable aspects to deontological ethics.

Utilitarianism emphasises elements that are relevant for prioritisation in all parts of health care: *benefits and consequences* (7). To evaluate actions with a view to their consequences and benefits includes the intention of prioritising health care on the basis of the benefit that treatment can provide. The choices between different actions, different treatment alternatives, different patients and / -or groups of patients are dependent on which actions serve the best aim, i.e. whether the consequences of certain priorities benefit a larger group of patients (6). How much weight should be given to benefit of treatment will always remain a question in this assessment. This assessment may be unproblematic in some cases, but very problematic in others, in particular if the costs of treatment for a few severely ill patients are considerable in relation to the number of persons who benefit from it (ibid.). This situation may sometimes occur in intensive care medicine. In a broad investigation undertaken in Australia, Erik Nord et al. found that the public preferred provision of life-saving treatment of a few, rather than less effective treatment of many people (124).

Benefit of treatment is associated with *the principle of beneficence,* taken from the principle-based approach to medical ethics of Beauchamp and Childress, where *beneficence* first and foremost concerns doing the most good for the particular person as well as maximise goods for the majority, and to assess risk against the potential benefit of the selected treatment or actions, and to assess good against bad (91). However, the assessment of risk is not uncomplicated either, as shown by several authors and research contributions. Some authors have launched a quite strong criticism of the powerful belief in risk assessment, a criticism relevant for ICU as well. They claim i.e. that risk assessment does not sufficiently take into account phenomena such as uncertainty, indefiniteness, ignorance and bad luck (125-127).

One major problem with using utilitarianism as a normative ground for action is the problem of ranking the consequences that should be taken into account when consequences are summarised. Some consequences we may not even be able to foresee or to conceive (7).

Another strong critique of utilitarism and the principle of benefit is that they do not sufficiently take the worth of individual humans into account. Benefit point towards what is the best option for most people (ibid). How is it possible to get the most health care from the available use of resources, distributed fairly within the population? With this question, I turn to the next important issue and challenge for setting priorities at the macro level as well as at the bedside: justice as a core principle.

2.1.3 Justice as a core ethical principle for prioritising patients

The principle of justice is a core value in Norwegian prioritisation policies (6, 7). The principle is based on international human rights, and is a basic principle for the Norwegian welfare state for distribution of all welfare goods, not only health care services. Equality and justice was emphasised in the first White Paper on health care priorities and followed up in the second (4, 6). The principle of justice has its roots in ancient Aristotelian philosophy, and the phenomenon of justice is still of major interest for philosophers worldwide. Common to all theories of justice is the "formal principle of justice": *"Equals have to be treated equally, and unequals must be treated unequally"* (91, p. 227). This 'formal principle of justice' makes no specifications with respect to which individuals should be considered as equals. It just states that what is relevant is that equals should be treated equally, meaning that individuals in like situations should be afforded the same benefits and burdens (91, 128). Justice is as also one of the four basic principles in the principle-based ethics of Beauchamp and Childress, and their interpretation of the principle concurs with the formal principle of justice (91). Applied to health care, the focus is placed on distributive justice, and several medical ethicists and philosophers base their ideas regarding provision of health care goods on the theory of justice developed by John Rawls (84, 91, 93). As I read the white papers from the Lønning I and II commissions, the governmental report on health care values in Norway, as well as other Norwegian literature on health care priorities, this theory also forms the basis for fair distribution of health care in our country (6, 7, 84, 129).

Rawls' theory is a contractualist theory based on the principle of "reflective equilibrium" or "fair equality of opportunity" (91, 93). If we apply this theory to health care, health services should be distributed in a way that allows each person to achieve a fair range of the opportunities that are available in society. This equitable distribution should take place under a "veil of ignorance", which implies that no characteristics of persons, e.g. their success, lifestyle or position, should make them more or less eligible for health care. Beauchamp and Childress claim that: *"This theory, like Rawls, recognizes a positive societal obligation to eliminate or reduce barriers that prevent fair equality of opportunity, an obligation that extends to correct or compensate for various disadvantages"* (91, p. 234). In a Rawlsian perspective, fair distribution of health care resources will consequently imply a particular responsibility for those that need it most, which is an important value in Norwegian health care and the professional ethics of nurses and physicians (6, 122, 123). The principle of justice reflected in John Rawls' ideas about justice is also meant to prevent health care goods from being unfairly distributed on the basis of gender, ethnicity, religion, age and the self-inflicted nature of the illness. The "Rawlsian" way of thinking provides no concrete guidance for how a fair distribution should be conceived with regard to various issues. Several medical ethicists have attempted to find a way to identify a set of values that a particular society can agree on, in its health care priorities (93, 130, 131). John Harris takes advanced age as an example, and uses 'the fair innings argument', which implies that people are entitled to equal opportunities for health care up to a certain age. Beyond 'the fair innings' they are given lower priority in some parts of the health care system because of their life expectancy, based on the argument that they have already received their fair share of these particular health care goods (99). The issue of advanced age is a very relevant priority challenge in intensive care. In 2007 the oldest ICU patient was 101 years old[31]. In a perspective of fair provision of health care, the question will be whether it is legitimate to treat a 101-year-old patient in intensive care, or whether it should be regarded as legitimate to provide ICU resources according to a 'fair innings' argument, which imposes age limits. In The Swedish priority guidelines the Principle of Human Dignity is established along with the principle of right to equal treatment, which I believe emphasise the respect for each human being as a solid moral base for prioritisation and may help to distinguish between patients rights to fair care (132).

I believe that in an open and democratic society the issues about what is fair resource allocation of health care need to be discussed and available for open debates, although some issues remain delicate and difficult questions.

Norman Daniels and James Sabin have developed a four-step procedural framework called "Accountability for Reasonableness" as a requirement for making decisions about priorities at the micro level of health care (93, 131):

1) *Publicity* defines the first requirement, which requires that any priority decisions that limit access to health care should be open to the public and that the deliberation behind the decision should be accessible to the public.

---

[31] Annual report NIR 2007, http://www.intensivregister.no/Annet/%C3%85rsrapportar/tabid/55/Default.aspx (assessed June 29th 2009)
Using this data it is important to say that I do not know anything about this patients except the age. Nothing of what this particular patient was treated for, or the outcome. It is also worth to mention that this also shows the complexity in the ICU decisions, in particular by age, where a very old patient can be "young" in his biological age and visa versa.

2) *Relevance* identifies the second step. The decisions must be based on evidence and documentation, reasons, principles and values in which there can be a broad agreement from all parts: politicians, health care professionals, patients and the public.
3) *Appeals* represent the third step, which includes that there should be a mechanism for appeals, criticism and correction in cases where there are disagreements about decisions that limit health care services. This mechanism should include possibilities for revision of decisions on the basis of on new arguments and documentation.
4) *Enforcement* is the final step in the procedure, which includes that there should be public or voluntarily regulations that ensure steps 1-3.

The framework has been tested in different studies, also in intensive care, and its supporters have been positive with regard to its functionality (8, 133-135). By way of a framework such as this, priorities can be based on values that most people in society can agree on, values as Knut Erik Tranøy characterized as “Common Morality” (120). With a framework as such, the priorities may be more transparent and open to debate and dialogue, which is an important value in itself in a democratic society.

2.1.4 Justice and proximity – contradictions for nurses and physicians?

According to their ethical codexes and social mandates nurses and physicians are partly obligated to assume responsibility for distributing health care resources fairly. Health care professionals are also liable for the responsibility towards their actual and concrete patient. They are obligated to provide defensible and individual nursing and medical care to each of their patients (122, 123, 136-139). The distinction between these two perspectives can be explained as a tension between an ethics of proximity as opposed to a consequentialist or utilitarian approach to ethics. Nurses and physicians on one hand have the moral obligation for the actual patient. On the other hand they also remain morally responsible for distributing nursing and medical resources in a manner that maximises the value of health care goods in society and that take into account other and future patients. Tranøy emphasises, however, that the primary moral obligation of nurses and physicians is associated with their actual and real patient (120). An ethical perspective often named ethics of proximity tries to capture the value of relationships to particular persons and personal relations as special sources of differential and also equal treatment 138, 139).

The Norwegian philosopher Kari Martinsen and the medical ethicist Per Nortvedt have made this tradition well-known and well-established in Norway as an important approach to understanding the foundations and values of nursing (136-143). I believe that their work is of fundamental impact and value for understanding the various dimensions involved in caring for patients in a modern, technological and “quick-fix” health care system.

The ethics of proximity, focus on subjects who are in a definite caring relationship to each other (138, 139)[32]. The basis for an ethics of proximity is the understanding of an ethical demand which are the source of particular demands of responsibility for the other person. This ethical perspective originates from the philosophy of E. Levinas and his philosophy of the Face”. According to Levinas the Face issues an ethical demand that is infinite as well as pre-ontological and pre-intentional. The Face claims non-violence and responsibility for the concrete and particular other person (139). Alluding to health care, all patients will represent an appeal of care and responsibility that nurses and physicians need to be receptive towards. Moreover, understanding as well as responsibility for what is at stake for a patient is fundamental to good clinical judgment and thereby for provision of adequate medical and nursing care. It is also basic for establishing trust between the patient and the nurse and / -or the physician (136, 139, 141, 142).

In health care there will always be asymmetrical relationships of power, where the patient remains dependent on the physician and nurse relationally close. Trust between the patient and the health care professional is essential for appropriate treatment, in which the patient’s vulnerability is perceived and taken seriously. Without trust, patients will be unable to share and be frank, and neither will the next of kin, which often are vital sources of communication and information, as often is the case within intensive care (63). The patient depends strongly on being confident that he or she is ensured the best treatment and is in good hands and cared for in a professionally competent manner. Patients have a right to be certain that their best interests are attended to and that they are treated fairly in relation to other patients (136). In order to gain someone’s trust and to be able to give adequate help in accordance with patients’ needs and professional standards, an interpersonal relationship with the patient is required. The increasing tenuousness of such personal relationships represents one of the major dilemmas in contemporary health care. Some patients are not seen or heard, and they do not

---

[32] There are several traditions and directions of ethics of care which I cannot discuss in this dissertation.

always perceive that they are provided with sufficient help for their illnesses. On the other hand, health care professionals also have the experience of being unable to provide sufficient help, because of resource scarcity or a number of other reasons (98-119).

Nortvedt and Nordhaug argue that there must be ethical legitimacy for giving preference to an ethics of proximity and to a special interest and attention to the individual and real patient (138). They support their arguments in, among others, the work of Samuel Scheffler, in which he to some extent grants legitimacy to giving preference to personal relationships at the expense of justice. Nortvedt and Norhaug also base their argument on Tranøy’s claim with regard to preference to the concrete and actual patient (120, 138, 144). I support their argument, and also believe that without the immediate and specific patient as the primary priority, important information will fade from clinical evaluation and judgment, and in the long run this might result in inadequate care and more resources spent on health care to each patient. However, health care professionals also need to be aware of the responsibility of distributing the available resources in a fair and just manner and avoiding arbitrariness caused by insufficient attention to how resources are delivered on a daily basis. Provision of nursing care and medical treatment implies always keeping in mind that every day and every decision are filled with priorities (6, 98,117, 119). In situations of resource scarcity, careful considerations must be made of who needs the resources most, and in what way. In my opinion, these deliberations are impossible without basing professional activities in an ethics of care, where the other is met skilfully “with the heart’s eye” as Kari Martinsen also claims (141).

3 THEORY OF SCIENCE AND PRECONCEPTIONS

This study takes a phenomenological-hermeneutic approach to the development of knowledge, but is primarily a hermeneutic interpretative study based on field observations and qualitative in-depth interviews (145-147). This chapter will briefly describe phenomenology and hermeneutics as the study's basis in the philosophy and theory of science. In addition, the chapter will describe aspects of the researcher's and the supervisors' preconceptions.

3.1 Phenomenology

The choice of a phenomenological-hermeneutic approach, in preference to a purely hermeneutic interpretation, is based on the view that hermeneutics alone is insufficient to elucidate sensibility and thereby to capture immediate experience-based knowledge (148). Sensibility represents a non-reflexive perceptiveness with regard to various phenomena and concerns the sensitive relationship to other people's experience of illness (139-142, 148). [33] In the study it was important to bring out these aspects of immediacy that give rise to this intuitive and non-reflexive perceptiveness in the mind of the individual clinician. For example, in some situations the physician or the nurse could perceive the treatment as undignified. This perception of indignity was often emotionally tinged and characterised by an impressionistic receptivity that reflected the individual's own self-conception. It was important to bring out this intuitive understanding that precedes hermeneutic interpretation in order to elucidate phenomena that have a bearing on prioritisations in intensive care medicine and nursing. These phenomena served as the basis for further reflection and interpretation. To achieve this, it was necessary to proceed by way of phenomenology (149).

---

[33] Sensibility allows for an understanding of the bodily, intuitive and immediate aspects of our relationship to the world. This applies not least to situations where physicians and nurses need to interpret and relate to patients who are acutely ill, unstable, perhaps anxious and worried, and suffering pain. In the ICU practice, sensibility could also concern the immediate and impressionistic aspects of clinical discretionary judgement, leading to an almost intuitive understanding of how something is about to happen with a patient with regard to a circulatory or respiratory situation.

The German philosopher Edmund Husserl (1859-1938) is regarded as the founder of modern phenomenology[34]. Phenomenology is based on a view of reality presupposing that human beings identify meaning and understand the world through experience, and that human consciousness creates meaning and shapes our understanding of the perceptible, experienced world. Thereby, Husserl turns the subject, through the creative activity of consciousness, into a key notion for understanding the world and the experienced phenomena. In other words, there is no reality outside of human perception and experience. Another basic concept in phenomenology is that *human consciousness is always directed towards something*. This directedness is referred to as the *intentionality* of consciousness (149, 150). Consciousness is constitutive of meaning as well as perceptive, and provides direct access to phenomena that are carriers of meaning and that confront us (148, p. 43).

A phenomenological approach to knowledge implies investigating matters directly, the way they appear to the human consciousness (150). It involves going to "the matter itself", to the lived experience, to the subject and its world. *"Phenomenological inquiry brings to language perceptions of human experience with all types of phenomena"* (149, p. 43). The efforts to gain insight into the grounds for decisions to forgo treatment and the prioritisation dilemmas in the field of intensive care medicine and nursing have been directed towards obtaining knowledge of the practical experiences of clinicians and their moral intuition about right and wrong. Furthermore, the phenomena at stake have been made the object of interpretation and analysis in light of a hermeneutic-interpretative tradition.

3.2 Hermeneutics

Hermeneutic philosophy focuses on the preconditions for understanding and interpretation and on how one should proceed to arrive at valid interpretations (151, p. 139). The understanding and interpretation of contents of meaning are sought in a dynamic and living

---

[34] Husserl sought out a philosophy that could serve as a "first philosophy" that could form the basis of our understanding of all science and knowledge, i.e. it should be pre-scientific. Husserl gave rise to a phenomenological movement which has developed throughout the generations in a variety of directions (Crotty 2006)

process, thereby reflecting a scientific tradition that recognises the existence of the preconceived notions that people bring with them, even into the field of research (146, 151)[35].

Reference is made to two main traditions in hermeneutics: traditional hermeneutics and philosophical hermeneutics. Traditional hermeneutics is methodologically oriented and focuses on arriving at a correct interpretation of the author's message. Philosophical hermeneutics, on the other hand, concentrates to a greater extent on ontological issues, on basic characteristics of humankind and universal preconditions for understanding (ibid, p. 140). The philosophers F. Schleiermacher[36] and W. Dilthey[37] are key figures within traditional hermeneutics, while H.G Gadamer[38] and M. Heidegger[39] represent the shift of perspective between the two traditions (151, p 142).

In their philosophical works, Heidegger and Gadamer make no clear distinction between subject and object. On the contrary, their main idea is that cognition takes shape through interaction between historic and social persons, and that we invariably see and understand on the basis of a perspective that has been shaped by the past and that carries with it an implicit interest in the future. Our experiences, historicity and our lifeworld set the direction and limit our abilities to perceive, understand and interpret (ibid. p. 152).

Hermeneutics employs the concept of *horizon of understanding* to denote all that comprises our totality of comprehensions, experiences and expectations . The horizon of understanding is alive and in motion; it is constantly changed, varied and renewed, and implies that we as human beings invariably bring with us perspectives and comprehensions of the world and our surroundings, consciously and unconsciously. The horizon of understanding comprises *preconceptions* and *prejudices* (151, p. 142).

A key difference between traditional and philosophical hermeneutics was the recognition of the importance of prejudices for our understanding. Traditional hermeneutics emphasised the liberation from prejudices because they could form an obstacle to the understanding of the author's message. Philosophical hermeneutics, on the other hand, regards prejudice as an

---

[35] The hermeneutic tradition originated in the interpretation of biblical texts and the classics of antiquity with the purpose of arriving at a valid and universal understanding of the meaning of the texts (151).

[36] (1768-1834) http://en.wikipedia.org/wiki/Friedrich_Schleiermacher

[37] (1833-1911) http://en.wikipedia.org/wiki/Wilhelm_Dilthey

[38] (1900-2002) http://en.wikipedia.org/wiki/Hans-Georg_Gadamer

[39] (1889-1976) http://no.wikipedia.org/wiki/Martin_Heidegger

essential part of the human horizon of understanding. A prejudice *precedes* or is *previous to* something else (151, p. 142).

Philosophically oriented hermeneutical ontology recognises human beings as understanding and interpreting individuals, where our experiences and self-conceptions will be included in our understanding and interpretation of the phenomena that we encounter (151). In this manner, my preconceptions will have a bearing on my impression, understanding and interpretations of the observations and interviews in the ICUs.

Interpretation and understanding of meaning take place in a *hermeneutic circle*. Meaning is produced by way of an “endless” alternation between the whole and its constituent parts on the road to new insights. Neither the whole nor its constituent parts can be understood without reference to each other. With the aid of this alternation, new and alternative perspectives will emerge, meaning will change and gradually manifest itself more clearly. Our horizon of understanding is changed in pace with a more adequate understanding of the meaning of the studied phenomenon. In hermeneutic philosophy, this road to understanding is endless. In qualitative research it has to end somewhere. The end point must be found where it can be claimed that a sound interpretation has been achieved in the form of a valid, consensually based meaning (146, 151).

3.3 The researcher’s preconceptions

A particular characteristic of qualitative research is the key role it bestows upon the researcher. The researcher is the actual instrument and thereby exercises a major influence on the creation of data and the entire research process (145, 146, 152, 153).

As a researcher, I bring with me a number of preconceptions and experiences to this study. I am an experienced intensive care nurse and have worked for many years on ICUs and this affected my preconceptions in several ways. My experience represented a strength because I could recognise and understand the complexities of the ICU context. On the other hand, this background could imply a risk of disregarding essential details and of taking some of the aspects of the practices for granted. Too close familiarity with the context constituted a risk of not being able to explicate preconceptions and field-blindness (145, 146, 152).

As an experienced ICU nurse I had previously observed a number of phenomena that were similar to those that I was supposed to study. On several occasions, in the role of ICU nurse, I have faced situations where treatment was discontinued, and I have often pondered the issues at stake. In addition, I have experience from difficult prioritisations, and I have personal as well as professional opinions and preferences with regard to the limits of intensive care. I had formed opinions on matters pertaining to what I personally perceived as indignities in the maintenance of life-prolonging treatment, and I had close familiarity with dilemmas involved in prioritisations that are made in ICUs on a daily basis. I was unable to delete my subjective experiences and preferences from my horizon of understanding, but I was obliged to recognise them with a view to how they could interfere with the research process and the work itself. However, in the interpretation of the data it had to be recognised that aspects of my consciousness would nevertheless exert some form of influence.

My preconceptions and my familiarity with the ICU context could be influential in several ways. They could give rise to prejudices and impose limitations on the creation of data, and thereby produce premature interpretations of the issues at stake. On the other hand, my preconceptions could form the basis for particular sensitivity and perceptiveness to the complexities of life on the ICU. I was able to sense some of the matters that were problematic when priorities became difficult and / -or decisions to withdraw treatment were to be made. I could intuitively grasp how the cooperation between the parties involved functioned or when hectic activity gave rise to feelings of bad conscience and despondency. My preconceptions of the ICU context also formed the basis for a sensitivity that encouraged the respondents to share their experiences since they were meeting someone who understood their everyday problems and the dilemmas they were facing.

Lykkeslet and Gjengedal have elucidated problems associated with preconceptions in the context of research undertaken in close proximity to practical activities. Their conclusion, however, is that such proximity to practices offers an excellent opportunity for gaining valuable insights, but presupposes that the researcher always needs to engage in self-reflection and to see beyond obvious positions and perspectives (152).”

My preconceptions are also associated with my identity as an individual and my values. The perspectives that form the basis for this dissertation are part of these preconceptions. It reflects my concerns and the issues that I ponder over, also in terms of research. In the multitude of available research topics, the selection of research literature will be coloured by preconceptions. Even when making an honest attempt to search broadly to capture the entire field, attention will invariably be drawn to some aspects rather than others.[40] The recognition of how preconceptions govern notions and interpretations of reality applies to all research, including research into the natural sciences (153).

My supervisors, Per Nortvedt and Reidun Førde, have participated in the study by reading, analysing and interpreting the data material. They are co-authors on all articles. Neither of the supervisors possesses practical clinical experience from intensive care medicine; their backgrounds are found in clinical general practice and anaesthetic nursing respectively. Both have strong affiliations with clinical medical ethics.

---

[40] An interesting aspect in this context is found in the basic assumption that phenomenology makes of the intentionality of consciousness. In this lies the basis for what moves us and how we interpret and understand the world, which in turn has a bearing on what and how I will be moved as a researcher by the issues that confront me in the field – as an observer or in the context of interviewing.

4 RESEARCH PROCESS AND METHODOLOGY

This chapter describes the qualitative research paradigm and elucidates methods for access to and provision of information to the research field. Furthermore, the research units and the sample are described, and an account is given of the empirical part of the study and considerations of research ethics.

4.1 The qualitative research paradigm

This dissertation aims to reveal the deeper meaning of the actions and choices taken by health personnel in their clinical prioritisations in bedside intensive care practices, with particular focus on the limitation of treatment provided to ICU patients. The selection of a research strategy required an approach that could produce knowledge of the complicated phenomena that are found in clinical prioritisations within one of the most complex practices within the health care sector. To collect the data, a qualitative research design was selected, involving participant observation and in-depth interviews as triangulation strategies[41] (145-147, 153, 154).

Qualitative research seeks to understand various phenomena that are related to subjective human experience, practices and perceptions. Figures alone lose their power of expression and fail to capture the nuances and depth of personal experience and interpersonal relationships. The qualitative research paradigm is rooted in the humanities, and its theory of science is found in the interpretative research tradition. Furthermore, this research tradition possesses a number of methodological aspects and draws inspiration from several philosophical perspectives. Research that is based on gaining access to and understanding subjective human experiences is often, as in this study, inspired by phenomenology and hermeneutics (145-147, 153, 155, 156).

---

[41] Triangulation strategies involve the combination of different approaches to research, either by combining data collection strategies (as in this study), methodologies, theoretical perspectives or the work of several researchers. Triangulation is further described in Chapter 3.3.1.

Some of the most prominent criticisms raised against qualitative methodologies refer to its lack of rigour and its often opaque research processes, making the results difficult to recreate. Several key authors and researchers emphasise the necessity of making the forms and processes of work employed by qualitative researchers more transparent and open to criticism (146,147,153, 157-159).

In later years, qualitative methodologies have assumed a defined position in health research and are widely used in research on nursing in particular (146, 153, 155, 156). In intensive care medicine there is an increasing acceptance of qualitative research contributions, demonstrated for example by the acceptance of the articles in this dissertation (1-3). In ICU nursing, qualitative methodologies are regularly used to study the lifeworlds of patients during or after acute and critical diseases, e.g. Storli et al.'s study on understanding meaning in memories after intensive care treatment (160). Research areas that could be suitable for study by qualitative methods are currently sought by intensive care medicine (17, 83, 161). Sinuff et al. point out a number of areas where qualitative studies could provide important contributions, including research that could elucidate decision criteria and the ethical considerations that form the basis for priorities formed in ICUs (83). The advantages of qualitative research, in particular with regard to knowledge on clinical prioritisations, are emphasised by Stretch et al. (97, p. 82):

> "Findings from qualitative interviews with physicians on issues related to BSR (Bedside Rationing) are important for several reasons. First, the revealed themes and narrations are helpful to identify factors that might influence rationing decisions. Second, the knowledge about the variety of determining factors can inform the conceptual work in health policy and health-care ethics and provides a pertinent basis for sound development of hypotheses that can be further evaluated within quantitative research projects in the field of HCR (Health Care Rationing)".

4.2 Access to the research field

The research field of this study is intensive care units. In the selection of departments it was essential that these were representative of the complexity of intensive care practices. Furthermore, it was necessary to collect data at several hospitals in order to obtain a broad basis for the material and maintain anonymity. The research field comprised three intensive care units located in different parts of the country.

Informal contacts were initially established with the heads of the three selected units.[42] I met the heads of the units in person to enable them to assess their confidence in the project as well as in me as a person. Katrine Fangen emphasises this initial and informal contact as a good starting point for further fieldwork (145, p. 60). The informal enquiries were received positively, and the conviction of implementing a project on prioritisations and decision criteria in intensive care medicine was strengthened by this response.

On the basis of the positive response from the research field and the resulting faith in the feasibility of the project, applications were submitted to the Norwegian Social Science Data Services (NSD) and the Regional Committee for Medical and Health Research Ethics (REK). The project was approved. An application for exemption from duty of confidentiality was submitted to the Norwegian Directorate of Health and accepted after an appeal (see chapter 4.9 on research ethics). In addition, formal applications for permission to use the ICUs as research fields were submitted to the management of the divisions at the hospitals concerned. Access was granted to all research fields.

The heads of the ICUs played a key role in ensuring real access to the research fields. They acted as *“key contact persons”* or *“gatekeepers”* for regulating admittance and achieving acceptance in the ICU environment and thereby the access to respondents. The need for “gatekeepers” is also described as required in methodological literature on field-based research (145, 162). Miller & Bell claims “*The notion of ‘gate-keeper’ has frequently been used in sociological and anthropological research, referring to those who are in position to ‘permit’ access to others for the purpose of interviewing”* (162, P. 55). The “gatekeeper” arrangement is by no means unproblematic, in terms of research ethics as well as with a view to possible research bias. The gatekeeper is potentially able to influence the final selection of respondents and can “open and close many doors” unless the researcher is aware of the processes that may unfold (145, 162).

---

[42] “Head of unit” refers to the most senior person with responsibility in the unit, irrespective of profession.

4.2.1 Description of the intensive care units

Out of consideration for the anonymity of the respondents and the units, I have chosen to provide only a relatively general description of the units.

The research field consisted of three intensive care units (ICUs) at the university-hospital level, each comprising eight to eleven intensive care beds. Units I and III were primarily surgical units, i.e. most of the patients had *initially* been given a surgical diagnosis and surgery. The remaining unit (Unit II) was a combined medical and surgical intensive care ward, and this entailed a somewhat different group of patients. This unit had patients with primary diagnoses based on internal medicine and surgery. All patients in the three units suffered from severe conditions and often multiple organ failure, requiring advanced intensive care and nursing as well as sophisticated medical technology for treatment and life support.

The organisational structure of the three units varied, but a common feature was that the ICU patient had several “stakeholders”. All units endeavoured to adhere to the principle of having specific physicians and nurses responsible for treatment.

4.2.2 Time for data collection

The collection of empirical data took place during the period from January 2005 to April 2006. I spent the period from early January 2005 until June 2005 on Unit I, whereof the first month was used as a pilot period. In total I undertook 210 hours of observations and 19 in-depth interviews (11 nurses, 8 physicians) on Unit I. The period from early September until mid-December 2005 was spent on Unit II, resulting in approximately 200 hours of observations and 18 in-depth interviews (9 nurses, 9 physicians). Intensive care Unit III was visited for only one week, yielding 40 hours of observations combined with nine in-depth interviews (5 nurses, 4 physicians). This hospital was located far from my hometown, and a presence over a longer period of time was not necessary since I already had a quite comprehensive data amount.

4.3 Project presentation and information to the research field

Once access had been granted, the process of providing information about the project to the employees on the units was initiated. Accompanied by the supervisors, I had information and presentation meetings with the physicians and nurses. All staff also received written information on the project by e-mail. Identical information was provided through the post boxes to ensure that everybody received the information.[43] The information material described the purpose of the project, formal approvals, methods and adherence to considerations of research ethics such as confidentiality, anonymity, consent and the right to refuse to participate (attachment 1).

ICUs have a specific character since many people enter and leave the unit on a daily basis. These could be health personnel from other units that were directly involved or interested in the treatment processes. They could also be next of kin, students, scholarship holders, other researchers, technicians, equipment salespersons, cleaners etc. To ensure that required information was provided to "those who come and go", a brief project presentation was posted in the units' corridors and next to the entrance to the units. The presentation had a small picture of me (the scholarship holder) to make me easily recognisable (attachment 2). The provision of thorough and detailed information to the research field is a significant consideration of research ethics in all studies (7, 163). Fangen describes how a specific project presentation is often complicated in the context of field-based research because of the structure and dynamics of the activities (145). I maintain, however, that the information on the study provided to the staff, the next of kin and others was appropriate. During the process there were no indications of dissatisfaction with regard to the sufficiency of the information provided (see also Chapter 4.9 on research ethics).

---

[43] There is a very thin line of division between "overinforming" and "underinforming". By duplicating the information through internal mail and e-mail, most would receive this information twice, and this could possibly evoke irritation and take more of people's time than they would appreciate. On the other hand, experience indicates that not everybody reads incoming e-mails. Duplication was therefore required to ensure that everybody was reached.

4.4 Sample

The study's sample comprises those who have provided written informed consent and who, in addition to having been observed, have also provided an in-depth interview . This comprised 21 intensive care physicians, 14 ICU physicians only connected to ICU and 7 physicians connected to ICU and the anaesthetic unit, and 25 intensive care nurses (22) / nurses (3). The ICU physicians were all at the level of head physician and had responsibility for decision-making in the ICU. The nurses were directly responsible for patients and had a key role in the treatment and care of the actual patients. Defining the exact composition of the sample in a study that also comprised field observations presented a problem. In a sense, all physicians and nurses employed on the units where the observations were made are constituents of the sample. However, I have chosen to associate the sample with the respondents I interviewed and monitored most closely with regard to decision-making processes in specific situations. The data creation has nevertheless been influenced by general observations on the units.

Demographic data of respondents are presented by units in Table 1 and as a whole in Table 2:

Table 1: Composition of the sample by units

	ICU I ICU physicians	ICU I ICU nurses /nurses	ICU II ICU physicians	ICU II ICU nurses /nurses	ICU III ICU physicians	ICU III ICU nurses /nurses
Women	3	9	4	6	2	4
Men	5	2	5	3	2	1
Experience (years) (Mean =M)	19.3	19.2	19.4	12.2	14.2	19.2
Exp. from int. care unit (years) (M)	10.1	7.1	13.1	7.1	8.5	13.8
Age (M)	46.1	39.9	48.8	38.5	39.7	42.2

Table 2: Total overview of all three units

	ICU physicians (N=21)	ICU nurses / nurses (N=25)
Women	9 (43%)	19 (76%)
Men	12 (57%)	6 (24%)
Experience (years) M (range)	10.8 (6-34)	15.1 (4-34)
Experience from int. care unit	10.9 (1-26)	8.6 (1-26)
Age	45.6 (35-60)	39.4 (28-57)

4.4.1 Recruitment of respondents

The recruitment of respondents (physicians and nurses) was undertaken on the basis of patient situations that presented or could develop into a problem of prioritisation in terms of intensive care, with possible limitation of the treatment as the end point. The specific situations were mainly identified by the responsible head physician and /-or the responsible nurse in the unit at the prevailing moment. It should be noted that the impact on decisions stemming from the priority considerations and value choices of the respondents was kept in focus. The patient situations formed a “backdrop” that served to contextualise the decisions.

On ICU I and II, direct contact was made with the respondents. The relevant physicians and nurses received an initial oral request, and if the response was positive, they received an envelope containing a written request to act as a respondent. The envelope also contained more detailed information on the project, on voluntariness and considerations of anonymity, as well as a declaration of consent and a stamped response envelope (attachment 3 and 4). Because of the short duration of my stay on Unit III, the respondents were approached in a different manner. The head of the unit had facilitated my stay in advance, and the field and the staff were prepared for my visit. The respondents had been queried and provided with information and a declaration of consent in advance.

Addressing respondents directly as a researcher involves a number of ethical implications. There was a risk that they would feel pressured into participating. I was very aware of this risk, and made it absolutely clear that participation was voluntary. Non-response to requests was decided not to follow up in order to avoid situations where refusal to participate might be perceived as uncomfortable. I received positive consent from all respondents.

4.5 Processes of data creation

Participant observation in an ICU involves access to confidential information and contact with people who are seriously ill and in a very vulnerable position. This requires particular caution and respect on my part as a researcher in order not to violate the integrity of the people involved.[44] As “part of the unit’s staff” I was subject to the Health Personnel Act and its provisions on the duty of confidentiality §21 (96)[45]. I signed declarations of confidentiality in all three units. Signing the declaration of confidentiality also constituted a visible pledge on my part, signalling that all information subject to confidentiality was safeguarded in a legal and ethical manner[46].

4.5.1 Triangulation of data

In this dissertation I have chosen to triangulate different strategies for the processes of data creation by using participant observation and in-depth interviewing. This choice was based on a desire to produce data that were as “truthful and complete” as possible (154). Triangulation can be undertaken in various ways. One possibility is triangulation of data as used in this study. Other approaches to triangulation include the use of several researchers or a combination of qualitative and quantitative methods. Various theoretical perspectives can be used to elucidate the phenomena being studied (154, 164). Jenks defines triangulation as “*[…] an approach to research that uses a combination of more than one research strategy in a single investigation*” (154, p 299).

The concept of triangulation is taken from shipping and navigation, where two points are used to determine the unknown distance to a third point. Thereby, triangulation acts as an aid to mark out a steady and safe course through unfamiliar waters. This metaphor can easily be applied to qualitative research since this may also involve travelling through an unpredictable landscape that requires navigation skills to cross safely (154, 164).

The purpose of this work was to obtain knowledge of priority considerations and grounds for decisions that involved limiting treatment. A comprehensive insight into the experiences and

---

[44] In my work as an ICU nurse, values such as respect, care and support for vulnerable and ill persons have been fundamental. This attitude also governed the manner in which I approached the staff, patients and next of kin in the units and is at the core of the issues of research ethics involved in the processes of data creation and the implementation of the project.

[45] Section 21, *General rules relating to the duty of confidentiality:* Health personnel shall prevent others from gaining access to or knowledge of information relating to people’s health or medical condition or other personal information that they get to know in their capacity as health personnel.

[46] Considerations of research ethics are described in Chapter 4.9

assessments of the clinicians would be unfeasible without in-depth interviewing. On the other hand, there was a risk that to a larger extent interviews alone would reflect the opinions of clinicians regarding how decision processes concerning such limitation *ought to* be rather than how these *in fact* are. The interviews could easily become too *normative*, rendering it difficult to reveal any underlying and more concealed considerations and assessments. On the basis of these viewpoints, it was decided to triangulate the data sources by combining participant observation and in-depth interviews. In this manner the actual decision-making processes were monitored more closely, forming the basis for the interviews that could elaborate and specify the matters at hand. The observations contextualised the interviews and put them in perspective. Triangulation of data served to bring out a more distinct and complete understanding of the complexities of the prioritisations. Triangulation also reduced the uncertainty of the findings by having different sources that could corroborate, vary and modify the data. In this manner, the results of the study emerge as more convincing and strengthen the validity of the study (154).

4.6 Participant observation

Participant observation originated in field-based research. My approach to participant observation is mainly inspired by Katrine Fangen's book on participant observation, based on her own fieldwork among extreme right-wing groups in Norway (145). Fangen takes a scientific approach to field-based research while remaining pragmatic and practically oriented, and I found this to be highly useful during the preparatory stage. It was particularly essential to develop an understanding of the method and how to obtain appropriate and targeted observations. Furthermore, it was important to obtain knowledge of part of the dynamics that can and will occur between the *observed* and the *observing* party. The ethical aspects of observations were also decisive, including aspects concerning confidentiality and caution in meeting with vulnerable individuals, informed consent and the establishment and maintenance of trust in the field situation (145, 162, 163, 165, 166).

Participant observation is a method for creating data through participation in "the daily grind" of the people who are being studied (145, p. 28). As a participant observer I entered into the daily lives of ICU physicians and ICU nurses, and to some extent came to establish personal familiarity with the complicated decisions regarding treatment and the scarcity of resources that they encountered in their daily work. Participant observation gave me an opportunity to obtain knowledge through first-hand experience. As a researcher I came close to the realities faced by the ICU physicians and ICU nurses, and obtained personal knowledge of their daily work and environment, while my own impressions and emotions also became part of the database. The participant observation went on over some time, thus creating a more comprehensive impression of the studied phenomena. Knowledge developed in interaction with and in relation to the ICU physicians and ICU nurses. The time perspective involved in participant observation contributed to a more pronounced sensitivity to the less obvious aspects of the field. A more complex impression could be formed over time of the people as well as of the processes being studied, and I developed close familiarity with the respondents. Participant observation also provided an opportunity to test the statements of the respondents against my own specific experience as a researcher in various situations. This gave me the chance to discuss topics that would not otherwise have been as easy to bring up, thereby providing access to more sensitive aspects of the practices being studied – aspects that the interviews alone could not reveal since they to a larger extent represent a constructed situation (145).

Participant observation does not necessarily entail performing the exact same tasks as the observed respondents. It is possible to become fully integrated in the specific practices of the field, but there is no rule saying that this is expected or required in order to be a satisfactory participant observer (145, 167). In many cases this will even be impossible because the researcher will not possess the same skills as the persons being observed, and legal and ethical considerations pertaining to job content and responsibilities may also impose limitations – all of which applied to this study.

Stella Reiter-Theil has engaged broadly in issues of how empirical research in the field of medical ethics may achieve legitimacy in the clinical field (167). She recommends observation as an appropriate method, in intensive care medicine in particular, in situations where limitation or discontinuation of treatment may become relevant. Reiter-Theil refers to this methodological approach as "*the embedded researcher*" (ibid.). As I understand Reiter-Theil, this involves being "corporally" present, as an integrated part of a unit, without necessarily performing the tasks of the profession concerned. Fangen portray the role of the participant observer in the same terms, describing how the researcher acts as a *methodological tool* and a *ticket of entry* to various environments (145).

4.6.1 Implementation of participant observation

In this PhD project, by means of the research issues I had clearly defined the main objects of study in advance before venturing out into the field to observe them. The ICU field is a complex one, and it was therefore necessary to target attention towards specific areas, even if this entailed a risk of losing some detail. Several authors emphasise the necessity of delimiting the field of study in advance of an investigation involving observation methods (145, 167-169). Prior to entering the field to undertake observations it may be difficult to determine the degree of rigour and the specificity that the research issues or hypotheses should have. Fangen recommends an intermediate position, offering sufficient rigour to avoid "fumbling in the dark", but not so rigorous as to block out substantial elements that would constitute key contributions to the study (145). Reiter-Theil, on the other hand, refers to a relatively rigorous position containing several pre-defined categories (167).

4.6.1.1 Being trusted by the field

Participant observation takes place through interaction, and the researcher depends fully on trust in order to obtain valid and credible data. In fieldwork, the field acts as a host who can invite the researcher in or lock the researcher out. Being trusted by the field entails confidence in the researcher as a person, as well as in the agenda that is at the base of the research effort. Trust is not achieved once and for all, but remains vulnerable, and the researcher must at all stages prove worthy of this trust in order to retain it (145, 170, 171). If this trust is eroded, part of the precondition for acting as a participant observer will disappear with it. This process required some effort, and remained possible only by demonstrating respect to the field and its people and by keeping an open mind and a humble and reflecting attitude to the tasks at hand.

To identify an appropriate approach to the participant observations on the ICUs, I undertook a period of *pilot observations* on Unit I. At this stage I had two key respondents whom I needed to relate to. Here, I spent some time acquainting myself with the routines and cultures of the unit, establishing trust and making contact with the staff. During the pilot period I worked with considerable determination to identify appropriate methods of observation and to gain access to formal and informal arenas where I could become a “normal occurrence” in the everyday life of the respondents. I needed access to arenas where exchanges that could have a bearing on decisions regarding treatment or its withdrawal were made. In Unit II as well, considerable time was spent establishing contact, but here I could draw on my experience from Unit I. On Unit III, most of my stay had been facilitated in advance.

4.6.1.2 Entering the ICU physicians’ “daily life”

In implementing the observations I encountered difficulties in establishing trust among the physicians and being invited into their daily lives. Previous “common experiences” with regard to physicians had been obtained from a physician-nurse relationship, and I struggled to identify a natural approach to establishing a dialogue. I had to concentrate on establishing a role as a researcher, combating my insecurity, rethinking my attitudes and breaking through some personal barriers. Barriers of this kind quite naturally imposed some limitations on approaching the research field with an open, reflecting and analytical attitude.

I had the impression, however, that some physicians also needed to overcome some barriers. Initially, some of them felt some insecurity in having someone looking “over their shoulders”. They needed time to get to know me. Several of them also openly questioned nursing research in general and the use of qualitative methodologies in particular. I needed to establish personal trust as well as scientific confidence. My role as a helper to the nurses on the unit constituted a key contribution to the establishment of respect, trust and recognition among the physicians. Through their repeated meetings with me in this role, they gradually came to perceive me as a person who was familiar with their daily lives and who wanted to make a contribution to the unit. Gradually, their attitude changed, and the physicians became more curious about my work, asked more questions, became more openly positive and invited me more often into their domains.

After having spent some time on the units, I entered the *formal arenas* of the physicians. I was regularly invited to the morning meetings, and joined pre-visits and doctors’ rounds. Furthermore, I participated in cooperation meetings with the head nurse and the responsible head physician, with particular focus on resource issues and troublesome issues in the unit. On several occasions I participated as an observer in interdisciplinary meetings between the

ICU physician, the ICU nurse and the responsible surgeon. On these occasions, the surgeon gave consent.

During my three periods of observations I found it a challenging task to become included in the *informal arenas* of the physicians, for example over lunch. These arenas remained closed to most “outsiders”, i.e. non-physicians, even at the unit level. Most physicians left the unit with their physician colleagues to have lunch, and most of them also left the unit for coffee or to “take five”. The physicians to a varying extent maintained such separate informal arenas, which appeared to provide little generosity to others. This culture was relatively similar in all three units, but depended to some extent on the persons involved. Some physicians (very few) included themselves in the social and informal culture of the unit by occasionally having lunch within the unit accompany the nurses.

4.6.1.3 Entering the “daily life” of the ICU nurses

Given my own background as an ICU nurse, I could participate somewhat more directly in the daily life of the ICU nurses. The nurses quickly included me in their daily work, almost as a colleague. They soon started to share their experiences in a confident manner. My relatively easy access to the nursing community was facilitated by a number of circumstances. First, my own training and identity in the nursing profession was decisive. This simplified my approach to them, we had a lot in common, and I quickly grasped the atmosphere and the issues at stake in various situations. I had the impression that the nurses to a large extent wanted to share their experiences and discuss ethically difficult situations and priorities. They had a lot on their minds, and they were deeply involved in their work. As their assistant, I also became a helper and a relief in their daily grind. This made their days less busy and helped them achieve more treatment goals, all of which spurred the establishment of trust and positive attitudes.

To perform tasks along with the nurses it was essential that I had received the nursing report out of consideration to the patients. In all observation periods I participated in the morning report round and in joint meetings (cooperation meetings, pre-visits, doctors’ rounds and resource allocation meetings). I had lunch with the nurses as well as the occasional “breather”. “Becoming one of the nurses” was easier – a fact that had to be kept in mind with regard to the reliability and validity of the study.

4.6.1.4 Dress codes

In my efforts to be invited into the daily life on the ICU, while retaining my identity as a researcher, I spent some time finding the right way to dress. After some trial and error, I chose to wear a doctor's coat over hospital trousers and top. This dress code singled me out and distanced me from the role of nurse, and I had the impression that the white doctor's coat facilitated my contact with the physicians because my appearance was closer to their sphere.[47] In her study of the hospital as a classroom, Heggen describes how dress codes had an impact on her approach to the field and made a difference in her contacts with the respondents (172).

4.6.2 Observation guide and observation notes

To structure the observations I used the research issues to compile an *observation guide* that was applied as a tool for field observations (attachment 5). The observation guide focused on describing the context and establishing an understanding of the situation. It targeted resource issues such as bed capacity and occupancy, personnel and technology, as well as the emergence and form of decision-making processes. Furthermore, it focused on patient situations that involved complicated prioritisations and the degree of explicit ethical discussions and reflections concerning difficult prioritisation dilemmas.

4.6.2.1 Observation notes

The observation guide formed the basis for structuring the observation notes. I wrote daily field reports, using the observation guide as an aid for identifying the matters to be emphasised in the notes. The observation notes had a more narrative form than that indicated by the structure of the observation guide, and I included my own thoughts, reflections and emotions. By writing down my own personal experiences I also became more aware of my preconceptions and potential prejudices. Many details and nuances were lost by waiting several hours before writing the notes. At the same time, I am convinced that much more would have been lost if I had chosen to establish insecurity and distance to my field of study by taking notes as I went along. A "recording observer" may easily generate insecurity and appear intrusive in the respondents' work. I carried a small notebook in my pocket, and when

---

[47] The dress code served to shift the focus from nurse to researcher and made me more self-confident. I am still a carrier of a specific culture from many years of work in hospitals where power and position to a large extent are reflected in dress codes – for example in types of uniforms and their colour, whether this is a dress or a coat, or whether technological objects are worn visibly.

I wanted to record some special situations or statements that were made, I withdrew to jot down some keywords and /- or the statement. The writing of the field reports was important for the initial analytical efforts (145).

No observation notes contain any data that can identify recognisable individuals. The field notes contain descriptions of situations, but references to persons have been removed, as has the most detailed level.

The text below shows an excerpt from the observation material to illustrate how my field notes were written:

> Values and attitudes:
>
> “There is a lot of discussion concerning some patients in the unit. Some believe that a particular patient is left in the ICU just because this is so-and-so (...) Today there was also a discussion concerning lifestyle and weight, and many claimed that patients who are overweight or have alcohol problems encounter attitudes that are not always favourable (...) there are many underlying attitudes to their lifestyle. Some previous cases were mentioned, when a very overweight person was often referred to as “the fatso”. When the physicians from the department arrived, they often asked for the big one, the fat one etc., instead of using the name. People dropped by just to have a look at him. The same applied to a person who was brought in with alcohol-induced liver failure, and this brought out a lot of attitudes...

4.7 Qualitative in-depth interviewing

In addition to participant observation, this study makes use of qualitative research interviewing. Interviewing is a suitable method for obtaining in-depth knowledge about various phenomena. The interview represents an interpersonal situation in which the interviewer as well as the interviewee may obtain new insights through the interview process and the reflections that follow (146, 147, 153, 173). Kvale describe the qualitative research interview as a seven-stage process, based on the research process from the planning stage to the end point when the findings are reported (146, 147).

The strength of interviews rests on their ability to provide direct access to the perceptions and experiences of the respondents. A good-quality interview often takes the form of a conversation characterised by openness, wonderment and a deliberate naivety with regard to the knowledge stored in the experiences of the interviewee (ibid.). The purpose of the qualitative research interviews undertaken in this study was to obtain exactly this detailed knowledge of the experiences that ICU physicians and ICU nurses had collected from the many priority considerations and value choices facing them on a daily basis – in particular with regard to decisions to limit treatment. While the observations provided access to daily life on the ICU and its difficult prioritisations through the eyes and experiences of the observer, the interviews gave direct access to the experiences of the respondents, expressed in their own words. The knowledge that emerged from the interviews therefore had other overtones and depths regarding the *grounds* for decisions and processes, while the observations to a larger extent constituted *descriptions* of these. The observations provided a somewhat fragmented image of the practices, but nevertheless gave me as a researcher important knowledge about what was at stake regarding the cultures, languages and the atmosphere of the ICUs. I claim that this knowledge had an impact on the interviews as it served to put them in the proper context. The observations provided room for a more open and honest discourse in the interviews on the matters that could have a bearing on various decisions on providing or withdrawing treatment.

4.7.1 Interview guide and interview preparations

The interviews in this study were semi-structured, i.e. they comprised a number of clearly worded but open questions that were based on the research issues of the study (146, 147, 153).

To ask appropriate questions and to ensure an open-ended wording, an *interview guide* was developed that covered the topics to be elucidated (attachment 5 and 7). Care was taken to formulate the questions in a way that allowed for an open, curious and reflecting conversation on the topics at hand (ibid.). To ensure the quality of the wording of the questions and the interviews as a whole, all questions were reviewed by the supervisors as well as by an independent researcher who possessed experience from the use of qualitative research methods in the field of emergency medicine. Furthermore, two pilot interviews conducted with ICU nurses[48] served as a basis for adjustments and corrections to the interview guide. One of the key lessons from the pilot interviews consisted of the necessity of keeping the wording open-ended, and I became aware of the importance of holding onto issues that needed further elaboration. The pilot interviews were also important with regard to becoming aware of the need to refrain from interrupting the respondent and maintaining the silence that sometimes occurred. Silence and thoughtful pauses were often followed by important reflections, and could thereby be crucial for the process of reflection that took place during the interview. By using an interview guide based on the research issues and making the interview relate to experiences in the immediate past, the interviews sought to focus on specific issues and to relate to the context.[49] My presence as a participant observer in the various units also contributed to maintaining focus on specific issues in the interviews. Occasionally, the observations were used to regain the focus of the interview and to specify and challenge particular statements.

---

[48] The pilot interviews were conducted with ICU nurses because nurses are more readily available than physicians. I did not wish to “consume” respondents who were physicians for the pilot interviews. The pilot interviews are supplementary to the total data material and are not included in the analysis.

[49] Kvale (1996, 1997) and Kvale & Brinkman (2009) emphasise the importance of having interviews contain descriptions and reflections concerning specific topics and not only reflect general opinions on a certain topic.

4.7.2 Practical implementation of the interviews

Appropriate planning of interviews also includes the concrete implementation of the interview (146, 147). According to plan, the interviews should be conducted during the first two to three days following a period when the respondent had acted as an ICU physician with decision-making responsibility or as a nurse working bedside[50] in a situation that had involved limitation of treatment. In practice this did not always prove feasible since life on the ICU can be unpredictable and the workload and the staff roster had to be taken into account.

4.7.2.1 External setting and a safe atmosphere

The interviews took place in a room adjacent to the units where we could be left undisturbed. The room had a telephone to enable the respondent to be available on call.[51] During the 46 interviews no interview ever had to be aborted completely, although the physicians received occasional short calls. The interviews lasted from 45 to 90 minutes.

I used a digital voice recorder with an in-built microphone to record all interviews, which I could subsequently convert to a digital audio file. The respondents had been informed that the interviews would be recorded before they provided consent to participate. However, the information concerning confidentiality and safe storage of the audio files was repeated at the start of the interview.

My key instrument in my meetings with the respondents consisted of taking a personal approach, showing great respect for the unique work they undertook on a daily basis, combined with thorough preparation in qualitative research interviewing.

A research interview represents a situation with an asymmetry of power, where the interviewer appears to wield most of the power while also remaining totally dependent on gaining trust and establishing assurance in the relationship in order to produce a good interview (146, 147). One respondent pointed out this asymmetry by stating: *"You're in*

---

[50] The nurse who was responsible for the patient was the one who had the primary or secondary responsibility, and/or had the nursing responsibility for the patient in the context of bedside rationing.

[51] The opportunity to abort the interview and quickly return to work was especially crucial for physicians who were on call. The nurses rarely had an opportunity to be interviewed during working hours because of the shortage of personnel. Most nurses wished to be interviewed before the evening shift or after the dayshift, and sometimes – but rarely – after the night shift.

charge here, you know". This served as a reminder of the fragile nature of the relationship between power and trust, and the decisive importance of acting in a manner that *imparts* and *demonstrates* trust to the respondent (174).

As an interviewer, I did not wish to transgress somebody's personal boundaries, while it was still vital to show interest in the experiences that the respondent wanted to share (147). The conversation must be kept balanced and within the framework of a research interview in order to prevent it from developing into a consultation or a therapeutic session. Malterud points out that this is especially important in situations where health workers[52] act as interviewers because they are familiar with the role of therapist (153). The interviews in this study concerned emotional aspects of the work of ICU physicians and nurses. They concerned decisions on life or death and similar difficult choices, decisions that by many were described as emotionally very demanding. The respondents allowed concealed conflicts, insecurity, values, attitudes and doubts to rise to the surface and to become explicit. For me as an interviewer it was essential to remain aware that the respondent may have disclosed matters that were not often discussed in daily life. To balance my role and present myself as both a researcher and a fellow human being, during the interview I emphasised giving recognition to the respondents, remaining open, present and interested, while also retaining a clear focus on the interview and the questions.

4.7.3 Transcription of the interviews

The transcription of the interviews turned speech into text, and as such constituted a reduction of the data. Transcription is a deconstruction of reality. When data are converted from speech to text something is lost: the nuances, moods and intonation disappear. Because the transcription limits the fullness of the data, it is essential to render the method used for transcription visible. The purpose of the study has a bearing on how the material is transcribed (146, 147). In this study, the interviews are transcribed almost verbatim, i.e. elements like *"hmm... yes and no ..."* as well as repetitions of words and confirmative expressions like "... *isn't it?"* were included. Prolonged pauses, sighs etc. were noted. I desired to reconstruct the full density of meaning in the text to prevent an incomplete transcription from giving rise to

---

[52] Malterud (2003) describes these issues in the context of physicians, but this can also be applied to other groups of health personnel, including nurses, as in this study.

unnecessary bias in the interpretation of the content of the textual material during the data analysis.[53]

Aspects of research ethics were kept in the foreground during the transcription of data. Anonymity was maintained. Figures of speech may reveal identities, e.g. 'personal formulations and expressions' (ibid.). It was therefore important to be cautious with the presentation of the transcribed material in publications, where direct quotes were made available to others.

Figures of speech that become decontextualised in the manner of transcribed interviews may appear different and at worst even erroneous when they are taken out of their original context (146, 147). Examples found in the data material included descriptions of serious and vulnerable experiences that were portrayed with an undertone of black humour. In an analysis, a grasp of the context in which these statements were made is required.[54] An erroneous presentation may do the respondent, the practices and findings of the study an injustice and thereby also assume considerable moral and scientific implications (ibid.). I transcribed most interviews myself, but was provided with research assistance for a total of eight interviews.

4.8 Data analysis of observations and interviews

I have chosen to present the analysis of the observations and interviews in the same subsection. The approaches to the two types of material had much in common, even though the observations were inspired by methods of field-research and the interviews by methods for qualitative in-depth interviewing (146, 147, 153, 168).

The analytical work started at an early stage, in parallel with the collection of data, the writing of field notes and by listening to and transcribing the interviews. During this process I could

---

[53] In some rare cases, sentences have become blurred because the interviewer and the interviewee were speaking at the same time.

[54] Taken out of its context in the form of transcribed material, such elements of black humour may appear brutal and insensitive, but this form of expression could equally well symbolise a vulnerability or a method of bringing out what was on a respondent's mind altogether. Black humour can constitute a cultural code and a "survival strategy" in everyday life in the ICU where many different human destinies are encountered.

identify tendencies, main features and a lot of detail. A number of characteristic and meaningful topics stood out quite clearly. The process of data creation and the data analysis therefore proceeded in parallel throughout the empirical work, even though the final analysis was undertaken subsequent to the completion of the data collection (145-147, 153).

The analysis involved adding elements to the data. Broader connections of meaning found in the material were brought forward and new perspectives were revealed. The analysis of qualitative material has been undertaken as a dialectical process between myself as a researcher and the material itself in order to reveal and understand its meanings and perspectives (145-147). This dialectical process functioned, as described by the hermeneutic circle, as an alternation between focusing on the whole and the constituent parts in order to develop new insights (146, 151).

Analysis of qualitative data offers many alternative and valid interpretations. The hermeneutic form of understanding that lies at the basis of this study allows for interpretative diversity as long as the researcher makes clear to the reader how he/she has reached the various interpretations (145-147, 153). The research issues and the theoretical perspectives of this study are associated with notions of priorities and ethics linked to limitation of treatment in intensive care. This approach has characterised the analysis and thereby served to elucidate other and more in-depth aspects of the daily prioritisations and considerations made in ICUs in the context of decisions to forgo treatment other than those that have emerged in related studies of the discontinuation of intensive care.

The research issues and the perspectives of the study have governed what I *have seen* as well as what I *have not seen* during the creation and the analysis of the data, and it is essential to remain aware of this in the interpretation and presentation of the data. In this context it should be pointed out that my supervisors have read and analysed most of the material and that we have arrived at identical conclusions independent of each other.

4.8.1 Interpretative levels in the analytical work

Kvale and Fangen describe how the analysis of qualitative material moves through several interpretative levels or interpretative contexts. This movement through the various interpretative levels formed the basis for my work with the analysis of the observations and interview data.

Fangen refers to these levels as *first-, second- and third-degree interpretations* (145). *First-degree interpretation* involves rendering the perspective of the persons studied to the largest possible extent (the practical perspective), the *emic* perspective. In this context this comprises the perspective of the ICU physicians and nurses, but nevertheless seen through my eyes and reflected through my perceptions. I claim that my familiarity with their everyday life had a major impact on the way in which I described and perceived their perspective. Fangen likewise states that background and preconceptions may form key contributions to a description of the emic perspective. The *second-degree interpretation* served to raise the interpretative level, and included additional perspectives. Critical questions were asked, reflections based on personal experience were added, and a quest for deeper meaning was undertaken in the observed material. At this level, the queries to the material were characterised by theoretical perspectives but without a deeper theoretical interpretation. In field research, this is referred to as the ethical perspective, in which the perspectives of research and the researcher are allowed to affect the interpretation. Third-degree interpretation comprised the theoretical analysis in which the findings was analysed and challenged in light of theory, principles and values relevant for patient priorities (ibid.).

Kvale describes three interpretative contexts: 1) *self-understanding*, 2) *critical common-sense understanding*, and 3) *theoretical understanding*. *Self-understanding* seeks to a large extent to render the perspective of the interviewees. C*ritical common-sense understanding* goes beyond the self-understanding of the interviewees but stays within the limits of what could be perceived as a sensible interpretation. This stage comprised, for example, searching for the content of interviews and raising critical questions regarding the texts, including theoretical reflections, but without any deeper theoretical analysis. In the *theoretically interpretative context* the theoretical framework of the study is used for interpreting meaning units in the main topics and the subtopics. Findings, interpretations and theories can be challenged, and new theories can be generated (147, p. 146-147).

The interpretative levels presented by Fangen and Kvale have a lot in common (145-147). They move from an interpretative context that closely resembles practical experience, which is as close as possible to the perceptions of the respondents, upwards to higher analytical levels. Kvale and Fangen both describe how the interpretative contexts can be further differentiated, and how the researcher to a larger or lesser extent can move across these interpretative levels in the analysis of a body of material, as was done during the analysis of data from this study (ibid.).

4.8.2 Analysis of data through gradual meaning condensation

In the analysis of data I moved through the interpretative levels described in the previous chapter, and I have sought inspiration in condensation of meaning as a method of analysis (146, 147, 153). According to Kvale, the method seeks to condense the expressed meaning, so that more basic structures gradually appear in the studied phenomena (147, p. 128). The method is inspired by phenomenology and the phenomenologist Giorgi, but its application is not restricted to phenomenological methods and is also used in other qualitative studies (147). Malterud gives a modified description of this form of analysis, and my approach coincides to a large extent with her description (153).

4.8.2.1 Gradual condensation of meaning – Stage I

Condensation of meaning as a method of analysis is described as a process comprising several stages (147, 153). The first stage involves a naïve reading of the entire material with the purpose of capturing the content of the material in as sensitive and unbiased manner as possible (153). In this study, this “naïve reading” took place during and after the process of data creation. The meaningful topics began to crystallise while I was still at the empirical stage, writing and reading observation notes, listening to and transcribing interviews. When all the data had been collected and all the interviews had been transcribed, I undertook another complete read-through. At this stage new shades of meaning emerged and some key impressions from the material were confirmed.

Phenomenological approaches were most evident during the early stages of the study. Here I encountered the material in a manner that was more open to first impressions and more non-reflexive than at the later stages of the analytical process. The analysis consisted of viewing the content of the material as closely as possible in light of the specific experiences of the respondents and my perception of their reality. This analysis took place within the interpretative context described by Kvale as self-understanding and by Fangen as first-degree interpretation (145-147).

4.8.2.2 Stage II

Stage II consisted of a further search for and identification of the meaning units in the material. Gradually, through a dialogue with the material and queries to its content, the meaningful topics emerged. I searched for the topics that carried essential meaning in light of the research issues that constituted the framework around the main structures I sought in the material. I have chosen to refer to the general topics that reflect the meaning of the study as *main topics*, and meaning units that describe, contextualise and specify the general ones as *subtopics*.

Malterud recommends that meaning units are coded (153). Coding can be undertaken in several ways, with the aid of structured computer applications for qualitative analysis or manually. In this study I coded manually using colour codes. The initial coding was undertaken by adding words and expressions in the margin to identify dilemmas and various topics. Areas that had a common topic were given the same colour. After having worked back and forth through the material I succeeded in condensing the meaning of the text sequences that identified topics that served as carriers of meaning in a manner that condensed the text while retaining the meaningful content. These condensed text elements were validated against the original text (ibid.).

The text box below shows how the interview text has been condensed and structured into main topics and subtopics.

Marginalising of medical and nursing care (main topic)	
Perceived resource scarcity (subtopic)	**Consequences of resource scarcity** (subtopics)
... make a real extra effort, we rarely de-prioritise the normal things, we work really hard to do absolutely everything. But what suffers most (...) is the communication with the patient because it takes time (...) I often think of how that's neglected. (...) all these things we need to do, medical things. We do that, and then these other things suffer, of course. And that's the way it is when we are given extra jobs. Because other things are pushed aside. And the mobilisation, that we have a lot of and that's important, that's the importance	Consequences for "softer care" Consequences for "non-measurable care" Consequences for relational care, like communication and presence

of getting the patient up, mobilised, putting them in a chair, (...) it sounds so simple and easy, but it's a big job, for the patient and for us. And it takes time. And all these things that cannot be measured directly. Like you can probably measure the time that a particular procedure will take, but these things like mobilisation and stuff, they take time (...) Sometimes I think that we try, we make an effort (...) and go to great lengths. So if we had been more strict, and then in a way, how can I say it, protected ourselves more, then we wouldn't have done all the things we do (interview, ICU nurse).	Consequences for mobilisation Measurable medical procedures have priority Nurses go out of their way "to do everything"

The following text box shows an excerpt from an observation on a day when resources most definitely had been put on the agenda. This condensed text shows how I added some reflections to the field notes on the consequences of resource scarcity at several interpretative levels.

Marginalising of medical and nursing care (main topic)	
Perceived resource scarcity	Consequences of resource scarcity (subtopic)
The resource situation on the unit was obviously a topic this day. Among the patients, nobody was a clear candidate for transfer. A major problem was that the current situation implies that no personnel or ICU beds are available for emergencies (...) Those who are there are taken care of, but if [new] patients are reported in, problems occur (...) The situation on the unit to a larger or lesser extent has a bearing on the possibility for providing intensive care with regard to late admission as well as early discharge. It is thus a problem of just priorities. How just it turns out to be depends on the situation in the unit. The thing is that those of us who are on the unit do not have to relate to this unfairness because we don't see the patients who are in the queue. However, the patient who could not be admitted last night but came this morning would in fact really have needed to be admitted far earlier. The physicians probably perceive this as more pressing than the nurses since they visit the patients and know how difficult it can be to "keep them afloat" on the ward until a bed becomes vacant. They feel a responsibility to transfer them [to the ICU] as early as possible if they see that this is required. At least, they [the patients] should receive satisfactory monitoring, to prevent them from collapsing without anyone really paying sufficient attention (Observation notes).	Contributes to late arrival and early transfer Raises the threshold for monitoring Reduces opportunities for preparedness Gives rise to arbitrary priorities Counteracts just prioritisation Prioritises those who already are in the unit Appears to be perceived as more pressing for the physicians, who are medically responsible for patients who need monitoring and possibly intensive care

4.8.2.3 Stage III

The next stage of the analysis consisted of continuing to query and remain “in dialogue” with the material, to make the meaning and its nuances emerge as increasingly clear, until the end product was satiated and no further elements appeared (146, 147, 153). This part of the interpretative efforts was to a large extent placed within the interpretative context of *critical common-sense understanding* and *second-degree interpretation*. However, the process at this level also comprised certain elements of the theoretically interpretative context and third-degree interpretation (145-147). The theoretical basis determined, for example, *what* the queries sought to clarify and *what kind of dialogue* I should maintain with the material in order to identify deeper levels of content, recognise contradictions, and ask questions that challenged the material.

4.8.2.4 Stage IV

The final stage of the analysis consisted of approaching the findings in light of the theoretical framework of the study and existing research. The findings and the research questions that the findings had generated were analysed and interpreted in the light of aspects including regulations for the prioritisation of Norwegian health services, health legislation and guidelines (6, 94-96). I questioned how the principles and values that applied to priorities were applicable to clinicians who work bedside. Furthermore, notions of fairness and notions of the provision of care provided key perspectives, in combination with research and literature on limiting treatment and on prioritisations used as the study’s’ theoretical basis enlightened in the first and second chapter in this summary. .

4.9 Considerations of research ethics

Undertaking research on an ICU is a particularly challenging task. Most patients on the ICU are very ill and vulnerable people who balance on a thin line between life and death. For this specific reason, research on ICUs requires special considerations and assessments of research ethics (176-178). This also applies when health workers act as respondents, as was the case in this study.

Informed consent functions as the most important requirement defined by research ethics with regard to the protection of individuals (7, 163, 179). To protect the research subjects against offensive and unfortunate research, a number of generally valid principles of research ethics and statutory regulations have been enacted (ibid.) The Helsinki Declaration was established in 1964 by the World Medical Association (WMA) against the background of the Nuremberg trials in 1947. The Helsinki Declaration has gone through several revisions, the latest one in 2008, with the goal of providing increasingly better protection to individuals against research that does not have their best interest in mind (7, 180). More recently, a European Union directive has been enacted with the purpose of regulating clinical medical research and enforcing a common EU research policy (181, 182). Studies have revealed that practices for obtaining informed consent, as well as for approval by committees for clinical research in ICUs, vary considerably (183-185). Requests for guidelines for research related to ICU medicine have been made, and a need for more pronounced and consistent research practices has been revealed (185). Attention has been directed at studies that have failed to adhere to considerations of research ethics with regard to informed consent, protection of the patients' integrity as research subjects and/or risk assessments for the inclusion of patients in clinical studies[55] (184). On the other hand, there have also been concerns that the highly rigid and strict demands related to consent established by the EU directive may represent an obstacle to research in ICUs. Among other things, it will be impossible to comply with the absolute demand for consent, thus establishing a barrier to valuable research and subsequent improvements in the treatment provided (178, 182).

---

[55] This refers to studies for testing various forms of therapies.

4.9.1 Norwegian Social Science Data Services (NSD) and the Regional Committee for Medical and Health Research Ethics (REK)

As a rule, research that involves information that could allow for identification of individuals, is subject to a licence and must be reported to the Norwegian Social Science Data Services (NSD) (163). This study had a duty to notify NSD, and the procedures for notification were complied with.

The study comprises demographic data of the health workers who acted as respondents, as well as sensitive material in the form of audio files, observation notes and transcribed interviews. Large amounts of sensitive material are typical for qualitative studies, and this requires special caution (7, 147). This study contains no links between names, audio files and the textual material. Names are only found on the return slips from the consent form. Audio files from the interviews were stored on a local hard drive, and the consent forms were stored in a locked and fireproof safe. The interviews were coded with markings for person, unit and profession.

Norwegian regulations require regional committees of research ethics (REK) to approve medical and nursing research (7, 163)[56]. For this study, approval by REK was applied for because it involved participant observation of health personnel in ICUs, and this implied that the patients became indirectly involved parties with no real right to refuse. REK approved the study with some comments that were taken into account.

4.9.1.1 REK's comments

REK was of the opinion that the informed consent of the health workers who acted as respondents was acceptably catered for by way of the written and oral information provided to them about the project and their voluntary informed consent.

The feedback from REK reported differences of opinion in the committee with regard to the requirement for consent by next of kin as the patients' guardians . A minority in the

---

[56] Amendments to research legislation enacted in 2009 require REK to approve all studies. All functions that previously were assigned to NSD and the former Directorate of Social Affairs and Health have accordingly been transferred to the Regional Committees for Medical and Health Research Ethics, with a view to better ensure compliance with research regulations and avoid the need to apply to several authorities for approval. This study has been undertaken under the regulations of the previous scheme.

committee claimed that the patients should be regarded as real research subjects since participant observation of health personnel in clinical practice constituted part of the methodology. This minority therefore claimed that the next of kin should provide a presumed written consent on behalf of the patient. The majority of REK, on the other hand, were in favour of the provision of written and oral information to the next of kin, with an opportunity to refuse participation on behalf of their relatives. The viewpoints of the majority formed the basis for the committee's conclusion.

On the basis of the recommendations made by REK, the next of kin received written and oral information on the research project, on the duty of confidentiality pursuant to Section 21 of the Health Personnel Act, and their right to make reservations on behalf of their relatives. Information with a picture of the researcher was posted on the wall in the lounge used by the next of kin, in the unit's corridor and outside the entrance to the unit, making the researcher recognisable among the other staff members (attachment 2). During the observations I acted with special caution in relation to the patients and the next of kin. I continuously focused on not violating personal integrity. The protection of the private space of the patients and the next of kin was my most prominent concern in terms of research ethics, and far more important than my presence in various situations and the research results.

4.9.2 Exemption from the duty of confidentiality

In studies where the researcher obtains information subject to the duty of confidentiality concerning possible identifiable individuals, and where these persons are unable to provide consent, an application for exemption from the duty of confidentiality must be submitted to the Directorate of Health (ShDir) (163)[57]. The feedback provided by NSD indicated the need to apply to the Directorate of Health for exemption from the duty of confidentiality, and this application was duly submitted.

On the initial application, the directorate declined to grant exemption from the duty of confidentiality for this study, and claimed that informed consent should be obtained from the next of kin as the patient's guardian instead of this exemption. The decision was appealed, with the argument that *consenting health workers* constituted the sample of respondents, not

---

[57] Directorate of Health is the former Directory of Health and Social Affairs.

the patients obtaining and that informed consent from the next of kin would constitute a major strain on them in a crisis situation, represented by having a relative admitted to an ICU (63). A requirement for consent could also give the erroneous impression that their relatives were part of a study of withdrawal of treatment. Furthermore, the appeal was grounded in prevailing legislation and guidelines for research ethics and pointed out that an absolute demand for consent can be waived if the research implies little or no risk and will benefit individual patients and /-or the group of patients and society as a whole[58]. The study was also reviewed by experts in the National Committees for Medical and Health Research Ethics (NEM), which concluded that the study adhered to considerations of research ethics with regard to the patients and their next of kin. NEM claimed that the approval of the study established a precedent for the admission of research to clinical practice settings that are usually closed. Therefore, arguments were presented on the basis of the purpose of the study, i.e. to obtain knowledge of circumstances pertaining to prioritisations and decisions to limit treatment, which often take place in closed processes. Further knowledge on clinical prioritisations are of significance with regard to Norwegian prioritisation policies (5, 6, 8, 119, 133, 185, 187). Openness in processes of prioritisation will be of key importance for the highly vulnerable group of ICU patients. This is also a societal issue since a considerable proportion of the resources allocated to the specialised health services is devoted to ICU treatment and nursing care. This study entailed no risk for the patients on the ICU, and the integrity of the patients was well protected during the fieldwork.

On the basis of the appeal, the directorate granted exemption from the duty of confidentiality, but pointed out that later observations would require the collection of informed consent from the next of kin. This whole process raises a number of important and fundamental questions regarding participant observation of health personnel in hospital wards where the patients are unable to provide informed consent. If the requirement for consent remains absolute even for indirectly involved parties, this requirement will represent an obstacle to research that could be of great benefit to patients, groups of patients and society as a whole (188). A very rigid interpretation of the requirement for consent could also generate situations where the patients and their relatives are subjected to unnecessary strain and misunderstandings regarding their role in the project.

---

[58] (Health Personnel Act, Sections 21 and 29; The Declaration of Helsinki 1964 / 2008, Section 24)

4.9.3 Other considerations of research ethics

A dilemma that was not pointed out by REK, NSD or ShDir, but that I personally experienced as an ethical problem, was represented by all those staff members who were not direct objects for my research and thereby had not provided consent. These persons were nevertheless indirectly involved parties by being part of the ICU context, and thereby contributed to the culture and the atmosphere. In field studies, an understanding and experience of the context constitute an essential component (145, 168). In some ways, it therefore felt rather uncomfortable that not all staff members had provided written informed consent. On the other hand, this would have proven practically unfeasible in the complicated context of the ICUs with their large number of employees. The nursing services alone accounted for 60 to 100 employees on each of the three units.

Whom to obtain consent from is an issue that is particular to field-based research, but has not been widely discussed in research involving observational studies on ICUs (166, 134, 135, 169). Consent in field studies is a topic among some well-established ethnographers, including the elucidation of questions concerning whom to obtain consent from and in what manner. Several researchers argue in favour of process-oriented consent based on the dynamic nature of the fieldwork (166, 170, 171). I approached this problem of consent by supplying appropriate and sufficient information to all staff members, including an opportunity to make objections to my presence. I received no negative reactions, and chose to believe that I had fulfilled their need for information in an appropriate manner in terms of research ethics.

Irrespective of the regulations and restrictions imposed on research, at the end of the day the moral conscience and ethical discernment of the researcher will constitute the decisive factor in clinical research. Without a genuine sense of responsibility for the best interest of the respondents as a fundamental basis for research, it would be possible to cause considerable harm. In his article Koski quotes Henry Beecher’s famous article from 1966 (179) and make a wide-ranging claim in favour of the unquestioned ethical responsibility of the researcher:

> “ the only truly effective way of protecting for the safety and wellbeing of human subjects in research, namely a committed and caring investigator with keen intelligence and good judgement, unselfish enough to put the interest of the subject ahead of interest of science” (188, P. 119).

5 PRESENTATION OF FINDINGS

This chapter provides a description of findings on the basis of the three articles that constitute the dissertation. By way of an introduction to this chapter I will emphasise that the results are based on experiences and descriptions provided by clinicians who encounter extremely complex and difficult decisions on a daily basis, for which a right or wrong solution cannot be found in a “crystal ball”.

It is essential to emphasise that situations involving prioritisation problems served as the main basis for the field observations and the interviews. The results thereby illustrate the issues at stake in some of the most complex prioritisation decisions in the ICU practice that involve limitation of intensive care treatment.

5.1 Article I: Professional Challenges of Bedside Rationing in Intensive Care

Nursing Ethics 2008 15; 715-726

The purpose of this article was to elucidate in what ways national prioritisation criteria, the severity of the illness and the benefits of treatment in a reasonable relation to the costs involved were used as prioritisation criteria for ICU treatment and ICU nursing. Furthermore, the article focused on how resource constraints entailed consequences for medical treatment and nursing provided to ICU patients.[59] The article sought to provide answers to research issues a) and b).

Findings presented in this article reveal that the strain on available health care resources to an increasing extent was perceived as an ethical problem by physicians and nurses in ICUs. The

---

[59] Unfortunately, in the printed version the description of the purpose of the article has been deleted from the introduction after final proofreading. The purpose is clearly described in the abstract and should have been formulated in the introductory section as follows: *“The aim of this paper was to explore if and how limitation of resources influences nursing care and medical treatment in bedside intensive care (ICU) and whether the clinical decisions are in line with the national guidelines for priority setting in health care”*

results further show that resource allocations in ICU practice entailed consequences with regard to a fair distribution of ICU resources.

Most respondents experienced regularly a dilemma in the provision of extensive aggressive ICU treatment to patients where this no longer was meaningful. Most respondents provided several, but relatively concurrent, explanations of why ICU treatment in some cases was extended considerably; these are detailed in the article II.

The national prioritisation criteria were seldom explicitly discussed in the ongoing treatment of patients with reference to the guidelines (6, 94). The seriousness of the illness served as the basis for ICU treatment to a decisive extent, in the context of an increasing imperative to provide treatment. Assessments of benefits were associated with meaningful treatment, often described in bio-medical parameters, short-term benefits and survival per se, but to some extent also in terms of quality of life. The more value-oriented aspects of benefits of treatment did not appear to be prominent in the prioritisation of treatment provided to patients and was mostly put on the agenda fairly late in the treatment process, when it had become evident that treatment was futile and the patient was dying. In general, during the interviews more emphasis was placed on the importance of provision of treatment which is meaningful (beneficial) with regard to values and quality of life as prioritisation criteria when facing complicated treatment decisions than what was reflected in the discussions during the morning meetings, pre-visits and actual practices.

An aspect that is not clearly reflected in the article, but was revealed in the field observations, is that on occasions when value issues pertaining to treatment were brought to the fore in discussions various perspectives regarding treatment would emerge.

The costs of treatment and open discussions of resource use were almost “non-topics”. The respondents only to a limited extent related to this issue. Some respondents, physicians and nurses cautiously questioned the use of resources and the responsibility for careful management of public health care resources, but without letting this entail any consequences for their own assessments and decisions.

The findings further reveal that the respondents perceived resource constraints as constituting a growing dilemma and conflict of care where physicians and nurses were forced to ration less acute medical and nursing care. Rationing and a concomitant marginalisation of relational care constituted a prominent consequence of the resource scarcity.

The results reveal that physicians and nurses sometimes expressed demoralisation in relation to their own work. Some respondents described feelings of powerlessness and disheartenment in the face of a development that they to some extent felt to be “pulling them along”, without giving voice to any co-responsibility for this development.

5. 2 Article II: Value choices and considerations when limiting intensive care treatment: a qualitative study

(Acta Anaesthesiologica Scandinavia 2009; 53: 10-17)

This Article sets out to answer research question c) and describe some of the value choices and considerations that had a bearing on decision-making processes and decisions to limit ICU treatment. The article is written in light of findings that show that the provision of too much, too prolonged and too aggressive ICU treatment for patients for whom this no longer appeared to be the right solution represented a growing challenge for physicians and nurses at the ICU.

Findings reveal that *aspects of the basis for decision-making* had an impact on decisions to limit ICU treatment. These decisions were most often taken under uncertain circumstances, and the consequences of refusing treatment most often would involve the death of the patient. Rejecting a patient who ought to receive ICU treatment was considered to be professionally and ethically more questionable than provision of treatment in situations where such ought not to have been provided. Several respondents, physicians as well as nurses, described experiences where the patients had survived against all odds. This experience had given rise to a sense of never being able to feel completely certain.

The results further revealed that in addition, certain *aspects of the decision-maker(s)* had an impact on decisions to limit ICU treatment.

Several physicians perceived the limitation of ICU treatment as an emotionally difficult decision. Some recounted how they felt this to be a major strain. Others did not involve themselves as much.

Many respondents, ICU physicians in particular, but also a fair number of nurses, described how the pressure from the physician in charge of the “home-ward” that had assigned the patient to the ICU could often be intense and hard to endure. The severity of the situation and a strong imperative to provide treatment involved an expectation to “do everything possible”. Physicians who were not working on the ICU tended to have less knowledge of intensive care medicine and thereby interpret the patients situation “with other eyes”, causing them to have unrealistic expectations of its potential. ICU physicians and ICU nurses, rarely openly challenged the perspectives of the physicians from the home-wards in their care of patients.

The respondents and the physicians in particular, *ascribed concealed motives* to the physicians in the other departments for their insistence on provision of continued treatment, and for their neglect of discussing treatment that ought to have been questioned. In particular, these motives were said to include feelings of bad conscience and guilt associated with unexpected complications of surgery and / -or insufficient follow-up of patients. Some respondents modified this assertion by pointing out the major sense of responsibility that surgeons in particular may have felt by meeting the patient face to face prior to the operation, thereby giving rise to expectations of an operation that could cure or alleviate the patient’s afflictions.

A further motive which is only touched upon in the article, but which is found in the material, concerns issues pertaining to surgical statistics. Several respondents claimed that the surgeons’ reluctance to discuss the benefits of treatment was associated with their fear of causing a patient’s death as a consequence of an operation.

The results reveal that physicians and nurses, among themselves and as professionals, placed different emphasis on issues like age, responsibility for illness and social status, and in terms of how these were assessed in relation to the illness. Others respondents, on the other hand, emphasised how the life that had been lived was a narrative of a life, and nobody had the authority or the right to pass moral judgement. Some respondents nevertheless claimed that negative attitudes toward patients contribute to the emergence of unclear goals for treatment and less appropriate treatment.

Finally, the article touches upon issues concerning *the dynamics of the decision-making process*. These decision-making processes are dependent on the persons involved as well as the cultures in the units concerned. In particular, the attitudes of the ICU physicians with regard to discussion of problematic issues during the treatment process had a major impact on the decision-making processes. Furthermore, the findings revealed variations in the routines used by the home-wards for follow-up of the patients while they were assigned to the ICU.
The findings revealed shifting power structures, in particular between certain surgical positions and ICU physicians, and these were equally dependent on the persons involved, for ICU physicians and surgeons in equal measure.

The nurses’ role in decision-making processes regarding limitation of treatment varied considerably, from significant involvement to total neglect. During the interviews most physicians in the sample nevertheless indicated the attitude that the nurses could provide important perspectives. The field observations showed that the nurses were included or made themselves available as decision-making actors to a varying extent.

The main impression from the field observations, which was corroborated by several physicians and nurses during the interviews, was that nurses were quicker to consider withdrawal of treatment. This was described as annoying as well as a sore point and a lack of understanding of the complicated nature of these decisions. On the other hand, the findings revealed that nurses were fully aware of the complexities of prioritisation decisions and demonstrated a great deal of respect to the physicians’ decisions and their need to defer the decision

The role and preferences of the significant others on behalf of the patients wishes were said to be taken into account by most of the respondents. Nevertheless, actual practices showed that the impact of these viewpoints on decisions of whether or not to limit treatment varied, and that other considerations and value choices were perceived as stronger.

5.3 Article III: The principle of justice in patient priorities in the intensive care unit: the role of significant others

(Accepted for publication in Journal of Medical Ethics, final proofread June 17th)

This Article also claims to answer perspectives of value choices and considerations influencing patient priorities. The Article focuses on findings from the study showing that the presence of significant others who were involved in the patients' situation had an impact on the provision of appropriate treatment. Findings described in this article are mainly based on the interviews since the researcher chose not to be present in conversations with the next of kin or on the patients' ward when the patients received visits from their families.

First of all this article shed light on the issue that having a family is a value in its own. It points out that some patients are extremely lonely. They do not have anyone to share their struggles with and to fight for them. They go through critical illness alone and they die alone, without anyone close that care particularly for them.

The interviews from physicians and nurses revealed further that the availability of resources to a large extent determined the amount of attention that could be devoted to the significant others. In this context, relatives who were assertive, resourceful and made their presence felt were given most attention. This resulted in better follow-up of the next of kin, but according to, in particular a number of nurses, also to more attentive treatment of the patients.

Furthermore, the findings revealed that significant others, who for various reasons were resourceful, for example by being highly educated and /-or having a high social standing, were given more time and more thorough information, and the treatment provided to the patient also improved, for example in the form of more numerous and advanced therapies. Intriguing and "unusual" diagnoses in their own right spurred an interest in the patient and the next of kin. This gave rise to a willingness to make a major treatment effort, even in cases where it was claimed that further aggressive ICU treatment was of little value to the patient since he or she was dying. The interviews also illustrate the opposite situation, where the patient's social status and "unhealthy lifestyle" in combination with very reticent significant others resulted in unclear treatment and vaguely defined treatment goals, leading to less purposeful treatment. The nurses claimed that the physicians were responsible for the differences in the treatment provided in cases where a patient or his/her family aroused special interest. The physicians did not give similar descriptions of the nurses. A number of the physicians in the sample reject the notion that the identity or presence of significant others had an impact on the nature of the treatment provided.

Physicians in particular described that next of kin who made demands regarding treatment were often accommodated in order to avoid complaints, media attention and dissatisfaction. On these occasions, patients could be provided with treatment beyond what was deemed as appropriate by medical health personnel. At one occasion a physician on a morning meeting explicitly pointed out that pressure raised from particular significant others contributed to injustice towards other patients.

Occasionally the significant others exerted pressure for the treatment to be limited, and this could have an impact in several ways. This could cause limitation of treatment to be postponed since the arguments of the next of kin were called into question, and it could mean that the next of kin were listened to in the sense that the issue of limiting the treatment was put on the agenda.

In situations where the next of kin required more time, this request was mainly complied with. Although these requirements had to be within the limits of what the physician who was medically responsible deemed to be defensible out of concern for the patient and in terms of professional ethics. Nurses and physicians both were of the opinion that giving significant others time was morally right. During the field observation no situations occurred where significant others did not get enough time to come to terms with decisions of limiting treatment of their close ones. Several occasions took place where the withdrawal of treatment was postponed to wait for everyone to be prepared.

In situations where patients had no close relatives, it was described as “simpler” to withdraw a treatment that from a medical point of view was deemed to offer a poor prognosis. In such situations it was also more acceptable to terminate the treatment of the patient on a ward with other patients.

The discussion in the article concludes that several aspects of the role of next of kin have an impact on proper treatment of patients.

6 CRITICAL REVIEW OF THE METHODOLOGY

In the study I have chosen to use the terms reliability, validity and generalisability in order to undertake a critical review of the methodological approach. These concepts are controversial in qualitative research and are rejected by some as restrictive, positivist notions that erect barriers to liberating qualitative research (147, p- 159). However, these concepts are well known for evaluation of research and I perceived them as feasible in criticising this research. In my Master thesis, I used these concepts within equivalent methodology and found them very constructive (190). Malterud, Kvale and Fangen, who have inspired the methodological approach to this study, use these concepts, and this has strengthened my choice (146, 147, 153). It is, however, in deliberation of reliability and validity essential to recognise that qualitative methodologies represent a different truth value than their quantitative counterparts, in particular causal approaches and experimental research (145-147. 153, 157, 158).

6.1 Reliability of the study

The reliability of a research result refers to the dependability, accuracy and quality of the instrument. In qualitative research, the researcher constitutes the instrument (145-147, 153). In this work involving observations and interviews I have played an active role as instrument, using myself as a human being and as a professional in the processes of data creation. To assess the reliability of a specific piece of research it is necessary to be able to monitor the research process (ibid.). I will present the implementation of the study in some detail to allow for an assessment of the strengths and weaknesses of the instrument.

6.1.1 Reflections on the researcher as an instrument in participant observation

A strength of the observations was found in the implementation of “pilot observations” to establish a role as a researcher, generate trust, and correct and focus the observations. A weakness during the observations consisted of the different degree to which I was able to enter into the daily lives of physicians and nurses. Another weakness was that the observations only provided a fragmented impression of the complicated processes involved in prioritisations and withdrawal of treatment in the daily ICU context. It was impossible to capture all details. Often, several processes ran in parallel, i.g. rounds related to actual situations that generated priority challenges found place at the same time, and choices about where to attend had to be made. It also happened that I was hindered from following up situations closely all the way due to my duty of work. These aspects may have had an impact on the issues that were observed, resulting in data-creation bias.

Using the guide helped to focus the observations. I claim that this had a major positive influence because there was an imminent risk of losing the focus in this complicated context. However, a structured observation guide, in combination with relatively clearly defined research issues, may have constituted a weakness since it had an effect on what I was looking for, what I actually saw – and did not see.

Proper observation notes have a bearing on the reliability of the study (145, 168). I chose to write the observation notes following the completion of each observation. The notes were therefore written with some distance to the experience itself, and my preconceptions may have coloured the notes after having time to reflect on different issues, thereby leading to bias. On the other hand, the distance may have been constructive to be aware of preconceptions. Nevertheless, the distant in time between writing notes and the experience paled the immediate impressions.

Another factor that could have an impact, with regard to the observations in particular, was the fact that as an observer on these ICUs I also encountered some dramatic human destinies that affected my life and myself. The staff members could discuss these matters informally and sometimes even in formalised debriefings. I did not have this opportunity, and in specific situations this may have made an impact on how my emotions could colour not only the observations but also the interviews. From time to time, during these observation months I felt emotionally very moved by what I witnessed.

6.1.2 Reflections on the researcher as an instrument for interviews

The interviews were implemented with the aid of an interview guide containing open but semi-structured questions reflecting the research issues of the study. With regard to the reliability of interview-based studies, Kvale emphasise the importance of clear, open and non-biased interview questions (146, 147). In order to ensure appropriate and open-ended questions that could reflect the research focus of the study, the interview guide was tested in advance by a researcher with experience from qualitative research, and it was reviewed by the supervisors. Two pilot interviews were undertaken, providing an opportunity for corrections. It should nevertheless be noted that such relatively structured questions may inhibit openness. This factor could also to some extent have caused the respondents to emphasise issues that were not very relevant in their own decisions involving prioritisations, but to answer the questions anyway.

My preconceptions, generated by my experience as an ICU nurse and my consequent familiarity with the ICU context, have been described in Chapter 3. The influence stemming from my preconceptions with regard to my role as an instrument in the interview context should be taken into account. I have systematically attempted to recognise these preconceptions and prejudices as recommended by Kvale, Fangen and Malterud, but preconceptions will invariably comprise unknown elements that are difficult to neutralise in any kind of research effort (145, 146, 153).

6.2 Validity of the study

Validity refers to the truthfulness and credibility of the research results. Kvale describes validation in seven stages that reflect high-quality research work throughout the research process – from the initial, theoretical assumptions, via the formulation of a research focus and questions to the final stage involving reporting of findings. According to Kvale validation equals control. The researcher is encouraged to act as “the devil’s advocate” in relation to his or her own work throughout the research process and to constantly question the *what, why* and *how* of the research effort (146, 147).

6.2.1 Conceptual validity

One of the weakest aspects of this study is found in its wide scope and the somewhat unspecific nature of its concepts referring to the limitation of treatment and prioritisation in relation to the respondents. Thereby, this serves to weaken the conceptual validity of the study (146, 147, 153). One may therefore with some justification inquire whether I have investigated the issues that I set out to study. The study has a wide scope and sways somewhat between the limitation of treatment as a phenomenon and problems involved in prioritisations as another. A more specific delimitation would probably have been beneficial to the research effort, but I claim that the wide scope of the study has served to elucidate intriguing and important perspectives pertaining to the real complexities of prioritisations. In the conversations with ICU physicians and nurses that formed part of the preparations for the study, as well as in the data-creation process, it was made clear that decisions to forgo treatment involved some of the most complicated priority considerations in the ICU context, and this perspective was therefore clearly called for.

6.2.2 Weaknesses of the sample

Another weakness regarding the validity of the study can be detected in the sample, which includes only ICU physicians and nurses. With regard to decisions that involve several groups of professionals in addition to the ICU clinicians, i.e. surgeons, specialists in internal medicine etc., this severely limits the conclusions that can be drawn from the findings. The sample provides only views from its own perspective, while the findings reveal that the constituents of the sample also make a number of assumptions about the motives of their co-decision-makers. The co-decision-makers have no opportunity to elaborate, correct, emphasise or de-emphasise these assumptions, and as key actors in the decision-making processes with regard to the patients, their voice is not heard.

6.2.3 Reflections on the validity of data collection and analysis

The choice of method for the collection of data will have an impact on validity (153). For this study, triangulation of methods for data creation was chosen. This strengthens the validity of the study by having observations that provided a descriptive account of the actual practices, combined with the in-depth knowledge generated by the interviews (145, 154). In spite of some weaknesses, the triangulation revealed content and contradictions that could not have been detected without this combination of methods.

A further weakness of the validity is found in the utilisation of findings from both methods of data collection. The interview material is larger in volume than the observation material. The observation material to a larger extent reflects fragments of reality, while the interview material reflects the voice of the respondent. On the other hand, the interviews would not have been the same without the observations, which form a significant contextual fundament. I also have been very cautious in my direct use of observation material since observation in the ICU context is a sensitive issue, but the observations are at the base of the interpretation of findings. The observations have not been described as transparently, and are thereby more difficult to validate for outsiders, and this has weakened the validity of these data as well as the combination of methods.

Given the amount of data material generated by this study, the choice of a representative selection for presentation purposes constituted a challenge (146). The risk of bias is present. My more extensive reference to text elements from the interviews constitutes a further risk of bias in the presentation of findings. In making the selection I have emphasised the use of textual elements that are clear, credible, descriptive and expressive with regard to their inherent meaning. In addition, I have emphasised selection of texts that can provide necessary nuances to the findings.

The methods used for analysis and interpretation will likewise have an impact on the validity of the study. An essential element of the criticism directed against qualitative methodologies in general refers to the impossibility of imposing traditional requirements to objectivity, i.e. that different interpreters may discover different meanings (146, 147). To ensure an interpretation that is as unequivocal as possible given the perspectives of the study, one of the supervisors has read through the entire material and the other supervisor has reviewed parts of it. Our experience was that we all detected many of the same topics inherent in the material. We may therefore claim that the findings of the study represent interpretations that give rise to a common understanding within the perspectives of the study.

6.2.4 Communicative validity

Kvale and Fangen emphasise the necessity of communicative validity when the research results are made available to the research community and the public (145.147). This study has resulted in three scientific articles (1-3). These have been accepted by international journals, ensuring wide dissemination of the findings. Publication does not exempt the researcher from the particular responsibility placed on him or her with regard to the integrity of research and the integrity of publication (7). I claim to have upheld this integrity. Responses to the articles have emphasised their discussion of important and relevant issues. The results have been discussed in the professional community, and clinicians who work in the field of ICU medicine and ICU nursing have pointed out that these results have major relevance and reflect their daily situation.

6.3 Generalisation of the findings

Results from a qualitative study of this nature cannot be generalised in the same manner as those emerging from quantitative studies (145-147). The purpose of this study has not been to generate statistical generalisations on the basis of large populations from which more superficial impressions of assessments, ethical considerations and opinions will emerge. On the contrary, the purpose has been to gain knowledge of arguments, various ethical assessments and considerations, concealed and open values, relationships of power and emotions that could be at the base of prioritisations and value choices concerning patients undergoing intensive care. Qualitative investigations can contribute to exactly this kind of in-depth knowledge (83, 97).

Findings from the study can fundamentally only be applied to the three ICU units where I was present as an observer and to the experiences of those who have participated as respondents in the study. It is necessary to take a humble view of the value and transferability. On the basis of the response that the articles and the discussion of findings have elicited in the professional and ethical communities, it can be claimed that the study describes a number of fundamental issues that are relevant to the daily work and prioritisations made by ICU clinicians.

7 DISCUSSIONS OF FINDINGS

In this chapter I will discuss findings on the basis of the Articles and the data material as a whole. In comparison with the large data material assembled for the study some important nuances and reflections had to be left out, and hopefully these will be made more explicit in this discussion.

7.1 Introduction to discussion

> “When you have worked as many years as I have, you have been in touch with everything. Very difficult situations and very precious ones (….). So, even if you feel that the circumstances are gruesome and awful, it turns out right anyway. This is what makes you hang in there, that makes you live for this job and stay there year after year. You are doing something very good for people. It is not all bad, absolutely not. Yes, we have a lot to fight for. We have a professional community that is strong and conscious (…). We have a lot to be proud of even if there is much to work with.” (interview, intensive care nurse).

This quotation reflects the character of the clinicians I met in these ICUs: strong, knowledgeable, courageous, and with compassion for their patients and their work. They were fearless enough to provide me with insight into the dilemmas and problems that they faced in their daily care of patients.

By way of an introduction to these discussions it should be noted that this study reflects the experiences of ICU physicians and ICU nurses (clinicians). The roles and motives of other actors are seen through the experiences of the respondents.

One main finding in this study was that the clinicians experienced more often now than previous, to be in situations where some patients were given intensive care treatment that no longer was achieved as meaningful and was perceived as undignified and not in the patient’s best interest.

An additional finding was that providing sustained intensive care to patients for whom treatment appeared futile and undignified was a conflict of care and a dilemma for physicians as well as nurses. Terje Mesel has very recently in his doctoral thesis of physicians' moral self-conception illuminated that these types of conflicts could be morally very stressful (192).

A further finding was that clinicians had to struggle with scarcity of resources that marginalised important medical and nursing care. The respondents described powerful dilemmas that, when seen in a resource perspective, turned into a kind of contradiction – a dilemma and a paradox – consisting of a general scarcity of resources on the one hand, and in some cases application of the ICU's resources to treatment that no longer appeared meaningful on the other.

In addition the findings elucidated that bedside priorities with regard to limit intensive care treatment were influenced by several values, hidden and conscious and that these values in different ways seem to override each other and influenced medical and nursing assessments of the intensive care patient. These values also seem to inflict with how and to which extent that national priority criteria made a basis for priorities of limiting intensive care treatment.

In this discussion I will by an introduction shed light on how values are communicated among physicians and nurses. I will debate some aspects of the use of the national priority criteria as the clinicians' guidance for bedside priorities. In the further I argue that different values affected the decision-making processes of limiting treatment. Finally I will discuss some consequences of marginalising of medical and nursing care as a fundamental value in health care. In the very last part of the discussion I will give some visions for the "road ahead".

7.2 Communicating values

All respondents elucidated in the interviews a number of values, considerations and underlying motives that had a bearing on decisions to limit ICU treatment. On the other hand, the observations showed that value considerations were not very explicit in discussions among the professionals concerning the further treatment of these patients with very complex clinical pictures and dark prognosis. In light of the fact that values and motives were so clearly communicated between the clinicians and me as a researcher, it is however reasonable to assume that the values at stake were under-communicated, rather than overruled by the ICU clinicians. This issue is also elucidated by J. Jones and she claims that dilemmas perceived on the ICU are not all ethical dilemmas per se, rather under-communication of values and poor interdisciplinary work (193, p 163). The fact that underlying values and cultures, as well as personal and professional preferences, all contribute to govern bedside priorities has been established in several research contributions, from the ICU context as well as in other fields of medical practice (16, 33, 41, 42).

7.2.1 Differences in communicating values among professions

The observations shed light on an aspect which has not been made very explicit in the articles, namely that in everyday ICU practice there were differences between physicians and nurses with regard to how and when they communicated the values at stake within their respective groups, i.e. within the group of ICU physicians and within the group of nurses. The nurses maintained an open internal dialogue and were more explicit regarding value perspectives and matters related to suffering and a dignified end of life. These observations concur with international studies that perceive nurses as more open with regard to value issues than physicians (48, 73). This does not imply, however, that physicians do not experience moral dilemmas in their daily work. A recent study from Norway revealed that physicians regularly experience moral conflicts and distress in their work (194).

The openness of the nurses can probably be ascribed to several circumstances, including their form of work involving continuous presence at the bedside or value orientations incurred by their professional training, but possibly not least the fact that nurses do not have the final responsibility for decisions and thereby feel more “liberated” to have a value-laden and subjective opinion.

In their relationships to their colleagues, the physicians on the other hand, appeared more reticent in expressing the values at stake with regard to provision of treatment that they perceived to be not meaningful. On the basis of parts of the data I nevertheless assume that the physicians had access to “informal spaces”[60] where they could also discuss more value-oriented aspects of their medical decisions and priorities. In addition, the interaction between the physicians also depended on the persons involved; in the interviews several physicians described their fear of being criticized by their colleagues, in particular with regard to admission of patients that could represent a problem in carrying out the ICU treatment. Others described the interview as a positive situation, because they rarely had an opportunity to linger on difficult experiences, frustrations and emotions associated with the most complex decisions that they had to make in their daily ICU practice.

Research indicates that the ICU physicians fail to take sufficient note of the value aspects of end-of-life decisions, but focus on discussions of medical parameters (16, 195). This focus on “objective medicine” is corroborated by our study, although we have the impression that most ICU physicians, as professionals, took note of the value aspects of the treatment, but only to a limited extent made these value aspects into an explicit part of the basis for their decision-making or as a support for their decisions. In clinical ICU medicine there was not much room for raising issues of a more normative character with regard to the provision of treatment, especially in the early stages of the treatment process. In my opinion, some of the dilemmas perceived by ICU clinicians with regard to excessive treatment as well as to resource scarcity are caused by absence of value-oriented communication concerning difficult issues pertaining to provision of treatment. Such normative deliberations do not concur with the ideal of ‘objective medicine’.

7.2.1.1 When values are made subject to a normative discussion

Another important finding that has not been discussed in the any of the Articles was associated with one particular situation where the medical decisions were made subject to a more normative discussion and a number of values emerged. Various perspectives on the treatment were elucidated, widening the basis for decision-making. An elderly patient suffered from a “locked-in syndrome” and had an unpromising prognosis, but remained conscious and appeared to understand the situation. Several clinicians explicitly stated that withholding further treatment would be appropriate. Non-initiation of life support concurred

---

[60] The physicians had a separate lunchroom that they used for coffee and lunch breaks. This room was inaccessible for nurses as well as for me as a researcher. In the interviews, however, some physicians told me about these “free spaces”.

with the opinions of the next of kin of what was the patient's own wish. However, in the ensuing discussion it appeared that there was disagreement in a number of respects. Several professionals were uncertain of whether withholding treatment would be a correct decision, of who would be responsible for informing the patient (the next of kin or the physician), and of whether the patient should be informed at all. Important issues were raised and various perspectives were elucidated. This experience concurs with studies that reveal how bringing out ethical issues is beneficial, and that reviewing decisions in several perspectives will almost invariably constitute a gain in terms of making an appropriate choice, in consultation with and on behalf of the patients and the next of kin. This situation corroborates the assertion that an explicit discussion of values is essential for appropriate and correct treatment of patients (44, 193, 196, 197). Explicit discussion of values is also important with regard to making well-considered prioritisations out of concern for individual patients and other patients as well as appropriate use of ICU resources (198).

7.2.2 Repudiation of liability

As shown in Article II, and to some extent in Article III, a recurring feature of the respondents in our study was that the ICU clinicians often ascribed "illegitimate" motives to others and to physicians in the assigning department in particular, for wishing to continue treatment that no longer was meaningful or for having initiated treatment that could be questioned. Some nurses again had opinions of physicians making moral judgements of patients' negative lifestyles or caring for patients and next of kin in a more attentive way if they took special interest in the diagnosis or the patient. ICU physicians again assume that the nurses criticise them for being hesitant in decisions of limiting treatment. In this respect the respondents, nurses as well as physicians, engaged in a relatively systematic repudiation of liability for matters that they perceived as being the most difficult to handle in their daily practices. The consequences of this repudiation are not discussed in the Articles. However, in my opinion, this repudiation of liability contributed to making the prioritisations more difficult since some of the factors that motivated and influenced treatment decisions were hidden and rarely discussed openly, beyond proposals for new medical interventions and medical reasoning. In this manner, the real values at stake were concealed by involved parts.

7.3 National priority criteria as a basis for decision-making

Article I sheds light on in what ways and to what extent ICU physicians and nurses made use of national prioritisation criteria, and elucidated how the prioritisation criteria only to a limited extent were explicitly rendered visible in professional assessments in these situations that included the most difficult priorities in intensive care. The criteria were not prominent as actual prioritisation criteria that formed the basis for limiting medical treatment and nursing of a patient, in order to accept something else that could have a better effect. However, it is nevertheless correct to claim that the prioritisation criteria had an implicit importance for clinical assessments based on the clinicians' clinical competence and judgement of each particular situation.

An important impression that was gained through the data material, but not discussed in any of the articles, was represented by an insufficient awareness of the fact that most decisions have implications in terms of priorities. These findings concur with the impression from other studies, where physicians seem reluctant to make prioritisations (97, 117, 133.) Norheim claims that Norwegian physicians are averse to making priorities, and that they tend to be unaware that they in actual fact undertake clinical prioritisations continuously (133). This impression may, however, also result from a weakness of the study, in that insufficient focus was devoted to what constituted the basis for prioritisations as opposed to clinical or medical decisions.

7.3.1 Severity of illness as an imperative criterion

Article I describes how the severity of the patients' illness appeared to be an exclusive criterion for provision of intensive care, and in these situations the ICU clinicians found provision of treatment to conflict with their comprehension of right and wrong (1). The first White Paper on prioritisation of health care services gave exclusive emphasis to severity of illness as a prioritisation criterion (4). Based on the experience that an unbalanced emphasis on severity would not sufficiently account for the benefits and cost-effectiveness of the treatment, these principles were also included in the subsequent report (6). Article I shows that the criterion of severity of illness still holds a undisputed "first place" in assessments of treatment, which gives rise to a treatment imperative in ICU medicine legitimised in terms of vital indications and measures for life support. This definite acceptance of severity of illness as a priority criterion concerns the obligation of health care personnel to provide treatment aimed at saving the patient's life (94-96).

A limitation of ICU treatment will in most cases cause the patient to die within a relatively short time. Decisions that cause the death of patients are contrary to one of the most prominent values in medicine and nursing: *to save lives* (7, 91, 120). Saving lives is also the very foundation of intensive care medicine, which was established in order to save lives that were threatened by severe, acute and life-threatening diseases (10, 15). In some cases the obligation to save lives may come into conflict with another basic principle of medical practice, *"first and foremost to do no harm"* (120), and this was definitely brought to the fore in this dissertation. In a perspective of medical ethics, the principle of "to do no harm" may be perceived as stronger than the obligation to save lives (7, 91, 120). The principle of "no harm" appears to be restrained by the fact that the severity of the illness embodied a treatment imperative which proved difficult to resist. One may ask whether dying in an ICU was perceived as a medical failure and that ICU treatment by all means should defeat death. Research supports this assumption and claims that this perspective on intensive care may make the transition from curative to palliative care even more complicated in cases where treatment is futile (44). In the perspective of by all means defeat death it ought to be taken into account that limitation of treatment in ICU practice affects the clinicians and their relationship to life and death. Death and dying makes most people vulnerable and obliged to face own vulnerability, values and lethality.

A treatment imperative which contributes to a prolongation of suffering is contrary to the professional ethics of both physicians and nurses, focusing on compassion and care, on treatment, alleviation and comfort, but also for physicians which entails the obligation to discontinue or not to initiate meaningless treatment[61] [62](122, 123). There is a risk of violating the inherent dignity of the patient when providing aggressive ICU treatment rather than palliative care at the end of life. When life no longer can be saved, people need care, proper nursing, presence and analgesic treatment. As described in Article I, this conflict of care turned into a dilemma for nurses and physicians, because they perceived this as giving patients undignified care for dying patients. Problems concerning continued aggressive

---

[61] http://www.legeforeningen.no/id/485.1 (§1 og § 5) (accessed 02016-2009)

[62] https://www.sykepleierforbundet.no/portal/page/portal/NSF?p_menu_id=17036 (accessed 0206-2009)

treatment at the end of life have been described in a number of studies and physicians and nurses admit that it happens quite frequently (14, 35- 37, 70, 72, 73, 198). Internationally, there is widespread legitimacy for discontinuing futile ICU treatment, and it is done on a daily basis in ICUs. Draper underscores that *"There is absolutely no obligation on doctors to maintain life; rather all treatment should be given or withheld with reference to the doctor's assessment of the patient's best interest […]"* (11, p. 181)

In Swedish health care, the Principle of Human Dignity is an explicit priority criterion (132). More explicit reference to what is perceived as dignified treatment in these situations that the clinicians refer to could possibly make these decisions less complicated. This could possibly also ensure a more equitable allocation of resources.

7.3.2 The perspectives of benefit

As described in Article I, as a consequence of the emphasis placed on severity, the other criteria - benefit seen in relation to cost-effectiveness - were given less attention in the assessments of treatment, however emphasised by the respondents that treatment must have some breed of meaning.

In Article II it is elucidated how the professions may regard the patients and their medical condition on the basis of different perspectives, and thereby also give different assessments of the benefit of the treatment provided (2). Clinicians in ICUs claimed that surgeons, who have a more organ-oriented focus, often assessed the patient's condition differently from the ICU physicians, whose medical focus is directed towards the totality of the patient's situation, including pre-morbid factors that impinge on the ability to make it through ICU treatment. The nurses could possibly be even more patient-oriented and possess more knowledge of the patients' life world, and through their position bedside they were able to observe all major and minor responses to treatment, nursing and care, which is important in benefit assessments. As Article II emphasises, the majority of the clinicians shared the view that different stakeholders have different perspectives. However, these different perspectives were rarely made explicit in discussions of the benefits of treatment. The value of sharing these perspectives with regard to benefit of treatment for patients is evident in research from intensive care (48, 73).

Article I revealed that resource scarcity often meant that potentially beneficial treatments had to be scaled down or postponed, because patients with more life-threatening conditions had to be given priority. It as well documented that the focus on benefits did not take sufficient account of the consequences for other patients in the short or long term. This result concurs with research undertaken in other parts of the health services in Norway (98, 119).

Wiederman & Druml state the following about the ability of ICU physicians to confront the benefits of treating a patient with the benefits of treating other patients: "*Most ICU physicians refuse to make choices based on estimates of who might benefit the most*" (46, p 1142). Their statement concurs well with the findings in this study. The respondents very explicitly described the dilemmas they perceived as inherent in the continuation of futile treatment of individual patients. However, clinicians rarely confronted these dilemmas with the fact that other important forms of treatment and nursing care of other patients had to be compromised. Nurses described how they often had to postpone catering to the oral hygiene of the patients, in spite of their knowledge of the increased risk of, for example ventilator-associated pneumonia (VAP) and increased risk of death, in addition to the loss of comfort for the patient (200). Consequences of complications that could occur as a result of postponed treatment on patients in recovery phase were not weighed against the fact that considerable nursing resources were devoted to follow-up of sophisticated and costly ICU treatment undertaken on patients with a very marginal prognosis. On few occasions, however, did it occur that one patients' benefit of treatment was explicitly compared to other patients, in particular under the strain from extreme scarcity of available technology or once in relation with what the nurses found as a very questionable discharge of a patient.

In Article I we discuss how this reluctance to take benefit of treatment for actual patients more explicitly into account may lead to arbitrariness and unjustified priorities and in some cases lead to aggressive treatment of those patients' who benefit the least in the long run. International research emphasises that available resources are decisive priority criteria that sometimes may constitute a significant threat to fair patient care (32, 33). Wiederman et al. claim that in the future ICU physicians will be required to assess the value of a specific course of treatment in light of the treatment of existing and future patients (46). The availability of resources is limited and the strain on them is constantly increasing, a proposition which concurs totally with the predictions made by several respondents in this study, as well as other studies on prioritisations in ICU medicine and in the health care services in general (17, 118, 186,198, 201, 202).

The guidelines for prioritisations in the health care services include assessments of prognoses and notions of quality of life as part of the assessment of benefit (6). As stated in article II, many of the physicians and nurses were of the opinion that prognoses are statistical magnitudes, and different from actual life. Patients responded in mysterious ways, and some survived conditions that had been deemed to be terminal. In this manner the ICU clinicians embodied practical experience that gave a face to even the most sombre assessments of prognosis, and made it difficult to say that "enough is enough" and to trust the prognosis and outcome studies. Research also documents that clinicians are better at judging potential survivals from non-survivals in ICUs than exciting mortality predictions of different courses of treatment (111).

Inherent in the assessment of benefits of treatment is an assessment of quality of life (6). The notions of quality of life that are used in Norway have partly been exposed to very severe criticism because they fail to measure real quality of life and disvalue disabilities (203). Our respondents described qualitative assessments of quality of life as being very difficult to make. Most respondents associated these assessments with the meaning of treatment, but had problems in articulating what meaningful treatment involved, apart from "objective medicine". Other studies also show that measurement of quality of life is difficult, because the only person who can assess quality of life is the patient himself/herself, and patients are rarely able to recount their life stories in the ICU (16). As shown in Articles II and III, the fact that clinicians often had no knowledge of what the patient would have wished is described by several respondents as a factor that renders benefit of treatment and prioritisation difficult, even in situations where the next of kin could provide information on the patient's quality of life and possible wishes with regard to treatment. Research from larger European studies on end-of-life decision-making emphasises the necessity to strengthen patients' preferences and autonomy in these difficult decisions (16, 42, 195). The role of significant others in providing information on the patients preferences and possible benefit of treatment has proven to be problematic in some cases (53-55, 198). This research corresponds with points made by the clinicians in our study, as elucidated in article II & III.

Research that describes the perceived quality of life of patients following ICU treatment is available (75, 116, 204, 205), but evidence from studies of quality of life appears to be used as support for decisions among our respondents only to a limited extent. The clinicians, on the other hand, bore with them narratives of patients whom they never would have believed to be able to achieve a good life, but who continued to live well even with major disabilities, while other patients, who were believed to have good chances survived only to face continued agony. These experiences served to a higher extent as an argument for continued ICU treatment than prognosis and statistics.

7.3.3 The costs of treatment – an unethical and unacceptable argument?

In Article I it was emphasised that costs were something of a "non-topic", and the respondents related to this aspect only to a limited extent. It could appear as though arguing in favour of limitation of treatment on the basis of cost was perceived as "unethical". An assessment of provision of treatment on the basis of costs would involve a balancing of human suffering against finances, , and this appeared to be rather contra-intuitive to the clinicians. The second report from the Lønning Commission states that the benefits of treatment shall be assessed in terms of their cost-effectiveness (6). This implies that very costly forms of treatment that produce only marginal benefits shall not be given priority. Article I describes how very costly treatment processes were continued if one of the actors in the medical team refused to discontinue or limit the treatment, without any explicit reference to motives and purposes. As shown in article II, forces like feelings of guilt and a bad conscience and grave uncertainty of decisions in some cases overshadowed the fact that the treatment process devoured huge costs and resources at the expense of other patients inside and outside the ICU. One may also ask whether this eagerness to provide very costly forms of treatment could be based on professional and research interests. As shown in Article I, such indications were present in some situations, where sophisticated, innovative and very costly therapeutic methods were used, and where the ability of the patient's organs to function was maintained only by very advanced technological means. It is very important to shed light on these concealed factors, because they may give rise to priorities that are not in the patient's best interest, as well as contribute to injustice in patient care (5-7). One should also take into account the consequences that this kind of resource use entails with regard to other patients that could have been helped, and who would have far better prospects for a favourable outcome. I believe all three articles in the dissertation contribute to elucidate some of these concealed factors that are behind certain prioritisations.

Article I shed light on that some respondents, physicians and nurses alike, cautiously questioned the use of resources and the responsibility for administering public health care resources, without letting this entail any consequences for their own assessments and decisions. The ethical obligation imposed on physicians and nurses by their code of ethics, to ensure a fair distribution of resources and assume a co-responsibility for the distribution of resources undertaken by the health care services, was taken into account only to a limited extent (122, 123, 192). On the contrary, some respondents expressed a certain relief for not being held responsible for the use of resources. Nortvedt and Nordhaug argue for a certain bias in favour of individual patients at the expense of assessments of a fair distribution of health care resources (138). These authors raise key issues, but against the background of the findings shown in Article I, II, and III it is also fair to question whether the clinicians' bias is lopsided, causing the specific, clinical prioritisations regarding existing patients to some extent to lose sight of perspectives focusing on a more equitable distribution of health care resources.

7.3.4 Age as a priority criterion

Age is a prominent topic of ICU medicine, and there is widespread disagreement over the emphasis to be put on the patient's age, while the average age of ICU patients is also increasing (12, 13, 74, 74, 206). The Norwegian report on prioritisations in the health care system allows for using age as a criterion for prioritisations wherever this has a bearing on the prognosis and benefit of the treatment (6). As shown in Article II many of our respondents were concerned with the issue of age and the fact that a growing number of elderly patients were offered sophisticated ICU treatment, and they called for a more open discussion of this issue.

As shown in Article II, There is no basis for claiming that patients were discriminated against on grounds of (advanced) age, but it can be claimed that the age factor was assessed differently by different clinicians, and this may have had an effect on the intensity of the treatment provided. As shown in Article I, priority criteria such as age also became a more explicit issue when there were few available ICU beds or other resource constraints, and in these cases it was used more as an isolated priority determinant. Conversely, termination of treatment was very rarely brought up with regard to young patients. These patients were treated as long as signs of life could be detected, or as the clinicians said: “Until we stand with our backs against the wall.” These treatment decisions were totally independent of any assessments of prognosis and costs. In these cases it was evident that young age by itself served as an inducement to continue treatment.

Some respondents pointed out that in some cases ICU treatment was initiated on patients of very advanced age, and they reacted negatively to this. This practice was associated with the treatment imperative, which indicated that treatment should be undertaken at any cost, at any age. Some respondents claimed that “we are losing the proper perspective,” and that “common sense” sometimes ought to be brought into the assessments. For instance, it was recounted how “ambulatory and healthy” people in their nineties could fall over, for example following a massive brain haemorrhage, resulting in fatal injury. In these cases the question was asked whether these patients ought to have been allowed to die in a natural and dignified manner. In these cases the perspective of dignity presented by Collste (132) could possibly be brought in as a priority criterion. This could serve to make the decisions clearer as well as fairer.

7.4 Value choices affecting priority decision-making

In the previous section we have discussed how the national prioritisation criteria are used, and demonstrated that these do not constitute objective criteria, but are followed by value deliberations. In the following section we will discuss other value choices and considerations that have a bearing on decisions to limit ICU treatment.

7.4.1 Uncertainty – a value at stake

As shown in Article II, the uncertainty related to decisions to limit or initiate ICU treatment often proved to be decisive for acceding to treatment. Medicine is not an exact science, and decisions made by ICU physicians or co-decision-makers with regard to initiation or limitation of ICU treatment involved a certain amount of uncertainty, where the consequences of not providing life support included a prominent risk of death. Physicians recounted how decisions in acute situations had to be made on the basis of relatively limited background information and documentation of the patients' condition and other aspects of their ability to function. The ICU physicians also pointed out that in this context there was often insufficient information available from the wards regarding the condition of the patients. They tended to view the lack of patient data as a considerable problem. The Health Personnel Act defines requirements to sufficient documentation of patients (96). Better documentation requires more thorough conversation with patients, at stages of the illness where this is possible. There is a dearth of documentation of the patients' functional ability and the topics that have been discussed by the physician and the patient, for example with regard to patients who suffer from chronic illness at advanced stages. The same applies to conversations on risk and the preferences of patients who face major surgery. When no such support for decision-making was documented, it was natural for the ICU physicians to use the severity of the condition as a basis for prioritisation in these unpredictable and acute situations. Clinical intuition alone was insufficient as a basis for making such wide-ranging decisions, which required documentation of the condition, quality of life and functional ability. In such circumstances and facing such consequences, it was easier *"to just say yes"*, and as described by another physician, "to choose the path of least resistance."

Making a decision that could involve refusal of treatment and thereby the death of another person was described by several respondents as impossible and as a far greater strain than providing treatment to patients who should not have been admitted to the ICU. Moreover, when treatment first had been started, it was difficult to terminate. A fact that is not shown very well in the articles, but which is evident from the observations, was that if the patient was on a respirator, all means were used to extubate and discharge him or her, even though the prospects of survival were marginal. It may appear that this was a way to avoid taking a definite decision. A recent Scandinavian study highlights that end-of life decisions are more difficult on patients in respirators than those who are breathing themselves, and may be associated with a feeling of a more active involvement in the process of death (102). In this vein, D. Cook emphasises that it is important to focus on the purpose of technology in intensive care as a means to help patients through crises, and not to prolong death (209).

7.4.1.1 Concealed disagreement

Some respondents (physicians) perceived limitation of ICU treatment to be a relatively uncomplicated decision, giving the reason that these decisions tended to be based on a consensus. On the basis of the data material this viewpoint is understandable, because in these cases the treatment had been extended very far before the decision to limit it was made, as shown in article I. At that time, the patient had been treated well into the process of death (1). Then any possible moral or medical disagreement was no longer present, even though it might have been present at an earlier stage in the process. Draper refers to the consensus which is proclaimed with regard to limitation of treatment as apparent agreement, because the process towards a consensus comprises a large number of potent and value-laden topics (126) (p. 175). In addition, she states that no real consensus can be said to exist until the values and attitudes that characterise the decision are made explicit. The ideas described by Draper are recognisable for some of the decision-making processes in the investigated ICUs. This involved treatment processes that the observations showed to be highly complicated and conflict-ridden until the decision to limit the treatment was made, but that subsequently were described in interviews as involving consensual and “uncomplicated decisions” to discontinue treatment. The observation of these situations contributed to more nuanced insights into actual practices. In a study among Norwegian physicians, Førde and Aasland found that there is little tolerance for conflict and few “spaces” that can be used to discuss ethically challenging situations (194). Little tolerance for conflict could have served as a contributory cause for the respondents’ reluctance to reveal their real perspectives and motivations for undertaking treatment that they found to be unethical or illegitimate. Sprung claims that the reason why a majority of the ICU physicians in the large ETHICUS study find decisions to discontinue treatment to be uncomplicated is the fact that the process of treatment has been taken so far that no doubt any longer remains regarding the irreversibility of the illness (16), a claim which concurs with those situations where physicians find the limitation of treatment to be an uncomplicated issue. They appear to forget the process and remember only the decision.

7.4.1.2 The fear of wrongdoing

In Article II we have elucidated that the fear of making a wrong decision was prominent in the assessments of whether or not to initiate ICU treatment, as well as was present in relation to bringing up proposals for limiting treatment. In his research Terje Mesel has shown how physicians describe a strong sense of self-judgment with regard to medical errors, and that they often found it easier to tolerate the mistakes of others than their own mistakes (192). Limiting treatment most often involves what is described by Calbresi and Bobbit as tragic choices (208). They most often involve someone's death. Irrespective of whether the medical professions claim how limitation of treatment is in the best interest of the patient, it is a tragic and difficult decision. It involves suffering as well as grief for people other than the patient. Physicians interviewed recounted how they had nightmares and an inner uneasiness that could follow them for a long time after they had decided to limit ICU treatment. None of the units in which this study was undertaken provided any structurally appropriate arenas, cultures or strategies for discussion of ethically challenging decisions, even though some opportunities were provided on an ad hoc basis for use in particularly demanding situations. Some nurses called for more formal settings and were glad to have their informal spaces. Decision-making processes that involve an uncertain basis of information and the decision itself are of a life-and-death nature that underscores the need for decision-making support in the form of interdisciplinary processes, guidelines and supervisors[63] for limitation of ICU treatment. A minority of the physicians interviewed called for guidelines for limitation of ICU treatment, and claimed that these could constitute an appropriate aid for making increasingly difficult prioritisations. However, very few responded positively when they were asked whether they used existing international guidelines. Research also elucidates that clinicians are not familiar with using guidelines, irrespective of whether they are recommended, in particular with regard to end-of-life decision-making and thereby as criteria for rationing (102, 209, 210, 211).

7.4.2 Guilt, bad conscience and responsibility

As highlighted in Article II, a recurring issue in the material was that guilt, remorse and self-reproach acted as strong inducements for surgeons in particular to be reluctant to limit ICU treatment, even in cases where it was evident that treatment would be futile. They associated this claim with the tendency for increasingly sophisticated surgery to be undertaken on patients with a high degree of pre-morbidity and with a high risk of complications. However,

---

[63] http://www.helsedirektoratet.no/publikasjoner/veiledere/nasjonal_veileder_for_beslutningsprosesser_for_begrensning_av_livsforlengende_behandling_hos_alvorlig_syke_og_d_ende_400374 ; (accessed 0206-2009.)
http://www.bma.org.uk/images/Endoflife_tcm41-146693.pdf (accessed 0206-2009).

a key problem of this interpretation is that this is an assertion made by a group of clinicians about another group of clinicians. This weakens the tenability of a topic which in my opinion concerns prominent dimensions that impinge on decisions to limit ICU treatment and the difficult prioritisations that are made in the field of ICU medicine.

As shown briefly in Article II, some respondents (physicians) described situations where they had ‘felt co-responsibility for the development of illness because the patient’s condition had deteriorated following surgery or because a reoperation had been postponed for too long. They referred to this as “hospital-acquired complications”, which appears to act as a spur to continue treatment of patients beyond what most people would perceive as ethically defensible. As far as I can ascertain from existing research, the phenomenon of guilt and particular responsibility has not been widely studied, although several research contributions related to “end-of-life issues” have studied matters pertaining to the perception of moral stress among clinicians (70, 71, 192, 194). I consider this is a key topic. Future medical practices will involve treatment of patients with complex disease pictures and high risk. The risk of complications will increase, and outcomes will sometimes be fatal. This development requires challenging assessment prior to provision of treatment and it will require difficult and complex priorities bedside in ICU and health care in general in the future.

7.4.3 The patients’ preferences and the role of significant others

Article III elucidates perspectives on the role of significant others. Preferences communicated by relatives served as a key decision-making support for ICU physicians, but we found that several circumstances could have a bearing on how the next of kin were listened to and given an opportunity to provide adequate information about the wishes of the patient. International research on decisions to limit ICU treatment also point out this problem, underscoring the need to have better information on the patients’ wishes (16, 42, 43). Existing research also emphasises the necessity of providing adequate care to the next of kin in order to obtain adequate and correct information about the situation of the patient (63). As shown in Article III, some physicians, in our study in particular, perceived the preferences of the next of kin as presenting a problem, because the next of kin are also in a crisis. It was possible that the preferences of the next of kin do not always concur with those of the patient. In this context, the time available for exchange of information and conversation with the next of kin becomes a key issue. This part of the care for patients often turns into a balancing item when resources are scarce.

Respondents in our study pointed out that in light of contemporary medical and technological developments introduction of measures that can reveal patients' ideas about provision of life support at the final stage of life will be required *before* they are admitted to the ICU. It will be essential to facilitate medical practices that allow physicians to provide information on risks in a manner that patients can understand, and that allow patients to state their views on measures to be taken in the event that something should go wrong, as well as their preferences regarding provision of life support. Documentation of the exchange of information between the physician and the patient is required. In the United States "Advanced Directives" are routine (16, 36). In Europe this is less common, and the wishes of the patient are not taken into account to the same extent. However, Norwegian legislation and recently published guidelines for ending life sustaining treatment emphasise the necessity of listening to the patient and that the wishes of the patients shall be complied with if continued life support is not wanted, provided that this desire is not contrary to what is deemed to be ethically and medically defensible (95, 207). It may appear as if the high expectations to medical science has led to a belief that everything can be cured, and that resources constitute the decisive factor, but even medical science has its limitations. Life imposes restrictions, and at one point it will end. This idea is a simple one, although it appears as though this can be difficult to accept within a medical environment that offers so many possibilities. In this context the medical expertise has a major responsibility that requires some courage, because patients must be confronted with a refusal to provide treatment and physicians must undertake difficult prioritisations. My opinion in this respect is that the guidelines that currently emerge from the medical community, with guidance for prioritisation in the medical field, will constitute essential contributions to the decision-making support available to physicians.[64]

7.4.4 The influence of attitudes

The national guidelines for prioritisations clearly state that equitable prioritisations should be undertaken on the basis of the patients' need for health care, irrespective of factors such as social status, ethnicity, geography, lifestyle and self-inflicted illness. The medical assessments

---

[64] http://www.helsedirektoratet.no/publikasjoner/veiledere/.

should govern the decision to provide treatment, without interference from attitudes to the way the patient in question has chosen to live his or her life (6). In Articles II and III we have elucidated how the social status of patients, in particular if they held some kind of position of prominence, could have an influence on the interest in providing treatment. Interesting diagnoses gave rise to particular attention, and patients and next of kin who were resourceful attracted closer follow-up. The study also revealed that patients who were strongly overweight and had a low social standing elicited less interest and less commitment to their treatment process. On the other hand, a particular patient who had succeeded in maintaining a prominent social standing in spite of a lifestyle that had been very detrimental to his health, and that finally caused organ failure and death, nevertheless enjoyed respect and recognition. The nurses in particular, claimed that patients were treated differently and enjoyed different degrees of respect. Physicians tended to be less perceptive with regard to these issues, and in the interviews they mainly denied that any distinction was made with regard to patients on the basis of their social status. However, as described in Article III, during the observations I could witness how certain patients and families enjoyed more commitment, and I also realised that the treatment was extended very far in some individual cases.

Physicians and nurses are human and have their sympathies and antipathies, even though it is deemed to be illegitimate and improper to let such attitudes interfere with treatment and nursing. All patients should be met with empathy and attitudes that have their best interest in mind. This is a basic tenet of the professional ethics of physicians and nurses, as well as of the values and principles that are the base of the health care services (6, 7, 96, 120, 122, 123, 139). In my opinion such topics ought to be discussed among clinicians. The health care professions must admit to their human nature and the less positive aspects of it, in their professional practice as well, but not let it influence their practice and care. Openness can contribute to placing a focus on negative and positive attitudes and values, and to helping professionals interact with each other and assist each other to ensure that all patients are met with the same dignity and respect.

7.4.5 Decision-making hierarchies

All three Articles, however focused in Article II, more or less directly demonstrate how the complexities of the decision-making process, that involved a number of actors, had a bearing on how the decision-making processes proceeded and decisions were made. The inter-disciplinary and inter-professional cooperation functioned in widely different ways, and this was brought out in the observations and the interviews.

7.4.5.1 Decision-making hierarchy between physicians

In two of the ICUs in particular, it was obvious that the medical professions were ranked in a hierarchy of power, in which the power appeared to be especially associated with certain surgical fields. In the third unit this was less obvious, but this was a hospital that did not possess similar surgical specialisations. A study by Album and Westin revealed that prestige and hierarchy are associated with medical diagnoses, with thoracic surgery and neurosurgery ranked on top (212). However they do not argue that directly, it may be assumed as a result of findings that prestige may also be associated with the positions that “serve the diagnosis”, as indicated in different ways in Articles I, II and III. One could nevertheless ask why professionals with a pronounced disciplinary integrity choose to place themselves in a decision-making hierarchy that renders cooperation difficult and invariably does not serve the best interest of the patients. The ICU physicians who claimed that they contributed to a continuation of treatments that they found to be inappropriate or incorrect are part of this picture. In spite of this conviction they rarely opposed the surgeons who pressed on for provision of treatment.

In the study, there were also examples of how ICU physicians provided little support for each other when one colleague attempted to raise the issue of limiting treatment of high-risk patients at an early stage. Part of the explanation of why ICU physicians do not assume a more critical attitude in situations involving treatment that they contend to be questionable could be found in the situation where physicians are described as having a high degree of loyalty to each other and are very reluctant to express disagreement openly (192, 194). This loyalty may stem from the fact that all physicians to a large extent are living with the need to make complex decisions. They have a sense of their own vulnerability and fear of making a mistake that could cause them to come under scrutiny, and therefore choose to be protective of each other. Another, but probably less plausible, explanation could be found in the historical context, in which the anaesthetist originally served as the surgeon’s assistant (10) and that surgeons thereby have a kind of unspoken authority in relation to the anaesthetists. A third possibility, mentioned in Article II, may be that the intensive care clinicians also understand the responsibility of the surgeon, who met this patient face to face and probably felt a particular responsibility for the outcome, even if the patient may have been informed of the risks beforehand.

A further problem which has not been widely elucidated in the articles was found in the context of cooperation between co-decision-makers. It was an evident inconsistency in the follow-up of patients by the co-decision-makers. In general, their visits to the patients appeared not to be based on a preconceived plan, even though this to some extent varied between departments and persons. In order to ensure well-considered, fair and correct prioritisations and decision-making processes in ICU medicine, the roles of the various actors in the decision-making processes ought to be reviewed to establish appropriate structures for cooperation and follow-up by the departments responsible for the patients.

7.4.5.2 Decision-making hierarchy between physicians and nurses

In Articles II it is elucidated how the role of the nurses and their involvement in the decision-making processes varied considerably. The main impression from the study is that the nurses mostly acted as passive partners, as has also been shown by Bunch in a previous study from Norwegian intensive care (68). Further, Article II has elucidated how some physicians claim that the nurses often tend to consider treatment to be futile at an earlier stage, and are quick to conclude that further treatment is meaningless. These findings concur with the results of several other studies on the role of nurses in decision-making processes in ICUs and other parts of the health services (66, 68, 73, 98). In all Articles, and also in international research, a similar emphasis is placed on the necessity of listening to the nurses when decisions to limit treatment are made, with reference to the nurses’ close familiarity with the patient and the next of kin. This raises a key issue: Why are nurses mainly found in this passive role with regard to decision-making processes that to such a prominent extent affect their professional and ethical responsibility towards the ICU patients? One aspect of this issue is found in the fact that physicians have the responsibility to make medical decisions. A further reason is that several physicians excluded the nurses from decision-making processes, and paid little attention to the nurses' ethical perspectives in the discussion of treatment alternatives and decisions, as is shown in Articles II and III. There is a long history of relationships of power and professional rivalry between physicians and nurses, and these issues remain active. Nevertheless I wish to dwell on an issue that is mentioned, but not widely discussed in the articles (2), an issue concerning the nurses' own responsibility for promoting their viewpoints and becoming active partners in the decision-making processes. In the observations relatively often I witnessed how opportunities for raising issues pertaining to treatment were present but left unused by the nurses. To a large extent the nurses allowed themselves to be socialised into a passive role with regard to decision-making processes, even though this could vary.

One situation that I observed clearly describes the necessity of implementing the perspectives of the nurses when limitation of treatment is being discussed. Following discussion of a potential limitation of treatment with the nurse who was responsible for a patient who had been subject to long-term intensive care, the surgeon and the ICU physician could agree on new interventions that succeeded in reversing the condition of the patient. On inquiry, the nurse claimed that a limitation of treatment would *not* be the correct course of action. Through close monitoring of the patient, the nurse had observed minor signs of recovery, in the form of better contact and a better stability of the patient during care and mobilisation. This information proved crucial for the decision to continue, rather than to limit, the further treatment. First, this situation is a response to the assertion that "nurses always want to withdraw treatment", and second, it documents a situation in which a limitation of treatment had been considered, but in which this was averted through provision of essential clinical information by the nurse.

How can appropriate cross-disciplinary processes be established? Physicians have a responsibility for including all relevant perspectives when complicated medical decisions involving potential limitations of treatment are made. ICU nurses have a responsibility for contributing key perspectives of their own into the decision-making processes. Not least, heads of department have a responsibility for establishing cultures that have the best interest of the patient in mind, and where power and professional arrogance are excluded from exerting an influence on treatment-related decisions.

7.5 Resource scarcity and marginalisation of care

In Article I we revealed that a general resource scarcity exited. To a large extent, the reality described by the respondents was one of deficient nursing resources and to some extent physician resources, and also of insufficient bed capacity and a concomitant lack of personnel to cater to all the beds. ICU physicians and ICU nurses provided specific descriptions of how resource scarcity had an influence on medical treatment and nursing. One especially alarming issue shown in Article I, was that the resource scarcity tended to push aside aspects of the treatment that affected the patients' more basic needs for medical and nursing care. These included specific measures for care like basic nursing, oral hygiene and mobilisation, as well as time available for motivating, informing and comforting the patient. Some patients had to be discharged even if they still had a prominent need for close and caring follow-up and monitoring. They tended to be unstable and needed a lot of assistance, especially with regard to respiration, because they often suffered from secretions of phlegm and needed help to eject pulmonary secretions by coughing. The respondents also reported that they had fewer opportunities to facilitate circumstances that could make the end of life peaceful and dignified for the patient and the next of kin, or to shelter patients who needed a quieter environment. Another aspect of this situation is that on weekends in particular, some patients had to be sedated in order to allow the nurses to cater to other patients. This would prolong the patients' stay in the ICU.

Having to administer extra sedation to keep the patient still, instead of being able to take care of the patient to alleviate his or her anxiety, also constituted a compromise and represented a conflict of care. The nurses' moral intuition indicated that having to sedate the patient was wrong, for physiological as well as interpersonal reasons. Nevertheless, when weighed against i.g. the risk of an involuntary extubation, they saw themselves as left with no other choice. They were forced to choose one of two evils, and at the same time they were forced to disregard the need for care and presence that this patient had in the process of waking up from a critical disease. This represents a real moral dilemma and a moral conflict that occurs in practical situations on a daily basis, because of the insufficiency of resources (86, 91, 199). Several studies have made it evident that premature discharge, delayed admission and limited availability of personnel on weekends or at night, increased workload raise mortality rate in ICUs (24-28). The nurses and physicians however, stretched themselves far and showed an incredible working morality in their attempt to fight resource scarcity and give the best possible medical and nursing care.

With reference to prioritisation, Tranøy emphasises that the specific patient who is present before the physician or nurse has priority, rather than any potential or possible future patients (120). The situations described by the ICU nurses and physicians involved making a choice *between* existing patients who were in their care. Treatment and nursing of certain patients required immediate action because the patients were in a life-threatening condition. When confronted with vital treatment and measures for immediate life support, needs for fundamental nursing and care will have to yield. This could even be described as defensible. However, the Lønning II White Paper emphasises that necessary care and nursing shall have equal priority to the severity of the illness (6). Giving low priority to fundamental nursing care for ICU patients and their next of kin should not be acceptable. Hospitals must be held accountable for prioritising recourses in a manner that compromises provision of care for critically ill patients.

Kari Martinsen is critical of current development in the health services, because this development leads to an insufficient emphasis on the basic dimensions of care in interpersonal relationships, but values result-oriented care for the sake of results (141, 142). Some of the nurses pointed out that an increasing number of tasks related to treatment and technology were allocated to them, and this replaced more time-consuming but less measurable activities in the form of motivation, mobilisation and consolation of the patient. Basic health services based on the patients' right to receive health care imply an absolute entitlement to receive care and to be looked after (6, 7). The ICU nurses made a considerable effort to cater to the ICU patients' comprehensive need for treatment and care. They regarded this part of their function as a key element of their competence, and worked hard to provide the patients with all the care, treatment and nursing they required.

7.5.1 Vulnerability and care

Based on several traditions of moral philosophy it is fair to claim that interpersonal relationships include a moral response grounded in mutual vulnerability and a particular responsibility for the other (138-140). I do not set out to elaborate on these traditions in this dissertation. I nevertheless take a position by claiming that the ethical and personal self-conception of ICU physicians and nurses include a fundamental moral and professional obligation to approach the ICU patients and their needs for care. As described in Article I, being unable to fulfil this dimension of their professional practice had turned into a problem for physicians and nurses in the ICUs. The physicians were less concerned with this issue than the nurses were, in particular because they believed that the nurses attended to the patients' need for the care elements of the ICU treatment process. Nortvedt et al. have claimed that the nurses' conception of their role has changed, leading to a diminished focus on the care aspects of the profession caused by an increasing number of functions related to technology and specialised treatment (213). The ICU nurses in our study quite to the contrary claimed that this increasing number of tasks associated with technology and sophisticated forms of treatment came at the cost of provision of care to the patient, and this had caused them to lose a significant dimension of their profession. As shown in Article I, in this context the nurses also emphasised how they assumed a growing number of "physicians' tasks", without any concurrent increase in the availability of nursing resources.

Professionally skilled care for patients and next of kin is a cornerstone of ICU medicine and nursing. The ICU patient is totally dependent on those who care for him or her. The provision of dignified medical and nursing care must be based on a notion of care that goes beyond its practical expressions and that represents a value unto itself. Vetlesen and Henriksen give the following description of care as a fundamental value in relationships with others, 214, p. 25:

> ”Care is support of life. This is care at its most fundamental: To protect life. However, care is more than just maintenance of life: Care is support of a dignified life. Providing care is a qualitative activity: It implies responding to the needy person's need for dignity.” [65]

From what is shown in article I and the data material as a whole, I feel able to claim that this fundamental notion of care was present in the ICU clinicians' self-conception, but that everyday circumstances tended to put this essential value dimension to the test. One could ask whether sophisticated therapeutic methods, increasing amounts of technology and advanced medical practices tended to be given moral precedence, to the detriment of the patients' need for dignity and more time-consuming activities. ICU nurses, in the plural, but also some physicians, described how they were forced to "pass by" some patients and next of kin. As

---

[65] My translation

shown in article II, one physician described how he almost felt a sense of relief when a patient died in the admissions department, causing him not having to relate to difficult or even impossible prioritisations regarding discharge of patients with comprehensive needs for treatment, nursing and care. The clinicians had to remain distant by refusing to respond to the moral appeal found in the vulnerability and specific needs of patients. Gutierrez (2005) has described how ICU nurses experienced powerlessness and a loss of initiative and commitment by being unable to respond to patients' need for care at the end of life, and were obliged to participate in a spiralling treatment sequence that they perceived to be morally wrong (71). Similar experiences were also described by the respondents (physicians and nurses) in this study, described in Article I. They felt despondent, demoralised and powerless. The experience of inadequacy in relation to patients and next of kin gave rise to these feelings.

On the basis of ideas of ethics of proximity, the act of "passing by" will prevent a necessary sensitivity with regard to the ill person, and block the physicians' and nurses' attentiveness to the issues that are at stake for the patient. Nortvedt and Nordhaug describe how the qualities inherent in the ethics of proximity contribute to moral sensibility. To use Martinsen's expression, this will cause us to see with *"the eye of the heart"* (141). Nortvedt and Nordhaug claim that: *"An ethics of proximity emphasises and elucidates the significance of moral sensibilities as central to moral judgment and clinical wisdom in health care "* (138, p. 160) From this we can conclude that failing to respond to the impression, or "have no time" to become aware of it, will cause clinical discernment and judgement to be weakened. The ability to notice clinical indications that are essential to treatment could also be weakened, in light of the view that sensory perceptiveness is a key part of clinical wisdom and understanding. The immediate impression of the patient's condition and of small signs of change that can represent a promise for treatment requires more than just an analytical eye, it requires sensibility and compassion (141, 142, 215.)

7.5.2 Provision of care – a precondition for trust

In Article I we have described how trust in the health services depends on the way in which patients and next of kin are seen, heard and attended to, with humaneness and high professional skills. One of the characteristics of ICU medicine is exactly this professionalism and interpersonal character of its relationship to the patients and the next of kin. However, trust is fragile (174). Skirbekk describes how trust must be negotiated, and how trust, as well as distrust, never are static phenomena (216). Løgstrup states that trust must be earned (142). To earn the trust of the patient in the ICU context will have to involve exactly this care that caters to medical and interpersonal aspects of the treatment. My point here is that if the time and opportunity to feel compassion and to ponder and to allow the patient to make an extra step must be renounced, this may serve to weaken the trust in ICU medicine and nursing. This is an essential part of the treatment, and needs to be given priority.

ICU patients who are at a more recovering stage of the treatment process are no less dependent on basic nursing, care and presence than nursing provided to unstable patients who are in an acute phase. An essential difference, however, is that treatment and nursing in the context of acute conditions require immediate action because of its “life-or-death” nature. Care must be assessed in a wider context. Marginalisation of fundamental and necessary care would be likely to aggravate the suffering of the patient, reduce the long-term benefits of the treatment and weaken the confidence in the health services. Providers of health care run a considerable risk by turning aspects of care into a balancing item.

The respondents also described how they perceived an increasing dilemma in the continuation of sophisticated treatment of patients in situations where the patient needed care at the end of life. One consequence of the prioritisations undertaken may indicate that priority was given to ineffective measures rather than to effective ones, at the cost of the opportunity for catering to dimensions of care. Phee et al. describes how health services in the United States spend inordinate resources on finding ways to treat patients well into the death process, rather than on identifying appropriate ways to provide care and treatment in the final stage of life (217). This development may also be a warning to Norwegian intensive care and health care as a whole. Provision of aggressive and sophisticated ICU treatment in the final stage of life represents an ethical problem as well as a prioritisation problem. It is urgently required to cast a critical eye on the use of resources, to prevent health personnel from becoming inadvertent agents for rationing and inadvertent substitution of the care values of the services.

7. 6 The road ahead

We have elucidated and discussed how decision-making in ICU medicine and nursing is complicated and characterised by values and preferences among the actors. We have discussed in all three Articles how hidden values, consideration and the resource situation may lead to injustice and arbitrariness in bedside priorities. Here we need to raise the question of where the road ahead will lead.

Article I shed light on that resource scarcity tended to give rise to more rigorous assessments of the benefits of treatment, particularly with regard to the severity of the patient's condition, but also to a larger extent to inclusion of other criteria such as age level and various pre-morbid circumstances that could entail a less promising prognosis. I am of the opinion that the criteria that are at the base of prioritisations in Norwegian health services are important and useful as decision-making support for prioritisations made at the clinical level, but in isolation they remain insufficient. The work being undertaken in the medical communities on recommendations for prioritisations will constitute a key contribution for more nuanced assessments with regard to severity, benefits and costs.[66] These guidelines have the potential for contributing to increased legitimacy of decisions to refuse treatment as well as to prioritisations to be included in ICU practices. Guidelines pertaining to various diagnoses will fine-tune the prioritisation criteria and thereby facilitate their practical application. Furthermore, this will increase the transparency of prioritisation decisions.

Guidelines for termination of life-supporting treatment have recently been published (207)[67]. These guidelines have been compiled following instances of very complicated cases involving termination of treatment in Norwegian hospitals, among other things. There has been disagreement in the medical community concerning the necessity of such guidelines, because decisions to terminate treatment mainly involve clinical assessments that must be undertaken on an individual basis. International studies also show that there is disagreement over the use of guidelines, and that they are used only to a limited extent (211). On the other hand there have been calls for more consistency in decisions to terminate treatment as well as guidelines

---

[66] www.shdir.no/veieldere/ (accessed June 27th)

[67] http://www.helsedirektoratet.no/publikasjoner/veiledere/nasjonal_veileder_for_beslutningsprosesser_for_begrensning_av_livsforlengende_behandling_hos_alvorlig_syke_og_d_ende_400374 (accessed May 14th 2009)

for this field, since studies have revealed highly varying practices even within the Nordic countries (102).

Guidelines are what they are intended to be: a set of guiding principles. They are not intended to replace or restrict clinical assessments. All patients shall and must be subject to an individual assessment. The guidelines have been compiled as support for clinicians when making difficult decisions, and for contributing to more explicit as well as more well-founded argumentation. The guidelines for termination of life support elucidate the values at stake. They elucidate strategies for well-conceived decisions and problematise situations where the patient is permanently or temporarily incapable of providing consent. Temporary loss of ability to provide consent represents a problem for ICU patients because of the severity of their condition. By rendering visible the rights of patients as well as of health personnel the guidelines also elucidate legal aspects of termination of treatment. In this manner they also maintain the autonomy of the health care professions. By way of all these aspects, the guidelines are intended to assist a decision-making team in the context of difficult issues pertaining to treatment and prioritisations. I am of the opinion that good clinical judgment combined with the national prioritisation criteria such guidelines will constitute a key contribution to prioritisation efforts.

Good management in each individual department is required in order to obtain appropriate and open decision-making processes. An appropriate environment at the department level is required, as are transparent and regularised strategies for establishment of open decision-making processes that allow the viewpoints of all actors to be heard. In our study we have seen that values and attitudes, power and powerlessness are part of the situation when decisions are made. Many of these factors are “part of the interior” and elements of the prevailing culture. Dismantling this pattern can only be done by way of determined leadership that demonstrates the courage to call attention to unfortunate aspects of prevailing practices and do not tolerate that power is wielded to suppress the views of other employees or to gain the “upper hand” with regard to treatment decisions or prioritisations. A leadership that shows the courage to transcend professional barriers is thereby required.

As shed light on in the theoretical perspective of the dissertation Daniels and Sabin have proposed a procedural framework for rendering prioritisations explicit (93, 131). [68] This framework has been tested in various settings, included ICU medicine (133-135). The framework is based on a constructionist theory of justice, and is inspired by John Rawls in particular. This framework offers an opportunity to render prioritisations transparent, and for the health services and the public to assess the legitimacy of these prioritisations. Using this framework could be possible, although in my opinion it does not offer decision-making support to the individual prioritisations and nuances found within each professional community. I therefore claim that it is decisively important to base efforts on existing Norwegian criteria supplemented by guidelines compiled by the professional communities. The framework proposed by Daniels and Sabin however, could constitute a key contribution for rendering prioritisations transparent.

There is a need for a better recognition of the fact that prioritisations also involve assessments of values that need to be done in an explicit manner. There must be room to pose challenging questions with regard to value-related issues in the health services without passing judgment.

The Ministry of Health and Care Services has decided that all the nation's hospitals shall have committees of clinical ethics. These are advisory bodies where ethically difficult decisions can be discussed. Some time will still remain before these bodies can be used in a manner that could provide key decision-making support to clinicians, but studies have shown that such bodies can have a positive effect (196-197). In my opinion, these bodies could also be drawn into more informal discussions at the ward and department level to contribute to appropriate inter-disciplinary processes for elucidation of perspectives pertaining to the value of treatment.

In all articles we have discussed how value-related considerations are made in a non-transparent manner and thereby may give rise to arbitrariness and unfairness in resource allocation and the treatment of patients. Deficient openness is thereby a threat to one of the most fundamental principles of Norwegian health services, the basic human-rights principle of justice and equal treatment. Openness is required in order to elucidate considerations of resource availability, and for a critical examination of the distribution and allocation of

---

[68] Described in the chapter on theory

resources. Only openness can ensure that any new, legitimate resources can be supplied according to the principle of equitable distribution. Openness concerning prioritisations in ICU practices is thereby an essential normative argument in order to ensure equal treatment and avoid arbitrariness in the treatment of patients.

Finally, I want to point out that openness is a key contribution with regard to the expectations of the public, and possibly even with regard to individual responsibility for lifestyle and health. A change is needed to clarify that medical science cannot achieve everything. There are widespread and unrealistic expectations regarding the actual possibilities of medical science as well as regarding resources. In this context health workers have a responsibility to society, in cooperation with political authorities and not least the media. Through their handling of situations involving difficult prioritisations, politicians and the media also contribute to making resource use spiral upwards. When politicians reverse their own decisions when they are forced to relate to individual people, how can they expect clinicians to behave when they face individual destinies and difficult choices on a daily basis? It is difficult to refuse. Helping people restore their health is a fundamental tenet of the health professions’ ethical code.

8 CONCLUDING REFLECTIONS

In this dissertation we have investigated the ethics of bedside priorities in intensive care, one of the most complex areas of our health care services, where professionals confront life and death issues when making prioritisations of whether to treat patients or not. We found that clinicians struggled with powerful treatment imperatives and conflicts of care, causing intensive care treatment in some cases to be sustained longer than what was perceived as meaningful and dignified.

Efforts have been made to elucidate the basis for decision-making with regard to clinical priorities in intensive care in situations where decisions about limitation of treatment were made. Medical assessments of the patients’ condition were interwoven with explicit and implicit values that influenced bedside priorities. These values comprised complex phenomena such as uncertainty, responsibility, guilt, reproach, moral judgement of patients, dignity and indignity. Clinicians were convinced that these values of the professionals could influence priority decisions; however, our study did not, since it has been a quality study, identify the relative importance or actual strength of these values. Our study did, however, highlight the significance of accepting that clinical decisions are priority decisions that comprise values that need to be made transparent in interdisciplinary decision-making processes.

Our study revealed that nurses and physicians struggled with scarce resources in daily medical and nursing care of the intensive care patients. Comprehensive care is a cornerstone in intensive care practice, and a key issue in protecting the personal well-being and integrity of the patients and their relatives. Establishing trust in the ICU probably rests on the protection of these standards, and having to compromise on care was a prominent concern for physicians and nurses.

8.1 Further research

Coming to an end of this dissertation, I believe this research has shed light on important issues related to bedside priorities in the context of intensive care and raised many new questions. To investigate whether these findings have significance for a larger population of ICU personnel, I propose that a survey is undertaken among these groups.

One of the main weaknesses of this study is the lack of knowledge of how clinicians from the home ward, who refer patients to the ICU, reason. Respondents in this study voiced a number of assumptions concerning the motives and priority considerations of referring clinicians. Further research that focuses on the prioritisations of these stakeholders of intensive care patients is imperative.

This dissertation has also shed light on several phenomena, which in themselves could be of interest for further research on bedside priorities. Studying hierarchies of power and how groups of professions and professionals relate to each other in terms of their respective power and status would be of importance.

Guilt, responsibility and expectations have also been elucidated as significant phenomena, in particular for clinicians from “home wards”. A more in-depth investigation of the impact of these phenomena on concrete priorities is important. Equally significant would be a more specific investigation of the conflicts of care elucidated in this study, and their implications for marginalisation of care in a situation with scarce resources.

The study has also focused on the impact of old age with regard to provision of intensive care. I claim that this is an essential perspective, both in terms of whether and how patients are discriminated against, because of advanced age per se, as well as with regard to more careful investigation of opinions and reasons of how old age ought to be taken into account.

We have seen that the principle of justice is violated in several ways. Attitudes toward social status and position are unduly allowed to enter into decisions concerning priorities. The effect of such attitudes among groups of professions and professionals on prioritisations of different groups of patients in intensive care requires further in-depth investigation.

New national guidelines to support end-of-life decision-making have recently been published. How these will be used and turn into a support for practical decisions is also a significant subject for future research.

9 REFERENCES

1. Halvorsen K, Førde R, Nortvedt P. Professional Challenges of Bedside Rationing in Intensive Care. *Nursing Ethics* 2008;15 :715-27.

2. Halvorsen K, Førde R, Nortvedt P. Value choices and considerations when limiting intensive care treatment: A qualitative study. *Acta Anaesthesiologica Scandinavia* 2009; 53: 10-17.

3. Halvorsen K, Førde R, Nortvedt P. The principle of justice in patient priorities in the intensive care unit: the role of significant others. *Journal of Medical Ethics* 2009; in press.

4. NOU (1987:23). Retningslinjer for prioriteringer innen norsk helsetjeneste. Oslo: The Ministry of Health care Services http://www.regjeringen.no/nb/dep/hod/dok/nouer/1999/nou-1999-2/4/2.html?id=350994

5. Den Norske Legeforening (DNLF). Lang Lang rekke - Hvem skal vente hvem skal få? en status rapport om prioritering i helsetjenesten, 2008. (Norwegian Medical Association, in Norwegian) http://www.legeforeningen.no/id/120932.0 (accessed June 29th 2009)

6. NOU (1997:18). Prioritering på ny (Priority setting anew) Oslo: The Ministry of health care Services. http://www.regjeringen.no/nb/dep/hod/dok/regpubl/otprp/19981999/otprp-nr-12-1998-99-/2/4.html?id=305814

7. Ruyter K, Førde R, Solbakk JH. *Medisinsk og helsefaglig etikk*. (Medicine and health ethics) 2nd ed. Oslo: Gyldendal akademiske; 2007. (In Norwegian)

8. Norheim O.F. Reasonable Rationing International Experience of priority setting in Health Care: Norway. In (ed.): Hamm C, Robert G, ed. *Reasonable Rationing International Experience of priority setting in Health Care*. Philadelphia: Open University Press; 2003. p. 94-172.

9. Holm S. The second phase of priority setting: Goodbye to the simple solutions: the second phase of priority setting in health care *British Medical Journal* 1998; 317: 1000-1002.

10. Strømskag K.E. *Et fag på søyler. Anestesiens historie i Norge*. (A discipline on pillars) Oslo: Tano Aschehoug; 2002. (In Norwegian)

11. Miracle VA. The Life and Impact of Florence Nightingale. *Educational Dimension*. 2008; 27: 21-3.

12. Flåtten H. Intensive care in the very old: Are we prepared? *Acta Anaesthesiologica Scandinavia*. 2007; 51: 519-21.

13. Reinikainen M, Uusaro A, Niskanen M, Ruokonen E. Intensive care of the elderly in Finland. *Acta Anaesthesiologica Scandinavia*. 2007; 51: 522-9.

14. Hov R, Hedelin B, Athlin E. Being and intensive care nurse related to questions of withholding and withdrawing curative treatment. *Journal of Clinical Nursing* 2007; 16: 203-11.

15. Stubberud D.G. Intensivsykepleierens målgruppe og arbeidsted (The critical care patient and the critical care unit). In: Guldbrandsen T, Stubberud DG, ed. *Intensivsykepleie* (Intensive Care Nursing). Olso: Akribe; 2005. p. 23-25. (In Norwegian).

16. Sprung C, Woodcock T, Sjökvist P, Ricou B, Bulow H, Lippert A, et al. Reasons, considerations, difficulties and documentation of end-of-life decisions in European intensive care units: the ETHICUS study. *Intensive Care Medicine* 2008; 34: 271-7.

17. Sinuff T, Kahnamoui K, Cook D, Luce J, Levy M. Rationing critical care beds: a systematic review. *Critical Care Medicine* 2004; 32: 1588-97.

18. Musschenga A. Empirical Ethics, Context-Sensitivity, and Contextualism. *Journal of Medicine and Philosophy* 2005; 30: 467-90.

19. Hov R. *Nursing Care for patients at the edge of life*. Doctoral thesis. Karlstad University; 2008.

20. Adam SK, Osborne S. *Critical Care Nursing. Science & Practice*. Oxford: Oxford Medical Publications; 1997.

21. Cook DJ, Giacomini M. The sound of silence: rationing resources for critically ill patients. *Critical Care*. 1999; 3: R1-R3.

22. Vanhecke T, Gandhi M, McCullough P, Lazar M, Ravikrishan K, Phillip Kadaj, et al. Outcomes of patients considered for, but not admitted to, the intensive care unit. *Critical Care Medicine* 2008; 36: 812-7.

23. Uusario A, Aarno K, Ruokonen E. The effects of ICU admission and discharge times on mortality in Finland. *Intensive Care Medicine* 2003; 29: 2144-8.

24. Obel N, Pedersen L, Storgaard C, Pedersen H, Sørensen H, Hansen B. Mortality after discharge from the intensive care unit during the early weekend period: a population-based cohort study in Denmark. *Acta Anaesthesiologica Scandinavia.* 2007; 51: 1225-30.

25. Goldhill DR, F MA, Hadjianastassiou VG, Tekkis PP. The longer the patients are in hospitals before Intensive Care Admission the higher their mortality. *Intensive Care Medicine* 2004; 30: 1908-13.

26. Gajic O, Malinchoc M, Comfrere T, Harris M, Achouiti A, Yilmaz M, et al. The Stability and Workload Index for Transfer Score predicts unplanned intensive care patient readmission: Initial development and validation*. *Critical Care Medicine* 2008; 36: 676-82.

27. Garland A, Shaman Z, Baron J, Connors AF, Jr. Physician-attributable differences in intensive care unit costs: a single-centre study. *American Journal of Respiratory & Critical Care Medicine* 2006; 174: 1206-10.

28. Wunch H, Mapstone J, Brady T, Hanks R, Rowan K. Hospital mortality associated with day and time of admission to intensive care. *Intensive Care Medicine* 2004; 30: 895-901.

29. Priestap FA, Martin CM. Impact of intensive care unit discharge time on patient outcome. *Critical Care Medicine* 2006; 34: 9246-51.

30. Jacobs P, Rapoport J, Edbrooke D. Economies of scale in British intensive care units and combined intensive care/high dependency units. *Intensive Care Medicine*. 2004; 30: 660-4.

31. Boots R, Lipman J. High dependency units: issues to consider in their planning. *Anaesthesia & Intensive Care* 2002; 30: 348-54.

32. Hurst S, Hull SC, DuVal G, Danies M. Physicians' responces to resource constraints. *Archives of Internal Medicine* 2005; 165: 639-44.

33. Tallgren M, Klepstad P, Petersson J, Skram U, Hynninen M. Ethical Issues in intensive care - a survey among Scandinavian intensivists. *Acta Anastesiolologca Scandinavia* 2005; 49: 1092-100.

34. Pronovost P, Angus D. Economics of end-of-life care in the intensive care unit. *Critical Care Medicine*. 2001;29 :N46-51.

35. Palda V, Bowman K, McLean R, Chapman M. “Futile Care: Do we provide it? Why? A semi structured Canada-wide Survey of intensive care doctors and nurses. *Journal of Critical Care* 2005; 20:207-13.

36. Moselli NM, Debernardi F, Piovano F. Forgoing life sustaining treatments: differences and similarities between North America and Europe. *Acta Anaesthesiologica Scandinavica* 2006; 50: 1177-86.

37. Middlewood S, Gardner G, Gardner A. Dying in Hospital: Medical Failure or Natural Outcome? *Journal of Pain and Symptom Management* 2001;22(6):1035-41.

38. White D, Luce J. Palliative care in the intensive care unit: barriers, advances, and unmet needs. *Critical Care Clinics* 2004 2004; 20: 329-43.

39. Nolin T, Andersson R. Withdrawal of medical treatment in the ICU. A cohort study of 318 cases during 1994-2000. *Acta Anaesthesiologica Scandinavia* 2003; 47: 501-7.

40. Rubenfeld G. Principle and practice of withdrawing life sustaining treatment. *Critical Care Clinics*. 2004; 20: 435-51.

41. Rydvall A, Bergenheim T, Lynoe N. Decision-making in a life threatening cerebral condition: A comparative study of the ethical reasoning of intensive care physicians and neurosurgeons. *Acta Anaesthesiologica Scandinavia* 2007; 51: 1338-43.

42. Cohen S, Sprung CL, Sjökvist P, Lippert A, Ricou B, Baras M, et al. Communication of End of Life decisions in European intensive care units. *Intensive Care Medicine* 2005; 31: 1215-1221.

43. Gedge E, Giacomini M, Cook D. Withholding and withdrawing life support in critical care settings: ethical issues concerning consent. *Journal of Medical Ethics* 2007; 33:215-8.

44. Cook D, Rocker G Giacomini M, Sinuff T, Heyland D. Understanding and changing attitudes toward withdrawal and withholding of life support in the intensive care unit. *Critical Care Medicine* 2006; 34: 317-323.

45. Pettila V, Ala-Kokko T, Varula T, Laurila S, Hoviletho S. On what are our end-of-life decisons made? *Acta Anaesthesiologica Scandinavia.* 2002; 46: 947-54.

46. Wiederman C, Druml C. End-of-life-decisions in Austria's intensive care. *Intensive Care Medicine.* 2008; 34:1142-4.

47. Cohen J, van Delden J, Mortier F, Löfmark R, Norup M, Cartwright C, et al. Influence of physicians' life stances and attitudes to end-of-life decisions and actual end-of-life decision-making in six countries. *Journal of Medical Ethics* 2008; 34: 247-53.

48. Wax ML, Ray SE. Dilemmas within the surgical intensive care unit. Journal of the American College of Surgeons. 2002; 195: 721-8.

49. Vincent J-L. Cultural differences in end-of-life care. *Critical Care Medicine.* 2001; 29: 52-55.

50. Miccinesi G, Fisher S, Eugenio P, Bregje D, Onwuteaka, Cartwright C, van der Heide A, et al. Physicians attitudes towards end-of-life decisions: a comparison between seven countries. *Social Science & Medicine* 2005; 60: 1961-74.

51. White D, Curtis J. Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Critical Care Medicine*. 2006; 34: 2053-9.

52. Heyland D, Cook DJ, Graeme RM, Kutsogiannis DJ, Peters S, Tranmer JE, et al. Decision-making in the ICU: perspectives of the substitute decision-maker. *Intensive Care Medicine* 2003; 29: 75-82.

53. Robert A, Kellum J. Moral justification for surrogate decision-making in the intensive care unit: Implications and interventions. *Critical Care Medicine* 2003; 31: 347-53.

54. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capasity. *Critical Care Medicine* 2001; 29: 1892-7.

55. Kirchhoff KT, Song M-K, Kehl K. Caring for the family of the critically ill patient. *Critical Care Clinics* 2004; 20: 453-66.

56. Curtis JR. Interventions to improve care during withdrawal of life-sustaining treatments. *Journal of Palliative Medicine* 2005; 8: 116-31.

57. Azoulay E, Pochard F, Chevret S, Adrie C, Annane D, Bleichner G, et al. Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. *Critical Care Medicine* 2004; 32: 1832-8.

58. Azoulay E, Pochard F, Chevret S, Adrie C, Bollaert P-E, Brun F, et al. Opinions about surrogate designation: a population survey in France. *Critical Care Medicine* 2003; 31: 1711-4.

59. Treece P. Communication in the intensive care unit about the end of life. *Advanced Critical Care* 2007; 18: 406-14.

60. Rodriguez R, Navarette E, Schwaber J, McKelroy W, Amy C, Kerrigan S, et al. A prospective study of primary surrogates decision makers' knowledge of intensive care. *Critical Care Medicine* 2008; 36: 1633-6.

61. Reiter-Theil S. The Complex Role of Relatives in End-of-Life Decision-Making: An Ethical Analysis. *HEC Forum* 2007;19: 341-6.

62. Myhren H, Ekeberg Ø, Langen I, Stokland O. Emotional strain, communication and satisfaction of family members in the intensive care unit compared with expectations of the medical staff: experiences from a Norwegian University Hospital. *Intensive Care Medicine* 2004; 30: 1791-8.

63. Browning A. Empowering family Members in End-of-Life Care Decision-Making in the Intensive Care Unit. (review) *Dimensions of Critical Care Nursing* 2009; 28: 18-23.

64. Booij L. End-of-life decisions during intensive care treatment. *Current Opinion in Anaesthesiologica.* 2003; 16: 221-5.

65. Baggs J, Norton S, Schmitt M, Sellers C. The dying patient in the ICU: role of the interdisciplinary team*. *Critical Care Clinics* 2005; 20: 525-40.

66. Frick S, Uehelinger D, Zuercher Zenklusen R. Medical Futility: Predicting outcome of intensive care patients by nurses and doctors - a prospective study. *Critical Care Medicine* 2003; 31: 1485-91.

67. Studdert D, Mello M, Burns J, Puopolp A, Galper B, Troug R, et al. Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. *Intensive Care Medicine* 2003; 29: 1489-97.

68. Bunch E. Delayed clarification: information, clarification and ethical decisions in critical care in Norway. *Journal of Advanced Nursing* 2000; 32: 1485-91.

69. Mc Bride C, Clark A. Practice of Expert Critical Care Nurses in Situations of Prognostic Conflict at the End of Life. *Journal of Critical Care* 2006; 15:480-8.

70. Mc Millen RE. End of life decisions: Nurses perceptions, feelings and experiences. *Intensive and Critical Care Nursing* 2008; 24: 251-259.

71. Guiterrez K. Critical Care Nurses' Perceptions of and Responses to Moral Distress. *Dimensions of Critical Care Nursing* 2005; 24: 229-41.

72. Espinosa L, Young A, Walsh T. Barriers to intensive Care Unit Nurses Providing Terminal Care. An Integrated Literature Review. *Critical Care Nursing Quarterly* 2008; 31: 85-93.

73. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *Journal of Advanced Nursing* 2001; 33: 707-15.

74. Somme D, Mailet J-M, Gisselbrecht M, Novara A, Ract C, Fagon J. Critically ill and the oldest-old patients in intensive care: short term and long term outcomes. *Intensive Care Medicine* 2003; 29: 2137-43.

75. Merlani P, Chenaud D, Marotti N, Ricou B. Long-term outcome of elderly patients requiring intensive care admission for abdominal pathologies:survival and quality of life. *Acta Anaesthesiologica Scandinavia* 2007; 51: 530-7.

76. Baggs JG, Mick D. Collaboration: A tool Addressing Ethical Issues for Elderly Patients Near the End of Life in Intensive Care Units. *Journal of Gerontological Nursing.* 2000; 26: 41-7.

77. Reiter-Theil S. The ethics of end-of-life decisions in the elderly: deliberations from the ECOPE study. *Best Practice & Research Clinical Anaesthesiology*. 2003; 17: 273-87.

78. Dodds S. Gender, aging, and injustice: Social and political contexts of bioethics. *Journal of Medical Ethics* 2005; 31: 295-8.

79. Degenholtz H, Stephen T, Miller M. Race and the intensive care unit: Disparities and preferences for end of life care. *Critical Care Medicine* 2003;31:373-8.

80. Tilford J, Parker J. A gender bias in the allocation of intensive care resources? *Critical Care Medicine* 2003; 31: 2073-4.

81. Valentin A, Jordon B, Lang T. Gender related differences in intensive care: A multiple-centre cohort study of therapeutic interventions in critically ill patients. 2003; 31: 1901-1907.

82. Doolen J, York N. Cultural differences with end-of-life care in the critical care unit. *Dimension of Critical Care Nursing* 2007; 26: 194-8.

83. Sinuff T, Cook D, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *Journal of Critical Care* 2007; 22: 104-11.

84. Norheim O.F. *Limiting access to health care: a contractualist approach to fair rationing*. Doctoral thesis. The Institute for Medical Ethics, University of Oslo; 1996.

85. Guldbrandsen T. Livets sluttfase In (ed.): Guldbrandsen T, Stubberud D. *Intensivsykepleie*. (Intensive Care Nursing) 1st ed. Oslo: Akribe; 2005, p. 146-55. (In Norwegian)

86. Grady C. Ethical Issues in Critical Care Nursing. In (ed.): Morton P, Fontaine D, Hudak C, Gallo B, *Critical Care Nursing. A Holistic Approach*. 8th ed. Philadelphia: Lippincott Williams & Wilkins; 2005, p. 75-88.

87. Miljeteig I, Johannesen K, Norheim OF. Etiske valg ved medisinsk nytteløs behandling. (Ethical choices in medical futile treatment) *Tidsskrift for Norsk Legeforening* 2008; 128: 2185-9. (In Norwegian)

88. Brock D. Medical decisions at the end of life. In (ed.): Kuhse H, Singer P. *A companion to bioethics*. 2nd ed. Oxford: Blackwell Publishing; 2001, p. 231-41.

89. Ewer M. The definition of medical futility: Are we trying to define the wrong term? *Heart & Lung* 2001; 30: 3-4.

90. Schneiderman L, Jecker N, Johnsen A. Medical Futility: Response to critique. *Annals of Internal Medicine* 1996;125:669-74.

91. Beauchamp T, Childress J. *Principles of biomedical ethics*. Oxford: Oxford University Press; 2001.

92. Holm S, Liss P, Norheim O. Access to health Care in the Scandinavian Countries; *Ethical Aspects. Health Care Analysis* 1999; 7: 321-30.

93. Daniels N. *Just Health*: Cambridge: Cambridge University Press; 2008.

94. Prioriteringsforskriften. Helse og Omsorgsdepartementet (The Ministry of Health and Social Affairs); 1999/2001. (www.lovdata.no/for/sf/ho/ho-20001201-1208.html)

95. The Patients' Rights Act. Oslo: The Ministry of health and Social Affairs; 2000. (www.lovdata.no/all/nl-19990702-063.html)

96. Health Care Personnel Act. Oslo: The Ministry of Health and Social Affairs; 2001. (www.lovdata.no/all/nl-19990702-064.html)

97. Strech D, Synofzik M, Marckmann G. How Physicians Allocate Scarce Resources at the Bedside: A systematic Review of Qualitative studies. *Journal of Medicine and Philosophy* 2008; 33: 80-99.

98. Halvorsen K, Slettebø Å, Nortvedt P, Pedersen R, Kirkevold M, Nordhaug M, et al. The impact of old age? Priority dilemmas in dialysis treatment and nursing care. *Journal of Medical Ethics* 2007; 34: 585-9.

99. Harris J. Micro-allocation: deciding between patients. In (ed.): Kuhse H, Singer P. *A companion to bioethics*. Blackwell Publishing; 2002, p. 293-306.

100. Draper H. Withdrawing and Withholding Life sustaining Therapy and Euthanasia. In (ed.): Draper H, Scott W. *Ethics in Anaesthesia and Intensive Care*: Butterworth Heinemann. Elsevier Science; 2003. p. 175-192.

101. Svantesson M, Sjökvist P, Thorsén H. End-of-life decisions in Swedish ICUs. How do physicians from the admitting department reason? *Intensive & Critical Care Nursing* 2003; 19: 241-51.

102. Rydvall A, Lynöe N. Withholding and Withdrawing Treatment: a comparative study of the ethical reasoning of physicians and the general public. *Critical Care* 2008; 12 R 13. doi: 10.1186/cc6786.

103. Sjökvist P, Nilstun T, Svantesson M, Berggren L. Withdrawal of life support - who should decide? Difference in attitudes among the general public, nurses and physicians. *Intensive Care Medicine* 1999; 25: 949-54.

104. Rosèn P, Karlbergt I. Opinions of Swedish citizens, health care politicians, administrators and doctors on rationing and health care financing. *Health Expectations* 2002; 5: 148-55.

105. Ohno-Machado L, Resnic F, Matheny M. Prognosis in critical care. *Annual review of Biomedical Energieering* 2006; 8: 567-99.

106. de Rooij SE, Abu-Hanna A, Levi M, de Jonge E. Factors that predict outcome of intensive care treatment in very elderly patients: a review. *Critical Care Clinics* 2005; 9: 307-14.

107. Needman D, Dowdy D, Mendez-Tellezz P, Herridge M, Pronovost P. Studying outcomes of intensive care unit survivors: measuring exposures and outcome. *Intensive Care Medicine* 2005; 31: 1153-60.

108. Joynt G, Gommersall C, Tan P, Lee A, Ai Yu Cheng C, Lai Yi Wong E. Prospective evaluation of patients refused admission to an intensive care unit: Triage, futility and outcome. *Intensive Care Medicine* 2001; 27: 1459-65.

109. Williams T, Dobb G, Finn CJ, Knuiman MK, Geelhoed E, Webb S. Determinants of long term survival after intensive care*. *Critical Care Medicine* 2008; 36: 1523-30.

110. Williams TA, Dobb G, Finn JC, Webb S. Long-term survival from intensive care: a review. *Intensive Care Medicine* 2005; 31: 1306-15.

111. Sinuff T, Adhikari NK, Cook DJ, Schunemann HJ, Griffith LE, Rocker G, et al. Mortality predictions in the intensive care unit: comparing physicians with scoring systems. *Critical Care Medicine* 2006; 34: 878-85.

112. Berge K, Maiers D, Schreiner D, Jewell S, Bechtle P, Schröder D, et al. Resource Utilization and Outcome in Gravely Ill Intensive Care Patients In hospital Mortality Rates of 95% or higher by Apache III score: The realtionship With Physicians and Family expectations. *Mayo Clinic Proceedings* 2005; 80: 166-73.

113. Haagensen R, Jamtli B, Moen H, Stokland O. Experiences with scoring systems SAPS II and NEMS for registration of activity in an intensive care unit. *Tidsskrift for Norsk Legeforening* 2001; 6: 687-90. (In Norwegian)

114. Moreno R, Metnitz P, Almeida E, Jordan B, Bauer p, Campos RA, et al. SAPS 3- From Evaluation of the patient to evaluation of the intensive care unit. Part ": Developemnet of a prognostic model for hospital mortality at ICU admission. *Intensive Care Medicine* 2005; 31: 1345-55.

115. Talmor D, Shapiro N, Greenberg D, Stone P, Neumann PJ. When is critical care medicine cost-effective? A systematic review of the cost-effectiveness literature. *Critical Care Medecine* 2006; 34: 2738-47.

116. Flåtten H, Kvåle R. Cost of intensive care in a Norwegian University hospital 1997-1999. *Critical Care* 2003; 7: 72-8.

117. Carlsen B, Norheim O. "Saying no is no easy matter". A qualitative study of comparing concerns in rationing decisions in general practice. *BMC Health Services Research* 2005; 70.

118. Førde R, Pedersen R, Nortvedt P, Aasland O. Får eldreomsorgen nok ressurser? (Enough resources to the care of the elderly?) Tidsskrift for Den Norske Lægeforening. 2006; 10: 126:1913-6. (In Norwegian)

119. Pedersen R, Nortvedt P, Slettebø Å, Grøthe KH, Kirkevold M, Nordhaug M, et al. In Quest of Justice? Clinical prioritisation in health care for the aged. Journal of Medical Ethics. 2008; 34: 230-235.

120. Tranøy KE. *Medisinsk etikk i vår tid.* 2nd ed: Fagbokforlaget; 2005. (Medical Ethics in our time) (In Norwegian).

121. Tollefsen T, Syse H, Nicholaysen RF. *Tenkere og ideer.* (Thinkers and ideas) Oslo: Ad Notam Gyldendal; 1998. (In Norwegian).

122. Den Norske legeforening. Etiske regler for leger. 1961/2002 http://www.legeforeningen.no/id/485.1

123. Sykepleierforbundet / ICN. Yrkesetiske retningslinjer for sykepleiere. 1977/2007 www.icn.ch/icncodenorwegian.pdf

124. Nord E, Street RJ, Kuhse H, Singer P. Maximizing health benefits vs egatilarism: An Australian survey of health issues. *Social Science & Medicine* 1995; 41: 1429-37.

125. Skolbekken J. The Risk Epidemic in Medical Journals. *Social Science & Medicine* 1995; 40: 291-305.

126. Fredriksen S. Bad luck and the tragedy of modern medicine. Doctoral thesis. Oslo: University of Olso; 2005.

127. Tanenbaum S. Uncertainty, consultation and the context of medical care. *British Medical Journal* 2005; 330: 515.

128. Day L. Distributive justice and personal responsibility for choices about health. *American Journal of Critical Care* 2006; 15: 96-8.

129. Om verdiar for den norske helsetenesta. Stortingsmelding nr. 26 (1999-2000) Oslo: Directorate of Health and Social Affairs. (www.regjeringen.no/nb/dep/.../1.html?id)

130. Emanuel E. Justice and Managed Care. Four Principles for the Just Allocation of Health Care Resources. *Hasting Center Report* 2000; 30: 3-8.

131. Daniels N, Sabin JE. *Setting Limits Fairly. Can We Learn to Share Medical Resources?* 1st ed: Oxford University press; 2002.

132. Collste G. Should every human being get health care? Priorities in health care and the Principle of Human Dignity. *Ethical Perspectives* 1999; 6: 115-25.

133. Norheim O. Hva hindrer åpenhet op prioriteringer? Tidsskrift for Norsk velferdsforskning. 2005; 15: 34-42. (In Norwegian)

134. Mielke J, Martin DK, Singer PA. Priority setting in a hospital critical care unit: qualitative case study. *Critical Care Medicine* 2003; 31: 2764-8.

135. Walton N, Martin DK, Peter EH, Pringle DM, Singer PA. Priority setting and cardiac surgery: A qualitative case study. *Health Policy* 2006; 1907: 1-15.

136. Nortvedt P. Etisk teoridebatt - forholdet mellom lojalitet og rettferdighet i helse fag. In: (ed.) Slettebø Å, Nortvedt P. *Etikk for helsefagene*. Gyldendal Akademisk; 2006. p. 50-61.

137. Nortvedt P. Needs, closeness and responsibilities. An inquiry into some rival moral considerations in nursing care. *Nursing Philosophy* 2001; 2: 112-21.

138. Nortvedt P, Nordhaug M. The principle and problem of proximity in ethics. *Journal of Medical Ethics* 2008; 34: 156-61.

139. Vetlesen AJ, Nortvedt P. *Følelser og Moral*. (Emotions and Morality) 2nd ed. Oslo: ad Notam Gyldendal; 2000. (In Norwegian)

140. Nortvedt P. Subjectivity and vulnerability: reflections on the foundation of ethical sensibility. *Nursing Philosophy* 2003; 3: 222-30.

141. Martinsen K. *Øyet og kallet*. Bergen: Fagbokforlaget; 2001.

142. Martinsen K. *Fra Marx til Løgstrup*. Oslo: Tano Aschehoug; 1996.

143. Nortvedt P. Clinical sensitivity: the inseparability of ethical perceptiveness and clinical knowledge. *Scholarly Inquiry for Nursing Practice* 2001; 15: 25-43.

144. Scheffler S. *Relationships and Responsibilities.* Oxford: Oxford University press; 2001.

145. Fangen K. *Deltagende observasjon.* (Participant observation) Bergen: Fagbokforl.; 2004. (In Norwegian).

146. Kvale S. *Interviews: an introduction to qualitative research interviewing.* Thousand Oaks, California: Sage; 1996.

147. Kvale S. Det kvalitative forskningsintervju. (InterViews) 1st ed. Oslo: ad Notam Gyldendal; 1997. (In Norwegian).

148. Nortvedt P, Grimen H. *Sensibilitet og refleksjon: filosofi og vitenskapsteori for helsefag.* (Sensibility and reflection: Philosophy and theory of science for health care) Oslo: Gyldendal Akademisk; 2004. (In Norwegian).

149. Carpenter DR. Phenomenology as Method. In (ed.): Streubert HJ, Carpenter DR: *Qualitative Research in Nursing. Advancing the Humanistic Imperative.* 2nd ed. Philadelphia: Lippincott; 1999.

150. Crotty M. *Phenomenology and Nursing Research.* Melbourne: Churchill Livingstone; 1996.

151. Thornquist E. *Vitenskapsfilosofi og vitenskpapsteori*. (Philosophy of Science and theory of Science) Bergen: Fagbokforlaget; 2003. (In Norwegian).

152. Lykkeslet E, Gjengedal E. Methodological Problems Associated With Practice-Close Research. *Qualitative Health Research 2*007; 17: 699-704.

153. Malterud K. *Kvalitative Metoder i medisinsk forskning: en innføring.* (Qualitative methods in medical research) Oslo: Universitetsforlaget; 2003. (In Norwegian).

154. Jenks JM. Triangulation as a Qualitative Research Strategy. In (ed.): Streubert H, Carpenter D: *Qualitative Research in Nursing. Advancing the Humanistic Imperative.* 2nd ed. Philadelphia: Lippincott; 1999. p 229-308.

155. Streubert H, ed. Philosophy and Theory: Foundation of Qualitative Research. In (ed.): Streubert H, Carpenter D: *Qualitative Research in Nursing. Advancing the Humanistic Imperative.*. 2nd ed. Philadelphia: Lippincott, 1999. p 2-12.

156. Streubert H, ed. The Conduct of Qualitative Research: Common Essential Elements. In: Streubert H, Carpenter D: *Qualitative Research in Nursing. Advancing the Humanistic Imperative.* ed. 2nd ed Philadelphia: Lippincott; 1999. p.15-30.

157. Koch T. Establishing rigour in qualitative research: the decision trial. *Journal of Advanced Nursing.* 1994 / 2006; 19: 976-86. (reprint).

158. Porter S. Validity, trustworthiness and rigour: reasserting realism in qualitative research. *Journal of Advanced Nursing*. 2007; 60: 79-86.

159. Rolfe G. Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Nursing research*. 2004:304-10.

160. Storli SL, Lindseth A, Asplund K. A journey in quest of meaning: a hermeneutic-phenomenological study on living memories from intensive care. *Nursing Critical Care*. 2008; 13: 86-96.

161. Giacomini MK, Cook DJ. Users' guide to the medical literature XXIII. Qualitative Research in Health Care B. What Are the Results and How Do They Help Me Care for My patients? *JAMA*. 2000; 284: 478-82.

162. Miller T, Bell L. Consenting to what? Issues of Access, Gate-keeping and 'Informed' Consent. In (ed.): Miller T, Jesspo J. *Ethics in qualitative research.* London: SAGE; 2002. p. 53-70.

163. Ruyter K. *Forskningsetikk : beskyttelse av enkeltpersoner og samfunn*. (Research Ethics: Protection of individuals) Oslo: Gyldendal akademisk; 2003. (In Norwegian).

164. Røykenes K. Metodetriangulering - et metodisk minefelt eller berikelse av fenomener? (Triangulation - a methodological mine-field or an enrichment of phenomenon?) *Forskning*. 2008; 4: 24-6. (In Norwegian).

165. Murphy E, Dingwall R. Informed consent, anticipatory regulation and ethnographic practice. *Social Science & Medicine* 2007; 65: 2223-34.

166. Burgess M. Proposing modesty for informed consent. *Social Science & Medicine* 2007; 65: 2284-95.

167. Reiter-Theil S. Does empirical research make bioethics more relevant? "The embedded researcher" as a methodological approach. *Medicine, Health Care and Philosophy* 2004;7:17-29.

168. Streubert H. Ethnography as Method. In (ed.): Streubert H, Carpenter D, *Qualitative Research in Nursing*. 2nd ed. New York: Lippincott, 1999. p. 145-169.

169. DPyipna C. Challenges of collecting data in the clinical setting. *Nursing Times Research* 2004; 9: 131-40.

170. Parker M. Ethnography and ethics. Social Science & Medicine. 2007; 65: 2248-59.

171. Boulton M, Parker M. Informed consent in a changing environment. *Social Science & Medicine* 2007; 65: 2187-98.

172. Heggen K. *Sykehuset som "klasserom": praksisopplæring i profesjonsutdanninger*. (The hospital as "class-room") Oslo: Universitetsforlaget, 1995. (In Norwegian).

173. Hummelvoll J, da Silva A. Det kvalitative forskningsintervju som metode for å nærme seg den psykiatriske sykepleiers profesjonelle livsverden i kommunehelsetjenesten. *Vård i Norden*. 1996; 16: 25-32.

174. Grimen H. *Hva er tillit?* Oslo: Gyldendal Akademiske; 2009.

175. Lillemoen L. Det er bare sånn jeg er...En undersøkelse om sykepleierstudenters utvikling av moralsk opptreden ("This is how I am"- A study of student nurses' moral development) (Monography). Oslo: University of Oslo; 2008. (In Norwegian)

176. Silverman H, Druml C, Lemaire F, Nelson R, European Union D. The European Union Directive and the protection of incapacitated subjects in research: an ethical analysis. *Intensive Care Medicine* 2004 Sep; 30: 1723-9.

177. Silverman H, Lemaire F. Ethics and research in critical care. *Intensive Care Medicine* 2006; 32: 1697-705.

178. Troug R. Will ethical requirements bring critical care research to a halt? *Intensive Care Medicine*. 2005; 31: 338-44.

179. Beecher HK. Ethics and clinical research. *The New England Journal of Medicine / Bulletin of The World Health Organization*. 1966;274 / 79: reprinted pages1354-60.

180. World Medical Association: Declaration of Helsinki: 1964 /2008. www.wma.net/e/ethicsunit/helsinki.htm

181. Directive 2001/20 EC of the European Parliament and Council of 4 April 2001. europa.eu/eur-lex/pri/en/oj/.../l_12120010501en00340044.pdf

182. Lemaire F. A European Directive for clinical research. *Intensive Care Medicine*. 2003; 29: 1818-20.

183. Luce JM. Research ethics and consent in the intensive care unit. *Current Opinion in Critical Care*. 2003; 9: 540-4.

184. Luce J, Cook D, Martin T, Angus D, Boushey H, Curtis J, et al. The ethical conduct of clinical research involving critically ill patients in the United States and Canada: principles and recommendations. *American Journal of Respiratory & Critical Care Medicine* 2005; 15:172-787.

185. Myles PS, Tan N. Reporting of Ethical Approval and Informed Consent in Clinical Research. *Anaesthesiology* 2003; 99:1209-13.

186. Hurst S, Slowther A-M, Førde R, Pegoraro R, Reiter-Theil S, Perrier A, et al. Prevalence and Determinants of Physicians Bedside Rationing: Data from Europe. *Journal of General Internal Medicine* 2006; 21: 1138-43.

187. Nortvedt P, Andersen B, Brinchmann B, Førde R, et al. *År til livene eller liv til årene? Kliniske prioriteringer i helsetjenesten til syke gamle*. (Years to life or life to years? Clinical priorities in health care of the aged) Report: The Directorate of health and Social Affairs /University of Oslo. Section for medical Ethics; 2006. (In Norwegian).

188. Hem M, Heggen K, Ruyter K. Questionable Requirement for Consent in Observational Research in Psychiatry. *Nursing Ethics* 2008; 14: 41-53.

189. Koski G. Research ethics and the intensive care unit: getting behind the wheel. *Critical Care Medicine*. 2003; 31: 119-20.

190. Grøthe KH. *Intensivmottaket: et livsavgjørende møte : mottak av akutt kritisk syk pasient i intensivavdelingen. En fenomenologisk studie*. (Admitting the intensive care patient: a life decisive meeting. A phenomenological study) Master thesis. Institute of Nursing Science, University of Oslo; 2002. (In Norwegian).

191. Hurst S, Perrier A, Pegoraro R, Reiter-Theil S. Ethical Difficulties in clinical practice: experiences of European doctors. *Journal of Medical Ethics* 2007;33(1):51.

192. Mesel T. *Profesjonell i klemme. en studie av 21 sykehuslegers refleksjon over seg selv som profesjonsetiske subjekter* (Monographic thesis). Oslo: University of Olso; 2009. (In Norwegian)

193. Jones J. The Nature of Dilemmas in ICU. In: Draper H, Scott W, In (ed.): *Ethics in Anaesthesia and Intensive Care*: Edinburgh: Butterworth Heinemann. Elsevier Science, 2003. p 163-175

194. Førde R, Aasland O. Moral distress among Norwegian doctors. *Journal of Medical Ethics* 2008; 34:521-5.

195. Fassier T, Laurette A, Chiroldi M, Azoulay E. Care at the end of life in critically ill patients: The European perspective. *Current Opinion in Critical Care* 2005; 11:616-23.

196. Førde R, Pedersen R, Akre V. Clinicians' evaluation of clinical ethics consultations in Norway: a qualitative study. *Medicine, health Care and Philosophy* 2008; 11: 17-25.

197. Schneidermann L, Gilmer T, Teetzel H, Dugan D, J B, Cranford R, et al. Effect of Ethics Consultations on Nonbeneficial Life-Sustaining treatments in the Intensive Care Setting - A Randomized Controlled Trial. *JAMA* 2003;290:166-1172.

198. Fins JJ, Solomon MZ. Communication in intensive care settings: the challenge of futility disputes. *Critical Care Medicine* 2001; 29: 10-5.

199. Wenstone R. Resource Allocation in Critical Care. In (ed.): Draper H, Scott W. *Ethics and Anaesthesia and Intensive Care,* Edinburgh: Butterworth Heinemann. Elsevier Science, 2003. p 145-155.

200. Kollef M. Prevention of hospital-associated pneumonia and ventilator associated pneumonia. *Critical Care Medicine* 2006; 32: 1396-405.

201. Mitchell M, Levi M, Mc Bride D. End of life in the intensive care unit: State of the art in 2006. *Critical Care Medicine* 2006; 34: 306-308.

202. Kahn J, Angus DC. Reducing the Cost of Critical Care: New Challenges, New Solutions. *American Journal of Respiratory & Critical Care Medicine* 2006;174: 1167-70.

203. Arnesen TM. *Counting Health?* Oslo: Doctoral thesis. The Faculty of Medicine, University of Oslo; 2005.

204. Ulvik A, R K, T W-L, Flåtten H. Quality of life 2-7 years after major trauma. *Acta Anaesthesiologica Scandinavia.* 2008; 52: 195-201.

205. Lindèn V, Lidegran, G, Frìsen G, Dahlgren B, Frenckner B, Larsen F. ECMO in ARDS: a long-term follow-up study regarding pulmonary morphorolgy and function and health related quality of life. *Acta Anaesthesiologica Scandinavia* 2009; 53; 489-485.

206. Rooij SE, Ameen A-H, Levi M, de Jonge E. Factors that predict prognosis of intensive care treatment in the very elderly patients: a review. *Critical Care* 2005; 9: R307-R14.

207. Nasjonal veileder for begrensning av livsforlengende behandling hos alvorlig syke og døende. [1]http://www.helsedirektoratet.no/publikasjoner/veiledere/nasjonal_veileder_for_beslutningsprosesser_for_begrensning_av_livsforlengende_behandling_hos_alvorlig_syke_og_d_ende_400374 (accessed May 14th 2009)

208. Calibresi B, Bobbitt P. *Tragic Choice*. New York: W.W Norton Company; 1978.

209. Cook D. Withdrawal of Mechanical Ventilation in Anticipation of Death in ICU. *New English Journal of Medicine* 2003; 349: 1123-32.

210. Sinuff T, Cook D, Rocker G, Griffith L, Walter S, Fisher M, et al. DNR directives are established early in mechanically ventilated intensive care unit patients. *Canadian Journal of Anaesthesia*. 2004; 51: 1034-41.

211. Sinuff T, Cook D. Guidelines in the intensive care unit. *Clinics in Chest Medicine*. 2003; 24: 739-49.

212. Album D, Westin S. Do diseases have a prestige hierarchy? A survey among physicians and medical students. Social Science & Medicine. 2007; 66: 182-8.

213. Nortvedt P, Pedersen R, Grøthe KH, Slettebø Å, Nordhaug M, Kirkevold M, et al. Professional roles in clinical prioritisations of health care for the aged. *Journal of Medical Ethics*. 2008; 34: 332-335.

214. Henriksen JO, Vetlesen AJ. *Nærhet og distanse*. (Closeness and distance) Oslo: Gyldendal Akademiske; 1997. (In Norwegian).

215. Grøthe KH. Intensivpasienten. (The intensive care patient). In (ed.): Bjørk, IT, Helset S, Nortvedt F. *Møte mellom pasient og sykepleier.* (The meeting between patient and nurse) Oslo: Gyldendal akademisk; 2002. p. 97-110. (In Norwegian)

216. Skirbekk H. Negotiated or taken for granted trust? Explicit and implicit interpretation of trust in a medical setting. *Medicine, Health Care and Philosophy.* 2009; 12: 3-7.

217. Phee SJ, W RM, Pantilat SZ, Markowitz AJ, Winker MA. Finding our way out - Perspectives on Care at the Close of Life. *JAMA*. 2000; 15: 2512-3.

ARTICLE I

Halvorsen K, Førde R, Nortvedt P. Professional Challenges of Bedside Rationing in Intensive Care. *Nursing Ethics* 2008; 15; 715-727

ARTICLE II

Halvorsen K, Førde R, Nortvedt P. Value choices and considerations when limiting intensive care treatment: a qualitative study. *Acta Anaesthesiologica Scandinavia* 2009; 53; 10-17

ARTICLE III

Halvorsen K, Førde R, Nortvedt P. The principle of justice in patient priorities in the intensive care unit: the role of significant others. *Journal of Medical Ethics* 2009; in press.

List of attachments

1. General information to employers in the intensive care units
2. Information for families
3. Information for respondents
4. Consent form (in Norwegian and English)
5. Observation guide
6. Interview guide ICU physicians
7. Interview guide ICU nurses / nurses

UNIVERSITETET I OSLO

Institutt for allmenn- og samfunnsmedisin
Seksjon for medisinsk etikk
Frederik Holsts Hus
Ullevål Terrasse/Ullevål sykehus
Postboks 1130 Blindern
0318 Oslo

DET MEDISINSKE FAKULTET

Generell informasjon til leger og sykepleiere vedrørende doktorgradsprosjektet ”Etikk og prioritering – Prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie.”

Stipendiat Kristin Halvorsen Grøthe vil gjennomføre deler av sitt doktorgradsarbeid i medisinsk etikk ved ....

Hensikten med forskningen er å få økt kunnskap om hvilke verdivalg som ligger til grunn for prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie, særlig rettet mot å sette i gang, unnlate å sette i gang eller avslutte intensivbehandling.

Det er gitt tillatelse fra ledelsen ved .... til å benytte intensivavdelingen ved ....som forskningsfelt. Det skal til sammen gjøres empirisk arbeid ved tre intensivavdelinger i Norge.

Forskningssubjekter er intensivsykepleiere / sykepleiere og leger tilknyttet intensivavdelingen, og som er involvert i beslutningsprosesser relevant for studien. Datamaterialet vil samles inn via deltagende observasjon og dybdeintervju. Observasjonenes hensikt er å få innsyn i beslutningsprosesser vedrørende prioriteringer og få en større forståelse for den sammenheng hvor slike beslutningene fattes. Intervjuenes hensikt er å få bedre innsikt i grunnlaget for prioriteringsbeslutninger og eventuelle dilemma som aktualiseres.

Tillatelse til observasjon er gitt fra avdelingens ledelse. Dere vil bli forespurt om å være respondent. Ved forespørsel vil det foreligge en mer utfyllende informasjon om prosjektet, samt samtykkeerklæring. Tillatelse fra avdelingsledelse anses som et felles samtykke til observasjon i avdelingen, men du kan reservere deg mot å bli observert ved å si ifra til undertegnede.

Ytterligere informasjon kan også fåes gjennom å ta kontakt med stipendiat Kristin Halvorsen Grøthe i avdelingen, eller på tlf. 922 16 250, evt. på e. post k.h.grothe@medisin.uio.no

Prosjektet er tilknyttet Seksjon for medisinsk etikk, UiO og ledet av førsteamanuensis dr. Polit. Per Nortvedt. Veiledere er Per Nortvedt og professor dr. Med. Reidun Førde.

Studien er godkjent i Regional Etisk Komité (REK) og meldt til personvernombudet for forskning (NSD).

Med vennlig hilsen

Kristin Halvorsen Grøthe (sign.)
stipendiat

UNIVERSITETET I OSLO

Til orientering!

Stipendiat Kristin Halvorsen Grøthe gjennomfører deler av sin doktorgrad i medisinsk etikk ved........i tidsrommet .... 2005. Grøthe er intensivsykepleier og doktorgradsstipendiat ved Seksjon for medisinske etikk, Det medisinske fakultet, Universitetet i Oslo.

Doktorgradsprosjektet hun arbeider med skal bidra til å gi økte kunnskaper om prioriteringsetiske dilemma i intensivmedisin og intensivsykepleie. Flere av avdelingens leger og sykepleiere deltar i forskningen gjennom å bli observert i sitt daglige arbeid.

Ingen pasienter er direkte involvert i forskningen, men siden stipendiaten observerer avdelingens leger og sykepleiere, vil hun få innsyn i pasientsituasjoner.

Stipendiaten har taushetsplikt. Ingen konkrete pasientopplysninger vil bli benyttet i forskningen. All informasjon som tilføres gjennom de som deltar i prosjektet vil bli anonymisert og alle opplysninger behandles konfidensielt.

Som pårørende kan du reservere deg mot at det gjøres observasjoner av leger og sykepleiere i tilknytning til en av dine nærmeste. Gi da beskjed til ansvarshavende intensivsykepleier eller den intensivsykepleier / sykepleier som har ansvar for han eller henne du er pårørende for.

Hvis du ønsker flere opplysninger, ta gjerne kontakt med stipendiaten når du ser henne.

Oslo ....

Kristin Halvorsen Grøthe
PhD stipendiat

UNIVERSITETET I OSLO

Institutt for allmenn- og samfunnsmedisin
Seksjon for medisinsk etikk
Frederik Holsts Hus
Ullevål Terrasse/Ullevål sykehus
Postboks 1130 Blindern
0318 Oslo

DET MEDISINSKE FAKULTET

Informasjonsskriv til leger og sykepleiere som vil være respondenter i doktorgradsprosjektet
”Etikk og prioritering – Prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie.”

Dette doktorgradsprosjektet har til hensikt å få økt kunnskap om hvilke etiske hensyn og verdivalg som ligger til grunn for både leger og sykepleieres prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie. Jeg ønsker å blant annet å få mer kunnskap om hvilke prioriteringsetiske dilemmaer som er mest fremtredende i den kliniske hverdag, hvordan det prioriteres og prioriteringenes beslutningsgrunnlag. Arbeidet er spesielt rettet mot prioriteringsbeslutninger relatert til å sette i gang, unnlate å sette i gang eller avslutte intensivbehandling og sykepleie, men vil også være åpent for eventuelle andre situasjoner hvor prioriteringer involverer etisk vanskelige beslutninger. I en tid med sterkt press på prioritering av helsetjenester, økonomi og ressursbegrensninger er dette doktorgradsarbeidet viktig i forhold til nåværende og fremtidig intensivbehandling og sykepleie. Jeg håper derfor at du vil stille deg positivt til å delta.

Det er gitt tillatelse fra ledelsen ved ….til å gjennomføre deler av studien ved intensivavdelingen, …. Universitetssykehus, …..

Datamaterialet skal samles inn via deltagende observasjon og dybdeintervju. Dette innebærer at jeg vil være en god del tilstede i avdelingen og ønsker mulighet til i bli inkludert i både leger og sykepleieres arbeid. Å være inkludert, betyr ikke at jeg skal gjøre det samme arbeid som dere. Sammen med intensivsykepleiere og sykepleiere, kan jeg evt. hjelpe til i enkelte gjøremål, som stell, snuing etc. Dette kan forsvares da jeg har lang klinisk erfaring som intensivsykepleier. Det er nødvendig at jeg får være med der prioriteringer diskuteres, vurderes og beslutninger fattes, som eks. previsitter, visitter, behandlingsmøter, rapporter etc. Jeg skal, i tillegg til observasjonene, også gjøre noen dybdeintervjuer med leger og intensivsykepleiere / sykepleiere. De vil vare ca. ½ - 1 time, tas opp på minidisk, for så å bli nedskrevet, anonymt. Observasjoner og intervju vil følge en fleksibel guide som til enhver tid vil være tilgjengelig for innsyn. De første 3-4 uker anses som en pilotperiode, slik at dere skal bli kjent med meg og for å finne hensiktsmessige former på observasjon og intervju.

For å delta i studien må det undertegnes et *skriftlig informert samtykke*. Respondentenes anonymitet og konfidensialitet vil være i varetatt. Alt datamaterialet blir anonymisert. Deltagelse i studien er frivillig og du kan trekke deg når som helst i prosessen, uten noen uheldige konsekvenser for deg. Dataene du da har tilført prosjektet vil bli makulert og ikke benyttet som en del av det empiriske materialet.

Det er nødvendig å presisere at ingen pasientsituasjoner vil bli benyttet direkte i prosjektet og det vil ikke gjengis noe i datamaterialet som kan være en trussel for pasientens anonymitet. Pasientsituasjonene vil kun danne et ”bakteppe” i datasamlingen, for bedre å forstå forhold som blant annet kontekst, beslutningsprosesser, beslutningsgrunnlag, hvordan dilemma kan aktualiseres og om det er fellestrekk til andre prioriteringssituasjoner.

Studien er godkjent i Regional Etisk Komité (REK) og meldt til personvernombudet for forskning (NSD). Doktorgradsarbeidet er tilknyttet seksjon for medisinsk etikk, Universitetet i Oslo og finansiert av Høgskolen i Akershus, avdeling for sykepleie, hvor jeg har 25 % arbeidsplikt. Prosjektleder og hovedveileder er førsteamanuensis, dr. Polit. Per Nortvedt. Biveileder er professor dr. Med. Reidun Førde.

Eventuelle spørsmål kan rettes til stipendiat Kristin Halvorsen Grøthe, tlf. 922 16 250, e. post. k.h.grothe@medisin.uio.no, evt. prosjektleder Per Nortvedt, tlf. 22844646, e. post. p.nortvedt@medisin.uio.no.

Ved ønske om deltagelse returneres samtykkeerklæringen i vedlagte frankerte konvolutt så snart du har bestemt deg.

Med vennlig hilsen

Kristin Halvorsen Grøthe
stipendiat

Vedlegg 1: Samtykkeerklæring med frankert returkonvolutt

UNIVERSITETET I OSLO

Institutt for allmenn- og samfunnsmedisin
Seksjon for medisinsk etikk
Frederik Holsts Hus
Ullevål Terrasse/Ullevål sykehus
Postboks 1130 Blindern
0318 Oslo

SKRIFTLIG INFORMERT SAMTYKKE

Til intensivleger, intensivsykepleiere og sykepleiere som er villige til å være respondenter i doktorgradsprosjektet *"Etikk og prioritering – Prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie"*.

Hensikten med doktorgradsarbeidet er å få økt kunnskap om hvilke verdivalg som ligger til grunn for prioriteringsbeslutninger i klinisk intensivmedisin og intensivsykepleie, særlig rettet mot å sette i gang, unnlate å sette i gang eller avslutte intensivbehandling og intensivsykepleie.

Når du sier deg villig til å være informant må du undertegne dette *frivillig skriftlig informert samtykke*. Jeg ber om at du leser denne samtykkeerklæringen godt. Din signerte retur av samtykkeerklæringen betraktes som ditt samtykke. Samtykkeerklæringen returneres i vedlagte frankerte konvolutt.

Gjennom innlevering av samtykkeerklæring bekrefter du:

Jeg har lest all informasjon om prosjektet og gjort meg kjent med forskningens hensikt.

Jeg er informert om at å være respondent er frivillig og at jeg kan trekke meg når jeg eventuelt skulle ønske det, uten noen uheldige konsekvenser for meg. Jeg vet at, hvis jeg trekker meg, vil alt datamaterialet jeg har gitt fra meg umiddelbart bli makulert, og ikke benyttet i studien.

Jeg er innforstått med at min anonymitet og konfidensialitet er sikret i behandling av datamaterialet.

På bakgrunn av den informasjon jeg har fått om doktorgradsprosjektet sier jeg meg villig til å delta.

Yrkestittel ____

Dato / sted ____________________ Signatur ______________________________________

UNIVERSITETET I OSLO

Institutt for allmenn- og samfunnsmedisin
Seksjon for medisinsk etikk
Frederik Holsts Hus
Ullevål Terrasse/Ullevål sykehus
Postboks 1130 Blindern
0318 Oslo

WRITTEN INFORMED CONSENT

Dear anaesthesiologists / intensivists, intensive care nurses and registered nurses, who are willing to be respondents in the PhD project *”The ethics of bedside priorities in intensive care medicine and intensive care nursing”*

The objective of the PhD project is to gain knowledge on value choices of bedside priorities in clinical intensive care, focusing in particular on deliberations and decisions of limiting intensive care treatment.

As you are willing to participate as respondent of the study, you may please sign this *free, written, informed consent.* You are asked to carefully read the consent-form before signing. Your signature is considered as your consent. The consent-form may be returned to the researcher in the enclosed, stamped envelope.

By returning this informed consent you confirm:

I have written all information of the project and am familiar with the objective of the research.

I am informed of being a respondent is voluntary and that I have the opportunity to withdraw whenever I prefer, without any unfortunate consequences. I know that if withdraw; all data from me will be maculated immediately and will not be of any use in the study.

I understand and trust that my anonymity and confidentiality is secured when dealing with the data material.

On behalf of the information I have been given of the PhD project, I am willing to participate.

Profession ____

Date / Place __________________Signature ___________________________________

Observation guide

Situation description

What is the situation about?
General description with no threat to identifiable information
Time aspect:

- When did the discussion of limiting treatment occur?

How is the actual context?

- Bed availability
- Beds filled up
- Personnel
- Pressure from “not yet arrived patients”

Decision- making processes

Who are involved in the discussions and decision-making processes?

- Which professions, significant others?
- How many?
- The role of actors?
    - What is the role of the nurses in these decisions?
- Do the decision-makers seem to agree?
- How does disagreement seem to be transparent?
    - Professional disagreement?
    - Disagreements with relatives?

Decision considerations - Criteria and values

What are the main considerations during discussions of further patient treatment?

- Prognoses
- Benefit
- Do they refer to any documentation of benefit and effect?
- Life quality
- Are value questions discussed? How?
- Patient wishes / significant others?
- Does anyone refer to any severity scales?
- How is severity of illness taken into considerations?
- Are there discussions about resource use?
- Are costs taken into consideration in medical treatment or in nursing care?
- Is just delivering of treatment and care discussed in any ways?
- How is benefit of treatment for one patient related to other patients?
- Are patients being weighed against each other in any ways?
- Does it seem like illegitimate criteria like attitudes towards self responsibility for illness have any kind of influence on priority decisions? How; if it does?
- Does there seem like there are differences in how patients are treated on the background of who they are?

Final arguments

What seem to be the most weighty and final arguments in the decisions whether to limit treatment or not?

Priority dilemma

Have any prominent priority dilemma been discussed or illuminated?
Do anyone illuminate and / -or discuss treatment and/ -or care that seem to be in conflict with the professional ethics?

- How do these seem to relate to the patients medical needs?
- How do they seem to relate to nursing needs?
- How do they seem to relate to value issues?

Personal reflections

What are my reflections of what I observe during the day?

- My feelings and thoughts?
- Reflection on preconceptions?
- How do I understand what that is happening?

Interview guide physicians

Demographic data:

- Profession
- Speciality
- Position
- Years educated as a physician
- Years working with intensive care medicine
- Years working in this intensive care unit
- Other work experience
- Gender
- Age

Interview questions:

You have recently been in a situation where intensive care treatment was limited. Can you please narrate experiences from that situation?

What did you in particular considered as important in the decision-making?

- How are usually the decision-making processes?
- Who are involved?
- How was it in this particular situation?

How do you collaborate with the nurses in decisions about limit ICU treatment?

- What do the nurses considerations mean for your decision-making?
- What did it mean in this particular situation?

How do patients and significant others preferences influence the decision-making process?

- How is it to agree with significant others in decisions to limit ICU treatment?
- What role do they play?
- Was it of importance in this particular situation?

How is it to agree on decisions on limiting intensive care treatment between the professions?

- What characterises the most prominent disagreements?
- Between whom is disagreement most frequently experienced?
- When do disagreements occur?
- How was it to agree in this particular situation?

What do you consider as the most prominent priority dilemma in your everyday practice?

Are there any situations where you think you can not take care of what you consider as good and necessary medical treatment of intensive care patients?

- What characterise these situations (if they exist)?

In what ways do you consider cost of treatment when you make treatment decisions?

How does resource consideration influence priorities of limiting intensive care treatment?

- In relation to withdraw / withhold
- On a daily basis in patient treatment and care
- What is your general impression of resource access into ICU?
- Did resource scarcity in any way influence this particular situation?

How do you consider age as a criterion in your decision-making whether to limit intensive care treatment?

- Did age mean anything on decisions with regard to this actual situation? How?
- Have you scaled down / scaled up ICU treatment due to age? Can you tell more about that?
- What do you consider as advanced age with regard to ICU treatment?

How can conditions related the patients "own responsibility" for his / her illness influence priority decisions?

- How can attitudes influence?
- Did these conditions have any impact in this actual situation?

How can conditions like social status and background have an impact on priority decisions?

How can gender, ethnicity, religion, geographic differences influence priority decisions?

- How did you consider these issues to influence the decision in this particular situation?

Do you discuss priorities in intensive care medicine among you physicians and with the nurses?
What do you discuss?
What are your concerns?

Do you / and if; how do you refer to the National Priority Criteria for health care when making priority decisions?

Do you have any kind of consensus to follow in this unit and how do you in that case experience the use of this?

Do you think that intensive care treatment can be suffering from arbitrariness sometimes? If you do; how does this happens?

When you are in situations where you refuse patients for intensive care treatment, what are your prominent considerations?

Is there anything you would like to say before we close up this interview?

Thank you very much for giving this interview!

Interview guide ICU nurses / nurses:

Demographic data:

- Profession
- Speciality
- Position
- Years educated as a nurse
- Years working with intensive care nursing
- Years working in this intensive care unit
- Other work experience
- Gender
- Age

Interview questions:

You have recently been in a situation where intensive care treatment was limited. Can you please narrate experiences from that situation?

What did you in particular considered as important in the decision-making?

- How are usually the decision-making processes?
- Who are involved?
- How was it in this particular situation?

How do you experience being listened to as a nurse in decisions about limit ICU treatment?

- How did you experience this in this particular situation?

How do patients and significant others preferences influence the decision-making process?

- Was it of importance in this particular situation, you think?
- How is it to agree with significant others about these decisions?

How is it to agree on decisions on limiting intensive care treatment between the professions?

- What characterises the most prominent disagreements?
- Between whom is disagreement most frequently experienced?
- When do disagreements occur?
- How was it to agree in this particular situation?

What do you consider as the most prominent priority dilemma in your everyday practice?

Are there any situations where you think you can not take care of what you consider as good and necessary nursing care for intensive care patients?

- What characterise these situations (if they exist)?

In what ways do you consider cost of treatment to be an issue in treatment decisions?
Are you concerned about costs in relation to nursing care / tasks etc.
How do you take cost into account, if you do?

How do you consider resource consideration influence priorities of limiting intensive care treatment?

- In relation to withdraw / withhold
- On a daily basis in patient treatment and care
- What is your general impression of resource access into ICU?
- Did you think resource scarcity in any way influence this particular situation?
- Did you have to scale down nursing care related to this particular situation?

How do you consider age as a criterion in decisions whether to limit intensive care treatment?

- Did age mean anything on decisions with regard to this actual situation? How?
- Have you experienced that ICU treatment is scaled down / scaled up due to age? Can you tell more about that?
- What do consider as advanced age with regard to ICU treatment?

How can conditions related the patients "own responsibility" for his / her illness influence priority decisions?

- How can attitudes influence?
- Did these conditions have any impact in this actual situation, you believe?

How can conditions like social status and background have an impact on priority decisions?
How can gender, ethnicity, religion, geographic differences influence priority decisions?

- How did you consider these issues to influence the decision in this particular situation?

Do you discuss priorities in intensive care medicine and nursing among you nurses and with the physicians?
What do you discuss? What are your concerns?

Do you / and how do you refer to the National Priority Criteria for health care when making priority decisions about nursing care to patients?

Do you know about any consensus with regard to limitation of ICU treatment? If you do; how do you in that case experience the use of this?

Do you think that intensive care treatment and nursing can be suffering from arbitrariness sometimes? If you do; how does this happens?

Is there anything you would like to say before we close up this interview?

Thank you very much for giving this interview!