

Family members' experiences of decision-making processes in the context of withholding or withdrawing treatment in the ICU

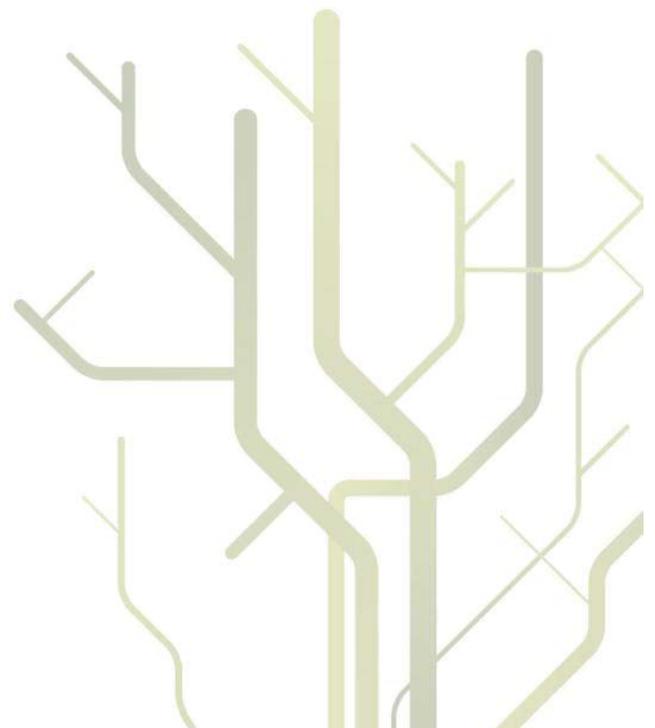
A qualitative interview study



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Lind, R., Lorem, G., Nortvedt, P., & Hevrøy, O. (2011). Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive Care Medicine*, 37(7), 1143-1150. doi: 10.1007/s00134-011-2253-x

Lind, R., Lorem, G. F., Nortvedt, P., & Hevrøy, O. (2012). Intensive care nurses' involvement in the end-of-life process – perspectives of relatives. *Nursing Ethics*, 19(5), 666-676. doi: 10.1177/0969733011433925

Lind, R., Nortvedt, P., Lorem, G., & Hevrøy, O. (2012). Family involvement in the end-of-life decisions of competent intensive care patients. *Nursing Ethics*. Published online 22 August 2012 doi: 10.1177/0969733012448969

Appendices

- 1: Letter of permission: Regional Ethical Committee (REK)
- 2: Letter of permission: Norwegian Social Science Data Services (NSD)
- 3: Request to ICUs to make a selection
- 4: Information for the respondents and Informed Consent Sheet
- 5: Interview guide
- 6: Time log for the research project

Abbreviations

- ICU Intensive Care Unit
EOL End-of-life

SAMMENDRAG

Avhandlingen tar utgangspunkt i beslutningsprosessen om avslutning av intensivbehandling. Intensivpasienter har ofte svekket bevissthet, og kan derfor mangle samtykkekompetanse. I slike tilfeller har helsepersonell beslutningsmyndighet, men i spørsmål som medfører et alvorlig inngrep for pasienten, skal det der det er mulig innhentes informasjon fra pasientens nærmeste pårørende om hva pasienten ville ha ønsket.

Bakgrunnen for å gjøre denne studien var at vi fra norsk intensivpraksis kjente lite til hvilke erfaringer pårørende hadde fra situasjoner der livsavgjørende beslutninger fattes på vegne av pasienter, og hvilke etiske og verdimeslige spørsmål pårørende opplever som kritiske. Avhandlingen undersøker derfor de etterlattes erfaringer fra beslutningsprosessen når behandling av intensivpasienter avsluttes.

Studien undersøkte hva delaktighet i beslutningsprosessen kunne innebære, hva det kunne bety å ha ansvar i slike situasjoner og om pårørende kjente pasientens preferanser for en slik situasjon. Spørsmål var også rettet mot familiens kommunikasjon med leger og sykepleiere.

Fire intensivavdelinger ved norske universitetssykehus foretok utvalg av potensielle deltakere. 21 kvalitative intervju med 27 pårørende til avdøde intensivpasienter ble analysert ved hjelp av to ulike kvalitative tilnærminger.

Det viktigste resultatet var at de fleste pårørende i studien hadde ønsket å være mer inkludert i beslutningsprosessen, for å kunne bidra med det de visste om pasientens preferanser og verdier. Bare et fåtall av familiene ble inkludert i en prosess over tid. Disse var svært godt fornøyd med måten de ble møtt på, omsorgen de ble vist, kommunikasjonen med helsepersonell og selve avslutningsprosessen. De andre familiene opplevde også å bli vist mye omsorg, men kommunikasjonen med leger var tilfeldig, for sjelden og kunne være krenkende. Familiene påpekte at sykepleiere deltok i liten grad i familiens møter med leger, og at sykepleierne formulerte seg vagt vedrørende behandlingsutsikter og prognose. Når behandlingen nærmet seg slutten, ble disse

familiene enten bare informert om at behandlingen skulle avsluttes, eller de ble informert og bedt om å gi sin tilslutning til beslutningen. Konsekvensene for de pårørende var usikkerhet om beslutningsgrunnlaget, opplevelse av ensomhet rundt ubesvarte spørsmål, usikkerhet om egen rolle og erfaring av ansvar for pasienten.

Studien konkluderer med at selv om kommunikasjon om behandlingsavslutning er krevende og situasjonsavhengig, kan likevel familiens perspektiv ivaretas bedre. Vi peker på flere konkrete forhold vi mener er av betydning for en forbedring av omstendigheter ved behandlingsavslutning. Fordi disse situasjonene er komplekse og sammensatte kan leger og sykepleiere for det første bli mer bevisst på og forholde seg til situasjonens etiske aspekter. Dernest mener vi det er nødvendig med mer trening på kommunikasjon med familier i etisk vanskelige situasjoner. Leger og sykepleiere kan og bør arbeide mer systematisk og planmessig som et team i tilnærming til pårørende.

ABSTRACT

This thesis is based on the decision-making process involved in treatment termination in intensive care. ICU patients often have impaired consciousness and may therefore lack capacity to consent. In such cases, the health care personnel have the decision-making authority, but where a serious intervention for the patient is involved, information should if possible be obtained from the patient's next-of-kin about what the patient would have wanted.

The reason for conducting this study was that we in Norwegian intensive care practice knew little of the experiences of family members from situations where life-critical decisions are made on behalf of patients and which ethical and value issues the families experience as crucial. This thesis therefore examines the experiences of bereaved family members from the decision-making process when treatment of ICU patients is terminated.

The study examined what participation in the decision-making process might involve, what it might signify to have responsibility in such situations and whether the family knew the patient's preferences for such a situation. Questions were also directed at the family's communication with doctors and nurses.

Four ICUs at Norwegian university hospitals selected potential participants. 21 qualitative interviews with 27 relatives of deceased ICU patients were analysed using two different qualitative approaches.

The most important finding was that most families in the study had wanted to be more included in the decision-making process, in order to contribute what they knew about the patient's preferences and values. Only a few of the families were included in a process over time. These were very satisfied with the way they were treated, the care they were shown, communication with clinicians and the termination process itself. The other families also experienced being shown much care, but communication with physicians was random, too seldom and could be disrespectful. The families pointed out that nurses generally did not attend family-physician meetings and nurses expressed themselves vaguely regarding treatment prospects and prognosis. When the end of treatment was

approaching, these families were either just informed that it was to be terminated or were informed and asked to consent to the decision. The consequences for the families were uncertainty about the basis for the decision, a sense of loneliness around unanswered questions, lack of clarity about their own role and a feeling of responsibility for the patient.

The study concludes that, even though communication about treatment termination is demanding and context-dependent, the family's perspective could still be given more consideration. We identify several specific factors which we believe to be important for the improvement of the circumstances around treatment termination. Because these situations are complex and compound, doctors and nurses could first of all become more aware of and relate to the ethical aspects of the situation. Secondly, we believe there is a need for more training in communication with families in ethically difficult situations. Doctors and nurses can and should work more systematically and methodically as a team in their approach to patients' families.

1 INTRODUCTION

1.1 My keen interest in the topic of the study

The idea for this research project stems from 2006, after important feedback from two relatives (next of kin)¹ of now deceased patients. The first feedback came in the form of a letter as early as 2001, in which the mother of a young adult wrote that it had been a tough decision for them to make as parents that the treatment of their daughter should be terminated. I had worked closely with the patient and her parents and siblings in the few days the treatment lasted. I had been involved in all conversations between the family and doctors, and I knew for certain that they were not held accountable for the decision. On the contrary, we had stressed as we always do that the decision was to be taken by the clinicians. How could they then be left with the perception they had? I never managed to shake off this disquiet, and discussed it with colleagues many times.

The other feedback also came from a parent of a young adult who had died in intensive care after a long illness. This time it was in the form of an interview in a national newspaper. This was in the wake of the “Kristina case”² in Bergen which shook the entire country in the winter of 2005/2006 by way of powerful and emotional media reports. The interview with “our” patient’s relative was of a similar nature to the letter I had received a few years earlier. He maintained that the hardest thing they had had to do as relatives was to decide that their son would be “taken off the respirator.” I discussed this interview with

¹ The term next of kin is closest to the Norwegian term “pårørende”. According to the definition in the Norwegian Patients’ Rights Act §1-3, the patient’s next of kin is: “the person whom the patient names as his or her kin or next of kin. If the patient is incapable of naming his or her next of kin, the next of kin shall be the person who to the greatest extent has had lasting and continuous contact with the patient, based however on the following order: spouse, registered partner, persons who live with the patient in a relationship resembling a marriage or partnership, children of full legal age and legal capacity, parents or other persons with parental responsibility, siblings of full legal age and legal capacity, grandparents, other family members who are close to the patient, guardian or provisional guardian.” In this study I will use the terms “family (member)” and “relative” as synonymous with next of kin. In international research, family is the term most used. In the methodology section I explain the relationships between the patients and family members in the study.

² Kristina was a four-year-old ICU patient, whose father strongly opposed treatment termination.

the attending physician who had followed the situation closely, and he too found it incomprehensible that they remained with the impression that the decision had been their responsibility. How could it be that the families' experiences are so different from ours? Do our procedures have a direct bearing on their experience of responsibility, or is their closeness to the patient so "binding" that they take full or partial responsibility for treatment termination decisions on the patient's behalf? How do we actually work with these difficult ethical decisions, as seen through the eyes of the relatives?

These experiences and thoughts aroused my keen interest in reviewing research on end-of-life decision making, in order to find a specific way to formulate suitable research questions for the topic in a Norwegian ICU context.

1.2 Review of the literature

In this chapter I review previous research about end-of-life (EOL) processes which forms a relevant reference framework for this study. There has been very extensive research on EOL in Intensive Care Units (ICU). The background to this study and the literature search that formed the basis for the research questions were of primary importance, but far from exhaustive. The references in the following review have been expanded from those employed when the study commenced, mainly to give the reader a broader introduction to the relevant EOL issues, but also because many of the references formed an important basis for my research as it evolved. However, for the initiated reader, the review of this research area may appear superficial and without clear boundaries. I have however attempted to be consistent with regard to the study's research questions in the literature selection, and have included additional research in the discussions in the articles and in the synoptic discussion section in the thesis. Much of the research on EOL in the ICU is conducted in the USA, where legislation gives family members proxy rights, with all the challenges this entails for communication and ethics. Some of the topics discussed in these studies are universal and generally applicable beyond the cultural context which emerges on the basis of US legislation. These include particularly communication, ethics, and the perspectives of families, nurses and doctors. There are also issues of general interest concerning conflict, although these largely relate to discussions about the termination of treatment, where families in a North American context have the last word.

Such issues may include discussions of prognosis and futility, where families and clinicians may have divergent views. I include some of this literature directly where relevant in the discussion section of the thesis.

Although this is a qualitative study, I have made a conscious effort to include articles from both quantitative and qualitative traditions. In my view, they can each in their own way shed light on the research field and help to provide important insights.

The literature search was mainly performed in large databases such as Cinahl, Pubmed, Medline and Web of Science. The search words relevant to the original basis for the study (ICU, end-of-life, decision making and family members) were later expanded with communication, ethics, nurses, relationship, collaboration, family participation, autonomy and competent patients. For some combinations of the search words I added subscriptions or alerts from search engines and journals. I also asked for alerts for new articles from researchers that I followed with particular interest, studied the references in the articles and followed useful leads. New searches with the same words obviously revealed new studies and review articles, but I increasingly found that such new searches led to studies with which I was already familiar.

1.3 Frequency of ICU deaths and limitation of ICU treatment

Questions relating to the decision-making process regarding treatment levels of intensive care patients³ form a vital part of everyday practice in intensive care medicine and nursing. Advances in medicine and medical technology have meant that patients who previously died due to the lack of treatment can now often receive treatment. But despite the advanced technology and modern medical treatment to sustain vital functions, 10-20% of patients die during their stay in the ICU (Angus et al., 2004; Wunsch, Harrison, Harvey, & Rowan, 2005). In a Scandinavian study based on the national intensive care

³ A patient is defined as an intensive care patient when there is impending or manifest acute failure of at least one vital organ, and the failure is thought to be partly or wholly reversible (Standard for intensivmedisin Dnlf, my translation).
http://www.nafweb.no/index.php?option=com_content&view=article&id=70:standard&catid=38:standarder&Itemid=27

registries in Finland, Sweden and Norway, the ICU mortality rate was reported to be 9.1% on average, although the Norwegian rate was somewhat higher, at 12.4% (Strand et al., 2010). Studies show that of those who die in an ICU, a large proportion are subject to treatment limitation or a decision to terminate treatment, varying between 35-93% (Prendergast, Claessens, & Luce, 1998; C. L. Sprung et al., 2003; Wunsch et al., 2005). In a recent Danish retrospective review of hospital records for all patients admitted to two regional Danish ICUs in 2008, 10.6% of patients died in the ICU. Of those who died, 80.7% died after a decision to withhold or withdraw therapy (H. Jensen, Ammentorp, & Ording, 2011). I have not found similar studies from a Norwegian context. However, the Nordic countries show only small variations in ICU mortality (Strand et al., 2010) and end-of-life practices, and we therefore assume that Norwegian practices regarding withholding and withdrawing treatment correspond to those in Denmark.

1.4 Patients' decision-making competence

According to the autonomy principle deeply rooted in the Patients' Rights Act, healthcare decisions involving serious interventions should be based on informed consent (Syse, 2009). However, due to the condition of ICU patients with impaired cognition, few of these patients are able to decide for themselves. A comprehensive European study (data from 1999/2000) revealed that fewer than 5% of ICU patients were alert and able to communicate and participate in decision making, and less than 1% initiate such discussions themselves (Cohen et al., 2005). A Swedish study from 1998 (data from 1993-1994), reported that the question of termination of treatment was discussed with only 1.6% of patients with documented treatment limitation, but that the decision was discussed with 61% of the families (Sjökvist, Sundin, & Berggren, 1998). In the recent Danish study referenced above, it was found that 2.2% of patients who had the treatment withheld or withdrawn were described as making the decision themselves. However, withholding or withdrawing treatment was discussed with 20% of the patients and with 79.1% of the relatives (H. Jensen et al., 2011).

The autonomy of incapacitated patients can be safeguarded by taking into account previously expressed preferences, either communicated by a family member or through

an advanced directive. Advanced directives are rarely available (Lautrette, Peigne, Watts, Souweine, & Azoulay, 2008), and in Norway they are not legally binding. None of the family members participating in our study could avail themselves of an advanced directive, and this topic is therefore not further addressed explicitly in this study. It may be assumed that changes in sedation routines have meant that more patients are now being kept awake during advanced intensive care than just a few years ago. It is however not clear whether these patients can still be said to have decision-making competence⁴. Six of the 21 families in our study were related to patients who were awake but had uncertain capacity to consent.

1.5 End-of-life decision making

If the patient no longer retains decision-making capacity, others have to decide on behalf of the patient. Different models of decision making exist, based on legislation and guidelines. North American caregivers, in accordance with laws and guidelines, approach the patients' proxy or closest relative either to leave the decision-making authority to them or to invite them to take part in a shared decision-making model. The rise of the shared decision-making model in the USA must be seen against the background of both legislation and other models of decision making, primarily paternalism, where physicians assume the dominant role. The paternalistic model is well known and articulated by for example Emanuel and Emanuel (1992a). The concept of shared decision making has received strong support from consensus conferences both in the US and Europe (Carlet et al., 2004; Luce, 2010; Thompson et al., 2004). Shared decision making is a process of communication between clinicians and the patient or surrogate family members. The process involves discussing the decision to be made, exchanging relevant medical information and also information about the patient's preferences and values, ensuring that all the information is understood, exploring the preferred roles in decision-making and achieving consensus about the treatment goals most consistent with the preferences and

⁴ Requirements for decision-making competence and obtaining consent will be presented in more detail later.

values of the patient (Charles, Gafni, & Whelan, 1997; Charles, Whelan, & Gafni, 1999; White, Braddock, Berekenyei, & Curtis, 2007). Several studies of surrogate decision-makers' perspectives emphasise that a majority of family members of critically ill patients wish to participate with doctors in EOL decision making (Anderson, Arnold, Angus, & Bryce, 2009; Heyland et al., 2003). In both a French (É. Azoulay et al., 2003) and a Swedish (Sjökvist, Nilstun, Svantesson, & Berggren, 1999) nationwide survey, most lay people favoured more family influence in the end-of-life decision-making process. However, the same Swedish study also addressed this topic to intensive care physicians and most regarded themselves as sole end-of-life decision makers.

Despite endorsement of the shared decision-making concept, there are challenges and limitations connected to the use of this model in the ICU. One important limitation is lay people's lack of detailed insight into medical issues. An example of this is that a minority of the family members in one study reported that they wanted to take part in biomedical decisions (Johnson, Bautista, Hong, Weissfeld, & White, 2011). Another limitation is that anxiety, depression and posttraumatic stress disorder may impair the capacity of a family member to take part in decision making (E. Azoulay et al., 2005; Pochard et al., 2001). If the family member should act as a surrogate for the patient, ethical and empirical doubts also exist about whether a surrogate is able to select the alternative that the patient would have selected (Emanuel & Emanuel, 1992b).

In Europe as elsewhere, if the patient is incompetent, the decisions are still most commonly left to the physicians, not to relatives (Lautrette et al., 2008; Moselli, Debernardi, & Piovano, 2006). However, some European countries are moving their legislation and practice in this area towards a more shared approach, giving more authority to advance directives and surrogates (Lautrette et al., 2008). The relatives' role has often been found to be consultative (Lautrette et al., 2008; Moselli et al., 2006). In Norway the end-of-life decision for incompetent patients is regulated by the Patients' Rights Act §4-6, which gives health care personnel the decision-making authority (The Patients' Right Act, 1999). However, the decision should be discussed with the patients'

next-of-kin, if possible (Syse, 2009). The procedures for end-of-life processes vary (Hynninen, Klepstad, Petersson, Skram, & Tallgren, 2008; Sjökvist et al., 1998; Svantesson, Sjökvist, & Thorsén, 2003), but some recommendations are given in the literature (Baum, 1980; Kaasa, 2008). There is strong recognition that a collaborative interdisciplinary care framework should be the basis for the provision of end-of-life care (Carlet et al., 2004; Puntillo & McAdam, 2006). In most Norwegian ICU contexts the patient is registered in and “belongs” to a medical or surgical ward, and a physician from this “home ward” has the primary decision-making authority regarding the patient’s treatment. However, in practice decisions are most often made in collaboration between this physician and the intensivists and other health care personnel.

The role of nurses in decision-making varies from active involvement in team collaboration on decision making to a more patient and family oriented approach with key nursing roles as information broker, supporter and advocate (Adams, Bailey, & Anderson, 2011; Bach, Ploeg, & Black, 2009). Despite the fact that both nurses and doctors often consider the nurses as actively involved with doctors in end-of-life decision making (Benbenishty et al., 2006; Latour, Fulbrook, & Albarran, 2009) and despite agreement that nurses should participate actively (Carlet et al., 2004), research indicates that nurses are in fact often not involved in such processes (Benbenishty et al., 2006; Ferrand et al., 2003). Both Norwegian and Danish nurses have reported unsatisfactory communication and collaboration with physicians and random participation in the information and decision-making process with physicians and families (Halvorsen, Førde, & Nortvedt, 2009; Hov, Hedelin, & Athlin, 2007; Hanne Jensen, Ammentorp, Erlandsen, & Ørding, 2011). The clinicians involved might not always assess the situation identically, thus challenging the interdisciplinary collaboration (Ferrand et al., 2003; Halvorsen et al., 2009; Hamric & Blackhall, 2007; Hanne Jensen et al., 2011; Tallgren, Klepstad, Petersson, Skram, & Hynninen, 2005). The transition from intervention to end-of-life care is identified as being the most problematic stage in the

end-of-life trajectory, involving complex ethical issues⁵ (Curtis & Vincent, 2010; Gavrin, 2007). Particular ethical challenges are discussions of the usefulness of life-sustaining treatments (Boyd et al., 2010), and communication with a competent patient and his or her family (É. Azoulay & Pochard, 2003; Puntillo & McAdam, 2006).

Until recently the use of guidelines on end-of-life decisions was not common in the Nordic countries. A survey among physicians from Denmark, Finland, Sweden and Norway found that written guidelines for end-of-life care are scarce in Scandinavian ICUs (Hynninen et al., 2008) despite the fact that international guidelines have been published by both North American and European professional ICU organisations (Thompson et al., 2004; Truog et al., 2008). However, both Denmark (Dansk Selskab for Anæstesiologi og Intensiv Medicin, 2009) and Norway (Norwegian Directorate of Health, 2009) have recently published national guidelines on end-of-life care, and some Norwegian ICUs have written local guidelines.

There is an increasing amount of research on the relatives' situation when a patient is critically ill in an ICU. Since Molter developed the Critical Care Family Needs Inventory (CCFNI) (Molter, 1979), many studies have focused on the needs of relatives, and found similar results in different cultural settings (Bijttebier et al., 2000; Leske, 1986; Takman & Severinsson, 2005; Yin King Lee & Lau, 2003). These studies point out that the relatives need hope balanced against reality, adequate and honest information, comfort and support. To be able to cope with the situation they also need proximity and accessibility to the patient. Some have stressed the importance of suitable physical surroundings, such as waiting rooms, patient rooms and access to suitable rooms for talks and meetings (Henrich et al., 2011). Results from qualitative studies complement the findings from quantitative approaches, but they also allow the participants to elaborate on

⁵ One example of such an ethically challenging issue for health care professionals is the distinction between withholding and withdrawing life-sustaining treatment, which are often perceived as ethically distinct actions. However, ethicists and critical-care societies state that there is no ethical distinction between withholding and withdrawing life-sustaining treatment (Carlet et al 2004, Truog et al 2008), (Melltorp & Nilstun, 1997). The families in our study do not generally mention this distinction and it is therefore not addressed in the articles or in the discussion section of the thesis.

their feelings and experiences in the totality of the situation (Linnarsson, Bubini, & Perseus, 2010). Examples of such findings are extensive descriptions of uncertainty and vulnerability (Ågård & Harder, 2007) and how the families strive to make sense of the situation by tracking and evaluating the care provided (Jamerson et al., 1996; McKiernan & McCarthy, 2010) and by forming personal cues (Ågård & Harder, 2007). An overall need was to receive timely, consistent and explicit information from, and communication with, both nurses and physicians (Engström & Söderberg, 2004; Ågård & Harder, 2007). Families have emphasised the need for an honest and timely discussion of the prognosis to be allowed to support the patient and to prepare for death (Apatira et al., 2008). Lack of information is described as a stressor (Bond, Draeger, Mandelco, & Donnelly, 2003) and was experienced as frightening, especially regarding prognosis and changes in the patient's condition (Eggenberger & Nelms, 2007). Several studies discuss family members' experiences of decision-making processes when they act as surrogates for the patient (Jacob, 1998; Swigart, Lidz, Butteworth, & Arnold, 1996; Wiegand, 2006). Experiences of conflict in the decision-making process are stressful, and found to be related to communication and clinicians' behaviour (Norton, Tilden, Tolle, Nelson, & Eggman, 2003; Tilden V.P, Toile S.W., Garland M.J., & Nelson C.A., 1995). Being uncertain as to what the patient would have wished and lacking the support of an advanced directive was found by Tilden, Tolle, Nelson, and Fields (2001) to be a stressor for families. Studies have also found moderate levels of agreement between patient preferences and surrogate perception of those preferences (Connors, Dawson, Desbiens, & et al., 1995), and if the family is to act as a surrogate, they need guidance from physicians (Meeker & Jezewski, 2005). Families need to believe that all has been done that could have been done, before they can bring themselves to agree that treatment termination is the right choice (Swigart et al., 1996).

The process of involving surrogate decision makers in the withholding or withdrawal of life-sustaining treatment is a factor closely linked to the patient's past and present condition, and the perception of past and future quality of life (Limerick, 2007). In a Norwegian context family members would not be asked to participate as surrogates for

the incapacitated patient. However, according to the The Patients' Right Act (1999) they are entitled to participate together with the patient (§3-1), to receive information about the patient's condition and the health care provided (§3-3), and as far as possible, when health care entails a serious procedure for the patient, information must be gathered from the patient's next of kin concerning what the patient would have wished (§4-6).

1.6 Summary

Research points to many ethical challenges related to the end-of-life decision making processes for both competent patients and those who lack decision-making competence. Challenges also exist in how to ensure involvement and suitable care for the family members of ICU patients in the EOL decision-making process.

2 ISSUES AND RESEARCH QUESTION

The aim of this study is to examine family members' experiences of participation in the end-of-life decision-making process for a close relative. Emphasis is placed on how they understood the patient's situation, their own experiences from participating in decision making and experiences of communication with nurses and physicians. The study will primarily focus on aspects of ethical significance in the decision-making situation.

In an attempt to obtain answers, the following issues and research questions were raised:

- Do the patient's family members have a sense of being genuinely involved in the decision to end the treatment of the patient?
- What may involvement imply for the family members?
 - Being informed?
 - Being asked for their opinion?
 - Being asked for consent?
 - What does family involvement imply if the patient is competent to consent?
- Do family members want to be more responsible in decision making, and do they in certain situations make decisions on behalf of the patient?
- What do family members believe they know about the patient's preferences, and how do they manage to refine this in relation to their own wishes and interests?
- How did family members experience their relationship and communication with doctors and nurses?
- What might it mean for the family to live with their experiences of EOL decision making in the ICU?

2.1 The dissertation – delimitation and specification

The aim of this dissertation is to highlight and discuss empirical findings and examine these in light of ethics, legislation and existing research. These knowledge areas form an overarching framework for the normative discussion in the study. The topics studied have several adjacent fields of interest, such as the organisation of ICU care, interdisciplinary cooperation and the impact of these on EOL processes. Although these are important topics in the discussion, I have chosen to maintain a focus on research findings in the field, and not expand into more formal theories. Neither is this study a discussion of philosophy based theory, although both the procedural ethics and aspects of the nursing ethics are closely aligned with philosophy in their basis for reflection.

On the basis of the study findings, the principles of autonomy, assessment of decision-making competence, beneficence and non-maleficence are integrated in the discussion. I will give a more detailed presentation of these principles as part of the theoretical reference framework.

3 THEORETICAL REFERENCE FRAMEWORK

Since this empirical study basically addresses ethical questions concerning end-of-life decision-making, my view is that a key reference framework must be medical ethics. A number of ethical perspectives are relevant to the data analysis and discussion of findings in this study. Norwegian Law, through the The Patients' Right Act (1999) and the National Guidelines on end-of-life (Norwegian Directorate of Health, 2009) also give more detailed information relevant to the ethical discussion here.

3.1 A relevant theoretical approach – medical and nursing ethics

The study findings are mainly grounded in clinical medical ethics. The concept of medical ethics is often associated with the ethics of doctors, which has led to increased use internationally of the term biomedical ethics (Ruyter, Solbakk, & Førde, 2000). Although medical ethics is often associated with doctors' ethics, it can also be described as area ethics, because of the systematic use of “ethical criteria and targeted ethical competence-building for decisions in a particular area of society” (Tranøy, 2005, p. 18). End-of-life decision making in ICUs includes both medical and ethical aspects in a very limited area, and the decision-making process with its consequences concerns the patient, the relatives and the healthcare professionals. The ethical aspects of the decision-making process are not limited to medical or biomedical ethics, but consist mainly of practical (or applied) ethics. The term practical refers to the use of norms in deliberating about moral problems in a limited area of society (Beauchamp & Childress, 2009; Ruyter et al., 2000, p. 2). This is an expanded understanding of ethics in the interaction between professionals, patients and relatives (Ruyter et al., 2000). Practical ethics, in contrast to more theoretical ethics, is not only concerned with what is right and true, but with what is useful and works in practice (Ruyter et al., 2000, p. 103). Because practical ethics is not limited to professional ethics, the implication is that it must have common morality standards as its starting point (before other theoretical positions). A short definition of common morality⁶ is that it is “the set of norms shared by all persons committed to

⁶ Tranøy (1998) elaborates on this, specifying how common morality must be understood: “Common morality is the set of moral values, norms and virtues - and the corresponding practices and institutions -

morality” (Beauchamp & Childress, 2009, p. 3). How the field of practice meets ethical dilemmas⁷ and ethical challenges is a matter of choices, decisions and actions. These are largely anchored in the four principles of ethics (Beauchamp & Childress, 2009). Decisions about the right course of action follow both deontological and utilitarian directions, both of which are fundamental ethical principles. I have chosen to present ethical principles as a reference frame for the questions raised by this study. Ethical principles also form part of the foundation of current legislation, and these are presented in brief as a basis for analysis and discussion in the study. These principles are particularly pertinent in relation to patient and family autonomy and rights in end-of-life decision making. However, the relational aspect - the role of the family in relation to the patient and clinicians - also necessitates a consideration of other types of ethics. I have therefore chosen to present briefly ethics of proximity and the philosophy of caring as ethical interpretive frameworks.

3.2 Professional ethics

Professional ethical codes describe ethical values and attitudes that are shared or ought to be shared by e.g. health care workers in general or by members of a profession in particular. Professional ethics contribute to helping the members of a particular profession to focus on the ideal objectives of their practice (Ruyter et al., 2000). Both physicians’ and nurses’ ethics centre on how they ought to respond to the moral situation in the encounters between health care personnel and patients, as well as towards relevant others - such as the patient’s family. The professional ethics of both groups have a deontological basis formulated as categorical rules which are also related to legislation and professional standards (Ruyter et al., 2000), and use the same ethical concepts such

that have broad acceptance and are internalised and respected in a given culture for a certain period of time” (p.132). In the same section, he gives a detailed synopsis and delineation of the concept of common morality.

⁷‘Moral dilemmas are circumstances in which moral obligations demand or appear to demand that a person adopt each of two (or more) alternative but incompatible actions, such that the person cannot perform all the required actions’ (Beauchamp & Childress, 2009 p.10).

as respect, care and compassion⁸. However, in spite of applying similar concepts in their work ethics, there are significant ontological and epistemological differences in the ethical ideals of doctors and nurses. Deontological and consequentialist moral theories⁹ form the main bases of medical ethics. The ideal in these traditions is that decisions are made by rational, independent and autonomous subjects. In nursing, caring for others constitutes an important part of the self-understanding of the profession, with a relational ontological basis for its ethics (Martinsen, 1989). Several points in the nurses' professional ethical code demonstrate this. In relation to the theme of this study it may be mentioned that the latest revision of the Ethical Guidelines for Nurses (2011) now explicitly includes a reference to the responsibility of nurses in EOL decision making: "The nurse takes an active part in decision processes concerning life-prolonging treatment" (Section 2.10). It is also explicitly stated that the nurse is to help ensure the right to information of the patient's family.

3.3 The four principles approach

The 'four principles' approach to ethics as described by Beauchamp and Childress, first published in 1979, is today the most generally accepted school of thought in medical ethics; the principles are autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2009). Applying the principles to the ethical questions raised in the EOL decision-making context of the ICU might function as a suitable position for analysing what we mean by e.g. respecting autonomy and what the consequences of our alternative choices might imply. These principles are founded on both common morality and other well-established types of ethics such as duty-based ethics, consequence-based

⁸ Medical ethics refers to the Hippocratic Oath for doctors, which also manifests itself with similar formulations in nursing ethics. But Norwegian nurses also have a separate, brief but explicit statement representing a basic tenet for nursing, presented as an introduction to their Ethical Guidelines. This states that: "The foundation of all nursing shall be respect for the life and the inherent dignity of the individual. Nursing shall be built on compassion, care and respect for human rights, and be based on knowledge". The Ethical Guidelines for Nurses, Norwegian Nurses' Organisation (NNO) 2011.

⁹ e.g. Kantian moral theory and utilitarianism

ethics, etc. They do not constitute a general ethical theory but provide a framework of norms as a basis for deliberating and analysing difficult ethical problems in practical ethics (Beauchamp & Childress, 2009, p. 16). Three of the principles have a long tradition in medicine dating back to the Hippocratic Oath, but the autonomy principle is relatively new. Not until 1994 was it added to the code of ethics of the Norwegian Medical Association and later included in the Patients' Rights Act (Ruyter et al., 2000; Syse, 2009). All the principles have relevance to the analysis of the empirical findings in the present study, and are also explicitly expressed in the dialogue between patients, families and health professionals. They are emphasised as *prima facie* principles, each one characterised as "one that must be fulfilled unless it conflicts, on a particular occasion, with an equal or stronger" (Beauchamp & Childress, 2009, p. 15). The four principles are considered to be morally equal, and they have to be weighed against each other in specific practical situations in order to decide which principle to act upon, and in some cases also balanced against other moral norms (Beauchamp & Childress, 2009).

The principle of non-maleficence is formulated as an obligation not to inflict harm on others (Beauchamp & Childress, 2009). This principle is well known from the ICU context when discussing the withholding or withdrawing of treatment, often coupled with beneficence. However Beauchamp and Childress, with reference to William Frankena (1973), distinguish between the two principles since there are morally significant differences between the duty to beneficence and the duty not to harm. They divide the principles of non-maleficence and beneficence into four norms, which are not arranged hierarchically (Beauchamp & Childress, 2009, p. 151):

Non-maleficence implies:

One ought not to inflict evil or harm

Beneficence implies:

One ought to prevent evil or harm

One ought to remove evil or harm

One ought to do or promote good.

The last three principles are given a positive wording, i.e. one takes action by helping, whereas non-maleficence takes the form of a duty: ‘Do not...’ (p.151).

The principle of beneficence points towards acts of mercy, kindness and charity (Beauchamp & Childress, 2009). The principle is characterised as an obligation to act for the benefit of others. Tranøy (2005) emphasises the universal moral foundation of these principles, i.e. that we all have a duty not to cause harm to others. In addition, doctors and nurses have a “duty to be of benefit to their patients, to do something good for them, precisely by virtue of being a doctor or a nurse’ (Tranøy, 2005, p. 84).

In their presentation of the concept, Beauchamp and Childress (2009) distinguish between two principles of beneficence: positive beneficence and utility. The utility form of beneficence requires a focus on the overall result, by balancing benefits, risks, and costs. Positive beneficence is an obligation to do well or to act in a beneficent way towards others. The concept of beneficence is closely tied to benevolence, which ‘refers to the character trait or virtue of being disposed to act for the benefit of others’ (p.197). Some examples of rules of positive beneficence:

Protect and defend the rights of others

Prevent harm from occurring to others

Remove conditions that will cause harm to others (2009:199)

Of special interest in this study is the relationship and balance between beneficence and autonomy and the risk of acting paternalistically¹⁰ in order to “do good”.

The principle of justice states that “equals must be treated equally, and unequals must be treated unequally (Beauchamp & Childress, 2009, p. 242). This is a complex ethical principle of particular relevance in health care regarding distributive justice of limited

¹⁰ Paternalism is defined as “the intentional overriding of one person’s preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden” (Beauchamp & Childress, 2009, p. 208).

resources. The significance of the principle ranges from fair treatment of individuals to a fair distribution of health services and resources. Particularly intensive care medicine has in recent decades experienced a clearly increasing tendency towards limited treatment capacity, where the needs of individual patients are weighed against each other to decide who has the greatest need of intensive therapy. This is not an explicit topic in this empirical study, although some family members suggested that lack of resources may have been a factor in the speed of the decision to end treatment.

The principle of respect for autonomy concerns the patient's right to self-determination. Patient autonomy can be understood in several ways. As a principle it implies respect for the patient's wishes and needs when decisions are taken. Autonomy can also be understood as a characteristic of the individual, i.e. that one has the capacity to act in accordance with one's own wishes, and as a corresponding right to make decisions about one's own health (Ruyter et al., 2000). All three of these dimensions in the understanding of patient autonomy, separately and together, offer challenges in the care and treatment of critically ill ICU patients. The central challenge in any clinical work that combines these three dimensions of patient autonomy is to decide whether the patient can be said to be competent to give consent. I will return to this question later. The right to make autonomous decisions about one's own health is rooted in legislation. Before the Patients' Rights Act (1999/2001) there was no general requirement for consent to medical examinations or treatment, but there gradually emerged a need to strengthen the patient's legal status (Syse, 2009, p. 287). The Patients' Rights Act appears generally to fulfil the requirement for autonomy as a principle in medical ethics, which implies that "a person who is affected by a medical decision and who must live with its consequences, should also be involved in making that decision" (Tranøy, 2005, p. 32).

It is however important to emphasise that the patient's autonomy is balanced against the autonomy of the health professionals. This means that the patient's right to decide on his or her own behalf is regarded primarily as a negative right, understood as implying that patients and their relatives have no right to demand treatment or actions which are not in

the patient's interest or are contrary to professional responsibility (which includes evaluation of the costs and benefits of a treatment) and/or the autonomy of the health care personnel (Nortvedt, 2012; Pedersen, Hofmann, & Mangset, 2007; Tranøy, 2005). Thus asymmetry and power are revealed as important aspects of the principle of autonomy. Lay people do not possess the professional knowledge which enables physicians to diagnose and suggest treatment, but in order for the doctor not to act paternalistically, consideration of patient autonomy requires that the patient receives information and takes part in decisions by choosing between options, giving consent to or desisting from treatment. Informed consent in health care is regarded as an autonomous person's authorisation of the professional actions of health care personnel towards that person (Pedersen et al., 2007). Thus informed consent can be understood as a moral action or rule (Pedersen et al., 2007) to fulfil the autonomy principle (Beauchamp & Childress, 2009). Consent to health care decisions is also in intensive care medicine a valid requirement, but as we shall see this poses certain challenges where the patient's decision-making competence is unclear or lacking.

3.4 Decision-making competence

Four conditions are essential for an action to be autonomous: the patient must be competent to make decisions, must be informed (also about the possible options), the choice must be free and without external pressure (Ruyter et al., 2000) and the patient must express consistent preferences (Tranøy, 2005). The decision as to competency "is a determination of a particular person's capacity to perform a particular decision-making task at a particular time and under specified conditions" (Buchanan & Brock, 2004, p. 18). Decision-making competence presupposes that the patient has the ability to understand the information provided and realise its importance for his or her situation, and is also able to reason and weigh options and to communicate and express a choice. It is the task of the health care professionals to assess whether a patient is competent. However, it may be a considerable challenge to determine the decision-making competence of a critically ill ICU patient. In 6 of 21 families in this study's sample, the

relatives mention that the patient was alert, although several of these were uncertain as to whether the patient was capable of making autonomous decisions or giving consent.

The simplest form of consent, ‘implied consent’, is probably the most common in practice. This is interaction with a non-protesting person, which is often expressed through assenting behaviour (Syse, 2009, p. 297)¹¹. Another form of consent is oral consent, which would normally be equal to and just as binding as written consent (p. 299). We see here that matters of law become ethical matters, where the use of professional and ethical judgment gives clinicians considerable freedom to determine consent. Although tests have been developed as an aid in deciding consent (Lidz, Appelbaum, & Meisel, 1988) and there are various models to assist with the work of giving informed consent (Chow, Czarny, Hughes, & Carrese, 2010), little is known about how far such tools have been established as standards (Ministry of Health Care Services NOU No 9, 2011; Tunzi, 2001). A survey conducted in Norway revealed uncertainty about how assessment and documentation of decision-making competence should be established. Several of the respondents stated that assessment of consent capacity is mainly based on clinical judgement, some of them used tests and others believed that such assessments were rarely performed (Ministry of Health Care Services NOU No 9, 2011). My experience from practice is that assessment of competence is not based on criteria or tests, but rather on clinical judgment and dialogue between those involved in

¹¹ “Implied consent means that the patient has had the opportunity to assess his or her situation and that the patient has made a choice expressed through assenting behaviour. In some situations it will also be based on presumed consent, i.e. that it is assumed that the patient would have wanted the medical treatment if he or she had been able to assess the situation”. Source:

<http://www.regjeringen.no/nb/dep/hod/dok/regpubl/otprp/19981999/otprp-nr-12-1998-99-/6.html?id=159421>

Other forms of consent exist. One is hypothetical consent, which means that the clinicians assume that the patient, in a specific situation where he lacks consent capacity, would have wished for the treatment to take place. This form of consent is balanced against the duty of the clinicians to act, as for example in an emergency situation. But this is hardly suitable as a basis for invasive treatment procedures. Another form is presumed consent, which is similar to hypothetical consent in legal terms, but emphasises more what the opinion of a reasonable person would have been in a given situation, even though the person is now unable to give an opinion. Such consent is particularly relevant in cases of doubt about organ donation. Further, assisted surrogate consent is said to exist when a person is without consent capacity and others are legally authorised to make health care decisions on the patient’s behalf. In many cases, these are parents or other people with parental authority who make decisions on behalf of their children (Syse 2009:302).

the treatment and care regarding how they view the capacity of the patient. The medical record uses everyday language such as “awake”, “tired” and “sleeping soundly/lightly” as much as medical terms like “comatose”. The subjective and qualitative aspects of assessment emerge strongly, so that it must be recognised that the question of autonomy cannot necessarily be decided on the basis of standardised procedures. More formal concepts such as decision-making competence are little used in my experience. In some cases, there is an overall assessment of alertness based on sedation assessment scales such as MAAS¹², or in some patient groups the GCS¹³ (Gulbrandsen & Stubberud, 2010).

3.5 Best interest – the substituted judgement standard

The purpose of assessing decision-making competence in ICU patients is to determine whether the patient is competent or whether the right to decide should be transferred to others. The premise for surrogate decision makers, whether health care professionals or family members, is still that the right to decide belongs to the patient, but that he or she is at present not competent to make the relevant decisions (Beauchamp & Childress, 2009). The literature states that substantive standards for decision-making will be needed both in cases where the patient’s preferences are known from earlier discussions within the family or from advanced directives, and in cases where the patient’s preferences are unknown. If there are any relevant oral or written advance requests from the patient about health care or about whom the patient wants to make decisions on his or her behalf, these should weigh heavily (Buchanan & Brock, 2004). A further factor is that advance directives are not legally binding in Norway, and that the decision makers without regard for the ethical aspect could choose to disregard such requests. But if advance directives are taken into account, one can and should discuss whether these are consistent and may still be considered valid (Syse, 2009). Buchanan & Brock point out that even when

¹² MAAS, Motor Activity Assessment Scale. This is a list of items with a scoring scale for the assessment of alertness, often used in conjunction with giving sedatives to a patient (Gulbrandsen & Stubberud 2010).

¹³ Glasgow Coma Scale (GCS) is a scale from 3 to 15, where 3 represents deep coma without any response and 15 implies that the patient is awake, alert and fully aware of time and place. This scale is particularly used for recording consciousness in patients with traumatic head injury, brain haemorrhage and brain

advance directives exist, it requires authority and responsibility to interpret and implement them (Buchanan & Brock, 2004, p. 96). If preferences are unknown or no advanced directives are available, the substituted judgement principle may be used as a guideline. This states that one should “act according to what the incompetent individual, if competent, would choose”(Buchanan & Brock, 2004, p. 10). However, if there is a lack of sufficient evidence to exercise substituted judgement, one ought to rely on the best interests principle, which is defined as “acting so as to promote maximally the good (i.e. well-being) of the incompetent individual” (Buchanan & Brock, 2004, p. 10). This principle ranks the various interests involved, whereby some are regarded as more important because they benefit the patient more. In this way, specific choices will prioritise certain considerations, while other considerations are ranked lower, which may lead to conflict in the decision-making process. The principle involves both current and future interests and therefore must also take into account quality of life judgements. Factors taken into consideration might depend on both physical and cognitive capacities of the patient (Buchanan & Brock, 2004, p. 94). We can thus see a weighting of what is good and less good in a kind of cost-benefit calculation, where the sum total is a net benefit which must be decisive.

3.6 Legislation and other official frameworks

Norwegian legislation: The Patients’ Rights Act

3.6.1 The right to participation and information

The Patients’ Rights Act, Section 3-1, lays down the patient’s right to be involved in the implementation of health care services.

Section 3-1. The patient’s right to participation

The patient is entitled to participate in the implementation of his or her health care. This includes the patient’s right to participate in choosing between available and

tumours. The scale is limited to assessment of the level of consciousness, gives little or no information on

medically sound methods of examination and treatment. The form of participation shall be adapted to the individual patient's ability to give and receive information. (1st paragraph)

If the patient is not competent to give consent, the patient's next of kin is entitled to participate together with the patient. (2nd paragraph)

The Patients' Rights Act states that the patient's consent is the most important legal basis for providing the next of kin with information.

Section 3-3. Information to the patient's next of kin

If the patient consents thereto or circumstances justify it, the patient's next of kin shall receive information concerning the patient's health condition and the health care that is being provided. (1st paragraph)

When the patient is competent, the relatives' demand for information will normally yield to the patient's right to confidentiality, since the patient's consent governs what information will be provided to the relatives. Notes on this section comment that if there are reasons, e.g. unconsciousness, which prevent consent, an assumed consent (based on the interests of both parties) is applied, namely that a patient would normally wish for information to be provided to his or her closest relatives (Syse, 2009, p. 251). In Section 4-6, 2nd paragraph, the legislation assumes such consent as a basis and the notes specify that the next of kin have the right to information about the patient's medical condition, diagnosis, treatment prospects and health care (Syse, 2009, p. 273). The duty to provide information increases with an increasing degree of seriousness in the patient's condition. The Patients' Rights Act §3-5, with notes, emphasises that health personnel have a duty to adapt the information to the recipient and also ensure that the information provided is received and understood, whether the recipient is the patient or the next of kin (Syse, 2009, p. 279). This means that even though the information may be difficult to

cognitive functions and should not be used with sedated patients (Gulbrandsen & Stubberud 2010).

communicate, both due to its content and the communication context, health personnel have an ethical obligation to act in a considerate manner (Syse, 2009, p. 280).

3.6.2 Patients' competence to give consent

The Patients' Rights Act, Section 4-3, states the following on the subject of decision-making competence:

Section 4-3. *Who has competence to give consent* (3th to 4th paragraphs)

The health care provider shall decide whether the patient lacks competence to give consent pursuant to the second paragraph. Based on the patient's age, mental state, maturity and experience, health personnel shall do their best to enable the patient himself or herself to consent to health care, cf. § 3-5.

A decision concerning lack of competence to give consent shall state the reasons for the decision and shall be given in writing, and if possible shall immediately be presented to the patient and his or her next of kin. If the patient has no next of kin, the decision shall be presented to health personnel as stated in § 4-8.

The notes to these sections (Syse, 2009, pp. 263, 274) emphasise that the closest relatives should be informed if the patient partially or wholly lacks competence and ought not to make a decision, so that the relatives can help to find the best health care for the patient.

3.6.3 Decision-making authority if the patient is not competent

If the patient is not competent and of full legal age and legal capacity the Patients' Rights Act¹⁴ states the following:

Section 4-6. Consent on behalf of persons who are of full legal age and legal capacity and who are not competent to give consent

If a patient who is of full legal age and legal capacity is not competent to give consent, the health care provider may make decisions concerning health care that is not of a highly invasive nature with regard to its extent and duration¹⁵.

¹⁴ <http://www.lovdato.no/all/tl-19990702-063-004.html> Retrieved May 28th 2012.

Health care that entails a serious procedure for the patient can be given if it is deemed to be in the patient's best interests and if it is likely that the patient would have given his or her permission for such help. Wherever possible, information must be gathered from the patient's next of kin concerning what the patient would have wished. Such care can be decided by the person who is responsible for the health care following consultations with other qualified health personnel. The patient's record must contain any information from his or her next of kin as well as the opinions other qualified health personnel may have given.

Health care pursuant to the first and second paragraphs may not be provided if the patient objects thereto, unless special statutory provisions dictate otherwise.

Changes in Section 4-6, 2nd paragraph, imply that in situations where the patient is not competent to give consent, the decision-making authority is transferred from the patient to health personnel. This is enforced through a revision of the 2006 Act, valid from May 1st 2008; in the original version, the act stipulated surrogate consent where the next of kin could consent to care of a highly invasive nature, whereas the revised formulation makes it clear that it no longer emphasises surrogate consent (Syse, 2009, p. 334). The Act is thereby more paternalistic than previously. The comments to the Act stipulate, in line with the substituted judgement principle, that when the next of kin are heard, it is important that it is the patient's assumed preferences that are emphasised and not their own.

Summing up the changes made in Section 4-6 (2008), together with the relatives' right to information as mentioned above, Syse concludes that a disparity exists between the right of the relatives to participate according to §3-1 and their lack of a legal right to act as substitute decision makers in health care decisions (Syse, 2009, p. 132).

¹⁵ The first paragraph is retrieved from an officially translated pdf file at <http://www.ub.uio.no/ujur/ulovdata/lov-19990702-063-eng.pdf>. However, the second and third paragraphs

3.7 National guidelines for decision-making processes for limiting the life-prolonging treatment of seriously ill and dying patients

National guidelines were published in 2009 concerning the limiting of life-prolonging treatment (Norwegian Directorate of Health, 2009). The work on the guidelines was initiated by the Norwegian Medical Association and the Norwegian Directorate of Health (Markestad, 2008). The need for such guidelines had arisen on the basis of difficult ethical dilemmas, especially in the ICU context (Pedersen & Førde, 2008). The guidelines are however not only aimed at procedures in ICUs, but cover the entire health care system and all forms of life-prolonging treatment. The purpose of the guide is to contribute to the creation of a common understanding of key concepts and ensure decision-making processes that will provide security and prevent and limit conflicts (Markestad, 2008). The guide offers a framework for the decision-making process and is intended to lend support to clinicians, patients and their families. If patients are not competent to make decisions, the guidelines advise involving the next of kin. The guidelines were published about halfway through the data collection period for this study. It is not known whether any of the ICUs involved in the study had adopted them.

3.8 The ethics of proximity and Martinsen's philosophy of care

The ethics of proximity is not a fully developed theoretical perspective in ethics, but may be regarded as a philosophy of basic ethical principles (Nortvedt, 2012). It is well known in nursing ethics as one of the core ethical elements in Norwegian nursing education. In this study, the ethics of proximity and philosophy of care have been important analytical instruments in revealing individuals and relationships in the end-of-life decision-making process. They also add an alternative and complementary perspective to principlism, and constitute an ontological basis for nursing ethics (Martinsen, 1989). Important contributions to the establishment of the ethics of proximity are the French philosopher E. Levinas' theory of ethical responsibility and the Danish philosopher K. E. Løgstrup's

were changed by a revision of the Act in 2008, and have not been officially translated.

theory of the ethical demand (Nortvedt, 2012). The concept of proximity might be understood as physical and visual closeness between the parties but it can also refer to closeness through thoughts and reflections (Vetlesen, Bauman, Nortvedt, & Andersen, 1996). The ethics of proximity focuses on the fact that certain given conditions in human interdependence do not allow for choice. In Løgstrup's philosophy human interdependence with basic trust forms the ethical point of departure (Vetlesen et al., 1996). Trust as a phenomenon has the character of reality and is a given and predetermined part of our lives. One meets others with a natural feeling of trust. This also implies vulnerability. The fact that we are inevitably dependent on others involves an inherent power relationship, where Løgstrup emphasises the interwovenness of power and responsibility. By this he means that we "cannot be affected by the one (power) without being involved in the other (responsibility)" (Vetlesen, 2007, p. 93). One demonstrates trust in the other in the expectation of being accepted. The one who offers trust will thus, in becoming exposed, place an ethical demand upon the other (Løgstrup, 1991).

Another core element in nursing education is nurse-philosopher Kari Martinsen's philosophy of care, which, inspired by Løgstrup's thoughts, has strongly influenced Norwegian nursing for many years. In her analysis and interpretation of nursing, it is intrinsically a moral practice founded on care (T. K. Jensen, Jensen, & Kim, 1990; Martinsen, 1989, p. 60). Thus care not only forms the foundation in nursing, it is also a basic assumption for our lives. Care involves having consideration for, taking care of, and being concerned about the other. Martinsen describes caring as involving three aspects: a relational, a practical and a moral aspect. The relation between the patient and the nurse is the foundation for moral responsibility and actions in nursing (T. K. Jensen et al., 1990; Nortvedt, 2012). Preconditions for caring are knowledge, training and skills. In the moral aspect our attitude is expressed, i.e. how we behave towards one another. The particular quality of care is precisely the attitudes that express the care. Moral sensitivity and emotional affectability are characteristics of being human together with other human beings (Nortvedt, 2012). We are always receptive to others through our facial

expressions, body language, gestures and verbal language. Emotional affectability enables us to understand the other's expressions by first taking them in through our senses (Martinsen, 1993, p. 119). More specifically, she has stated that our emotions enable us to understand the phenomena of this world. However, after being touched by our emotions, we then require professional skill in interpretation to understand what the other's expressions require in terms of practical or moral action. This is a fundamental element of care in a professional context; we must be capable of recognising the other's needs.

Both the ethics of proximity and Martinsen's philosophy of care recognise the significance of virtues as an integral part of the foundation for being a good person and a good nurse. Virtues are character traits or stable attitudes that predispose the individual to a particular type of action. Examples of virtues are qualities such as courage, justice, prudence, temperance and truthfulness. The actor-orientation of virtue ethics implies that it is directed towards the good person and what characterises a well-developed and entirely human personality (Johansen & Vetlesen, 2000; Vetlesen, 2007). In this project elements of virtue ethics have not only been valuable in the analysis of the family-clinician relationship, but also important in the analysis of what it implies for the family to be responsible for the patient.

4 METHODOLOGY AND RESEARCH PROCESS

A qualitative research method was chosen with regard to the research topic and research questions. The aim of the study is to examine family members' experiences of participation in the end-of-life decision-making process for a close relative. There is considerable research into EOL in the ICU in a global context, but there are few studies of family members' experiences from Scandinavia. I discovered a need to conduct a qualitative study in which I could ask open-ended questions of people who were familiar with the topic (Polit & Beck, 2008). In contrast to quantitative studies which rarely deviate from the planned design, a typical feature of qualitative methods is a design that 'emerges as researchers make ongoing decisions reflecting what has already been learned' (Polit & Beck, 2008, p. 219). This study was planned on the basis of a narrative approach with methodological reflections on data grounded in a hermeneutic phenomenological tradition (Dahlberg, Dahlberg, & Nyström, 2008). The analysis of the EOL processes has also included Charmaz' interpretive constructivist grounded theory, which with its focus on social processes has helped to reveal new perspectives in the data (Charmaz, 2006). This is reflected in the work leading to the results in Article I. Initially in this chapter I will present our narrative approach, but also pay attention to the core elements of interpretive constructivist grounded theory. The main features of the approaches as analytical tools with principal differences will be revealed. Then follows a detailed review of our practical approach throughout the research process leading to the results presented in Papers I, II and III.

4.1 The narrative approach

Collecting stories and narratives in qualitative research is ever increasing and was as early as 1993 described by Riessman as the "interpretive turn" in social science (Riessman, 1993). Narrative inquiry refers to a group of qualitative research approaches that uses stories¹⁶ to describe human action, with 'events and happenings configured into

¹⁶ With reference to Riessman (2008) and Frank (2010), the terms narrative and story will be used interchangeably.

a temporal unity by means of a plot' (Polkinghorne, 1995, p. 5). No other temporal forms have been found to describe "lived time" better than narratives, even though a narrative often must be viewed as a selective achievement of memory recall (Garro & Mattingly, 2000). The temporal aspect of narratives is often expressed in causal connections; something happens as a result of something else, usually people's actions and their attempt to reach clarification, understand the meaning of events or find a solution. What makes this into a story is that it is character driven and performative, narrated from a special point of view and often with an inherent moral (Frank, 2010). However, a narrative is always relational, an interaction between narrator and listener.

The narrative approach embraces many different orientations and practical approaches to narrative analysis, with a corresponding lack of agreement between the various perspectives (Riessman, 2008, p. 11). It has been argued that narrative analysis ought not to be one method or prescribed set of steps to follow, because there are several possible approaches and combinations (Frank, 2010; Riessman, 2008). The narrative analytical approach of this project is based on its appropriateness for the data and involves both thematic and structural analysis. I have relied primarily on the literature on narrative interview and analysis of Riessman (Riessman, 1993, 2008), Mishler (Mishler, 1986), Polkinghorne (Polkinghorne, 1995), Coffey & Atkinson (Coffey & Atkinson, 1996) and Frank (Frank, 2010), but also on other more phenomenologically oriented works on methodology (Dahlberg et al., 2008).

In a thematic narrative analysis, the principle is to keep the narrative intact by arriving at theoretical assumptions from the case, rather than from component themes (Riessman, 2008). The size of the narrative will vary with the topic. The emphasis is placed on the action and the moral of the story (Riessman, 2008, p. 62). Criteria for the analysis are generally drawn up with the aid of research questions. Questions may also arise from the text itself as the analysis progresses, or be grounded in theory. The next step could then be to group the stories and create typologies (Riessman, 2008).

Riessman also recommends paying attention to the narrative's structure, not merely its content (Coffey & Atkinson, 1996; Riessman, 1993). In our study, preliminary analysis of the themes for Article II (and partly Article I) shows that the structure of the narrative, i.e. how the story is organised and how it develops, was important both to understand the temporality of the phenomena and to elucidate what the essence of the story meant to the narrator. I chose to follow the model of Labov & Waletzky (as expounded by Coffey and Atkinson (1996), which I had also worked with during a workshop in narrative analysis. The basic assumption of this model is that narratives have formal, structural properties in relation to their social functions, thus recurrent patterns can be identified and used to interpret segments of the narrative (Coffey & Atkinson, 1996, p. 57). A narrative often starts with an abstract (Ab), i.e. a brief introductory summary of its subject matter. However, Coffey & Atkinson point out that in a research interview the abstract may be missing, since it is part of the whole situation. Then follows orientation (Or), which is usually a description of events with a focus on who, what, when and where. These build up to a plot or a complicating action (Ca), 'which normally carries the major accounts of the events that are central to the story' (Coffey & Atkinson, 1996, p. 60). In our interviews the complicating action is not necessarily the decision to terminate treatment, but events connected to this, such as disrespectful communication or abrupt powerful emotional impressions. The evaluation (Ev) summarises the points of the narrative, often as a subjective valuation of the events. The result or resolution (Re) may occur before or after the evaluation. Some narratives may finish with a coda (Co) which marks the end of the narrative, returning the discourse to the present (Coffey & Atkinson, 1996; Frank, 2010). Many of the narratives in this study were rounded off with short statements like: "So that's how things went". This marked the fact that the narrator was handing over to the interviewer the responsibility for the next phase of the conversation.

4.2 Interpretive Constructivist Grounded Theory

Narrative analysis with a partial focus on structure made the processes in the stories more explicit as human actions. Therefore I found that a suitable supplement to the analysis of the EOL processes could be Charmaz' interpretive constructivist grounded theory (Charmaz, 2006) which with its focus on action and interaction could help to reveal new

perspectives in the data. This applies in particular to the work on the topic of Article I. Before giving a more detailed account of the analysis used in this study, I will take a closer look at this perspective and its epistemology. Since this is a study based on phenomenology, two pertinent questions arise. The first is whether it is possible to combine methods with different ontologies, and the other is whether it was necessary to introduce the constructivist perspective to find the answers to the research question in the first partial study. On the first question, I would argue that it is possible, but requires awareness of the ontological differences between these perspectives. The academic meeting point is therefore the interpretation processes justified in hermeneutics through both Charmaz (2006) and Riessman (2008)/Frank (2010). This is thus the interpretative method which has interested me, both as an inspiration and partly as a correction. With “The Discovery of Grounded Theory” (1967), Barney G. Glaser and Anselm L. Strauss launched a new research methodology which comprised a systematic, inductive and comparative approach for conducting inquiry for the purpose of constructing theory (Charmaz, 2006; Glaser & Strauss, 1967). They set out to legitimise qualitative methods by offering explicit strategies for research. Both scholars had a background in sociology, but from different positions: Glaser from Columbia University positivism and Strauss from Chicago School pragmatism. Their different backgrounds influenced their respective methods. Glaser emphasised the ideals of the positivist scientific tradition, where it is assumed that there is an external world where one as an ‘unbiased observer can discover abstract generalities that explain empirical phenomena’ (Charmaz, 2006, p. 128). By contrast, Strauss’ more pragmatic attitude involves the reservation that we constantly face moving and changing worlds and processes, and the recognition that people make use of multiple approaches to clarify and resolve challenges in their world. Epistemological differences gradually led to new directions in the methodology, mainly due to Strauss’ collaboration with Juliet Corbin (Bryant & Charmaz, 2007). In parallel with this, others have further developed the methodology and thus ensured a continued “methodological battle” (Morse et al., 2009). We have chosen to follow interpretive constructivist grounded theory (CGT), as propounded by Charmaz (Bryant & Charmaz, 2007; Charmaz, 2006, 2009). This reflects the pragmatic element from Strauss which

originates in a relativistic epistemology. This stance involves a recognition that the researcher is part of the multiple world he or she wants to study, and is thus a situated and embodied producer of knowledge. The researcher assumes and takes account of the fact that reality is fluid and to some degree indeterminate, and therefore also searches for multiple perspectives on the realities and a range of varieties in both data and analysis. Instead of abstract conceptualisations, the researcher aims at an interpretive understanding of data (Charmaz, 2009). Constructivists, in line with philosophical hermeneutics, thus seek to make their own position and viewpoint explicit and explain how their values, priorities, position and interactions in the research process have affected the analysis.

In contrast to a narrative approach which keeps the story intact, constructivist grounded theorists make comparisons of themes within and between individual texts through the entire research process. Charmaz (2009) points out that constructivists pay close attention to language and search for linguistic features and terms that we take for granted and thus may overlook at first reading. This approach, together with a concentrated focus on comparisons, allowing for variety, enabled us to examine more closely the concept of “wait and see” from our research. This concept is familiar from the ICU context and terminology, where treatment and effect are often uncertain and one therefore chooses to give the situation more time to see whether a new medication will work or to await the outcome of a new examination. But it was not until we analysed the participants’ experiences across interviews with reference to how they construed the “waiting and seeing time” that we gained more insight into how their experiences were constituted. This helped to narrow down the question of the essence of our emerging main theme of “wait and see”. My other question here is whether we would have arrived at the same result by keeping the analysis within the phenomenological narrative tradition. As a preliminary answer, I would argue that the phenomenological research tradition is more individually oriented, although interpretive grounded theory is also actor oriented and thus intersects with phenomenology (Alvesson & Sköldbberg, 2008). For us, however, Charmaz’ methodological perspectives with their significant focus on social processes served as a useful supplement to the narrative approach. That said, phenomenology is in

fact directed towards the intersubjective aspect and would not in itself be an obstacle to expanding our field of view towards a process orientation.

4.3 Epistemological considerations

The philosophical foundation that has guided this study and the methods used have not been elaborated upon in the papers, and will be presented in the following. Since the aim of the study was to illuminate family members' experiences of decision-making processes regarding the withdrawal or withholding of ICU treatment, a broad focus is placed on analysing the participants' experiences in this ethically demanding situation. The study is embedded in a hermeneutical tradition, with an understanding that hermeneutics and phenomenology as philosophical approaches are epistemologically linked (Dahlberg et al., 2008) and that the distinction between them may seem artificial. Phenomenology as a philosophy is connected to Gadamer's hermeneutic focus on the interpretation of meaning in texts where preconceptions are integrated into the research findings (Dahlberg et al., 2008; Norlyk & Harder, 2010). I have employed a phenomenological view as my philosophy or perspective in all phases of the research process, both in the interviews and in the various analytical approaches to the texts. Lifeworld is a central concept in phenomenology, understood as a pre-scientific concrete and perceptual world of experience that is a basic prerequisite for understanding and meaning (Zahavi, 2001). Our consciousness is always directed at something (intentionality), which implies that what we perceive has significance for us, that it contains meaning. A common meeting ground for phenomenology and hermeneutics is that the lifeworld and the intentional consciousness are interdependent and presuppose one another. Thus we cannot refer to experiences without talking about meaning at the same time (Dahlberg et al., 2008).

Edmund Husserl, considered the founder of phenomenology (Zahavi, 2001, p. 174), argues that lifeworld is not an individual but an intersubjective world where we cannot exist without continuous interaction with others. There is a dialectical relationship between the subjective, the intersubjective and the objective. Intersubjectivity is thus "a relationship between subjects, which includes myself" (Zahavi, 2001, p. 181).

Constructivist grounded theory (Bryant & Charmaz, 2007; Charmaz, 2006, 2009) is based on ideas which are fundamentally different from phenomenology, although this interpretive approach has a clearly hermeneutic foundation. My intention in introducing interpretive grounded theory into a narrative-based project has not been to adopt the epistemological foundation of the method, but to make use of its idea of focusing on how individuals are acting, situated and in interaction with others in their everyday world. As mentioned above, with reference to the focus on the actor perspective, methodology scholars have argued that there are aspects in common with phenomenology (Alvesson & Sköldbberg, 2008). When one considers the methods employed by phenomenologically oriented sociologists of knowledge like P. L. Berger and Luckmann (2000) and Schütz (2005) together with methods anchored in constructivist grounded theory and hermeneutic philosophy, one can envisage such similarities in relation to the interpretation process. In the early stages of grounded theory, particularly Anselm Strauss was keen to find the internal logic of social processes, and Schütz, through his social phenomenological interpretations of the structures of the lifeworld (which he terms everyday world), was precisely interested in the arrangement patterns which such internal logic must follow (P. L. Berger & Luckmann, 2000; Schütz, 2005).

Hermeneutics is the philosophy of understanding gained through interpretation (Palmer, 1969). Classical hermeneutics was originally applied to religious and legal texts. The basic aim was to comprehend the original meaning, understood as the author's intentions, and hence arrive at a correct interpretation. Philosophical hermeneutics may be seen as a criticism of this focus on objectivity and correct interpretation (Thornquist, 2003). Philosophical hermeneutics represents a shift from hermeneutics as a method to hermeneutics as ontology, and both Heidegger and Gadamer are considered to be representatives of this position (Dahlberg et al., 2008). We are present in the world as understanding and interpreting beings and philosophical hermeneutics makes explicit interpretation processes in daily life (Gadamer, 2004). The shift towards hermeneutics as ontology thus implies a focus on the researcher's role as interpreter. The researcher's preconceptions and prejudices become central in the research process. Our own self-

understanding is situated, both in the history we are a part of and in language, and is both a condition for and limitation of our understanding in the present situation (Dahlberg et al., 2008). Increased awareness of how one's own preconceptions may influence the questions addressed to the interviewee, the reading of the texts and the interpretation of the data is thus of vital importance. Both the study participant and the researcher come to the interview situation with their respective horizons of understanding. This implies that we see what we see against the background of our own experience (Gadamer, 2004). Gadamer describes the understanding process in text analysis as engaging in a thinking dialogue with the message of the text with openness as an overall methodological principle (Dahlberg et al., 2008; Palmer, 1969). Interpretation and understanding of meaning are the core of any explorative study. Text interpretation involves elucidating what the text states and finding its meaning. We cannot understand the text better than the author, but we can understand it in a different way by "seeing something new" (Dahlberg et al., 2008; Gadamer, 2004). This involves working in a continuous spiralling movement, where we continually arrive at new understanding through parts being understood on the basis of the whole. This is a dynamic process in which the text is brought into our horizon and we are brought in the text. The goal is "horizon fusion" where our original understanding incorporates that of the other in a new horizon (Thornquist, 2003). In this way our pre-understanding is altered. But because we are not always conscious of our pre-understanding, the researcher must be willing to work at putting his or her pre-understanding to the test.

4.4 The researcher's preconceptions

My preconceptions have throughout the whole research process been the object of a continuous reflexive approach. In qualitative studies the researcher represents the instrument which allows for the data collection (Fog, 2004; Gadamer, 2004; Kvale & Brinkmann, 2009). This study was prepared on the basis of my involvement with intensive care medicine and nursing. Awareness and evaluation of my preconceptions both as nurse and researcher may constitute important factors in the validation of this interview-based study (Lykkeslet & Gjengedal, 2007). A key point is reflexivity throughout the interaction with the participants in the interview situation. This enables

me as a researcher to interpret my own perspectives based on an awareness of preconceptions in the encounter with the participant's perspective. In my research this could result in fresh questions to clarify the interviewee's understanding where his or her perspective did not concur with mine. Examples of this will follow in the section which presents the interview process.

In my view, it was very important for this study that I was familiar with the ICU context as an arena for end-of-life discussions. I will now therefore explain in detail how I became familiar with ICU end-of-life decision-making processes. I have been working for some time as a bedside nurse, involved with patients and their families, but have also been in charge of an ICU for several years and participated on numerous occasions in interdisciplinary end-of-life discussions. I have experienced the importance of having established a relationship of trust, both directed towards the patient and family but also within the ICU team. Towards the family this implies considerate care, well-formulated, honest and factual information, and emotional support to help interpret impressions. Despite the ethically sensitive aspects of making end-of-life decisions, good processes over time with the relatives meant that I and my colleagues experienced the situation as being as positive as possible. Many families have also expressed satisfaction with the way this was dealt with. However, we have not had any systematic bereavement follow-up in the unit, and have little knowledge of family members' reflections on events and experiences with the passage of time.

I have found that it can often be difficult to come to a decision on the benefit of treatment and hence to determine a "turning point". This question has probably often been talked about separately in each professional group before being discussed in a joint session. However, I often found that nurses put the matter on the agenda earlier than doctors, which in several instances led to conflict and heated communication between the groups. The doctors would sometimes argue that the nurses neither knew all the details of the patient's medical condition nor had sufficient professional insight to be able to judge whether "every avenue had been exhausted". The nurses often presented value-based

arguments based on the patient's suffering, which they felt affected them more due to their close contact and continuous presence, whereas the doctors could leave after their visits to the patient. The small number of formal meetings between nurses and doctors seemed to limit the opportunities to increase understanding of a different point of view. Written guidelines for the EOL process have not been common in our department¹⁷. The authority for information and decision making rests with doctors more than nurses, and it has thus often depended on the doctor or mere chance whether nurses¹⁸ participate in family-physician meetings. An important exception is situations where the patient and family have been followed up by one or a few primary nurses. These have made more effort to start the discussion and to be involved themselves in the process. The decision to limit or terminate treatment may either take place over some days with several meetings, or in a more ad hoc manner related to the patient's condition. The number of doctors and which staff from the patient's primary ward¹⁹ or from service departments²⁰ participate will also affect the situation. I often felt that my role as a nurse and participant in interdisciplinary EOL discussions was important, particularly in terms of being able to support the family during the process. But it is also because the nurse has the main responsibility for organising and facilitating the termination. The actual decision to cease treatment was always explicitly defined as the doctors' responsibility, as a medically

¹⁷ As mentioned above, in spring 2009 the Norwegian Directorate of Health published a National Guideline for "Decision-making processes for the limitation of life-prolonging treatment for ill and dying patients". <http://www.helsedirektoratet.no/publikasjoner/nasjonal-veileder-for-beslutningsprosesser-for-begrensning-av-livsforlengende-behandling-hos-alvorlig-syke-og-doende/Sider/default.aspx> (Accessed March 3, 2012). The previously mentioned "Kristina case" was the direct cause of the decision to draw up the guideline. As will be apparent from Article 1 and the discussion later in this thesis, the use of guidelines in this area is disputed. Some Norwegian university hospital ICUs use locally adapted guidelines, but the ICU at the University Hospital of North Norway does not (2012). This study began in spring 2008, before the national guideline existed. My experiences referred to here relate to the period before the study started.

¹⁸ In a meeting organised by the ICU nurses' professional group in Troms in June 2011, where I presented end-of-life topics from the research project, several of the participants (mostly from "my" department) stated that their participation at the meeting was dependent on the doctor and the organisation of the agenda, and that meetings about patient treatment now more often took place without nurses.

¹⁹ At the University Hospital of Northern Norway, a patient is formally admitted to, and belongs to, the ward which deals with the kind of condition which corresponds to the patient's primary diagnosis at admission. The doctor responsible for the patient, as specified in the Patients' Rights Act (www.lovdata.no), is therefore a doctor from this "primary ward" who has daily contact with the patient and communicates with the ICU doctors, who have round-the-clock monitoring responsibilities.

justified decision. I regularly experienced the doctors pointing out to the relatives that they should be spared the possible stress of deciding on behalf of the patient. However, this was often not mentioned again in the short time remaining for the family in the ICU. During the research process it has been necessary to remain critical and be aware of my own proximity to the ICU field, to prevent my preconceptions from threatening the validity of the study, especially by causing certain aspects to be overlooked because they were taken for granted (Lykkeslet & Gjengedal, 2007).

My supervisors Geir Lorem, Per Nortvedt and Olav Hevrøy have been involved in the study by reading, analysing and interpreting the data material. They are co-authors of all the articles and have clinical ethics as their field of special interest. Hevrøy's practical ICU experience has been of particular value throughout the analysis and interpretation of the data material.

4.5 Study design

4.5.1 The setting

The doctors in charge of general ICUs at four university hospitals were asked to participate in the sample (Appendix III). For several reasons we assumed that hospital size was of importance. We considered that ICUs at both university hospitals and minor hospitals regularly made EOL decisions. However, the major hospitals (with ICUs >8 beds) care for patients where the ICU situation with advanced treatment is often acute, dramatic and may last only a few days. This complexity in itself could have significance for the progress of the decision to stop treatment. The age range of the patients would be greater at a university hospital with centralised functions for various serious conditions and advanced therapy (R. Kvale, 2010). This would probably also increase the age range and geographical spread of potential study participants. The above considerations demonstrate that the study uses a purposeful sample (Polit & Beck, 2008).

²⁰ A service department may be a microbiology or infection unit; these have separate responsibilities for advising on antibiotics, infection and infection control. Other doctors besides the "primary ward" doctor may be involved in the case of organ failure or other limited aspects of the treatment.

4.5.2 *The sample*

The requests to the heads of the ICUs were sent to one hospital at a time. In all four hospitals a research nurse performed the sampling and this work was later quality checked by the nurse and doctor together. Selection criteria were as follows:

- Closest relatives of patients who died in an Intensive Care Unit 6-12 months previously²¹, after a decision to withhold or withdraw ICU treatment.
- Deceased patient's age 18 or older.
- Decision to withhold/withdraw treatment documented in the patient record.
- Age 18 or older of closest relative²² receiving invitation to participate. Had visited the patient daily or very regularly.
- Exclusion of relatives who had been asked to consent to organ donation²³.

Detailed information on the study and an invitation to participate were sent from the research coordinators to selected family members within the first year of their loss of a close relative (Appendix IV). Those who agreed to participate returned the written consent in a prepaid envelope addressed to one of the researchers (RL) who was also the only interviewer. Participants' anonymity was assured by their replying directly to the researcher. The researcher only knew the identity of those who consented. Those who made the selection did not know which of the family members consented to participate in the research project. Invitations were sent out in seven rounds over a period of 18 months. The initial response was low; in the first three rounds, only 1 in 4 consented. This led to discussions in the research group as to whether the request came too late after death, or whether we could have worded the request more thoughtfully. We revised the

²¹ This limitation was later changed to 2-12 months after death. Arguments on the following page.

²² Defined earlier

²³ The decision to exclude families of potential organ donors was made after the considerations that consent to organ donation is in itself a difficult decision, and that treatment termination in such cases is a natural consequence of the fact that death has already occurred because the blood circulation to the brain has stopped.

information sheet and obtained permission from the Regional Ethical Committee to contact potential informants earlier after death (2-12 months) (Appendix I). This resulted in a better response, but out of a total of 53 requests only 21 families consented, represented by 27 people. Another two people asked for further information, but neither of these wanted audio recording of the research interview, and chose therefore not to participate.

Despite the fact that no groups based on race, class, gender or other person-related characteristics were excluded, only ethnic Norwegian families agreed to participate in the study.

The family member who received the invitation could decide to invite other relatives to also participate in the interview. This resulted in two family members participating in three interviews, and four in one interview.

The relationship of the participants to the deceased family member varied: there were 11 spouses, 2 sons, 8 daughters, 2 mothers, 2 brothers and 2 sisters. 20 of the participants were women, and 7 were men. The age range was 20-80, with an average age of 49.7 years. Length of care in the ICU until time of death varied from <4 days (5 patients) to 1-4 weeks (14 patients) to more than a month (2 patients). The average patient age was 61 years.

4.5.3 *Sample size*

Qualitative research often uses the concept of saturation (Polit & Beck, 2008). However, founded in phenomenology and hermeneutics, the research must “hold the ontological and epistemological idea that meanings are infinite, always expanding and extending themselves” (Dahlberg et al., 2008, p. 176). In the research protocol I indicated 18-24 interviews. Due to the slow interview tempo, interviews were transcribed and analyses

commenced before all interviews had been completed. I experienced very rich and compact narratives which presented new and different content despite recurrent themes and patterns of common features. One example of this was my discovery that the experience of the EOL decision-making process differed according to the duration of the ICU stay, which varied from 1-2 days to several weeks. My increasing awareness of this phenomenon led me to gather new data. Thus a final sample was made where an additional selection criterion on length of stay was added (>5 days ICU stay). The topics, however, followed the semi-structured guide²⁴ as in the first interviews. In some methods such a sample would be referred to as theoretical sampling (Bryant & Charmaz, 2007; Glaser & Strauss, 1967). However, it is suggested that any qualitative research project will include both theoretical and selective sampling (Sandelowski, 2004). Purposeful, selective sampling refers to a decision made in planning a study to sample subjects according to a preconceived set of criteria. In grounded theory theoretical sampling refers to a sampling decision which means seeking pertinent data to develop an emerging theory (Charmaz, 2006, 2009). In this project the goal was not to generate a theory, thus we view our purposeful sampling as part of the intention to achieve richer and more nuanced descriptions of the participants' experiences which could illuminate phenomena attached to different lengths of ICU stay. I will return to this point in the analysis section.

4.5.4 Data production and the interview situation

The data collection (Papers I-III) consisted of narrative interviews. All interviews began with the researcher introducing herself, not only as a researcher but also as a person with extensive ICU clinical experience as a trained ICU nurse from a similar hospital to the one the informant had experienced. The point of mentioning this was to help them

²⁴ In planning the guide I emphasised the importance of a carefully crafted opening question (Dahlberg 2008). It will become apparent in the following how this was appropriate, where subsequent questions could then follow up the participant's story. I had also emphasised giving the participants detailed written information about the purpose of the study. This was an important step, which together with the questions in the interview guide, helped to address the same phenomenon in all interviews. The preparation of questions for the guide was based on both my own clear conception of the phenomenon (Dahlberg 2008), which partly originated in my preconceptions, and also on my initial studies of the literature, where I found clues to suitable kinds of questions to elaborate on phenomena of particular interest for exploring the families' experiences.

understand that the context (the ICU with all its technological equipment, patients and clinicians) that framed their experiences was generally known to the interviewer. There would therefore be no need for the participant to stop to explain e.g. what a respirator is, but rather stop where such details had a special significance or meaning in their narrative.

4.5.5 Context

The participants were free to choose the venue for the interview. Most interviews were conducted in their homes, but two were held in quiet meeting rooms at their place of work and two in meeting rooms set aside in hotels. There were also two participants who chose telephone interviews.

A small digital voice recorder with an in-built microphone was used to record all interviews. The recorded interviews were subsequently converted to an audio file on my password-protected computer and deleted from the digital recorder. All participants had been informed of the recorder and gave their consent. The information on confidentiality and safe storage of the audio files was repeated at the start of the interview.

The setting for the interview is not an indifferent matter. Visiting the participants in their homes where they feel comfortable and secure would appear to suit most interviewees (Dahlberg et al., 2008). I found the participant's home to be a suitable setting to provide me with a deeper insight and understanding of who the deceased person had been and how important he/she had been to the family. In several homes I was shown pictures of the deceased in the family context or other objects which recalled their lives together. Sharing such memories with me as researcher also had a unifying function and helped to establish initial trust before the interview. Sometimes I was offered coffee, tea, a cake or a sandwich; this was relaxing and together with some small talk helped to open the situation. In interviews with three of the seven male participants this hospitality functioned as relief and protection against feeling embarrassed by crying in front of the researcher. When feelings became overwhelming, they simply stood up and went to the kitchen to make more coffee. Then they pulled themselves together, returned, picked up

the topic again and continued their narration. In this way they controlled their integrity and dignity in an encounter with a stranger in a very sensitive and personal dialogue. The two telephone interviews differed from each other. Both took place after the interviewee's decision to participate via telephone due to geographical distance. After the first interview, our conclusion was that we should have met face to face, since it was challenging to talk on the telephone about a serious personal matter with a person one had never met. However, in the second interview we achieved immediate contact, and maintained a focus on the phenomena and situation relevant to the research topic. We both evaluated the interview situation as having had an experience of "sitting at the same table".

4.5.6 *The narrative interview*

After the introductions, the aims of the study were presented and some points from the information sheet were repeated. I did not suggest any particular structure for the conversation, but confirmed how much time we had available. No one wished to schedule any breaks in advance, but in some interviews short breaks arose naturally. I had hoped that the conversation would start with a compact narrative as a basis for the interview, in keeping with the narrative tradition (Dahlberg et al., 2008; Mishler, 1986; Riessman, 2008). This was also based on the idea that life itself has a narrative shape or that humans naturally think in narrative terms (Garro & Mattingly, 2000, p. 182). Because the selection of participants had been made by the local research coordinators, I was unaware of the relationships between the deceased patients and the participants, or the basis for selection. Thus using a single initial narrative-inducing question: "Can you tell me what happened?" an extensive narrative was elicited. This initial question led in most interviews to long stories about the chain of events and the people involved. The stories were often of a sensitive nature, but I rarely experienced that the narrator stopped because he or she could not find words or seemed to be holding back. Most structured their narratives in a temporal order, from a normal, healthy life situation to the onset of the illness or the accident, which threw them into an unexpected uncertain existence which lasted through the ICU period until the death, followed by the transition to a life without

the loved one they had lost. This account varied in length from 10 to 25 minutes and was generally an uninterrupted narrative, while I listened and indicated this by saying e.g. *hmm, mmm, oh, yeah...*, *no...* and just occasional questions to validate my understanding.

The narrative structure proved to be natural for the participants, with a beginning, middle and end (Coffey & Atkinson, 1996; Frank, 2010). The way of telling the story underlined the importance of the experience. The middle section was usually built up around a point of tension or a plot about the worsening of the patient's condition and the decision to stop treatment. But the point of tension could also be the informants' experiences of disrespectful treatment by health care personnel. The end of the narratives was always marked by statements such as: 'Well, that's all then...' or: 'That's how things went...' followed by silence between us until I spoke up and acknowledged the story and the effect it had had on me. Then I might say, 'Well, that was a powerful story and I'm glad you were willing to share it with me.' In this way stories are always performative, where the act of telling is relational (Frank, 2010). I was often moved, both by the story and the powerful way it was told. This was visible through my active listening and body language. I felt confident enough to show emotion (without letting it take over), while maintaining dignity and respect for the narrator.

Only one interview differed from the others in being a kind of "chaos interview", without any real beginning or end, where themes were embarked upon only to be set aside, replaced by new ones, and then returned to. This interview was carried out as early as three months after the death. There and then I decided that my task was to witness the chaos, not to bring order into it. However, in the second part of the interview I felt responsible to ensure that the participant had expressed what she wanted to tell and what was at stake for her, yet at the same time I needed to show respect for the unfinished character of the story (Frank, 2010).

During the second phase of the conversation, the actual interview, the interviewee was asked to return to sequences of content that had been touched upon during the long narrative. Now the same content was retold, often with different words and an emphasis on what was particularly relevant to the focus of the study. But other topics closely linked to the research questions were also underlined by the participants who thus showed that they associated meaning with the events. I followed up with questions in a reflective dialogue which “steered” the story’s course of events, often connected to people and further events and the reflections of the participant on feelings and impressions (e.g. What did you think about what was said or what happened? Can you tell me some more about what happened then?). Emphasis was placed on following the participant in his or her tracks, but this was always within the theme. A semi-structured interview guide was available (Appendix V), but it was well memorised in advance and only used at the end of the interviews to ensure that all relevant topics had been touched upon in the conversation. Several participants had prepared for the interview themselves with a list of points they wished to talk about. One elderly man had eight handwritten pages which he used as support for his story and our conversation.

In the first interviews, I asked for permission to note down key words during the talk when there was a point I wanted to return to. However, in practice it was very difficult to divide my attention between the participant and my notebook. In fact I did not forget to return to points where I wanted more detailed answers. However, I made notes immediately after the interviews, describing the atmosphere and context, my reflections on the conversation and any aspects raised after the voice recorder was switched off.

4.5.7 Transcription of the interviews

The transcripts were written as faithfully as possible. Pauses, laughter and other wordless expressions of feelings were registered. However, I decided to “translate” the participants’ vernacular to standard Norwegian (bokmål). For the presentation of quotations in the articles, a few sentences have been tidied somewhat, e.g. where the same words are repeated three times for emphasis, this may be reduced to two. I have

also chosen to delete some subordinate clauses in the quotations, where the content does not concern or enhance the meaning, in order to keep sentences consistent and condensed. The deleted text in quotations is marked with brackets containing three dots [...]. To ensure anonymity, no names, locations or dates were recorded in the transcriptions.

In a period with several interviews over a short time, a professional typist transcribed six interviews. She gave a written promise of secrecy and promised to delete the audio files after completing the transcription. I read these texts carefully while listening to the audio files, and made any necessary corrections.

4.5.8 Ethical research considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK), the Norwegian Social Science Data Services (NSD), and subsequently by the participating ICUs. The ethical considerations throughout the research process were guided by REK policy and written recommendations in addition to the ethical guidelines for nursing research in the Nordic countries (Northern Nurses' Federation 2003) and the ethical principles for medical research involving human subjects in the Declaration of Helsinki (World Medical Association 2008).

Informed consent functions as an important protection for the participants in research (Ruyter et al., 2000). An information sheet was distributed to potential participants informing them about the aim and background of the study, that participation was voluntary and that they could withdraw their consent at any time during or after the interviews. They were also informed that the interviews would be digitally recorded and transcribed verbatim.

The research interview is a special form of relationship between the parties. It is an asymmetric relationship due to the researcher's professional interest in the research topic. Openness and enthusiasm may arise in research conversations, just as in everyday

conversations (Fog, 2004). However, the conversation is not a “true” conversation, but must be viewed as a professional activity which borrows qualities from the true dialogue. The conversation might invite the interviewee to confide in the researcher, leading to more openness than the interviewee could have foreseen (Fog, 2004). The moral aspect of this arises when the contact ceases. It is not unlikely that the participant, due to the close contact of the interview situation with the opportunity to talk about personal experiences with someone who is genuinely interested, would like to resume contact with the researcher. The participants were initially informed of my role as a researcher. However, because of the ethically sensitive nature of the interviews, touching upon personal and emotional issues, the written information for the participants contained the name and telephone number of a contact person from the unit which had selected them for the study. If new questions, problems or a need for further action arose from the interviews, the contact person would be able to put the participant in touch with the appropriate service. Although this would infringe upon the confidentiality principle, I considered such an offer to be necessary, a decision which REK supported. Additionally, if it was more convenient, they could ask for my help in contacting the appropriate service, but none of them did so. All this information was repeated at the start of the interviews, and confidentiality regarding participation and anonymity in relation to publication were emphasised. All participants gave their written, informed consent to participate in the study. Most participants said it had been good to have a talk and interview about the ICU events. Two participants emailed a comment following the interview expressing relief and gratitude for having had the possibility to share their narrative with a “qualified and skilled” listener.

The University Hospital of Northern Norway where I work in the general ICU was not asked to participate in the study. This was to prevent potential participants from feeling obliged to take part in return for the care provided by the ICU staff to the patient and relatives.

4.5.9 Analysis

Several approaches to analysis were employed; I will here present these in the order they took place and justify their selection.

Listening to audio files

An early stage of analysis was listening to audio files, reading and analysing post-interview notes and transcribing interviews on the basis of repeated listenings. This preliminary work constituted an important platform of impressions. As this analysis took place, it simultaneously implied recognition of my encounter with myself as a researcher. Listening to audio files also involved a new encounter with the power of the narratives through sensory expressions such as vocal pitch, tone of voice, wordless expressions like sighs and silence and reminders of body language in general.

The initial analysis

The interviews were transcribed and printed for reading with a column for notes, both for the descriptive analysis and for a possible incipient normative reflection. This line of action was suitable to gain an overall impression of the essence of the text or an initial superficial interpretation of the text as a whole. In the initial reading I distinguished between the primary narrative and the second phase of the more formal interview with open-ended questions. The primary analytical question to the text was how individuals express and account for their experiences of end-of-life decision making. The whole narrative was analysed without dividing it into component themes. The primary attention was on “what” is said, i.e. on the participants’ reports of events and experiences rather on “the telling” (Mishler, 1986; Riessman, 1993). The thematic analysis showed that issues connected to the relationship with the clinicians and communication about the patient’s condition and decision-making processes were emphasised in all interviews. However, the participants’ everyday experiences and commonsense understanding of communication and relationships appeared to be challenged in the face of the unfamiliar culture of an intensive care unit. The participants’ revelation of the patterns or framework

underlying their understanding enhanced my perception of what the experiences meant to them.

Although I had spent time listening to audio files and had transcribed most interviews myself, I often had to return to the audio files for re-listening to e.g. tone of voice, pauses or sequences of reiteration of earlier topics using other words than those in the initial narrative. In this way this phase was a continuous hermeneutic task. Through the way the voices emphasised seemingly identical linguistic content, I could precede with my own interpretation beyond the descriptive level. At this descriptive analytical stage the text was analysed according to the research topic and questions. However, reflections pertaining to ethics and law were made simultaneously. This led to analysis of larger text segments, marked with thematic tags, often the participants' own words or phrases. An example of this was a spouse's detailed story of her husband's rapidly worsening condition with several complications, which she experienced as "being in a drama". "To be in a drama" was her term for the plot itself, the crux in the narrative, while this in my preliminary interpretation also covered her way of holding her own (Frank, 2010) through the process, which implied a drama out of her control. The ethical aspects of losing control were reflected upon and discussed in notes.

Although I worked with one interview at a time, I often found themes familiar from one interview in the next. More specifically, this often concerned contrasts in value-laden topics, such as experiences of kindness or disrespect. This resulted in new questions to the texts, including the matter of the duration of the ICU stay. This then focused attention on the contextualisation of the narrative in time and space, and a preliminary structural analysis was performed. Are there relatively more examples of disrespect when the ICU stay is much longer? In this way, the analysis was brought into a comparative phase and I found inspiration to use Charmaz' analytical tools in the work with the themes presented in Paper I.

Analysis Paper I

The most urgent research question was to ascertain how and to what degree family members felt included in the end-of-life decision-making process. Reflecting on the actions and situations where interaction took place in this process, I was inspired to use the analytic tools suggested by Charmaz (2006) in her constructivist approach to grounded theory²⁵. A fundamental question is: How do the participants act upon their experiences, their view of reality?

Coding is described as ‘the first step in moving beyond concrete statements in the data to making analytic interpretations’ (Charmaz, 2006, p. 43). Grounded theory coding consists of at least two phases: initial and focused coding. My main supervisor (GL) was strongly involved in the coding and analysis of the first five interviews. They were initially coded either partly line by line or incident by incident. Later interviews were coded incident by incident. I constantly asked questions of the data which would help to focus on actions and identify and name significant processes which took place whether the participant were involved or not. Typical questions asked were: ‘What is happening?’ ‘What does the text suggest?’ ‘From whose point of view?’ ‘What does the participant profess to think and feel while processes are taking place?’ and ‘How does the process change?’ (Charmaz, 2006, pp. 47-51). In this way I did not only try to interpret how concrete actions or words appeared, but also why and how participants constructed meaning in specific situations (Charmaz, 2006, p. 130).

During the initial coding I remained open for many possible directions indicated in the data. The codes were thus provisional and were constantly compared with each other within individual interviews and between interviews. The initial coding established certain analytic directions, such as the significance of the length of the ICU stay for the families’ experiences, as mentioned above. When I compared and grouped families with shorter stays with those with longer ICU stays, I found more negative experiences

²⁵ In this phase I found it useful to organise the data using NVivo, a software package that facilitates sorting and coding. <http://en.wikipedia.org/wiki/NVivo>

connected to the longer stays, which was also related to the families' inclusion in the end-of-life discussions. The focused coding then followed, where the most significant or frequent earlier codes were used in reading larger amounts of data (Charmaz, 2006). This major selection stage was based on an investigation of the conditions forming the structure of the event or phenomenon under examination, whereby actions, interactions and their consequences were studied. The participants' experiences of inclusion in the decision-making process were then divided into two groups. Previously identified incidents or events were compared within and across the groups, with the same questions as before, focusing on structure, actions, interactions and consequences. The consequences were analysed by considering the results from the descriptive analysis on a normative level according to medical and nursing ethics and law.

To support and facilitate the coding, notes or memos were regularly written. Memos could be short associations noted down on paper, or more comprehensive notes on the computer on ideas and possible connections. At the same time this was a hermeneutic process where I often returned to texts behind initial codes and studied aspects of these to enable me to decide which codes were most significant. As this analytic process was driven further, I gained new insights into the ongoing processes; thus I attempted to grasp the meaning and implications for the families when the patient's condition and prognosis is uncertain and doctors and nurses have to wait and see and postpone decisions. In addition, I found it useful to draw situational maps (Clarke, 2005) with an overview of and connections among the participants and the clinicians, and also according to e.g. shifting structures like meeting arenas, frequency of communication or visiting times. The research process described above led to the results reported in Paper I. However, when analysing themes for Papers II and III, I found that I had to work differently with the data. I recognised a need for a reanalysis by keeping the text in larger segments, with a more comprehensive view of the ethical aspects in the participants' narratives.

Analysis Papers II and III

While working with the research question and the area of focus for Papers II and III, I returned to the initial thematic analysis. The research question for Paper II set out to explore through the participant's narratives how they experienced their communication and relationship with ICU nurses in the decision-making process and what these phenomena meant for them. The analysis led to a useful overview of the situations where nurses and families interacted, what they communicated and how the families perceived the nurses' role and responsibilities to them as family members of the patient. But it was more difficult to grasp what kind of meaning the families attributed to the nurses' actions and function towards them. I therefore chose to supplement the thematic analysis with a structural analysis based on Labov and Waletzky's model (Coffey & Atkinson, 1996).

This revealed several new elements. Firstly, it became apparent that the families' stories about the nurses' kindness, primarily towards the patient, but also towards themselves, were of considerable significance. Almost without exception, these "hero stories" were related at an early stage in the main narrative. My first assumption about this was that it matched my own experience in similar situations of nurses' far-reaching involvement and consideration for the patient's family in all areas. My second insight, which did not necessarily conflict with my initial assumption, was that this aspect of the stories was recipient designed. It may have been important for the participants to give the interviewer, who is a nurse, some kind of appreciation for the important work of intensive care nurses for patients and their families. However, the structural analysis showed that nurses' relation to the families changed over time in relation to various factors, particularly the patient's worsened condition. A focus on temporality thus revealed some cracks in the veneer surrounding nurses in the participants' "hero stories". Structural analysis was then applied to segments further on in the text where the narratives dealt with explicit relationships between nurses and families and brought forth complicating actions or events. These were mostly related to communication or lack of communication. An important factor in the analysis was to think in terms of a phenomenological contextualisation (Pahuus, 2011) or relevance (Schütz, 2005) for

phenomena such as ‘conversation’. By this I mean to grasp how the phenomenon of ‘conversation’ can be understood from its context of meaning. We always interpret phenomena in a broader context, the most important part of which is the individual context, the subjective basis, with experiences rooted in our everyday world. In order to delineate the phenomenon of ‘conversation’, it must be brought into a larger context (specific context, type of context, institutional context). When and where do important conversations take place? What is talked about? What is not talked about? What kind of expression is given to what is not talked about? What might this mean? A phenomenological analysis thus attempts to view a phenomenon in the light of a larger whole, in our case in light of the practice context in which the phenomenon takes place.

The same analytical steps form the basis for Paper III, but the structural analysis was there less prominent. In this partial study, only six participants were included; these were related to a patient who was awake and judged to be competent. The intention here was to address certain ethical challenges connected to family members’ participation in EOL decision-making processes when the patient is alert and assumed to be competent. The interview texts were analysed in several steps using a thematic narrative analysis. In the analysis, we were particularly concerned with phenomena in the relationship between patient and family and the particular nature of the state of being a close relative of a critically ill but autonomous patient. Our analysis focused especially on the social interaction implied in the texts and how the participants themselves found meaning and significance in the events. Relevant themes emerged from each interview; these would often be turning points in their narratives. The emergent themes were compared across the six narratives, revealing both commonalities and variations. A particular area of focus was the families’ experiences of EOL communication, both with the patient and with the health care personnel. Three variations of communicating EOL decisions were revealed, with certain ethical aspects to discuss. The analysis continued with a discussion in terms of the relevant ethics, guidelines and legislation. Alternative explanations for the findings were considered and agreed upon with the supervisors.

4.5.10 A circular interaction between the empirical and the normative ethical analysis

The hermeneutic aspects of ethics carry the key assumption that human life is a process of interpretation. A situation is always viewed from a certain perspective (Gadamer, 2004). An important goal of the ethical analysis was to seek a deeper understanding of the situation, including the subjective interpretations by the participants and their ethical meaning. To analyse their experiences in dialogue with ethics and law was simultaneously an attempt to reconstruct their meanings into a broader understanding of how the subjective and particular could inform practice. The participants' experiences are rooted in concrete situations, but they also express insights into what matters in human life more generally, and in our context the general aspects of what matters in the end-of-life situation. On this basis I have tried to remain in a circular movement between the data (reflecting moral experience), with the aim of exploring and articulating various and sometimes conflicting perspectives on a situation under consideration, and also bringing more normative reasoning and argumentation actively into the analyses. To varying degrees this is made explicit in the papers.

As the analysis progressed I found it important to consult research on end-of-life in the ICU. The research field is comprehensive and I conclude that discussions on several EOL issues are lacking in the Norwegian ICU context, but well-formulated in Europe and North America. Studying this topic thoroughly helped me return to my own research and to the various positions of ethics and legislation with refined analytical questions. My principal finding, running through all three papers, is that families experience a gap between the compassionate caring of health care personnel and their ability to communicate the end-of-life process in a readily comprehensible manner. One consequence of this is their experience of a role confusion linked to their sense of responsibility for the patients' interests. The discussion section will address this question more thoroughly.

4.6 Final reflections

I received valuable comments from the reviewers on all papers. Their critical queries on the drafts were very useful. The reviewers' comments and questions helped me to re-visit the findings with a new gaze, and in one case also enhanced the analysis (Paper I). My supervisors have throughout the research process asked pertinent questions, thereby helping me to keep the analysis on a reliable track. Colleagues have also made vital contributions by discussing the research issues and their implications, and posing constructive critical questions.

5 DISCUSSION OF THE METHOD

The purpose of this chapter is to present a critical review of the strengths and weaknesses of the study with regard to the quality of the research. The terms validity and reliability, commonly used in the quantitative tradition, have given rise to much discussion in qualitative research. Particularly the concept of reliability is troublesome in the criticism of qualitative research. The term has reference to repeatability, i.e. the question of whether another researcher using the same methods would arrive at the same result. Arguments for the need to use separate terminology are related to the fact that the philosophical underpinnings and goals in qualitative research are different, and therefore require a different terminology which can fulfil the requirements for the research process and results (Polit & Beck, 2008).

Researchers in qualitative traditions have however not managed to agree on precise concepts to replace validity and reliability. Lincoln and Guba (1985) developed standards of trustworthiness of qualitative research that parallel the standards of reliability and validity in quantitative research. The concept of trustworthiness consisted originally of four criteria: credibility, dependability, confirmability and transferability; they later added authenticity (Guba & Lincoln, 1994; Polit & Beck, 2008). The standards of trustworthiness of Guba and Lincoln (1994) were subsequently included by Whittemore, Chase, and Mandle (2001) in an expanded framework of qualitative validity criteria (Polit & Beck, 2008). Kvale and Brinkmann (2009) have described validation in 7 steps, with similar criteria to those mentioned above.

According to Kvale and Brinkmann (2009) and Whittemore et al. (2001), validation in qualitative research encompasses the entire process of questions for self-scrutiny during a study as well as final assessments on completion of the study. Before I proceed, I would mention that many elements one would expect to find in this section on methodological reflections have been described in the methodology chapter. This discussion touches on some of the same themes, but more critically.

The first question for self-scrutiny concerns the thematisation of the study, i.e. how it was planned and on which theoretical assumptions the research questions were based. The planning was grounded in an empirically based question of responsibility in EOL decision making, where the principle of autonomy as a fundamental right formed the theoretical foundation. With “responsibility and autonomy” in mind, the research questions were mainly developed in the light of legislation, ethics and present research in end-of-life issues. They were developed in a logical manner, both in relation to my preconceptions and to Norwegian legislation on end-of-life decision making (Polit & Beck, 2008). An important point not mentioned earlier is that neither in the information sheet nor in the interviews did I explain to the participants the constraints imposed by Norwegian legislation on the EOL decision-making process. Would the stories have been different if the participants had been made aware of the legal provisions? It is difficult to give a clear answer. Perhaps the stories of their experiences would have been restricted or regulated by what the law states, resulting in sparser descriptions of what they believed they had experienced. By not actively taking a position on rights, they were able to shed light on their experiences of the decision-making process from their own perspective.

Validation involves assessing whether the choice of method was appropriate for the topic of the study and represented a relevant way to knowledge that could illuminate the question at hand (Kvale & Brinkmann, 2009). In this study it would in my view have been very difficult to gain sufficient insight into the phenomena investigated by any other method. Interviews on sensitive issues, if planned and conducted in a professionally sound and ethically satisfactory manner, are highly suited to reveal the participants’ experiences of the meaning of phenomena in certain events (Dahlberg et al., 2008). Using an interview method, this study has provided important insights related to the research questions. However, a limitation is that it has only shed light on the perspectives of the families. In addition to interviews, participant observation of end-of-life family conferences could have enhanced and nuanced the findings. Combinations with other research designs, such as an initial survey aimed at families, nurses and doctors, could

have formed a useful Norwegian contextual basis for relevant questions for the interview study.

Validation of the analysis involves several important issues. Kvale and Brinkmann (2009) suggest that it is primarily a matter of whether the questions asked of the interview text are valid and whether the interpretations are logical. The analysis was discussed with the supervisors and we considered how different questions to the text could elicit distinct responses. A fundamental issue is what influence theory has had in the analysis (Alvesson & Sköldberg, 2008). In the later stages of the analysis I discussed the findings in terms of theory, as previously described. One criticism might be that my caring, ethically oriented nursing background unduly influenced me in my focus on the relational aspects of autonomy and communication. However, I have been aware of this and in fact consider that this insight has given me a sound basis and a fresh perspective in the face of principles and legislation. I believe I have had a keen and critical view of the place of theory in this study, and have therefore used parts of existing research findings with caution. One example is theories of stress and anxiety, which would have provided different orientations or approaches and placed greater responsibility for the poor communication on the family's faulty perception of the information.

It was possible to analyse a considerable portion of the interview texts on the basis of the research questions. In spite of this, we must consider whether the research results reflect participants' experiences and context in a believable way (Whittemore et al., 2001). This credibility check is somewhat difficult to guarantee in a qualitative project. Validity also encompasses the interviewer's credibility and ability to conduct interviews with validation of statements where something is unclear. I was many times surprised by experiences which ran contrary to my preconceptions. Sometimes it would not be sufficiently helpful to ask for clarification immediately, so I often postponed this until a later stage of the interview. I could thus approach the sequence from different angles and request elaboration in relation to the broader context the participant had provided.

Validation of the analysis is also related to reporting. Integrity is particularly necessary in the choice of quotations. I have tried to provide rich descriptions in my presentations, while avoiding extreme use of language. My interpretations are grounded in the data, so when the analysis led to certain themes, these were based on the main trends in the material. An argument that guarantees authenticity in the study is that multiple realities and voices have been represented (Whittemore et al., 2001). An example of this is the themes of Paper III. I was surprised and moved by the experiences of the relatives of the competent ICU patients. These six families represent only about a quarter of the sample, and the theme of “alert patients” has only a partial focus in the research questions. But the special nature of these participants’ experiences led to a clearer focus on the concept of responsibility in decision making than in the first two papers, and it could thus be included later in a more general discussion in the thesis.

Another validity criterion in qualitative research is the question of the sample. The selection was made by the chief physician and ICU nurse or research nurse in the participating ICUs. Potential participants were selected from the mortality registers of each unit, without any specific request to take account of the gender of patients or family members. There are more male than female ICU patients in university hospitals (R. Kvale, 2010). Female participants predominated in our study, and were correspondingly related to more men (13) than women (8). The response rate was low (see Chapter 4), which may be related to the fact that participation would involve the necessity to recount powerful emotional experiences, and becoming exposed in this way might require energy and a strong will. I observed that this was more difficult for many of the men who took part in the study, which may also be a reason why few men wanted to participate.

One weakness of the sample is that only ethnic Norwegians agreed to participate. Potential foreign language participants received the additional information that the interview would be in English, without an interpreter. Since many foreigners in Norway do not have a good command of English, this requirement may have prevented those approached from participating.

Another possible criticism of the sample is whether the person²⁶ who made the selection performed a qualitative assessment of individual potential participants based on a recollection of the situations with them as particularly harmonious, contentious or otherwise out of the ordinary. If so, this represents a potential bias. It is impossible to judge whether those who consented to participate differ from those who did not consent. I had the impression of meeting perfectly ordinary, normally thoughtful people, but was sometimes surprised by phenomena in the participants' experiences that were different and perhaps more negatively charged than I had expected. These were especially factors very familiar to us clinicians, such as general bustle and shortage of time leading to changes in plans. This happens continually in the type of ad hoc wards represented by ICUs. But the fact that this issue, especially with regard to communication, appeared to involve a much more serious intrusion into the life of the close relatives than I had seen as a nurse forced me as a researcher to take a major step aside from my preconceptions (Lykkeslet & Gjengedal, 2007) in order to be able to approach their experiences with an open mind. It was also important to meet all new participants in the study with an openness that did not put their experiences "in the same bag" as those of earlier participants.

The knowledge provided by this interview study, particularly because it involves relevant criticism of existing practice, will have the potential to improve the EOL decision-making process for future family members of critically ill patients. I would like to sum up these methodological reflections with the conclusion that I believe people in similar situations to those referred to in this study will be able to recognise themselves in the study's main findings. This is not limited to the findings being recognisable only to families, but in my view preferably also for doctors and nurses working in ICUs. The results may also be transferable to other settings where communication between clinicians and patients' families is under discussion.

²⁶ In all units the chief physician was responsible for the selection, but the practical work was undertaken by an ICU nurse or research nurse. These nurses also worked as regular bedside ICU nurses.

Because the interviews provided a rich source of information, I constantly had to consider whether the issues raised were keeping the project on its track in accordance with the research questions. A number of important issues were therefore put aside, but I have noted these associated topics as suggestions for further research.

6 RESULTS

6.1 Presentation of main findings in Papers I-III

Three papers have been published on the basis of their empirical data and analysis. These were the results of a research project focusing on the experiences of family members of ICU patients which challenged my previous insight into end-of-life decision-making from the perspective of a health care professional.

The study objective was to illuminate end-of-life decision making in four Norwegian ICUs through a family member perspective, with a significant focus on examining the family's role in the end-of-life decision-making process. An overall aim was to reveal areas for qualitative improvement regarding families' involvement and participation in this process.

The findings reveal that few family members felt included in the end-of-life decision-making process to the extent that they would have wished. The principal findings running through all three papers are that the relatives of ICU patients experience inadequate communication and that there is a diffuse understanding of the families' role in the decision-making process.

Paper I: Lind, R., Lorem, G., Nortvedt, P., & Hevrøy, O. (2011). Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive Care Medicine*, 37(7), 1143-1150. doi: 10.1007/s00134-011-2253-x

The purpose of this paper was to examine family members' experiences of end-of-life decision-making processes in Norwegian ICUs to ascertain the degree to which they felt included in the decision-making process and whether they received the necessary information. The article also focused on how the families were able to present the patients' preferences and how they viewed their own role in the decision-making process.

Overview of the main theme and subthemes that emerged from the analysis in a constructivist interpretive grounded theory approach:

Main theme	Subthemes
“Wait and see”	Unavailability
	Ambivalence
	Disparate comprehension
	Delayed communication
	Shared decision making

Findings presented in this paper revealed that the concept of “wait and see” expresses the uncertainty in the patient’s condition. This concept also reflects the communication process with the families in various ways. The participants’ experiences can be divided into two main groups, based on their understanding of the decision-making process and how they experienced their own role in this. Families with a short ICU stay (<4 days) felt the stay in the unit to be more positive than those with a longer stay. They experienced being more involved in the decision-making process, either through clear participation in the discussion or by deliberation of information on the patients’ values and end-of-life wishes. In the paper we propose a possible interpretation that the patient in these cases was expected to die soon after admission to the ICU, which thus led to a maximisation of communication efforts towards those families. Here the clinicians are characterised as experienced and available, compassionate and emotionally supportive. In the period of ‘waiting and seeing’, these families realise the uncertainty through honest communication with the physicians and nurses, tempering the risk with hope. The “wait and see” period is later interpreted as a fragile time for preparation towards the final end-of-life decision. I associated the experiences from this minor group of relatives with my knowledge gained from ways of working with acute trauma care patients and their families and with potential donor patients. Due to the word limit these associations were not brought into the discussion, although the comparison emerged early in the analysis. It is however an interesting parallelism which could be a topic for later research. Potential donor situations are always met with a well functioning and collaborative team. Protocols are followed, and communication with families is proactive, yet based on discretional discipline.

The experiences of the larger group are in partial contrast to the families mentioned above. They also refer to friendly, compassionate and caring nurses, but physicians are busy, distant and less available than the families need. Thus it is difficult to obtain enough information and support to interpret any information received. Nurses participate only occasionally in the families' encounters with physicians, and they are perceived as vague in communication on the treatment perspectives. The "wait and see" period does not function satisfactorily as a time for preparation. The ICU treatment continues as usual while the families are "waiting and seeing", and combined with the uncertainty of what will happen next, some of them experienced that the end-of-life discussions came up too abruptly. Hence, they felt that the communication was delayed and some struggled to understand their own role in the decision making. Despite the fact that several were relieved to discover that the doctors are responsible for the final decision, they would still have preferred greater involvement in the decision-making process, especially regarding the patient's preferences. In the paper we mention that some were left with unanswered questions, leading to doubt about whether the right decision was made. Due to the word limit in the paper we chose not to elaborate on the content of these unanswered questions. However, various arguments were raised by a number of participants. The patient's advanced age was assumed to be a reason for two of the EOL decisions. Others found that hospital finances must have been a reason. One son believed that his mother's treatment was delayed because the university hospital lacked money to hire nurses and thus refused to receive the patient early enough. Another ICU chose to terminate all treatment one hour after informing the family by telephone of the decision, without giving them the possibility to reach the hospital, and the family felt this was mainly an economic matter. Families of ICU patients express the need for unambiguous communication and clear information on the patient's condition and prognosis. The "wait and see" period could have been used more fruitfully in the end-of-life discussion and functioned as necessary time for preparing families for the final decision.

Paper II: Lind, R., Lorem, G. F., Nortvedt, P., & Hevrøy, O. (2012). Intensive care nurses' involvement in the end-of-life process – perspectives of relatives. *Nursing Ethics*, 19(5), 666-676. doi: 10.1177/0969733011433925

The purpose of this paper was to study how ICU families experienced the nurses' role in the end-of-life decision-making process. How did the families experience the relationship and communication with the nurses, and how did this meet their expectations and needs in the decision-making process?

Overview of the main theme and subthemes that emerged from the narrative analysis:

Themes	
	Compassionate caring
	Vagueness in communication
	Loneliness in stressful surroundings

Findings reveal that above all the nurses' caring attitude towards both patients and families is of utmost importance. The fact that the nurses cared for the relatives, gave them attention and found a way of working where they were welcome to visit the patient was appreciated by all participants. This caring attitude is not outlined further in the paper, because the theme is well known and widely described in other research. However, the paper may then appear to be unilaterally critical by not doing full justice to this aspect of the nurses' care for the families. Yet the empirical data show that the nurses' compassionate caring is fundamental and a premise for their behaviour in these difficult circumstances. The nurses' caring attitude is expressed through words showing understanding and empathy, through embraces and other physical contact and through helpful practical arrangements.

Our results reveal, however, that the nurses' compassionate care fails to meet the families' communication needs. Beside casual conversations, the talk with the nurses about the patient's condition was often limited to results of measurements on the instruments connected to the patient, such as oxygen saturation and blood pressure. By staying with the patient as much as possible, several described observing and interpreting the situation and thus forming their own

impression of the patient's condition. If they did ask the nurses, they usually received a complete answer, except regarding prognosis and risks. Several relatives therefore felt that the nurses expressed themselves in a selective and vague manner and kept information from them. Some assumed that this was due to the different roles of the nurses and physicians, placing responsibility for giving information solely on physicians. Because the doctors were so busy and the nurses so vague in communicating, many relatives felt a huge responsibility to acquire the necessary information themselves.

Many families express some form of loneliness in the ICU's stressful surroundings. We have interpreted this loneliness as a longing directed towards both recognition as an active participant and the opening of a dialogue about the patient's situation. Few participants experienced support from nurses in their end-of-life information meetings with physicians. They thus experienced a void in returning to the patient and the nurse after these meetings, and found it difficult to reveal words and feelings from the talks with the doctors.

Paper III: Lind, R., Nortvedt, P., Lorem, G., & Hevrøy, O. (2012). Family involvement in the end-of-life decisions of competent intensive care patients. *Nursing Ethics*. Published online August 22, 2012 doi: 10.1177/0969733012448969

The purpose of this paper was to address the ethical question: To what extent and in what ways can family members of alert and assumed competent patients be involved in information and decision-making processes regarding possible termination of treatment?

The patient was alert in the case of six of the 21 families interviewed in the study, represented by a total of 11 relatives, and their experiences stand out from the others, since the patient had been assumed competent in the decision-making process.

For the purpose of this article these six interviews were analysed using a thematic narrative approach. The results revealed communication challenges, role strain and strong feelings of responsibility in the process.

Interdependence; obligation to support and protect the patient		
	Main themes	Key concept
I	Transparency in communication; knowing what the other knows	Transparency
II	Participation in the end-of-life decision-making process; patient consent and the role of the family	Participation
III	Responsibility in the decision-making - a matter of ethical intertwinement	Sense of responsibility

An overall finding was that these families show a strong connectedness to the patient, and from their point of view the patient in this vulnerable situation is in distinct need of their support and protection. We have interpreted this connectedness as interdependence.

Communication with clinicians and patient was the most prominent theme in these interviews. Families who were allowed to participate in the physician's communication with the patient expressed satisfaction with the collaboration with the parties involved. Others, who were not allowed to participate in this way, remained unsure of how much information the patient had received and how this was understood, especially regarding his or her worsening condition.

The patients' autonomy, i.e. the right to make decisions for him or herself, was an underlying theme. However, some families doubted the patient's capacity to make an autonomous decision in end-of-life discussions. Within these six families there were three variations in the end-of-life decision-making process. One family experienced being part of a shared decision-making process. Three families found they were just asked to consent to the physician's decisions; in one case this seemed to be on an uninformed basis, in another case on an informed basis but without taking part in the preceding process, and in the third case after inclusion in the process with the alert and competent patient. The latter two families were just informed of the physician's decision and were not allowed to support the patient in his involvement in the decision-making process.

The ethical intertwinement and interdependency in the patient-family relationship release normative responsibilities in the families. Most important were their feelings of responsibility to support the patient in the decision-making process, to be physically present with the patient

and to help the patient to understand that life had come to an end. Those who were not invited into these processes felt responsible for having failed to re-establish a dialogue with the patient before he died, which could have meant a respectful farewell.

Our results, based on these few families' experiences of end-of-life situations, indicate that patients in the latter stages are highly vulnerable and dependent on others and their personal individuality is a fragile achievement. We suggest that patients faced with treatment termination should be supported and have their perceived preferences respected by both clinicians and their morally relevant family member. Models of shared decision-making based upon professional assessment of patient competency would considerably enhance respect for patients and families in these vulnerable situations.

7 DISCUSSION

This study has focused on how family members of deceased ICU patients experienced the end-of-life decision-making process. The findings in all three papers show that differences in perspectives and inadequate communication lead to variations in the comprehension of the EOL situation and the basis for decision making. A key question arising from the findings is the matter of fulfilment of the legislative intent regarding the family's right to participate in the decision making process with their view of what the patient would have wanted. On the basis of our findings, it appears that both health care professionals and families are unsure of what the family's role in decision making should be. Although the majority of the participants in this study had a very limited role in the EOL discussion, several families still experienced responsibility in the decision-making process. This constitutes a new question for the discussion which follows:

How is it possible to communicate with the families without leaving them with a burdensome sense of responsibility for the EOL decision?

I will approach this question by discussing the family's participation and responsibility for the patient in the EOL decision-making process in terms of ethics, legislation and the responsibilities of health care personnel, through the following points:

- Reflections on three experienced perspectives of participation
 - Being informed of the physician's decision to terminate the treatment
 - Being informed of the decision and asked for approval or consent
 - Being informed, participating in the discussion and arriving at a common understanding of the situation
- The ethics of the end-of-life situation
 - Futility – different understandings of the concept
 - Family involvement and conflict
 - What is at stake for the families?
- The role of the interdisciplinary team in communicating with families of dying patients in the ICU

7.1 Reflections over three experienced perspectives of participation

What kinds of experiences do family members have of participation in the EOL decision-making process? I have found that practically none of those participating in this study want to make the EOL decision themselves or bear the sole decision-making responsibility. However, several say that they should have been more involved in the EOL discussion. A majority are surprised at their limited position in these discussions and the ways the clinicians approach them in the process.

We may distinguish between three different perspectives or models of participation. Our arrangement is based on the division made in Paper III. In Paper I, the experiences are grouped somewhat differently as Perspectives I and II in the table below are combined. However, as the discussion will show, distinct ethical differences are revealed between them.

Experienced perspectives of family participation in the EOL decision-making process:

Being informed of the physician's decision to terminate the treatment	Being informed of the decision and asked for approval or consent	Being informed, participating in the discussion and arriving at a common understanding (family-centred decision making)
<ul style="list-style-type: none"> • Experienced by most participants • Physician's decision according to law • Medical decision based on treatment futility • Family not participating in decision-making process • Sense of responsibility 	<ul style="list-style-type: none"> • Experienced by some participants • Physician's decision according to law • Medical decision based on treatment futility • Poor preceding process, scant communication and comprehension • Sense of responsibility 	<ul style="list-style-type: none"> • Experienced by some participants • Physician's decision according to law • Medical decision based on treatment futility • Family participating in decision-making process • Sense of shared responsibility

Paternalism

Autonomy



Being informed of the physician's decision to terminate the treatment

The three perspectives on family involvement may be considered as a gradual shift from a purely paternalistic perspective to a more inclusive and active role for the family. This is paralleled in the well-known article by Emanuel and Emanuel (1992a), who divide the doctor-patient role into four ideal types. Our first perspective on participation has similarities with what the article describes as a paternalistic²⁷ role for the doctor. Here they depict the patient's role as passive, while the doctor provides the premises, with a basic justification in power through knowledge. Patient autonomy is weak, meaning in practice a lack of participation in decision making. The advantage of this ideal type is a clear and effective distribution of roles. Our study shows accordingly that families have great confidence in the doctor's professional knowledge (O'Neill, 2002) and therefore wish to let the doctor deal with medical decisions. However, this does not mean that they do not want to be involved in the process. In my interpretation of the first perspective in our model, this agrees with the legislative intent that gives health care professionals responsibility for decisions and limits the family's participation to the right to be informed. This can be considered as a practice justified by a good intention, based on the principle of non-maleficence (Beauchamp & Childress, 2009), i.e. a desire to spare the family the actual or perceived responsibility of participating in a decision that ends the patient's life. This approach to patients' families may also be culturally anchored in the individual ICU, through established "methods" of resolving the question of family involvement, and in the particular preferences and values of the individual physician and nurse. Since the principle of autonomy is relatively new (Syse, 2009) and intensive care patients generally lack capacity to consent, it is clear that paternalism may still be seen as a common feature of ICUs. Studies have shown that decisions to forego treatment in European countries are frequently made without any discussion with competent patients or families of incompetent patients (Cohen et al., 2005; Vincent, 1999). This means, just as our findings show in many cases, that the EOL decision has already been made by the time families are approached. Based on the patient's right to autonomous decision making, but where the patient is now incapable of consent, should one then consider the question of whether the family's lack of participation in the EOL process undermines patient autonomy

²⁷ Some choose to temper the term "paternalism" by using a milder version, "parentalism" (Curtis & White, 2008). As I understand the term parentalism, it allows for paternalism to be in line with the wishes of the autonomous individual. See also O'Neill (2002) and O'Neill (2003).

further? It is precisely the consideration of a value-based assessment by those who know the patient best which is the legislative intent on the point of family involvement when “health care entails a serious procedure for the patient” (The Patients' Right Act, 1999) (Section 4-6). Family involvement will link the individual patient's values to decisions, in contrast to values as an “objective standard” (Veatch, 2003). It is therefore a matter of concern that many of the study participants were given the impression that few other factors than purely medical possibilities and limitations played any part in practice during the decision-making process. Not until it was decided to terminate treatment was the patient's suffering considered. Here it is important to bear in mind that because most families viewed themselves as excluded, they could not have known in detail what aspects the clinicians had considered during the process. But the empirical data suggest that the patient's own values and preferences were not sufficiently taken into account in the end-of-life discussion.

Being informed of the decision and asked for approval or consent, in the second perspective outlined here, is perceived by several participants as real involvement since they are asked to give their approval or consent to doctors' decisions. However, the position of this perspective with regard to law and ethics may be questioned. In the legislation, the division of responsibility in the decision is clear: the health care professionals are to decide, but not until the family have informed them of the patient's preferences. As several family members feel responsibility for having taken part in decisions without having taken part in the process leading up to the decisions, this type of involvement clearly may make them feel the responsibility to be burdensome. This perspective therefore demonstrates the characteristic weakness that clinicians ignore the family's needs for regular information and procedural understanding, but soften the blow to their pride by involving them in the very last phase.

Being informed, participating in the discussion and arriving at a common understanding, the third perspective, is distinct from the first two perspectives. A greater degree of well-being and satisfaction is expressed by these participants. A significant difference from the previous two perspectives is that the families to a greater degree find patient autonomy to be at the centre. The communication is closely tied to value-laden terms, where the patient's values and preferences are taken into account. The few families included in this perspective also acknowledge that their

participation entailed responsibility, but this responsibility was not felt to be burdensome, since it was shared with the other parties involved. Those who experienced this form of participation found it completely natural, and it was formulated by one of them as “it would have been impossible for us not to be allowed to participate in this way”. Returning now to Emanuel and Emanuel (1992a), three other models of the doctor’s role are described: the informative, the interpretive and the deliberative. Particularly the latter two types of role represent an increase in patient autonomy and a decrease in the professional autonomy of the doctor. The increase in the patient’s autonomy implies a shift from passivity to activity, to be allowed to take charge of one’s own life and values.

It would be an oversimplification to suggest that these roles merge in our “family-centred decision making” perspective. But the perspective presents aspects of increasing humanity and respect for the importance of the patient’s values, represented by the family, in the choices made. In the few examples in this category, where treatment options naturally come first, it would appear that the discussion of values and patient preferences in an imagined EOL scenario is taken up early on in the process, before and perhaps instead of having to draw the conclusion that treatment is futile.

7.2 The ethics of the end-of-life situation

7.2.1.1 Futility – different understandings of the concept

There have been many attempts to frame the term futility in a clinical useful way, yet no professional consensus has been achieved on the definition. Medical futility is generally defined as treatment or clinical interventions that are not likely to result in benefit to the patient or produce the expected outcome (Schneiderman, 2011). The literature prescribes that a decision on futility should be made only after careful consideration of medical facts based on evidence that continuing life-prolonging treatment is considered of no benefit for the patient (Mohindra, 2007; Tonelli, 2007). The concept is not described in detail in the papers in this study, and I find it inadequately understood in the family context. The aspects of the concept presented in this study will therefore be discussed in the following. Such aspects may for example involve the

experience of conflict in situations where families want everything to be done for the patient, even though a medical limit has been reached.

By using the term futile with regard to ongoing treatment, clinicians are given a sort of power that is difficult to question or argue against for lay people (Zier et al., 2009). In our study the concept is used as a justification for terminating treatment. At the same time, families found it confusing that full treatment had been continuing right until a sudden point in time when “futility” was finally established. Thus, both on the basis of our empirical data and my personal experience as an intensive care nurse, the timing of the discussion of futility seems to be difficult, as well as the actual use of the concept. Criticism has arisen that the use of the term futility, based on scientifically indisputable evidence, represents a paternalistic approach used by clinicians who wish to hide or avoid the discussion of moral values (C. Sprung et al., 2008). With support from the literature, I would therefore ask whether the term futility should be avoided in talks with patient and family, and that attention should instead be directed towards improving communication (Tonelli, 2007). Our data show clearly that communication with the families in the “wait-and-see” period is inadequate, so that they are not sufficiently prepared when the end comes abruptly. In line with other research (H. Jensen et al., 2011; Nolin & Andersson, 2003), our study also reveals that as soon as the treatment was considered to be futile, only a short time passed before it was discontinued.

The families in our study want more information and more frequent contact with doctors, and from the nurses they ask for more help in interpreting signs of change in the patient’s condition which may have consequences for the outcome. In accordance with our findings, other research has shown that when clear and comprehensible communication is lacking, families use other sources, often outside the control of clinicians, to gain an insight (Boyd et al., 2010). There is here an inherent possibility of misunderstandings and conflict (Siegel, 2010; White, Engelberg, Wenrich, Lo, & Curtis, 2007). Even though our study presents situations with communication which is helpful and comprehensible, the experience of the majority indicates that without better communication it is confusing that full treatment is continued until the moment of death.

This leads to the question of whether treatment continues for too long before one starts to discuss if the treatment goals are within reach, and whether the goals could have been altered towards palliative care²⁸ earlier in the process. Specialists in end-of-life in the ICU point out that to consider palliative care as synonymous with end-of-life care is to define it too narrowly, and this prevents patients and their families from getting available support in an important phase of life (J.E. Nelson, 2012). A Norwegian study shows that both doctors and nurses to some extent find that intensive care is carried to excess, and to a degree which is ethically unacceptable (Halvorsen et al., 2009). However, in our study there are few families who express the same opinion about the treatment of their family member. But these few had a clear ethical justification for their view that the treatment and the uncertain hope of benefit were in no relation to the suffering of the patient. They appeared however to prefer not to mention this, so long as the doctors and nurses did not take a clear stand. Yet it troubled them later that the end of the patient's life had been marked by degrading suffering.

The fact that the clinicians postpone the final EOL decision is known from previous research, and is grounded in the prognostic uncertainty and the very challenging nature of the ethical considerations regarding futility (Halvorsen et al., 2009). Thus we know that EOL-decisions are extremely demanding for health professionals, especially when they are not in a position²⁹ to act according to ethical norms (Coombs, Addington-Hall, & Long-Suthehall, 2012; Long-Suthehall et al., 2011; Quenot et al., 2012). C. Sprung et al. (2008) have pointed out that this is so difficult that the decision in many cases is postponed until nature takes its course. The concern is thus that what remains is only the establishment of medical facts, without necessarily taking into account other ethical aspects than beneficence and non-maleficence; this was the experience of participants in our study. Reaching a conclusion on treatment benefit at a late stage must

²⁸ The term "palliative care" is broader than "comfort care". Palliative care refers to a multidisciplinary speciality focused on relieving suffering associated with serious illness. As such, provision of palliative care in the hospital may take many forms (e.g. pain relief, symptom relief, psychosocial intervention, family support) and may be provided at the same time as life-prolonging interventions. In contrast, comfort care refers to a treatment course focused only on alleviating symptoms rather than life prolongation. In the ICU, comfort care traditionally means withdrawal of life-prolonging measures and a transition to a sole focus on patient comfort. <http://www.capc.org/ipal-icu/>

²⁹ This may be due to internal conflicts and hierarchical structures. I will return to this point later.

however be balanced against the risk of deciding on futility too early. An early discussion or too rigid notions of futility may mean that there is “no turning back” in terms of self-fulfilling prophecies (Becker et al., 2001; Klepstad & Gisvold, 2003), with the consequence that treatment possibilities may be ignored or rejected on insufficient medical grounds.

Is there then anything to be gained in the EOL process by replacing or not expressing directly the word futility, or by letting it be part of a broader, more ethically based dialogue? As I understand the palliative trends in ICU (Mosenthal et al., 2012; J.E. Nelson, 2006), a shift towards palliative care does not imply abandoning treatment. It does however imply the beginning of a process where communication is more closely linked to the patient’s values, and where the value-based assessments of other involved parties are made explicit. It reveals that working towards a decision to limit or terminate life-prolonging treatment is not purely based on objective professional criteria rooted in clinical evidence, but also on assumptions, value considerations and personal preferences among the involved clinicians (Halvorsen et al., 2009; Mohindra, 2007; Pochard & Abroug, 2005; Tonelli, 2007).

The most important ethical question in the discussion of continued treatment is whether this is in line with the patient’s wishes and also takes into account his presumed future quality of life (Beauchamp & Childress, 2009; Schenker, Tiver, Hong, & White, 2012; Veatch, 2003). This is discussed with competent patients, although in Paper III we have shown that the relatives of the weakest patients doubted the patient’s capacity to participate in such conversations, and several were therefore uncertain whether the decision to cease treatment was in accordance with the patient’s wishes. As we have mentioned in the papers and as other research has shown (Shalowitz D.I, Garrett-Mayer E., & Wendler D., 2006), it may be difficult for the family to determine exactly what the patient would have wanted. But many of our study participants believed that they could draw certain conclusions based on random conversations on the subject, their close relationship and their knowledge of the patient’s life values (J. T. Berger, DeRenzo, & Schwartz, 2008; Ho, 2008; Torke, Alexander, & Lantos, 2008). However, what counts as good for others is extremely difficult to assess, both for family members and clinicians. Assessment of quality of life is particularly difficult when the patient is not competent to give consent, and when the patient’s best interest enters as an uncertain factor. Veatch argues that when the

concept of best interest is used in health care ethics, most seem to rely on some theory of objective goods as something external to the patient (Veatch, 1995). He continues: “What is striking here is that even with objective list theories, there is an enormous gap between what it would take to know what is ‘objectively in a patient’s interest’ and what the usual clinician can be expected to know about the patient” (p.7). However, if families are to provide such value judgements, they must be involved more strongly (Ho, 2008; Schenker et al., 2012). In our study few families were asked if they knew the patient’s end-of-life preferences or other questions about the patient’s life values.

7.2.1.2 Futility - family involvement and conflict

An important and familiar problematic aspect of cooperation with the patient’s family is conflict in the EOL decision-making process. Research into the relatives’ roles and attitudes when a family member is critically ill reveals that they may have unrealistic notions about the utility of management options and conflicts may arise when families insist on “doing everything” (Quill, 2001). It is important however to note that most EOL situations are without conflict. Where there is a conflict, it is not necessarily a bad thing; a period of dissent may be necessary because each side may have legitimate concerns (Breen, Abernethy, Abbott, & Tulsky, 2001). Central to any discussion about limiting or withholding medical interventions are the essential nature of clinical utility and the ethical tenets of justice and autonomy. Much of the debate around this subject is motivated by the question of a patient’s or family’s right to demand treatment that may be considered to have little or no benefit. Most clinicians, both physicians and nurses, have experienced and can recall situations of demanding family members who are unwilling to let the patient go, and thus might avoid discussion of hypothetical treatment options or value issues when considering the benefit of treatment. In this connection we must bear in mind that the principle of respect for patient autonomy is a negative right, understood as the right to protection from interference in the person’s thoughts and actions (Dworkin, 1988). The principle involves no right to formulate a positive requirement for further treatment, either for the patient or surrogate family members (Syse, 2009). Norwegian legislation gives neither patients nor their relatives any right to demand treatment that conflicts with the professional autonomy of health care professionals or with the patient’s best interest. Determining the patient’s best interest is however not a simple matter, as I have discussed earlier. Such situations are very challenging for

clinicians, especially for the doctors, who have the final say in decision-making, and it can be difficult to communicate effectively and helpfully on this matter.

Our study reveals a few examples where the idea of justice generates conflict, such as where economic priorities or the patient's age formed part of the basis for the decision. This was not an explicit topic which families discussed with clinicians, but the families picked up certain hints at various stages in the process. Guidelines in regulations concerning priorities require health care professionals to weigh up benefit and expected survival against cost (Ministry of Health Care Services NOU No 18, 1997), but it is a sensitive matter to mention to the families and could be perceived as degrading and disrespectful. However, the hints revealed in our study indicate that openness about such topics, where relevant, would also have had significance for the family's understanding and acceptance of the basis for decision-making. The issue here discussed is thus perhaps mainly a question of communication; how can doctors and nurses exercise their right to professional autonomy when they have arrived at a decision to withhold or withdraw treatment without prejudicing the patient's or family's autonomy or sense of justice in the decision-making process?

An additional burden for some of our participants was the experience of internal conflicts in the care team. It is well known that intensivists and physicians from other units may perceive the situation differently (Cassell, Buchman, Streat, & Stewart, 2003; Halvorsen et al., 2009; Mosenthal et al., 2012). Such conflict and dissent in the group involved can sow doubt and mistrust during the decision-making process (Breen et al., 2001) and in the period following the death. In our study, this kind of disagreement was randomly mentioned. It will probably vary whether the patient or family is informed about such dissent, although the law provides for transparency. Especially in cases where the dissent is connected to a "last resort", one can imagine that the patient or family would cling to the most optimistic treatment option and demand that it is chosen. An important question in this regard is again whether early, helpful involvement of the (patient and) family in the process could forestall such potential conflicts by shifting the focus at an earlier stage from "doing everything" to the patient's best interest.

7.2.1.3 What is at stake for the families?

What then makes it so important for families to be involved in the decision-making process, and not merely be informed about medical data? Can this study tell us what is at stake for the family and in what way this requires action from the clinicians? A number of studies have revealed ICU families' need to feel involved and be regularly informed about the patient's condition and prognosis (Clayton et al., 2008; Evans et al., 2009; Hancock et al., 2007; Linnarsson et al., 2010; Ågård & Harder, 2007). The importance of being able to trust the clinical staff is emphasised, with regard to both professional competence and a friendly interpersonal manner aimed primarily at the patient, but also at the family members. Studies have indicated that ICU families tend towards fatigue, sadness and fear, leading to experiences of distress at varying degree (McAdam, Dracup, White, Fontaine, & Puntillo, 2010), and that high levels of posttraumatic stress disorder (PTSD) symptoms are common in families of ICU patients in the months following discharge (E. Azoulay et al., 2005). In our three papers and earlier in this discussion, conflicts between clinical staff and family have been examined. Such conflicts may be expected to contribute to the families' experience of stress (Abbott, Sago, Breen, Abernethy, & Tulskey, 2001; Norton et al., 2003; Tilden et al., 2001). Previous research has taught us that powerful conflictual experiences are related to communication and staff behaviour (Tilden V.P et al., 1995) as we have also found in our study.

The families we refer to are not able to describe their experiences in diagnostic terms; for example, none use the term anxiety. But several said they felt "out of sorts", restless and uneasy. But despite this they give the impression of having been functioning "normally"; this has been described as common by other studies and is probably connected to the circumstances offered to them (Levine & Zuckerman, 2000; McAdam et al., 2010). They use a value-laden, everyday language, closely linked to the vulnerable situation they find themselves in. In my analysis of the interviews it has been useful for me to view the families' experiences from the standpoint of common morality (Tranøy, 1998). Few if any of the participants revealed knowledge of ethical terminology or theory, although they did use words such as fair, priority and benefit. It is rather the case that words like trust, honesty, love, reliability, politeness and attention are value-laden everyday concepts that characterise aspects of their circumstances as family members of an ICU

patient. I therefore consider it necessary to discuss their situation and what is at stake for them in terms of other positions than merely procedural ethics.

It is particularly the trust in health care personnel that stands out as a central ethical experience, perhaps the most important one. However, the importance of trust has not been discussed in the articles. Trust has not always been interpreted as being unconditionally positive in terms of its moral value (Nortvedt & Grimen, 2004), but I will not discuss this here. Scandinavian nursing has in recent decades been influenced by the Danish philosopher Løgstrup's emphasis on trust as a sovereign expression of life and constitutive of our way of being in the world (Martinsen, 1993; Nortvedt, 2012; Nortvedt & Grimen, 2004). According to Løgstrup (1991) trust is paramount. We normally meet others with trust, and therefore trust needs no justification. By demonstrating trust, the person becomes exposed and vulnerable and places an ethical demand on the other (Vetlesen, 2007; Vetlesen et al., 1996). The basic phenomenon here is that we are inextricably dependent on one other and are involved by virtue of encountering another person (Løgstrup, 1991). I have interpreted the study participants as having this kind of trust, a basic and natural trust. In this context, their trust is linked to their expectations that health care professionals have expertise, master the necessary technology and have good intentions and attitudes towards the patient and family (Nortvedt & Grimen, 2004). This kind of trust is characterised by epistemic asymmetry, where doctors and nurses know and patient and family do not know (Nortvedt & Grimen, 2004, p. 109). As the underlying premise, discussed in more detail in Paper III, medical expertise is acknowledged and the family trustingly "hands over" the patient to the ICU context. The asymmetry implies power and vulnerability. At the same time the family recognises a distance and perhaps a feeling of powerlessness in their sphere of action. The decision-making process itself has previously been discussed in terms of ethical principles and legislation. To the extent that families are made aware of laws and ethics as principles, and any other rules governing their interaction with the patient, they accept this. But what is at stake for families, in spite of laws and ethical rules, is the responsibility they feel for the patient. This responsibility is discussed in most detail in Paper III, but shines through in the other papers. Their relationship with the patient involves a given responsibility, which I suggest is of the same ontological character as trust. Løgstrup helps us to shift our focus from ethics as duties and rights to responsibility. We normally have responsibility for someone. The phenomenon of

responsibility reflects the fact that ethics is grounded in our relations with other people (Andersen, 1996; Vetlesen et al., 1996). The trust shown by the family towards the clinicians, such as trust in getting information, being involved in dialogue and the processes which concern the patient, forms a basis for them to realise their responsibility in a relationship which for them is of an emotional nature, based on love and interdependence. Few of the study participants were in dialogue with nurses and doctors about their perceived responsibility, but several experienced being told that they would be spared responsibility in the EOL process. What responsibility means and which responsibility weighs most heavily can certainly be debated and be the subject of further research into the EOL context. But if responsibility in relationships is something unavoidable as a commitment to wanting the best for the other for his or her own sake, perhaps this should be discussed with the families in order to establish limits of responsibility, instead of the present situation where it is declared to be entirely in the hands of the clinicians? The family's responsibility arises in a reciprocal relationship which requires their participation (Nussbaum, 1998). The offence caused by not allowing them to be involved in any other way than being informed affects them even more profoundly. It touches on the sense of self; what kind of person do I want to be in relation to my neighbour? Taylor argues that people take a stand on life through making strong evaluations, particularly in areas of emotional importance. Strong evaluations require qualitative distinctions in ethical behaviour and reasoning (Taylor, 1985). Dialogue, if the clinicians allow it, can thus have multiple meanings beyond providing the family with information. It can release thoughts and value-based distinctions related to patients' preferences, as we have shown in our idealised model of a form of shared or family-centred decision making.³⁰ Here responsibility is experienced as shared, based on a joint commitment to achieve the best for the patient, and it will thus be easier to live with subsequently.

³⁰ The term "shared decision-making" implies a greater focus on patient autonomy, but it can still be problematic in a Norwegian context where the law does not give the family surrogate rights. I would therefore suggest family-centred decision-making, which does not directly imply responsibility like the term "shared".

7.3 The role of the interdisciplinary team in communicating with families of dying patients in the ICU

The Norwegian Board of Health has stated that professionally responsible EOL care is a question of helpful mutual processes. The requirement for professional responsibility is not only tied to purely medical factors or individual judgements, but is also closely linked to ethical considerations in the preliminary work on the legislation. The Board therefore stresses that professionally responsible work must “be grounded in broad-based processes, where there is no doubt that the views of patients and their families are taken into account” (Braut, 2008).

As I see it, the experiences of the family members participating in this study challenge nurses and doctors to collaborate better in working with them in the EOL decision-making process. Essential elements of teamwork are shared goals and mutual interest (Spuhler, 2010). For example, shared goals allow for consistent communication with families of dying patients. The findings in Paper II show particularly well the gap which results from nurses not being sufficiently active participants in the end-of-life discussion, thus leading to inconsistent and vague communication (Puntillo & McAdam, 2006). The team does not take sufficient advantage of nurses’ unique position to take responsibility for communicative goals, such as helping families understand that the EOL process is underway (J. E. Nelson et al., 2011). Mutuality in teamwork therefore means that the nurses and attending physicians need one another’s experience, ability and judgement in the EOL discussion, in order to arrive at mutual goals (Spuhler, 2010, p. 156). The bedside communication can with prudence and skill divert attention from the measurements on the monitors to the sensitive and value-laden dialogue which we have shown that families yearn for, and which can serve as preparation for meetings with the family and the interdisciplinary team.

As described in Paper I, an important feature of ICU communication should be to establish a proactive approach to the families (Curtis & White, 2008; Machare Delgado et al., 2009; Norton et al., 2007), which implies that communication with the family will take place earlier than usual in the EOL process. The idea behind this approach is that it is difficult to predict on admission who will survive and who will die, and therefore effective communication with all families

should be established at an early stage (Curtis & Vincent, 2010). In our study it is particularly the relatives of long-stay patients who experience too little communication and a lack of involvement regarding the patient's values in the decision-making process. A new study supports these findings, pointing out that the neglect of quality-of-life considerations was more common among those with longer stay (Douglas, Daly, & Lipson, 2012). It is well-known that intensive care units struggle to arrange their work methods to include a common meeting point for communication about patient care. The general bustle and unpredictability of the work situation can mean that the flexibility that may benefit a dynamic organisation will often relegate communication with families in favour of more "essential" tasks³¹. I therefore believe in the usefulness of an early and more systematic focus on facilitating communication with families (A.J. Billings, 2011; A.J. Billings & Block, 2011; Lautrette, Ciroidi, Ksibi, & Azoulay, 2006). In addition to reducing their fear and anxiety by regularly providing updated information, such an approach will reduce the potential for misunderstandings and conflict when the time for EOL discussions arrives (Apatira et al., 2008).

To propose more structure is of necessity also to touch upon the need for guidelines. The use of guidelines for EOL processes has not been common in Nordic ICUs (Hynninen et al., 2008). We see this reflected in our findings. Not surprisingly, the three different perspectives of family involvement are found in all four participating ICUs. The fact that none of the ICUs has a uniform EOL practice suggests that the individuality of "ways to do this" and the internal culture in the particular ICU set the tone more than any guidelines and procedures (Baggs et al., 2007). The national guidelines for limiting life-prolonging treatment were published in spring 2009 (Norwegian Directorate of Health, 2009). It is not known whether these were in the process of being implemented when the interviews were conducted, but only one of the participating ICUs stated that they were following local guidelines for EOL processes when this study commenced.

³¹ An key factor in the importance of a good interdisciplinary team that deserves greater mention in the study is the weakness of a lack of continuity. Lack of continuity is touched upon in our study, but is excused by the participants because of duty shifts and other urgent matters. More serious and puzzling is the fact that totally unfamiliar doctors sometimes give the families the news that treatment will be terminated. This problem is not unknown in other studies. A new review article discusses the challenge for families "to identify from whom they should seek explanations and to whom they should express concerns in ICU situations" (Baggs et al., 2012, p. 61). The attending physician was in practice an ICU role filled with multiple physicians on a rotating basis. The consequences for families of lack of continuity in care is a topic needing more attention and more research.

Considering the fact that intensive care is an activity where guidelines are in use in a variety of medical and technological areas, it is cause for reflection that they are not thought necessary for such an ethically sensitive area. Yet I do not believe in detailed guidelines to be followed to the letter. Guidelines must be viewed as recommendations rather than rules, leaving room for discretion and individual adjustments. However, guidelines, check lists or protocols can safeguard the basic framework of the process (Weissman D.E., Quill T.E., & Arnold R.M., 2010). There are numerous studies that support the importance of such protocols for communication, where specific advice is given on how to talk about difficult, sensitive issues and how to avoid or resolve conflicts (Curtis & White, 2008; Schaefer & Block, 2009). Such protocols may be simple outlines that emphasise team composition and how to prepare for, carry out and follow up a family conference. Following guidelines alone, however, will not ensure that communication improves. The opportunity to listen and respond to family members' questions has in a study of ICU family conferences been described as "missed opportunities", leading to conclusions that improved communication skills are necessary (Curtis et al., 2005).

In the articles we have addressed the need to recognise that the EOL processes in the ICU require specific knowledge and skills, with regard to the ethical standards of each profession, ethics and communication in EOL decision making and legislation which sets limits for the area of authority of health care professionals and the right of families to participate in processes. Both nurses and doctors have a basic knowledge of EOL processes from their studies and further education courses (Klepstad & Petterson, 2008; Montagnini, Smith, & Balistreri, 2012). Curricula for the education of intensive care nurses in Norway (Utdannings og forskningsdepartementet, 2005) emphasise ethics and work with patients' families, but nursing education has generally not been particularly concerned with linking ethical theory to the analysis of ethical challenges with implications for action in practice situations (Benner, 2010; Fry & Johnstone, 2008). To my knowledge, it has not been common in Norwegian ICUs to practise such situations as a collaborating interdisciplinary team, as e.g. rescue situations are practised. I believe it would be useful to draw attention to the EOL situation as a case study for practical training for both doctors and nurses. I also believe that the acquisition of knowledge

and skills in EOL communication, such as how to prepare³² for, lead and participate in EOL meetings, must be achieved both through reading and studying role models in practice, through practical workshops (Back et al., 2007) and subsequently refined through reflection and plenary discussions³³. Our study reveals repeated examples of violations in the communication with health care personnel, with regard to information content, staff attitudes, shortage of time and lack of opportunity for dialogue. Communication skills can be learned: with colleagues for e.g. collaboration in interdisciplinary teams and with patients and families for navigating conversations involving difficult or sensitive topics or improving one's capacity to handle awkward moments. This could involve training one's ability to remain "present" and not divert when sad or emotionally charged topics come up. Finally, it is also possible to learn patience and the ability to be attentive and listen with sensitivity (J.E. Nelson, Mulkerin, Adams, & Pronovost, 2006). The families in our study reported missing empathy and compassion in situations where the clinicians provided prognostic information or the final message about treatment termination. A focus of attention on the family's emotional expressions with supportive recognition of these and a postponement of information until the family is ready to proceed are recommended by leading clinicians in palliative medicine (A.J. Billings & Block, 2011; J.E. Nelson et al., 2006).

Based on our findings from this study, we suggest that by being better prepared through enhanced knowledge and skills and following clear advice from experts in EOL discussions, both nurses and physicians will be able to improve communication with families so that their participation in the EOL process is in accordance with legislation and ethical principles. As the experiences of the minority in our findings show, communication is greatly facilitated when the family can participate in discussions closely linked to patient autonomy, focusing on the values

³² A pre-meeting can be useful for the team members to inform each other of special circumstances that need to be taken into consideration, e.g. who will participate from the family, how one sees the family dynamics and how is their comprehension of the patient's condition. The pre-meeting clarifies the agenda for the meeting: what are the communication goals and the anticipated outcomes. It can also be useful in planning the division of tasks in the team, e.g. leading the meeting (often a doctor), listening and addressing emotions (often nurses) (Weissman et al 2010).

³³ As an example, the European Society of Intensive Care Medicine has twice arranged post-graduate courses in Communication Skills Training. In 2010 I participated in the programme: "Talking with families of the critically ill: A two-day communication skills training programme for ICU physicians and nurses". The course addressed why it is both important and challenging to improve communication skills for ICU family meetings; how the physician and nurse can work as a team to meet communication challenges, such as delivering bad news and discussing goals of

and wishes of the patient when treatment goals are adjusted. The families found this important in safeguarding the dignity of the patient. Even in the case of the final conference before withdrawal of treatment, and where it was also emphasised that this was primarily a decision for the clinicians to take, the welcoming attitude towards the family's contribution helped them to feel that they were realising their sense of responsibility for the patient in a non-oppressive social situation.

8 CONCLUSION

The principal findings running through all three papers is that most family members in this study wish they had been included more in the end-of-life decision-making process. To be included implies primarily good communication with physicians and nurses, with open and honest information about developments in the patient's condition to enable the families to understand the basis for the end-of-life decision.

None of the study participants wish for more responsibility for the medical aspects of treatment. But greater involvement in the end-of-life decision-making process implies a realisation of the family's experienced ethical responsibility for including the patient's values and preferences in the basis for decisions. The families' desire for this is consistent with the legislative intent to include them in health professionals' discussions of serious decisions about patients who lack the capacity to consent.

The study shows that only a minority of the families are involved prior to the very last stage. We find that the question of whether the treatment limit has been reached and the necessary communication of this to the family are postponed in a period of "wait-and-see". Distinct boundaries as to what information may be given by doctors and nurses respectively result in a perception that nurses are vague and offer the family inadequate help in understanding what is about to happen. When the decision after the "wait-and-see" period is reached, this is felt by many to come too abruptly.

The decision process takes place in three different ways: 1) The majority find that they are only informed of the decision. 2) Some are informed of the decision and asked for approval or consent. 3) A minority experience involvement through a number of meetings with doctors (and sometimes nurses), resulting in a feeling of responsibility for the decision being in accordance with the patient's wishes and values. The first two methods present treatment futility as the sole basis for decision making, while it is too late to include value-based distinctions. The consequence for the families is uncertainty about the basis for the decision and a guilty conscience for not having done enough for the patient.

We recommend that doctors and nurses make efforts to improve the end-of-life decision-making process by taking into account the family's need for greater involvement. We conclude that this requires awareness of the relevant ethical issues, improved knowledge and skills in patient-

family centred care, more efficient team collaboration and a more systematic approach to communication with the patient's family.

9 FURTHER RESEARCH

As a final comment on this dissertation, I believe this research has shed light on important and previously unexplored phenomena in families' experiences of end-of-life decision-making processes. The interviews provided a rich source of information, and in keeping with the research questions, several associated issues were noted as suggestions for further research.

One important related issue is the circumstances surrounding the treatment termination itself and the transition to the patient's death. The interviews contain important reflections on phenomena in this fragile situation related to the interaction with nurses and doctors. The presence or absence of a priest is also linked to this phase. The analysis of this material has begun, and the results will be presented and discussed in a subsequent paper.

A further issue is the "significance of rooms" in the end-of-life process. There is a variety of rooms which all have significance, such as meeting rooms, patient rooms, relaxation rooms for families, corridors and waiting rooms. Many study participants showed surprising concern about this, although we tend to believe the matter of rooms to be of minor importance. The analysis of this theme has only just begun, but the findings should lead to new insights into the importance of the structural organisation of services for families who are about to lose a critically ill loved one.

In the discussion section I raised the issue of family responsibility. Several studies refer to the fact that experiences of guilt are common among family members. Even though the theme of responsibility in decision making is discussed here, it could be the subject of further research. It is particularly interesting since Norwegian legislation and ethical principles exempt the family from responsibilities.

On the basis of this study's results, it might be interesting to know more about families' perceptions and assessments of prognosis and futility in the ICU. What kinds of assessments are important to them and how is futility related to power, which is touched upon in this study. When is treatment futile as assessed by the family?

An extensive survey (multi-centre study) aimed at nurses and doctors in order to examine how end-of-life decision-making processes take place at Norwegian ICUs could generate important new knowledge. Such a study could shed light on key aspects of the practice of the individual doctor and nurse, and could also focus on team collaboration. The theme of

communication and conflict in decision making could be integrated into such a survey, but can also be studied through participant observation and research interviews.

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Paper I

Paper II

Paper III

Appendices

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9038 TROMSØ

Deres ref.:

Vår ref.: 200704778-3/MGA006/400

Dato: 07.11.2007

**P REK NORD 153/2007 PÅRØRENDES ERFARINGER FRA
BESLUTNINGSPROSESSER VED BEGRENSNING OG AVSLUTNING AV
INTENSIVBEHANDLING - PROSJEKT GODKJENNES**

Prosjektet ble lagt fram for Regional komité for medisinsk og helsefaglig forskningsetikk, Nord-Norge (REK NORD) i møtet 18.10.2007. I referatet heter det:

Prosjektet skal belyse pårørendes erfaringer med beslutningsprosesser på vegne av et familiemedlem som har vært kritisk syk og som døde i intensivavdeling. Få intensivpasienter har samtykkekompetanse og pårørende har heller ikke samtykkekompetanse på vegne av pasienten. Helsepersonell har da som hovedregel beslutningsansvaret for behandling og behandlingbegrensning for disse pasientene, men pårørende informeres om avgjørelser. Møter med familien er oftest planlagte og det brukes tid til de pårørende er innforståtte med beslutningen som er fattet. Fokus i prosjektet vil særlig være på pårørendes delaktighet i beslutning om å begrense eller avslutte intensivbehandling, og sentrale spørsmål er: Hvordan er de pårørendes oppfatning av egen delaktighet? Ønsker de mer ansvar og medvirkning? Hva slags erfaringer har de pårørendes om samarbeidet med helsepersonell? Det gjøres bruk av kvalitativ metode, med dybdeintervju av pårørende (/etterlatte) fra 4 større intensivavdelinger, 6-12 mnd. etter dødsfallet

Komiteen klassifiserer prosjektet som ikke-terapeutisk annen helsefaglig forskning på friske voksne. Doktorgradsprosjekt sykepleievitenskap.

Komiteen har følgende merknader:

Forespørsel/informasjonsskriv/samtykkeerklæring

I forbindelse med at forskningsetikkloven trådte i kraft 1.7.2007 endret komiteen navn til "Regional komité for medisinsk og helsefaglig forskningsetikk Nord-Norge (REK Nord). Fra samme dato skal komiteen også godkjenne/ikke godkjenne prosjektene. Opplysningene vedrørende dette bes endret i de aktuelle dokumenter.

**REGIONAL KOMITÉ FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK, NORD-NORGE
REK NORD**

Postadresse: Det medisinske fakultet, Universitetet i Tromsø, N-9037 Tromsø
telefon sentralbord 77 64 40 00 telefon ekspedisjon 77649180 e-post rek-nord@fagmed.uit.no
www.etikkom.no

Vedtak:

Komiteen godkjenner prosjektet.

Det forutsettes at prosjektet er godkjent av andre aktuelle instanser før det settes i gang. Prosjektet må forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger komiteen har basert sin avgjørelse på. Komiteen ber om å få melding dersom prosjektet ikke blir slutført.

Komiteens vedtak kan påklages av en part eller annen med rettslig klageinteresse i saken jf. fvl. §28. Klagefristen er tre uker fra det tidspunkt underretning om vedtaket er kommet fram til vedkommende part, jf. fvl. § 29. Klageinstans er Den nasjonale forskningsetiske komité for medisin og helsefag, men en eventuell klage skal rettes til Regional komité for medisinsk og helsefaglig forskningsetikk, Nord Norge. Det følger av fvl. § 18 at en part har rett til å gjøre seg kjent med sakens dokumenter, med mindre annet følger av de unntak loven oppstiller i §§ 18 og 19.

Vennlig hilsen



May Britt Rossvoll
rådgiver
77644876

Olav Hevrøy
KSK
Intensivmedisinsk seksjon
Haukeland Universitetssykehus
5021 Bergen

Deres ref.:

Vår ref.: 200704778-8/KST017/400

Dato: 20.01.2009

**P REK NORD 153/2007 PÅRØRENDES ERFARINGER FRA
BESLUTNINGSPROSESSER VED BEGRENSNING OG AVSLUTNING AV
INTENSIVBEHANDLING - PROTOKOLLENDRINGEN GODKJENNES**

Vi viser til skjema for protokolltillegg og endringer fra prosjektleder datert 30.12.2008, samt e-post av 23.12.2008 fra Ranveig Lind vedlagt revidert forespørsel om deltakelse datert 10.12.2008.

Det er på fullmakt fattet slikt

vedtak: *protokollendringen godkjennes.*

Det forutsettes at prosjektet er godkjent av andre aktuelle instanser før det settes i gang. Det forutsettes at prosjektet forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger komiteen har basert sin avgjørelse på. Komiteen ber om å få melding dersom prosjektet ikke blir slutført.

Komiteens vedtak kan påklages av en part eller annen med rettslig klageinteresse i saken jf. fvl. §28. Klagefristen er tre uker fra det tidspunkt underretning om vedtaket er kommet fram til vedkommende part, jf. fvl. § 29. Klageinstans er Den nasjonale forskningsetiske komité for medisin og helsefag, men en eventuell klage skal rettes til Regional komité for medisinsk og helsefaglig forskningsetikk, Nord Norge. Det følger av fvl. § 18 at en part har rett til å gjøre seg kjent med sakens dokumenter, med mindre annet følger av de unntak loven oppstiller i §§ 18 og 19. For nærmere informasjon om klageadgang og partsinnsynsrett se nettadressen <http://www.etikkom.no/REK/klage>

Vennlig hilsen

May Britt Rossvoll
Rådgiver/sekretariatsleder

REGIONAL KOMITÉ FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK, NORD-NORGE
REK NORD

Postadresse: TANN-bygget, Universitetet i Tromsø, N-9037 Tromsø
telefon sentralbord 77 64 40 00 telefon ekspedisjon 77 62 07 58 e-post rek-nord@fagmed.uit.no
www.etikkom.no

Kopi:
Ranveig Lind, ranveig.lind@unn.no

Region: REK nord	Saksbehandler: Monika Rydland Gaare	Telefon: 77620756	Vår dato: 09.12.2011	Vår referanse: 2011/2383/REK nord
			Deres dato: 30.11.2011	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

olav.hevroy@gmail.com
Kråkenesvn 28, Bønes

2011/2383 Pårørendes erfaringer fra beslutningsprosesser ved begrensning og avslutning av intensivbehandling

Forskningsansvarlig: Eva-Hanne Hansen
Prosjektleder: olav.hevroy@gmail.com

Vi viser til søknad om prosjektendring av 30.11.2011 hvor prosjektperioden søkes forlenget til 31.12.2012

Etter fullmakt er det fattet slikt

Vedtak

Med hjemmel i helseforskningsloven § 11 og forskningsetikklovens § 4 godkjennes prosjektet slik det nå foreligger.

Endringen godkjennes under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknaden, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom prosjektleder ønsker å foreta vesentlige endringer i forskningsprosjektets formål, metode, tidsløp eller organisering i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene av prosjektet er så store at det må anses å være et helt nytt prosjekt, må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Prosjektleder skal sende sluttmelding i henhold til helseforskningsloven § 12.

For øvrig gjelder de vilkår som er satt i forbindelse med tidligere godkjenning av prosjektet.

Vi ber om at tilbakemeldinger til komiteen og prosjektendringer sendes inn på skjema via vår saksportal: <http://helseforskning.etikkom.no>. Øvrige henvendelser sendes på e-post til post@helseforskning.etikkom.no.

Med vennlig hilsen,

May Britt Rossvoll
sekretariatsleder

Monika Rydland Gaare
seniorkosulent

Kopi til:

eva-hanne.hansen@unn.no



Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Ranveig Lind
Anestesiavdelingen
Universitetssykehuset Nord-Norge HF
Postboks 44
9038 TROMSØ

Vår dato: 24.09.2007

Vår ref :17371 / 2 / SF Deres dato:

Deres ref:

KVITTERING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 31.08.2007. Meldingen gjelder prosjektet:

17371 *Pårørendes erfaringer fra beslutningsprosesser ved begrenning og avslutning av intensivbehandling*

Behandlingsansvarlig *Universitetssykehuset Nord-Norge HF, ved institusjonens øverste leder*
Daglig ansvarlig *Ranveig Lind*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

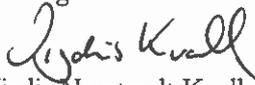
Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

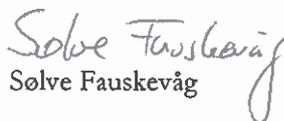
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/melding/pvo_endringsskjema.cfm. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/register/>

Personvernombudet vil ved prosjektets avslutning, 01.04.2011, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Sølve Fauskevåg

Kontaktperson: Sølve Fauskevåg tlf: 55 58 25 83
Vedlegg: Prosjektvurdering



Personvernombudet har vurdert prosjektet og finner at behandlingen kan hjemles i personopplysningsloven § 8, første ledd.

Informasjonsskrivet er godt utformet og ombudet finner det tilfredsstillende forutsatt at setningen "Ingen opplysninger vil i ettertid kunne spores tilbake til deg" slettes eller endres, da dette ikke vil være tilfelle så lenge det finnes lydopptak og/eller en koblingsnøkkel.

Tilsvarende setning må slettes/endres i samtykkeerklæringen. Vi anbefaler forøvrig at samtykkeerklæringen er helt enkel, for eksempel slik: "Jeg har mottatt skriftlig informasjon om prosjektet 'Pårørendes erfaringer fra beslutningsprosesser ved begrensnig og avslutning av intensivbehandling' og er villig til å delta i studien," med plass for signatur, dato, adresse og telefonnummer. All nødvendig informasjon står i informasjonsskrivet, og det er da tilstrekkelig at samtykkeerklæringen på denne måten viser til skrivet.

Ved prosjektslutt 01.04.2011 skal datamaterialet anonymiseres. Anonymisering innebærer at direkte og indirekte personopplysninger slettes eller omkodes (grovkategoriseres), samt at lydopptak og koblingsnøkkel slettes.

Prosjektet er meldt til Regional komité for medisinsk forskningsetikk (REK). Det forutsettes at REK godkjenner studien dersom den vurderes som meldepliktig til komiteen. Vi ber om at eventuell godkjenning fra REK ettersendes ombudet.



Ranveig Lind
Anestesiavdelingen
Universitetssykehuset Nord-Norge HF
Postboks 44
9038 TROMSØ

Dato: 09.04.2008

Vår ref: 17371 JE/RF

Deres dato:

Deres ref:

OVERFØRING AV OPPFØLGINGSANSVAR TIL NYTT PERSONVERNOMBUD FOR UNIVERSITETSSYKEHUSET NORD-NORGE HF

Viser til tidligere korrespondanse i forbindelse med prosjektmelding for forskningsprosjektet:

17371 Pårørendes erfaringer fra beslutningsprosesser ved begrenning og avslutning av intensivbehandling

Universitetssykehuset Nord-Norge (UNN) har, med virkning fra 31. mars 2008, sagt opp avtalen om at NSD skal fungere som personvernombud for forskningsprosjekter ved institusjonen. UNN har etablert en egen ordning med internt personvernombud for behandling av personopplysninger. Personvernombudet ved UNN har overtatt ansvaret for videre oppfølging av ovennevnte prosjekt. NSD har oversendt opplysninger om prosjektet til ombudet ved UNN.

Spørsmål om prosjektet eller personvernombudsordningen ved UNN kan rettes til:

Per Bruvold
Sikkerhetssjef IKT/Personvernombud UNN
Universitetssykehuset Nord-Norge
9038 Tromsø
Tlf: 77626119, mob: 97539771
E-post : Per.Bruvold@unn.no

Vennlig hilsen


Bjørn Henrichsen


Janne Sigbjørnsen Eie

Avdelingsoverlege/-leder
Olav Hevrøy
Anestesiavdelingen UNN
9038 Tromsø

Avdelingsleder NN
Intensivavdelingen
NN Universitetssykehus

Tromsø, 03.04.08

Pårørendes erfaringer fra beslutningsprosesser ved begrensning og avslutning av intensivbehandling

Ved Intensivavdelingen ved UNN, Tromsø ønsker vi å starte et forskningsprosjekt knyttet til de pårørendes erfaringer vedrørende beslutningsprosessen omkring behandlingsavslutning hos intensivpasienter.

Studien vil foregå ved å intervju et utvalg av pårørende til pasienter som har dødd på Intensiv der det er fattet beslutning om å begrense eller avslutte behandlingen i slutfasen. Prosjektet er et 3-årig doktorgradsarbeid finansiert av forskningsmidler fra Helse Nord. Prosjektleder er avdelingsoverlege Olav Hevrøy, Anestesiavdelingen Universitetssykehuset Nord Norge. Veiledere er førsteamanuensis Geir Lorem, ASH, Universitetet i Tromsø og professor i medisinsk etikk Per Nortvedt, Seksjon for Medisinsk Etikk, Universitetet i Oslo.

Hensikten med studien er å belyse pårørendes erfaringer med beslutningsprosesser når et familiemedlem/nærstående har vært kritisk syk og dør på intensiv. Fokus vil særlig være rettet mot pårørendes delaktighet i beslutning om å begrense eller avslutte intensivbehandling. Metoden i studien er kvalitativ og det empiriske arbeidet vil foregå ved dybdeintervju med et utvalg etterlatte til intensivpasienter der behandlingen ble begrenset eller avsluttet og pasienten døde under oppholdet.

Vedlagt ligger både en kort versjon av prosjektbeskrivelsen og den fullstendige protokollen for prosjektet. Prosjektet er meldt til Personvernombudet for forskning, Norsk Samfunnsvitenskapelig Datatjeneste AS og det er tilrådd av Regional komité for medisinsk og helsefaglig forskningsetikk, Nord-Norge.

Vi ønsker å rekruttere informanter (pårørende) fra fire ulike intensivavdelinger ved større norske sykehus. De pårørende det er aktuelt å henvende seg til velges ut etter følgende kriterier:

- Pårørende til pasienter som er døde på Intensiv 6-12 måneder tilbake i tid, der det ble foretatt beslutning om behandlingsbegrensning i slutfasen.
- Avdøde pasient må ha vært eldre enn 18 år (ingen øvre aldersgrense)
- Nærmeste pårørende som mottar henvendelsen må være eldre enn 18 år
- Pårørende må ikke ha fått spørsmål om organdonasjon

For å rekruttere deltakere til denne studien, er vi avhengig av hjelp til å komme i kontakt med de som kan være aktuelle. Vi vil derfor gjerne be dere være behjelpelig med å etablere slik kontakt med pårørende til pasienter som har vært innlagt og døde ved intensivavdelingen hos dere. Totalt er det ønskelig å intervju 24 pårørende til avdøde intensivpasienter.

Utvelgelsen kan skje ved at dere f. eks. innhenter informasjon fra deres pasientregistrering og på den måten finner navn på inntil 10 pasienter fra deres avdeling som oppfyller disse kriteriene. Ut fra pasientjournalen innhenter man så opplysninger om hvem som er oppgitt som pasientens nærmeste pårørende over 18 år.

Vedlagte forespørsel og samtykkeerklæring sendes til den aktuelle pårørende sammen med vedlagt svarkonvolutt. Det er viktig at utsendelsen av selve forespørselen om deltagelse formelt kommer fra avdelingsoverlegen ved den avdelingen der pasienten døde, og at vedkommende står som avsender på brevet. Samtykkeerklæringen vil imidlertid bli adressert direkte til den som er ansvarlig for studien, og avdelingen som sendte ut forespørsel vil ikke vite hvem som samtykker til å delta. Dette sikrer anonymitet til informantene, og den som intervjuer skal ikke ha noen tilknytning til den avdeling der pasienten har vært innlagt.

De som samtykker til å delta, vil bli kontaktet av Ranveig Lind som vil avtale intervju med den pårørende. Alle opplysninger vil bli behandlet konfidensielt og oppbevart i samsvar med krav til personopplysninger. Intervjuene vil danne grunnlag for en empirisk kvalitativ studie omkring de pårørendes opplevelse av deltagelse i beslutningsprosessen omkring behandlingsbegrensning. Etter slike samtaler vet vi at det ofte kan oppstå behov for oppfølging og en avklarende samtale med personell fra den avdelingen pasienten har vært innlagt. I brevet til de pårørende er det derfor avsatt plass til å fylle ut et navn på en kontaktperson. Vi vil be dere fylle ut denne, med opplysning om telefonnummer som den pårørende kan benytte seg av om det skulle oppstå behov.

Selve intervjuene av pårørende vil foregå i tidsrommet vår og høst 2008 og studien er planlagt avsluttet i 2011. Resultatene av undersøkelsen vil bli publisert på engelske i internasjonalt anerkjente tidsskrift.

Med vennlig hilsen

Olav Hevrøy
Avdelingsoverlege
Anestesiavdelingen UNN, Tromsø

Ranveig Lind
Intensivsykepleier/ Stipendiat

Ranveig Lind
Intensivseksjonen, Anestesiavdelingen
Universitetssykehuset Nord Norge
9038 Tromsø
tel : 776 26226

Tromsø, dato

Forespørsel om deltakelse i forskningsprosjekt:

Pårørendes erfaringer fra beslutningsprosesser ved begrensning og avslutning av intensivbehandling

Jeg er intensivsykepleier og arbeider med et forskningsprosjekt omkring pårørendes erfaringer fra intensivavdelinger. Prosjektet ledes av avdelingsoverlege Olav Hevrøy ved Anestesiavdelingen, UNN Tromsø. Som en del av forskningsprosjektet, ønsker jeg å samtale med personer som har vært pårørende ved en større intensivavdeling i Norge for relativt kort tid siden. Derfor får du denne henvendelsen fra meg gjennom avdelingen der du har opplevd å være pårørende til et familiemedlem som døde.

Vi vet at familiers opplevelser fra intensivavdelinger kan være sterke og ofte følelsesmessig vanskelige. Mange pårørende har opplevd et dramatisk sykdomsforløp der håpet etter hvert svinner og man til slutt opplever et ugjenkallelig tap av et kjært familiemedlem. Gjennom dette forskningsprosjektet ønsker vi å øke forståelsen for hvordan det oppleves å være pårørende i intensivavdeling i situasjoner når livet ikke står til å redde. Vi ønsker å rette fokus mot kommunikasjonen mellom leger, sykepleiere og de pårørende i slike situasjoner. Vi er særlig interessert i å undersøke hvordan dere har opplevd beslutningsprosessen i slutfasen av livet til pasienten. Vi tror det er viktig med mer forskning på dette området for å forstå hvordan samhandling med de pårørende fungerer når viktige beslutninger skal fattes.

Forskningsprosjektet gjennomføres ved samtaler med pårørende som har opplevd slike situasjoner. Jeg håper derfor å få samtale med deg om dine erfaringer. Samtalen vil særlig dreie seg om dine erfaringer fra de siste dagene i avdelingen. Vi er interessert i finne ut hvordan familier opplever sin egen situasjon som pårørende til familiemedlem som er kritisk syk, og om sykepleiere og leger møter dem på en forståelsesfull måte. Dette er særlig aktuelt i situasjoner der det blir spørsmål om behandlingen skal fortsette eller må avsluttes for den ikke har ønsket effekt. Det er viktig å finne ut hvordan dere som pårørende erfarte og følte dere inkludert i denne beslutningsprosessen

Denne henvendelsen blir derfor sendt til pårørende til pasienten som var behandlet i intensivavdeling for ca 6 – 12 måneder tilbake og døde under oppholdet. De som får denne henvendelsen er oppgitt som nærmeste pårørende i pasientens journal, og avdelingsoverlegen ved avdelingen der pasienten var innlagt står for utsendelsen. Først ved et svar på dette brevet, får jeg vite hvem du er. Avdelingen som står for utsendelsen, vil ikke få vite hvem som har svart. Dersom du svarer ja til å delta, blir svaret sendt direkte til meg. Dersom brevet går uåpnet i retur, vil returadressaten være avdelingsoverlegen ved den aktuelle intensivavdelingen som sendte ut forespørselen.

Hvis du samtykker i å delta og til å dele dine erfaringer med meg, ønsker jeg å ha en samtale med deg om dine erfaringer som pårørende på intensiv. Denne samtalen vil bli tatt opp på bånd. Jeg har taushetsplikt og vil behandle alle data konfidensielt. Lydbånd og utskrift fra båndet vil bli behandlet som fortrolige opplysninger og vil bli oppbevart forsvarlig. Når

prosjektet er avsluttet vil alle lydbåndopptak og utskrifter, bli slettet. Du vil få et brev fra meg om "resultatene" av undersøkelsen. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS og er tilrådd av Regional etisk komité for forskning.

Deltakelse i prosjektet er frivillig. Dersom du ikke ønsker å delta, må du ikke begrunne din avgjørelse nærmere. Samtykker du i å delta, kan du likevel når som helst senere trekke deg fra prosjektet, også i dette tilfellet uten begrunnelse. I så fall vil alt materiale som vedrører deg bli slettet. Om du velger å ikke delta, vil dette selvsagt ikke få noen konsekvenser for ditt forhold til sykehuset i fremtiden.

Hvis du kan tenke deg å dele dine erfaringer med meg, kan du returnere denne "Samtykkeerklæring" i underskrevet form i vedlagte frankerte konvolutt. Jeg vil så kontakte deg for å avtale tid og sted. Intervjuet vil ta 1 – 1,5 timer. Det kan være mest praktisk at jeg kommer hjem til deg, eller vi kan avtale et annet egnet møtested. Har du noe å spørre om, kan du treffe meg på telefon 776 26226, Intensiv, Universitetssykehuset Nord Norge, Tromsø.

Det å snakke om erfaringer fra ei tid med store påkjenninger, kan vekke mange følelser. Skulle du ha behov for å snakke mer med noen etter intervjuet, vil du få tilbud om det fra sykehuset som sender ut denne forespørselen. Du kan da ta kontakt med:

Hvis du ikke har lyst eller anledning til å snakke med meg, skal du bare se bort fra denne henvendelsen.

Vennlig hilsen

Ranveig Lind
Intensivsykepleier og stipendiat

Samtykkeerklæring

Jeg har mottatt skriftlig informasjon om prosjektet: "Pårørendes erfaringer fra beslutningsprosesser ved begrensning og avslutning av intensivbehandling", og er villig til å delta i studien.

Navn:

Adresse:

Telefon:

(signatur)

Sendes tilbake i vedlagt ferdig frankert svarconvolutt

Ditt eksemplar av samtykkeerklæring

Samtykkeerklæring

Jeg har mottatt skriftlig informasjon om prosjektet: ”Pårørendes erfaringer fra beslutningsprosesser ved begrenning og avslutning av intensivbehandling”, og er villig til å delta i studien.

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Adresse:

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Tromsø, 10.12.08

Forespørsel om deltakelse i forskningsprosjektet **”Pårørendes erfaringer fra beslutningsprosesser ved begrensnig og avslutning av intensivbehandling”**

Dette er et spørsmål til deg om å delta i en forskningsstudie omkring pårørendes erfaringer fra intensivavdelinger. Prosjektet ledes av overlege Olav Hevrøy ved Intensivavdelingen, Haukeland Universitetssykehus, Bergen. Som en del av studien, ønsker jeg å samtale med personer som har vært pårørende ved en større intensivavdeling i Norge for relativt kort tid siden. Derfor får du denne henvendelsen fra meg gjennom avdelingen der du har opplevd å være pårørende til et familiemedlem som døde.

Pårørendes opplevelser fra intensivavdelinger er sterke og ofte følelsesmessig vanskelige. Mange opplever et dramatisk sykdomsforløp der håpet etter hvert svinner og der man ugjenkallelig mister et kjært familiemedlem. Gjennom dette forskningsprosjektet ønsker vi å øke forståelsen for hvordan det oppleves å være pårørende i intensivavdeling i situasjoner når livet ikke står til å redde. Kommunikasjonen mellom leger, sykepleiere og pårørende i slike situasjoner betyr mye for de nærmeste. Derfor er vi særlig interessert i å undersøke hvordan dere har opplevd beslutningsprosessen i slutfasen av livet til den dere mistet. Vi tror det er viktig å forske på hvordan dere synes samhandling fungerer når viktige beslutninger skal fattes. Slik forståelse kan hjelpe oss til å møte de nærmeste bedre.

Forskningsprosjektet gjennomføres ved samtaler med pårørende som har opplevd slike situasjoner. Jeg håper derfor å få møte deg og at du vil dele dine erfaringer med meg. Samtalen vil særlig dreie seg om dine erfaringer fra de siste dagene i avdelingen. Vi ønsker å finne ut hvordan familier opplever sin egen situasjon som pårørende til familiemedlem som er kritisk syk, og om de føler at sykepleiere og leger møter dem på en forståelsesfull måte. Dette er særlig aktuelt i situasjoner der det blir spørsmål om behandlingen skal fortsette eller må avsluttes fordi den ikke nytter. Det er viktig å finne ut hvordan dere som pårørende erfarte dere inkludert i denne beslutningsprosessen.

Vi ønsker derfor å komme i kontakt med pårørende til pasienter som var behandlet i intensivavdeling for inntil ett år tilbake og som døde under oppholdet. De som får denne henvendelsen er oppgitt som nærmeste pårørende i pasientens journal, og avdelingsoverlegen er ansvarlig for utsendelsen. Først ved et svar på dette brevet, får jeg vite hvem du er. Avdelingen som står for utsendelsen, får ikke få vite hvem som har svart. Dersom du svarer ja til å delta, blir svaret sendt direkte til meg. Hvis brevet returneres uåpnet, går det tilbake til avdelingsoverlegen ved avdelingen som sendte ut forespørselen.

Hvis du samtykker i å delta, ber jeg om å få møte deg. Vår samtale vil bli tatt opp på digital lydopptaker. Jeg har taushetsplikt og vil behandle alle data konfidensielt. Lydopptak og utskrift vil bli behandlet som fortrolige opplysninger og vil bli oppbevart forsvarlig. Når prosjektet er avsluttet vil alle lydopptak og utskrifter bli slettet. Du vil få et brev fra meg om resultatene av undersøkelsen. Det vil ikke være mulig å identifisere deg i resultatene av

studien når disse publiseres. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS og er godkjent av Regional etisk komité for forskning.

Deltakelse i prosjektet er frivillig. Dersom du ikke ønsker å delta, trenger du ikke å begrunne din avgjørelse nærmere. Samtykker du i å delta, kan du likevel når som helst senere trekke deg fra prosjektet, også i dette tilfellet uten begrunnelse. I så fall vil alt materiale som vedrører deg bli slettet. Om du velger å ikke delta, vil dette selvsagt ikke få noen konsekvenser for ditt forhold til sykehuset i fremtiden.

Hvis du kan tenke deg å dele dine erfaringer med meg, kan du returnere denne "Samtykkeerklæring" i underskrevet form i vedlagte frankerte konvolutt. Jeg vil så kontakte deg for å avtale tid og sted. Intervjuet vil ta 1 – 1,5 timer. Det kan være mest praktisk at jeg kommer hjem til deg, eller vi kan avtale et annet egnet møtested. Har du noe å spørre om, kan du treffe meg på telefon 776 26000 Universitetssykehuset Nord Norge, mobil 911 84 108 eller gjennom e-post: Ranveig.Lind@unn.no

Det å snakke om erfaringer fra ei tid med store påkjenninger, kan vekke mange følelser. Skulle du ha behov for å snakke mer med noen etter intervjuet, vil du få tilbud om det fra sykehuset som sender ut denne forespørselen. Du kan da ta kontakt med:

Hvis du ikke har lyst til å delta eller anledning til å snakke med meg, skal du bare se bort fra denne henvendelsen.

Vennlig hilsen

Ranveig Lind
Intensivsykepleier og stipendiat

Samtykkeerklæring

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Sendes tilbake i vedlagt ferdig frankert svarkonvolutt

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Intervjuguide

Kontekst:

Tilsendt informasjon; spør om behov for utdypning/avklaring av informasjonen de har fått. Spesielt presisere at min forbindelse med sykehuset der de var pårørende kun har vært å be om deres hjelp til å finne potensielle deltakere ut fra bestemte kriterier, og at jeg ikke er kjent med hvem som var pasient eller andre detaljer. Gjenfortell om formålet med intervjuet, om bruk av lydopptaker.

Innledende samtale/fortelling

Kunne du tenke deg å fortelle om hvem du var pårørende for og hendelsene som førte til oppholdet i intensivavdelingen? (Spørsmålet tenkes å stimulere til åpen fortelling, og ideen er å la deltakeren snakke fritt, uten avbrytelser, men der intervjuer lytter aktivt)

Intervjuet, etter fortellingen

Punktene er veiledende, og planen er en diskret bruk. Temaene har en struktur, men er åpen for at deltakerens fortelling kan ha en annen, og for vedkommende bedre struktur, der temaene likevel berøres. Det vil derfor være aktuelt å komme inn på de ulike tema etter hvordan intervjuer erfarer hva deltakeren vektlegger mest i fortellingen, og ut fra disse be vedkommende utdype og gjenfortelle. I de tilfellene vil guiden være en "sjekkliste" mot slutten av samtalen.

Formen i intervjuet vil være; "fortell om":

- Erfaringer med **kommunikasjon** med leger og sykepleiere
 - Spontane situasjoner
 - Planlagte møter (Fortell om hvordan møtene foregikk, hvem som deltok, hva det ble samtalt om)
- Mellommenneskelig **relasjoner**
 - Forventninger, behov, ønsker og erfaringer
 - Situasjoner der relasjoner til andre fikk særlig betydning
- Opplevelse av **respekt, verdighet og omsorg** (evt utdype begrepene)
 - Av betydning for **deg selv**
 - Av betydning for **pasienten**
- Erfaringer fra **beslutningsprosesser (fram mot avslutning av behandling)**
 - Hvordan ble beslutninger tatt? (Innkretsende spørsmålsområde)
 - Dersom pasienten var våken, ble han selv inkludert i beslutningsprosessen? Var dette i så tilfelle en prosess den nærmeste pårørende ble trukket inn i?
 - Utdype
 - Opplevelse av delaktighet?
 - Hva innebar delaktighet for familien?
 - Å bli informert?
 - Å bli tatt med på råd?
 - Å bli spurt om hva de mener?
 - Opplevelse av at det var deres oppgave å være stedfortreder for pasienten (for ikke-samtykkekompetente pasienter)? (Varsom tilnærming)

- Hvilke vurderinger henviser pårørende til?
 - Erfaring av ansvar i beslutningsprosessen?
 - Hvis de kjente den sykes vilje, klarte de å formidle denne (Hvordan validerte de ønskene nå; var tidligere framsatte ønsker gyldige?)
 - Ble dette ønsket respektert av helsepersonell?
 - Hvordan klarte de å skille mellom pasientens og deres egne preferanser? Hvilke momenter var av betydning her?
- Kan du si noe om hva du har tenkt om dette i tiden som har gått?
- Praktiske forholds betydning for erfaringer fra tiden som pårørende
 - Besøktider
 - Eventuell ventetid?
 - Rom/miljø;
 - Intensivavdelingen/pasientrommet, utstyr, lyd, lys, personer
 - Under venting og hvile?
 - Seremonier, prest
 - Andre praktiske og relasjonelle forhold
 - Ansvar for andre, eks barn hjemme/tilstede i sykehuset
 - Organisering av overnatting, måltider, reiser, kontakt med sykehuset under fravær

Tidslogg for forskningsprosjektet

Forskningsprosessen	2007	2008	2009	2010	2011	2012
Innlesing på feltet, arbeid med prosjektbeskrivelsen, søknad om finansiering, godkjenning REK og personvernombud for forskning	**	*	*			
Prosjektstart april 2008		*				
Intervjuer		*****	***** ***** *****			
Transkripsjon og analyse		*****	*****	*****		
Memoskriving		***	* *****	**	*****	
Litteratursøk/studier			* ** **	**	*****	
Leste etisk teori		**	** **	*****	*****	
Phd-kurs; Kvalitativ metode, innføring, 3 poeng		*				
Phd-kurs, fag, etikk, 3 poeng		*				
Phd-kurs forskningsetikk, 3 poeng		*				
Phd-kurs N'Vivo, 5 poeng		*				
Phd-kurs vitenskapsteori, 7 poeng			*			
Phd-kurs Fenomenologi og Grounded Theory, 5 poeng			*			
Phd-Kurs Narrativ fortolkning, 5 poeng			*			
Phd-kurs fag, Teori, praksis, kontekst 3,5 poeng			*			
Phd-kurs langsgående (2 poeng/4 samlinger)		**	** * *			
Presentasjon på internasjonale forskningskonferanser			*		*	*
Skriving av artikkel 1				****		
Skriving av artikkel 2				*	***	
Skriving av artikkel 3					***	*
Publisering					*	**
Arbeid med sammendrag/sammenbinding						****



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