

End-of-life decision-making in nursing homes

A qualitative study

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Til

Ingunn, Magnus og Vegard

- det aller viktigste

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List of Papers

- Dreyer, A., Forde R., Nortvedt P. (2009). "Autonomy at the end of life: life-prolonging treatment in nursing homes- relatives' role in the decision-making process." Journal of Medical Ethics **35**(11): 672-677 (Paper 1)
- Dreyer, A., Forde R., Nortvedt P. (2010). "Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice?" Journal of Medical Ethics **36**(7): 396-400 (Paper 2)
- Dreyer, A., Forde R., Nortvedt P. (2011). "Ethical decision-making in nursing homes: influence of organizational factors." Nursing Ethics **18**(4): 514-525 (Paper 3)

Appendix

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Abbreviations

AD	Advanced Directives
ACP	Advanced Care Plan
A&E	Accident and Emergency
DPA	Durable Power of Attorney
GP	General Practitioner
HLR	Heart and Lung Resuscitations
SDM	Shared decision-making
SSB	Statistics Norway (Statistisk Sentralbyrå)
WHO	World Health Organization

1 Introduction

For me, it has been a privilege to be able to study issues pertaining to elderly ill nursing-home patients and the role they play with respect to their own departure from life. In the early 1980s I worked as a nursing assistant in three different nursing homes in Oslo, in Western Norway and in Northern Norway. This experience gave rise to a number of questions that I have gradually come to see as associated with medical ethics. All three institutions had several elderly residents with low consciousness and they were unable to communicate in any understandable manner. They were fed either manually or by way of a duodenal tube. They were bedridden and had remained in this state for several years. Now, several decades later, fewer end their lives in this manner. I have asked myself this: Why did the end of life turn out this way for elderly people? I have also wondered how this situation was perceived by the next of kin, when they saw their loved ones in this state for a long period of time. And last, but not least, what reflections and thoughts did the health workers have? Debates in the medical community have since given rise to a change in practices. The question remains, however, as to how elderly patients in institutions should end their lives.

Key normative debates in clinical health care should be undertaken in a dialogue between those who represent theoretical positions in medical ethics on the one hand, and professionals who face the clinical realities on a daily basis on the other. This may ensure the development of good medical and caring practices with regard to the provision of care for terminally ill elderly patients. The World Health Organization (WHO 2011) recommends that also relatives should be included in mutual processes of decision-making in end-of-life situations.

1.1 Background

In recent decades, medical research has made it possible to prolong the life of various groups of patients with the aid of new treatments. The boundaries of what is seen as a natural death have been constantly changed. Life-prolonging treatment raises a number of important ethical issues and the development of modern medicine has therefore made questions concerning the initiation and withdrawal of treatment at the end of life more acute and important (Beauchamp and Childress 2009).

Good communication is an essential part of medical decision-making and decisions about nursing care (BMA 2007). Conflicts with regard to the provision of treatment at the end of life can be avoided if communication between the physician, the patient and the next of kin is

established at the onset of illness (Lewis, Hanson et al. 2006, Norwegian Directorate of Health 2009). If the patient's wishes and views regarding the end of his or her life are known, this could prove crucial in order to establish a consensus once the patient has reached a stage where he/she can no longer make such choices (Husebo and Husebo 2004). In these cases, the ability to make decisions that concur with the patient's wishes will be a core issue regarding withholding or withdrawing life-prolonging treatment (Beauchamp and Childress 2009). Another key ethical issue pertains to who should make these decisions and the role that should be played by the next of kin in such situations. In Norway, the treating physician is granted such powers, but with the proviso that other health personnel and the next of kin should provide information on what the patient would have wanted if he/she had been able to provide consent (Norwegian Ministry of Health Care Services (HOD) The Patients' Right Act of July 1999).

In the US, patient autonomy plays a considerable role in discussions about medical ethics, where a main focus has been put on situations where the patient is unable to provide consent. The establishment of Advance Directives (AD)¹, or what we often refer to as a "living will", is intended to ensure that the patients retain their voice and can provide guidance at the end of life when they are no longer able to make choices and take care of their own interests (Cohen-Mansfield and Lipson 2006). This practice of relying on Advanced Directives is discussed and gradually being introduced in Europe as well, where additionally the appointment of a formal deputy is intended to ensure that decisions are based on the presumed wishes of the patient (and in compliance with the directive, if such exists)(Stratling, Scharf et al. 2004).

According to the Norwegian Medical Association's status report entitled "*When you are old and nobody wants you...*"² (2001), Norwegian research on the situation of the elderly lags behind the other Nordic countries. The report emphasises that research is required in order to ensure recruitment, competence-building and knowledge development. The elderly need to be met with understanding and competence. Patients as well as their relatives are also in need of human care when life is at its final stage. I have not been able to ascertain that any other studies of decision-making processes in the context of life-prolonging treatment in nursing homes have been done in Norway, in which the experience of relatives, physicians and nurses is described.

¹ Advanced Directives in several countries: <http://www.ethik.uzh.ch/ibme/veranstaltungsarchiv/2008/ESF-CountryReports.pdf>

² The Norwegian title: Når du blir gammel og ingen vil ha deg... <http://www.legeforeningen.no/id/5178.0>

Suhonen R et. al. (2010) conducted a literature search for ethical dilemmas in nursing homes. On finding that the available body of research is fragmented, they concluded that further knowledge is required. Further research on collaboration in this field is also recommended by the WHO in the *Palliative Care for Older People: Better Practice* (2011).

Every year, a large number of patients and their relatives come into contact with physicians and nurses who provide treatment and care at the final stage of life. Positive encounters between health care professionals and patients and relatives are crucial in these challenging situations. The end of a long life can be dignified if the physicians and nurses base their practices on solid professional and ethical foundations. These qualities in the encounter with relatives, who will go on living with the experience, could in the final analysis also constitute appropriate preventive health care. Mapping and understanding the workings of clinical practices are key steps to improving these practices.

1.2 Empirical ethics

Medical ethics have developed considerably since the end of World War II, and many ethical challenges have been at the centre of contemporary medical ethics (Tranøy 2005, Ruyter, Førde and Solbakk 2007, Beauchamp and Childress 2009). The past decade has in particular seen an increasing focus on empirical ethics. Empirical medical ethics are based on an approach to problems in clinical practice in which these problems become the object of normative discussions. The main contribution of empirical ethics concerns applying medical ethics closely to situations in which moral dilemmas arise, and the strength is to combine descriptive studies with normative analyses and reflection (Kon 2009, Leget et.al. 2009). The criticism claims that empirical ethics can be too separated from the normative basis of theoretical medical ethics. Further, inductive models are often criticised because they tend to give descriptive statements a normative status, which means that an “ought” is derived from an “is” (Beauchamp and Childress 2009).

According to Parker, Clayton et al. (2007), the development of empirical ethics is necessary in order to supply empirical data and elements to ethical discussions. Research that is based on clinical issues can challenge and develop philosophical ethics (Hoffmaster and Hooker 2009, Musschenga 2005). However, this should be done without the results from empirical ethics leading to strongly held moral conclusions based on individual cases from practice.

1.3 The nursing home as a research arena

Currently 15 per cent of those over the age of 80 in Norway live in nursing homes (Statistics Norway/SSB), and it is assumed that the number of people over this age will increase up to the year 2050 (WHO 2002). It is estimated that approximately 80 per cent of these are suffering from dementia (Norwegian Ministry of Health and Care Services (HOD) 2007, Selbaek, Kirkevold et al. 2007), and in addition many of them suffer from other severe medical conditions. A high proportion of these patients move between hospitals and nursing homes (Norwegian Ministry of Health and Care Services (HOD) (2005-2006). Approximately 40 per cent of the 45 000 annual deaths in Norway occur in nursing homes (Norwegian Medical Association 2001).

As institutions, nursing homes are faced with exceedingly demanding medical and ethical challenges. These challenges set considerable requirements regarding professional competence and collaboration – internally as well as externally vis-à-vis hospitals (Ministry of Health and Care Services (HOD) 2005-2006). In theory, end-of-life care has been prioritised for more than a decade in Norway. Although the need for more professionally qualified staff in the nursing home sector has been emphasised, the proportion of unskilled workers in these homes constituted more than one-third of the employees (Norwegian Directorate of Health 2008). Working in nursing homes has a relatively low status, and many such homes have problems recruiting qualified health care personnel such as nurses and medical doctors. Figures show that in 2003 there were 167 nursing home patients per full-time physician, whereas in comparison there was one full-time physician to every other hospital patient (Husebo and Husebo 2005).

1.4 The end of life of the elderly – relevant research

In the following I will present a representative selection of findings from international research literature published over the last decade. I will focus on the most relevant Norwegian studies and present these separately. Findings from the other Nordic countries are presented by topic in the overview of international studies.

Nursing homes provide the context for this study, but in order to sharpen the focus on decision-making processes related to life-prolonging treatment and care for the sick and elderly, research will also be presented which refers to the preferences of the elderly outside the nursing-home context.

1.4.1 The wishes of the elderly with regard to the end of life

Much of the literature focuses on searching for the patient's preferences with regard to medical treatment, but fails to include a more comprehensive picture of a patient's needs, personal history and values. In a qualitative survey, forty people aged 80 to 89 were interviewed about their thoughts relating to the final stage of life. The interviewees lived at home and were capable of deciding for themselves. The findings revealed what these elderly people thought about death. They were concerned with predictability and were afraid of pain. Many referred to their remaining life as short, because of their advanced age. They often thought of death, but were reluctant to discuss this with their family. They wished to preserve their dignity in the face of death. Some of them had made an Advanced Directive (AD), but still wanted to be able to express their preferences with regard to the end of life. They were not interested in futile life-prolonging treatment. The survey underscores the necessity of including the elderly in discussions pertaining to end-of-life care at an early stage, in order to learn how they want their lives to end (Lloyd-Williams, Kennedy et al. 2007). The study is corroborated by other studies (Schaffer 2007, Kahana, Dan et al. 2004).

According to Malcomson and Bisbee (2009), many elderly people believe that their next of kin are familiar with their preferences for the final stage of their lives. This study also showed that the elderly wish to discuss death. Another study indicates that competent elderly people are more concerned with the circumstances around death than with the treatment provided in the final stages when they are no longer competent to provide consent (Lloyd-Williams, Kennedy et al. 2007). Further, a focus-group study of 32 elderly informants in the UK showed that the elderly believe that the main purpose of an Advanced Directive (AD) is to ensure their personal integrity. The informants also saw this as an aid to reducing the burden on their next of kin and other decision makers (Seymour, Gott et al. 2004). A study made in the form of cross-sectional interviews with 130 patients with unpromising prognoses in the US investigated the roles that the patients wished the physician and the next of kin to assume if they themselves lost the ability to make decisions. The results do not reflect the patients' wishes with the regard to *what type* of treatment they would want, but rather *how* these decisions should be made. Even here, the patients wanted the physician and the next of kin to decide, rather than relying exclusively on their own previous preferences. The emphasis on the importance of substituted judgement is thereby reduced in favour of shared decision-

making in which the physician, the nurses and the next of kin participate (Nolan, Hughes et al. 2005).

1.4.2 Next of kin in end of life decision-making

Hansen, Archbold et al. (2005) have made a content analysis of interviews with 17 relatives who had made decisions regarding life-prolonging treatment for family members (USA). The study ascertained that the role of the next of kin in decision-making processes can be a burden for them. This applies in particular to situations where focus is put exclusively on life-prolonging treatment. Positive experiences were associated with contributions to this process when the next of kin did not make decisions, but only provided other information about the patient. A focus-group study from the US, comprising 28 family members of people suffering from dementia, further showed that making decisions on behalf of patients who had been cared for at home and later moved to a nursing home was a heavy emotional burden. The next of kin were not provided with necessary information, and felt that they were given insufficient psychological support by the nursing home staff (Forbes, Bern-Klug et al. 2000). If *one* family member has been charged with the authority to make decisions and disagreement occurs within the family, this can lead to negative long-term effects for the one who made a decision with which the others disagreed. Thus, the role of substitute decision maker can be a burden for the person shouldering it (Elliott and Olver 2005).

1.4.3 Decision-making processes

Literature describing various decision-making areas in nursing homes comprises a wide range of issues, including consequences for patients and their next of kin, degrees of participation by physicians, nurses and family members, use and interpretation of Advances Directives (AD), etc. A number of papers balance between organisational factors and decision-making processes, and I have attempted to present the respective findings separately. First, I will present findings associated with the process.

A review study of 13 publications³ focuses on the role and attitudes of nurses in the end-of-life decision-making processes. The results showed that nurses held key positions in processes associated with knowledge about the patient, but they perceived their role as diffuse and wished to be more clearly involved in processes pertaining to treatment. They often initiated such processes. There is a need to communicate to the nurses the content of the ongoing

³ Methodologies included in the papers: six quantitative, five qualitative, two with combined methodology

ethical debates and the latest clinical evidence (Bryon, de Casterle et al. 2008). Another review study of 28 individual investigations from the UK (11), the US (8), Canada (4), the Netherlands (2), Mexico (1), France (1) and Australia (1), most of which were qualitative, identifies barriers to decision-making processes. A total of 89 per cent of the participants in these studies were physicians. Lack of time and complicated practical circumstances made it difficult to implement processes with the patients. The study also notes that it is important that the participants are motivated to use Shared Decision-Making (SDM) as a process in order to ensure a positive outcome for the patient. The summary discussion concludes that those who initiate SDM must have knowledge of “the process as a tool”, and that all professionals need training in how to implement such processes (Gravel, Legare et al. 2006).

1.4.4 Advanced Care Plan (ACP) ⁴

To be able to cater to elderly people who are suffering from complex conditions and have multiple needs, assessment and continuity are essential. An evaluation study from the US examines the introduction of “Advanced Care Plans”. The background to the development of such care plans is found in the discrepancy between the wishes of dying patients with regard to the end of life on the one hand and the treatment that was actually provided on the other. Reference is made to retrospective studies showing that a care plan established at an early stage in the treatment process can ensure better concurrence with the patient’s wishes for medical treatment and care at the end of life. With the aid of appropriate interaction between the physician, the nurse, the patient and the next of kin, a plan can be drawn up for the treatment and care to be provided. By participating in the process, the next of kin can provide descriptions which can help understanding the personality of the elderly patient in a better way. They can also communicate the preferences of their elderly relative, if these preferences are known. The familiarity with the patient that the nurses have gained through the provision of daily care may also contribute important information about the patient in the prevailing situation. This plan also includes documentation of the processes associated with the end of life (Schwartz, Wheeler et al. 2002).

⁴ The statutory Norwegian Individual Plan (IP) for patients who are in need of long-term care may be useful if used as intended (The Ministry of Health and Care Services § 6.2 a). The purpose of an IP is to ensure that elderly people with a complex need for care will be catered to by services that appear coordinated, and to provide the patient with an opportunity for co-determination with regard to his/her own health. Thus, focus is primarily placed on the organisation of the services, and IP cannot be compared to ACP, in the form that the latter is described in international literature.

http://www.helsedirektoratet.no/individuell_plan_veileder_til_forskriften_87804

A review study underscores the importance of including the next of kin in processes together with the patient at an early stage to ensure sufficient knowledge of the patient. This is an emotionally demanding task, for patients as well as for their next of kin. At the same time, this could serve as a basis for the relatives' participation in end-of-life deliberations when the patient is no longer competent to provide consent. The assessment of competence to provide consent is a key element of the care plan (Allen, De Laine et al. 2003⁵). A study from the US refers to a review of 43 care plans for nursing-home patients, in which the main focus was put on issues pertaining to heart-lung resuscitation (HLR). These care plans were revised only in the context of acute illness or hospitalisation. The paper concludes that the content of care plans should transcend issues pertaining to life-prolonging treatment and focus more on pain relief and care (Happ, Capezuti et al. 2002).

Fifteen women and four men in a community centre for the elderly, aged from 60 to 94 years, participated in focus-group interviews on the topic of ACP. Based on the findings, it was proposed to establish an ACP when healthy people of advanced age first come into contact with various programmes for the elderly. This plan could then accompany the individual person and would be known if he or she falls ill and needs help (Malcomson and Bisbee 2009).

1.4.5 Forms of organisation and interaction that impinge on decision-making processes

A survey undertaken in the US among 440 next of kin in 31 nursing homes after the death of the patient shows that the relatives were dissatisfied with the communication with the physicians. The next of kin associate the physician with information about the diagnosis, but barely half of them were prepared when the patient was about to die. The quality of the care provided was not assessed in terms of the degree of medical intervention on the patient, but rather in terms of the time the physician devoted to them as next of kin. The physician overestimated the patient's remaining lifespan. One of the reasons was that the physician was rarely present in the nursing home. This also led to poor quality of the palliative treatment. The importance of talking to the next of kin at an early stage when the patient is admitted is underscored even here (Biola, Sloane et al. 2007). A literature study of ethical challenges in geriatric care confirms this view. This emphasis on appropriate communication between clinicians and patients'/next of kin shows that this can forestall ethical dilemmas. Weaknesses associated with interaction show that clinicians focus insufficiently on matters that are

⁵ This paper has a psychological focus, and brings in a number of key points

essential for the patients'/next of kin (Mueller, Hook et al. 2004). A thematic analysis of interviews with six relatives of patients who had died in Canadian nursing homes describes their experiences with end-of-life care⁶. These included inaccessible physicians, little information about the fact that the patient was dying, and poor communication. The researchers claim that this demonstrates a need for further training of physicians as well as nurses, focused on a joint professional approach to end-of-life care (Vohra, Brazil et al. 2006).

A review study of 87 research papers and public documents shows that there is a close correlation between the number of staff in nursing homes and the quality of the treatment and care provided (Bostick, Rantz et al. 2006). It also shows the correlation between a high turnover of staff and a lower standard of care provided to patients in nursing homes. A review of 23 studies further shows the perspectives of relatives and healthcare staff with regard to deaths in nursing homes (Carlson 2007). Various deficiencies are revealed. These apply to discrepancies between the need for and the provision of care. The study further reveals insufficient knowledge at various levels among the staff. A lack of meeting points and processes between the patients'/next of kin and the staff undermined quality. Relatives were troubled by witnessing that the needs of their loved ones were not met. Hospitalisation could have been avoided if the staff had communicated better with the family and if the family had received better information and support. Barriers to care at the end of life are associated with organisational structures and lack of knowledge in the nursing homes. This is confirmed by Cohen-Mansfield, Lipson et al. (2006), who also shows that personal abilities and poor communication between physicians and nurses in nursing homes will have an impact on the standard of care. The implementation of Advance Directive (AD) procedures in case of hospitalisation was shown to lead to a certain reduction in admissions of elderly dying patients.

A literature study of goal attainment in clinical practice in general points out how increased interaction and communication between physicians and nurses can improve satisfaction among physicians and/nurses as well as patients. The study also points out that there are no models or theories available that can provide guidance for interdisciplinary collaboration. Characteristics of collaboration described in the literature indicate shared responsibilities on the basis of professional competence and role-based authority, with non-hierarchical

⁶ These six formed part of a survey, and the analysis of their answers to open-ended questions confirms and expands on the survey findings

structures. It is further revealed that barriers to appropriate collaboration can be found in patriarchal relationships, timeframes and unclear role definitions. Because of the shortage of qualified nurses, unqualified staff provides a major proportion of the care. This is also a barrier to professional collaboration (Fewster-Thuente and Velsor-Friedrich 2008).

Much of the research on physician-nurse collaboration relates to the hierarchical relationships between these groups. This is clearly pointed out in a review paper which also underscores that appropriate physician-nurse collaboration increases job satisfaction among staff members, and at the same time entails positive effects on the quality of the treatment and care provided to patients (Lindeke and Sieckert 2005). A number of empirical studies corroborate the findings presented above, that appropriate collaboration is decisive for the quality of the treatment and care provided (Lockhart-Wood 2000, Sommers, Marton et al. 2000, McPherson, Headrick et al. 2001, Schmidt and Svarstad 2002). Conversely it is revealed that poor or absent physician-nurse collaboration entails negative consequences for patients and their next of kin (Shield, Wetle et al. 2005, Wetle, Shield et al. 2005, Wilson, Coulon et al. 2005).

In terms of documentation, an evaluation survey conducted in the US after the introduction of electronic patient records revealed failures in the collaboration between physicians and nurses⁷. Physicians are critical of the nurses' method of documenting by way of descriptions and narratives. They call for structured and formal data in order to ensure treatment quality (Green and Thomas 2008).

A number of papers reveal a lack of knowledge associated with required skills such as communication and empathy. A review of empirical research on patients with dementia (1990-2007) shows divided opinion among nurses regarding artificial provision of hydration and nutrition. Against this background, the paper proposes the development of practical guidelines based on medical ethics (Bryon, de Casterle et al. 2008).

Various studies show that physicians find it difficult to talk about death (Somogyi-Zalud, Zhong et al. 2000, Kayashima and Braun 2001, Schaffer 2007). This is reiterated in a study of attitudes among physicians (107), nurses (178) and next of kin (136) with regard to the end-of-life situations of demented patients (Rurup, Onwuteaka-Philipsen et al. 2006). Physicians

⁷ This was done in a paediatric ward, but the documentation traditions can be universal, and it highlights an important topic.

exert a significant influence on decisions, and they are urged to become more open with regard to issues pertaining to the end of life.

1.4.6 Norwegian research results pertaining to the end of life in nursing homes

Little relevant research has been undertaken in the Norwegian context. In recent years there has been an increasing focus on the end of life in nursing homes, a trend to which for example Bergen Red Cross nursing home⁸ has made key contributions. An increase in the number of master's theses and PhD theses written by nurses has also drawn attention to the provision of care in the final stage of life. *Cooperation on improving ethical competence in the municipal health services* – a partnership project involving the Ministry of Health and Care Services (HOD), the Norwegian Association of Local and Regional Authorities (KS)⁹ and the Centre for Medical Ethics at the University of Oslo (SME)¹⁰ – has focused on nursing homes as a specialist arena. A desire to establish a central research base for nursing-home medicine has been expressed. Currently, Norwegian research results associated with this field of study remain fairly inaccessible.

Research associated with the end of life in nursing homes indicates that elderly ill patients, and dementia patients in particular, receive insufficient pain relief. Husebo, Strand et al. (2008) have undertaken a cross-sectional study to investigate the relationship between various degrees of dementia and the use of analgesics with regard to pain intensity. The study comprised a total of 181 long-term patients, 43 primary nurses, one geriatric nurse and four physicians in a Norwegian nursing home. The study indicates that people with advanced dementia experience pain to the same extent as other demented people, but receive less treatment in the form of pain relief. Demented patients in general experienced higher levels of pain before treatment was administered than the control group, consisting of mentally healthy patients. A further study of patients in seven Norwegian nursing homes ($n = 307$) with 214 participants showed that pain represents a major problem among the elderly and ill, because reported or observed pain remains insufficiently treated. Patients with better cognitive functions more frequently reported suffering from pain, and were also provided with better pain relief than those who suffered from cognitive failure (Torvik, Kaasa et al. 2010). These

⁸ <http://brks.no>

⁹ <http://www.ks.no/Portaler/Samarbeid-for-etisk-kompetanseheving/Sentrale-dokumenter/>

<http://www.ks.no/etikk-kommune>

¹⁰ <http://www.med.uio.no/iasam/sme/eik/>

two studies are corroborated by several other Norwegian studies (Nygaard and Jarland 2005, Kongsgaard, Wyller et al. 2008, Gran, Festvag et al. 2010, Slettebo, Kirkevold et al. 2010).

A number of papers focus on issues relating to the hospitalisation of nursing-home patients. A review paper discussing findings in light of the authors' clinical experience indicates that a number of patients who become hospitalised ought to have been treated in the nursing home. Indications for hospitalisation should preferably be diagnostics and clarification, treatment to improve functions or ensure survival, or palliative treatment that cannot be provided in the nursing home. In cases where patients have a short expected remaining life span, hospitalisation should be undertaken only after careful consideration. The authors conclude that practices could be improved by increasing the presence of physicians and upgrading the knowledge of palliative treatments in the nursing home. The study points out that nursing-home patients have the same legal entitlement to good-quality health care as others (Ranhoff and Linnsund 2005).

One study undertook a review of patient records in the medical department of Haraldsplass Hospital in Bergen. The inclusion criteria comprised the records of patients who had been admitted for emergency treatment from nursing homes, and who had died after 48 hours in the hospital. The records of a total of 26 patients were reviewed. The study showed that the nursing homes had unsatisfactory routines for assessment by a physician prior to hospitalisation. The decision-making processes were flawed, and the cooperation between the nursing home and the hospital was unsatisfactory. There was poor collaboration between the nursing home and the hospital. The documentation that accompanied the patient was insufficient, and the instructions to the hospital were often vague. This study also emphasises that knowledge of palliative care for this group needs to be upgraded. When patients are admitted to hospital, they encounter physicians who tend to have a pronounced focus on curative treatment. Similar to the above, this study also emphasises that insufficient coverage by physicians represents a problem in terms of the ability to assess critically ill patients in nursing homes (von Hofacker, Naalsund et al. 2010). This point is reiterated in the paper of Bollig, Husebo et al. (2008).

In a survey of physicians in 15 nursing homes in Bergen, one third of them reported that patients often or invariably receive infusions when they are no longer able to ingest nutrition or fluids. The authors point out that this may mean a prolongation of a painful process of

death. The authors also emphasise that the objective should not be to initiate futile courses of curative treatment, but rather to focus on palliative measures to leave room for goodbyes and a dignified end of life (Husebo and Husebo 2004).

A qualitative study focusing on the role of nurses in life-prolonging treatment shows that they were torn between their extensive responsibilities, on the one hand, and their restricted formal participation on the other. The study recommends increasing the formal involvement of nurses in these processes, and increasing the training and support available to this group in such situations (Hov, Athlin et al. 2009). Eriksen (2006) has studied the workload of nurses in various parts of the Norwegian healthcare system to provide input to politicians and healthcare administrators. The workload was at its highest in nursing homes, somatic hospital departments and home-based care services. In nursing homes, there were fewer positive challenges and role conflicts were more frequent. Nurses participated in decision-making processes least frequently in nursing homes and in somatic hospital departments. The study concludes that focus ought to be placed on nursing homes, since the working conditions there tend to present most problems. This finding is corroborated by others (Jakobsen and Sorlie 2010).

A comprehensive national survey of 664 respondents in 364 nursing homes investigated ethical challenges in nursing homes. The net sample represented 68 per cent of all patients in Norwegian nursing homes, and 76 per cent of the total number of nursing homes. A general lack of resources and failure to meet the needs of patients were among the main challenges reported. Information and communication with relatives also represented a major challenge, in which issues pertaining to life-prolonging treatment were a key component. Poor treatment and patients being ignored represented further challenges. Interaction between various groups of professions and institutions was also regarded as a major challenge in terms of ethics (Gjerberg, Forde et al. 2010, Gjerberg, Forde et al. 2011).

1.4.7 Summary

Research indicates that many ethical challenges relate to how to preserve the best interests of the patient, and also how to ensure involvement and proper care for the next of kin in decision-making processes. Proper routines of care planning and good collaboration between nurses and doctors are issues of great importance to quality care for elderly in the nursing homes.

1.5 Issues and research questions

The aim of this study is to map what happens in Norwegian nursing homes in decision-making processes in advance of the end-of-life and when life-prolonging treatment and care are being considered. Focus is put on relatives' and the professionals' understanding of the role of the patient at this stage of his or her life, and how the parties involved related to the patient and this role.

Physicians, nurses and relatives have been interviewed to elucidate how and on what basis such decisions are made, and how the parties involved describe their experience in retrospect.

1.5.1 The dissertation – delimitation and specification

The topics studied have a number of adjacent fields of interest, e.g. focus on dementia as an illness and a medical phenomenon; decision-making processes as sociological or organisational phenomena; and nursing issues associated with the scarcity of resources and the consequent moral stress imposed on medical professionals as well as patients/relatives. These fields of knowledge provide an important framework for this study's normative discussion. This study is not a discussion of philosophically based theory. It is an empirical study from a clinical environment, in which I will discuss the findings in light of a body of literature that I find relevant. My goal is to bring the empirical findings to the foreground and elucidate the findings.

On the basis of my main findings, the principle of autonomy, and therefore also the concept of competence to give consent, are key to the paper's normative discussion. Other principles such as beneficence and non-maleficence are also integrated into the discussion. However, these concepts are not seen in relation to the specific stages of dementia diagnoses or specifically to other potentially relevant pathologies. Grounds given by physicians and nurses to explain their own practice are discussed in the light of medical ethics, and findings are also discussed which uncover organisational circumstances that influence end-of-life decisions relative to ethics and relevant legislation.

1.5.2 Research questions

Chapter 4 (Methodology) provides a thorough introduction to the background to the research issues. The original and main question concerned the role elderly patients in nursing homes play in their own lives when death draws near (What *role, involvement and focus* does the

patient have in the end-of-life discussions?). To obtain an answer to this, the other research questions are as follows:

- What *role and involvement* do relatives have in decision-making processes associated with life-prolonging treatment?
- What *experience* do doctors and nurses have of decision-making processes concerning questions of life-prolonging treatment where the patient is not competent to give consent?
- *How do relatives experience* decision-making processes in relation to life-prolonging treatment?
- What *reflections and reasons* lie behind relatives' views on treatment in decision-making processes where the patient is not competent to give consent?
- How do physicians and nurses describe their practice, and what *reflections and reasons* lie behind the professionals' actions in relation to life-prolonging treatment when the patient is not competent to give consent?

Additional research questions that emerged during the study:

- How do physicians and nurses describe the level of coordination with regard to life-prolonging treatment within the nursing home and externally vis-à-vis hospitals and A&E units?
- What consequences do internal and external professional organisation and coordination have for patients and relatives?

1.6 The disposition of the thesis

The next chapter will give a presentation of relevant terms. Chapter 3 presents the theoretical framework for the study. Medical ethics, Norwegian health legislation and official reports are central to this framework. The applied method is presented and discussed in Chapter 4, before the presentation of the results in Chapter 5. The findings are discussed in the light of medical ethics, legislation and relevant literature in Chapter 6. Methodological considerations are included at the end of this chapter. The conclusion of the study is presented as the final Chapter 7, in which suggestions for further research are given.

2 Explanation of terms

The purpose of this chapter is to place the study in a professional context and to give some guidance for further reading to those who may not have detailed knowledge of end-of-life issues in nursing homes. The chapter is intended to be a point of intersection between an explanation of terms and a presentation of necessary topics for the arena where questions concerning life-prolonging treatment for elderly, ill people arise. The terms and phrases that are defined here represent key areas that have been the subject of in-depth scrutiny throughout the entire research process.

2.1 Next of kin/relatives

The Norwegian Patients' Rights Act, Section 1-3 b (Norwegian Ministry of Health Care Services 1999), defines next of kin as follows:

- 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 has had the most lasting and continuous contact with the patient, based, however, on the following ranking: 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;

The family as a strong relational unit has been challenged in contemporary society, and the closest emotional next of kin – in the sense of a person who knows you and your values and feelings – can in many cases be a friend or neighbour rather than a family member. If the next of kin or relative is automatically assumed to be from the traditional family, this assumption may be wrong in today's society (Beauchamp and Childress 2009).

2.2 Medical treatment and care at the end of life

A major prerequisite for appropriate decisions in a specialised environment that involves both the patient and possibly relatives is that the individual should be familiar with the terminology used within this arena. Healthcare personnel have a professional responsibility to study this field, a responsibility that also includes communicating information and knowledge to patients and next of kin (Norwegian Ministry of Health Care Services. The Norwegian Health Personnel Act 1999). End-of-life care is a medical term related to care in the terminal phase of life (Watson, Hockley et al. 2006), and the aim is to create the conditions for a good death for the patient. According to Smith (2000) and Steinhäuser, Clipp et al. (2000), these conditions include understanding that death is approaching, maintaining dignity and a private sphere as

death draws near, continuing palliative treatment, providing information on the various options, planning the funeral and addressing financial issues. Last but not least is the importance of taking farewell with one's loved ones.

2.2.1 Ageing

To acquire a holistic understanding of the context in which old people are removed from a natural environment – from their home to a nursing home – it is important to view the patient's life in an overall perspective rather than concentrating merely on death. We must be able to focus on how old people experience their total situation – a standpoint that is also significant when issues of life-prolonging treatment are being considered. Bondevik's doctoral thesis on the oldest of elderly people is a supplement to this knowledge and emphasises the importance of not viewing age and death as purely negative events (Bondevik 1997). Relevant literature often refers to biological ageing and excludes the natural social and psychological changes that take place along with ageing as a natural process. *Psychological ageing* constitutes the direct and indirect consequences of a biological ageing process during which loss of functions as well as various ailments may have an effect. The indirect effect is related to how the elderly person adapts to the inevitable physical changes. *Social ageing* is about interaction with society and the surroundings as a result of changed roles and expectations – both of oneself and from others (Daatland and Solem 2000). Gerontology provides the necessary knowledge and an understanding of ageing; it is a multidisciplinary professional field – precisely because ageing includes a series of complex processes and factors. Death is a natural closure to all these processes.

2.2.2 Dementia

The number of dementia patients is increasing according to the WHO (2011), not least because the elderly population is on the rise and 25 per cent of people above the age of 85 are assumed to suffer from some form of dementia. The current edition of the WHO report (2011): "*Palliative care for older people: Better practices*" emphasises the need for new thinking with respect to the needs of dementia patients.

In a Norwegian context, the Dementia Plan¹¹ was published as part of Report no. 25 to the Storting (Norwegian Ministry of Health and Care Services (HOD) 2005-2006) which was intended to help strengthen dementia care. The plan has a long-term perspective (2030 and

¹¹ Dementia Plan: <http://www.regjeringen.no/en/dep/hod/documents.html?id=313901>

2050). At the time of publishing the plan, there were approximately 66 000 people suffering from dementia in Norway.

Dementia is a progressive disease, the main symptom of which is impaired memory. Other symptoms include cognitive impairment, impaired communication skills and difficulties in retaining other skills (Norwegian Ministry of Health and Care Services -HOD 2005-2006). This is one of the reasons why dementia sufferers have gradually increasing needs for assistance in their day-to-day lives. There are different types of dementia, and in short they can be described as: 1) Degenerative forms of dementia, 2) vascular dementia and 3) secondary dementia (Engedal and Wyller 2003). Alzheimer's disease is the most common cause of dementia, and is also a degenerative type. More than 60 per cent of all persons with dementia suffer from a typical Alzheimer's disease. There are also other typically degenerative diseases that cause dementia. Examples include Parkinson's disease and Huntington's disease (Engedal and Wyller 2003). Fifteen per cent of all patients with dementia suffer from a brain injury of a vascular character (Eschweiler et.al. 2010). This may occur after one or several cerebral infarctions. Secondary dementia occurs as a sequela of, for example, B12 deficiency, caused by alcohol abuse, herpes and various types of brain tumours (Engedal and Wyller 2003), and represent less than five per cent (Eschweiler et.al.2010).

Various factors play a role when a person develops a dementia syndrome, including the person's ability to cope and the structural damage in the brain, as well as other possible diseases. Dementia is often graded as mild, moderate or severe (Snoek and Engedal 2008).

Disclosure and decision-making: Based on a literature review Hogan et. al. (2008)¹² recommend that dementia sufferers be included in decision-making processes at an early stage, together with their relatives, in order to preserve their autonomy. They point out that there is little research available on how information about the dementia diagnosis is communicated to patients and relatives. The inclusion of patients at the time of providing information about the disease may be fraught with difficulties considering their loss of cognitive understanding. Consequently, it is essential that the inclusion of patients and their relatives be individually adjusted to accommodate the needs of the patients and relatives at the time. Hogan et.al. (2008) stress the importance of including patients and their relatives in the

¹² 954 articles were selected for the study, and 48 recommendations were made for the management of mild to moderate dementia. This paper focuses on family care.

decision-making processes, when communicating information about the dementia diagnosis, but also to secure collaboration in other matters.

2.2.3 The biological death process

Although I have just emphasised the fact that the issue of treatment must not be the only focus of attention, treatment represents a major element. A necessary focus is thus that the treatment is based on an understanding of biological ageing processes and of death as a biological process. Patients in nursing homes receive on average from five to six different diagnoses, several of which may be life-threatening conditions (Husebo and Husebo 2005, Norwegian Ministry of Health and Care Services 2005-2006). The treatment regimes for these often refer to younger individuals, whose biological processes are different from those of very ill, elderly people. A common understanding of the natural biological processes associated with an advanced age is thus of importance in the discussion of life-prolonging treatment.

Various age-related illnesses can be a direct cause of death. The final stage of dementia represents an illness where, for example, the body cannot utilise liquids or food. Providing nutrition through tubes or intravenous liquids has little or no impact on state of health and does not have a life-prolonging effect (Finucane, Christmas et al. 1999, Smith and Andrews 2000, Critchlow and Bauer-Wu 2002).

2.2.4 Life-prolonging treatment

The British Medical Association's publication *Withholding and withdrawing life-prolonging medical treatment: guidance for decision-making* (BMA 2007) is based on British law and general morals. Its definition of life-prolonging treatment is also applicable to Norwegian conditions:

Life-prolonging treatment refers to all treatments or procedures that have the potential to postpone the patient's death and includes cardiopulmonary resuscitation, artificial ventilation, specialized treatment for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection and artificial nutrition and hydration (2007:5).

It may appear to be easier not to initiate life-prolonging treatment than to discontinue treatment that has been started (BMA 2007).

2.2.5 Futile treatment

The Norwegian national guidelines for decision-making processes for limiting the life-prolonging treatment of seriously ill and dying patients were published in 2009 (Norwegian

Directorate of Health 2009) and give some examples of “futile treatment”. An unofficial translation of two of these examples is as follows:

- Treatment that with absolute certainty will not give any positive effect, for example neither palliative nor life-prolonging.
- The benefit of the treatment is small compared with the side-effects and risk, for example it may prolong life but cause considerable discomfort.

Providing fluids and nutrition through a tube and via PEG (percutaneous endoscopic gastrostomy) is part of this treatment. Closely linked to the issue of futile treatment is moving old, very ill patients from nursing homes to hospitals, which can also be related to the points above. The result of futile life-prolonging treatment can be the prolongation of a distressing death process (Norwegian Directorate of Health 2009).

2.2.6 Palliative treatment

The hospice movement has placed a clearer focus on palliative treatment at the end of life, thus drawing attention to life-prolonging treatment. When curative treatment is discontinued, palliative treatment along with good nursing care should predominate (Erlen 2003, The Norwegian Directorate of Health 2009).

In 2004, the World Health Organization (WHO) published a leaflet concerning palliative care for older people who suffer from progressive chronic diseases. This has now been edited and further developed (WHO 2011). The need for this guide emerged from the identification of under-treatment and unfulfilled needs in this group. Even though the number of palliation specialists has increased in recent years, it is pointed out that these specialists are not necessarily at the front line working with the elderly ill. A further point is made that the programme of high-standard palliative treatment and care provided for cancer patients must be expanded to include the elderly ill. The relevant part of the WHO’s definition of palliative care is as follows¹³:

“...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care (extract):

- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated ...”

¹³ www.who.int/cancer/palliative/definition/en

Palliative care for older people who suffer from chronic progressive diseases at the end of life, will often be required for an extended period of time rather than solely in the very last weeks and days. It is especially difficult to identify the terminal phase of dementia patient due to the disease trajectory (Harris 2007).

Palliative Care for Older People: Better practices (WHO 2011) points out that for older people in the last phase of life, quality of life will be more important than prolonging life itself. In order to achieve this goal, it is necessary for palliative care to become an integral part of the medical services offered to older patients. This requires development of good care services, identification of patients, and therefore collaboration between nursing homes and other bodies with specialist expertise within geriatrics and palliation. In conclusion, the leaflet lists a number of recommendations for the benefit of politicians, health professionals and research scholars. In brief, these recommendations point to the necessity of ensuring organisational and medical development of the standard of care provided for the elderly ill (WHO 2011).

Chapter 6 of a status report from the Norwegian Medical Association “*When you are old and nobody wants you...*” (2001) also provides guidelines for the palliative treatment of elderly dying patients in Norwegian nursing homes. This report mainly concurs with the recommendations by the WHO (2011).

2.2.7 Allowing death – taking life

My view is supported by the reasoning of Jeffery and Millard (1997) – which says that if one accepts the mortality of man, life need not be preserved at all costs – while at the same time one should show an absolute respect for life. Furthermore it is emphasised that a good clinician is able to distinguish between what can be treated and what cannot. If the body cannot benefit from treatment, continued treatment will deflect life from what is natural. A “limit” is reached in such situations, and the question of killing rather than “allowing death” arises. The article by Jeffery and Millard from 1997 holds that the causal connection must be viewed in relation to the intention: This means that euthanasia takes place when the direct purpose and the intentional action are to take life. Hence, to refrain from initiating treatment or to discontinue initiated treatment that is perceived as useless and that is also burdensome for the patient – and of which one of the consequences can be to advance death – is not viewed as taking life. In such cases the primary purpose is not to take life, and the “causal

chain” is broken (Jeffery and Millard 1997). This is in line with the Code of Ethics for Doctors in Norway (Ruyter, Førde and Solbakk 2007).

These terms are far from absolute. A reading of international literature reveals that the definition of the terms is subject to varied professional content. I view the variations in the reasoning as largely a matter of different religious, ethical and cultural understandings. In addition, the use of the terms often lacks the necessary foundation (Dickenson 1999).

Euthanasia is illegal in Norway. The Code of Ethics for Doctors says the following about allowing death – taking life in Section 5¹⁴:

A physician must, when a patient’s life is ending, show respect for the patient’s right to self-determination. Active euthanasia, i.e. measures intended to hasten a patient’s death, must not be engaged in. A physician must not help a patient to commit suicide. To terminate or to refrain from initiating treatment which is of no avail is not considered active euthanasia.

The ethical guidelines for nurses¹⁵ are concurrent with the rules for physicians:

The nurse protects and preserves life until it must be regarded as having naturally come to an end. Actions which are intended to advance a patient’s death, i.e. active euthanasia, must not be taken. A nurse must not help a patient to take his/her own life. Being a party to the cessation of purposeless life-prolonging treatment or refraining from commencing such treatment is not considered active euthanasia.

In the same way as there are international differences in attitudes to life-prolonging treatment, Norway reflects an increasingly more complex society in which diverse religious and cultural standpoints will have an impact on this discussion. A growing number of patients – and thus also next of kin – with different religious and cultural backgrounds are coming into contact with nursing home employees.

2.3 Organisational knowledge and decision theory

Figures show that approximately 80 per cent of all patients in nursing homes suffer from varying degrees of dementia (Norwegian Ministry of Health and Care Services (HOD) 2007, Selbaek, Kirkevold et al. 2007). A key question is therefore who is to take decisions when the patients themselves have become less competent to make choices. The national guidelines for discontinuing life-prolonging treatment (Norwegian Directorate of Health 2009) provide clear provisions for decisions on treatment when the patient is not competent to give consent. It is regarded as a prerequisite that decisions not only should, but must be taken in a decision-making process that includes the physician, nurse and representatives of the patient.

¹⁴ <http://www.legeforeningen.no/id/485.1>

¹⁵ <https://www.sykepleierforbundet.no/fag/etikkk>

Knowledge of key mechanisms in the field of communication and decision theory is required to be able to conduct good processes. The subject is also included in a Norwegian text book about organisational competence in nursing and health professional collaboration (Orvik 2004).

2.4 Medical ethics – positioned between the profession and politics

Medical ethics provide theoretical guidelines for approaching end-of-life issues. Such ethical issues must also be seen in connection with the fact that the nursing home as an arena is part of the Norwegian welfare state. In other words, this means placing focus on the context in which the ethical problems arise. Mechanisms in the modern welfare state are described by a number of different authors, among whom are Halvard Vike and Erik Oddvar Eriksen (Eriksen 2001, Vike, Brinchmann et al. 2002, Vike 2004). These mechanisms affect the frameworks that are required for clinical practice. In no way have I acquired in-depth knowledge of this area, but it was necessary to focus on it in order to acquire a wider perspective of the context in which situations involving clinical ethics arise in a Norwegian setting. The importance of such a context must be recognised when the focus is on clinical issues in the light of medical ethics (Reiter-Theil 2004).

2.5 Summary

The presentation in this chapter is based on relevant topics derived from different specialist fields about which I wanted to acquire in-depth knowledge at the beginning of the study. As the project has advanced and new questions have been raised, the collection of literature has grown. This is not intended to constitute a fixed theoretical basis, but to form parts of a knowledge base that I have had to address. As such it creates an understanding of the complexity of the issue of decision-making processes in the question of life-prolonging treatment in nursing homes. This knowledge forms a foundation for the study and facilitates a discussion of a normative nature. Medical ethics, the law and appropriate public documents are presented in the next chapter as the key theoretical framework for the project.

3 Theoretical reference framework

My assumption is that significant phases and parts of current clinical practice are inappropriate for elderly, ill people in the terminal phase of their lives. The assumption is based on national reports and studies, international research, media debates in Norway and personal experience. One key reference framework is medical ethics. Further, since the issue basically addresses questions concerning decision-making on life-prolonging treatment for patients in nursing homes where 80 per cent are estimated to be suffering from dementia (Norwegian Ministry of Health and Care Services (HOD) 2007, Selbaek, Kirkevold et al. 2007), Norwegian law – through the Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999) – provides some guidelines for the discussion on ethics. In addition, various public documents that draw on this Act and other Norwegian Acts give more detailed information for practice.

3.1 Medical ethics

Medical ethics have developed considerably since World War II when the Nuremberg Trials confronted unacceptable medical activities. Medical ethics have developed along with society, and is related to financial and political factors, and particularly to medical development, which has been astounding (Ruyter, Førde and Solbakk 2007; Beauchamp and Childress 2009). The growth of medical ethics is a result of a moral development process. During the past decades, criticism of paternalistic physicians has led to a strong focus on patient autonomy. Co-determination in issues of treatment is a key element, and in such cases medical ethics as a discipline have set guidelines that ensure that the principle of patient autonomy shall be secured. Where medical treatment is concerned, paternalism means that the physician has a mandatory obligation to act in the best interests of the patient – regardless of the opinions of the patients themselves (Tranøy 2005).

3.1.1 Cross-cultural positions

In an international context, the various positions within medical ethics depend on considerations of health policy and constitutional law in the different regions/countries. It is also possible to turn this around and claim that medical ethics supply the premises for health policy and the law. The American approach to ethics in health care has a strong focus on autonomy. For example Søren Holm argues that the focus on the principle of autonomy as seen in medical ethics in the USA cannot have a general validity for all cultures and health

care contexts. He refers to European responses that use other models (Harris 2001). Within Europe there are also different variations: Southern Europe, including Ireland, represents an attitude where the patients themselves are responsible for maximising their own health by following physicians' instructions. This means that a physician's role is governed by professional norms rather than patients' rights. Central Europe grants patients a strong negative right – almost a type of duty – to make their own independent decisions. The Nordic approach is characterised by the social welfare state, which entails patients having rights and being permitted to set requirements regarding treatment (Dickenson 1999). Reiter-Theil, Mertz et al. (2007) makes a significant contribution to discussions of relatives' roles in the decision-making processes on the basis of an analysis of cultural differences linked to an understanding of the patient's role. They refers to the fact that Europe has retained a more paternalistic attitude than that of the USA, where considerable priority is given to patient autonomy. Nonetheless, regulations, moral approach and clinical procedures vary substantially with regard to the status of the next of kin in cases where the patient is not competent to give consent. This is not very different from Norwegian conditions (See 3.2.1). Under such conditions, the application of ethical guidelines and other tools will be the best approach to individual patient situations. Making changes to ensure that such laws, ethics and practice are coordinated entails long-term processes that take time (Reiter-Theil, Mertz et al. 2007).

3.1.2 Relevant theoretical approaches

When discussing the issue of life-prolonging treatment, there are some approaches in medical ethics that I regard as theoretically necessary to consider since they form the basis of Norwegian healthcare legislation. None of these theoretical approaches represent independent philosophical movements but are based on more complex ethical positions and moral philosophies.

3.1.2.1 Professional ethics ¹⁶

I have chosen to present professional ethics first since it represents an important part of medical ethics (Ruyter, Førde and Solbakk 2007). Professional ethics concern encounters between healthcare workers and patients, as well as professional health activities seen in relation to society. Professional ethics can thus contribute to highlighting responsibility

¹⁶ This presentation of professional ethics is exclusively based on Norwegian literature since society sets guidelines for healthcare activities and professional ethics should therefore be related to these

through the profession's autonomy and to regulating practice in a wider sense (Christoffersen, Ruyter et al. 2005; Tranøy 2005; Ruyter, Førde and Solbakk 2007). Professional ethics are reflections on professional morals. According to Grimen (a chapter in Molander and Terum (red.) 2008), professional morals can be distinguished from general morals by the fact that the assignment and mandate are policy-based. Areas where professional actions are legitimate also affect the area of general morals¹⁷. Such activities must be made legitimate. Professional morals hence have a goal that goes beyond them – to protect patients. To do this, professional morals must ensure that health professionals have the competence, qualifications and licence required for their activities. Examples of a relevant basis for professional ethics are the ethical rules for physicians and the ethical guidelines for nurses (Ruyter, Førde and Solbakk 2007).

3.1.2.2 The 'four principles' approach

Ethical dilemmas related to the medical developments of the past ten to twenty years have posed great challenges to clinicians regarding finding good solutions to ethical problems. Beauchamp and Childress (2009) are regarded as the “founders” of principle-based ethics. One of the reasons for this was that they were trying to find a common starting point to discuss difficult ethical dilemmas across the various political, religious and ethical attitudes and philosophies of life (Ruyter, Førde and Solbakk 2007). The four principles they launched are intended to serve as a tool for analysing difficult situations since their content is specific to the individual circumstances. According to Beauchamp and Childress (2009) these four principles of; - beneficence, non-maleficence, autonomy and justice are given equal weight as *prima facie*¹⁸ principles. Principle-based ethics are more of a tool than philosophy-based ethics, and they are founded on other well established types of ethics such as duty-based ethics, consequence-based ethics etc.

The principle of respect for autonomy concerns, in brief, the patient's right to self-determination, and rests on the fact that the patient is to act in agreement with his/her own competence to give consent. In a Norwegian context, both self-determination and co-determination are used in the relevant legislations. To enable patients to make competent decisions, health personnel are subject to a requirement concerning the duty to inform, as well as to other formal requirements regarding the part of the treatment they themselves are

¹⁷ As an example; the surgeon operates on patients, nurses ask patients to undress before an examination, etc.

¹⁸ *A Prima Facie obligation is one that must be fulfilled unless it conflicts, on a particular occasion, with an equal or stronger obligation* (Beauchamp and Childress 2009:15)

responsible for or are to conduct (Section 3.2 and Section 4.1 of the Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999), and Chapter 2, Section 10 of the Health Personnel Act (Norwegian Ministry of Health Care Services (HOD) July 1999). In addition, an assessment of the competence to give consent forms a basis for the autonomy principle. Section 4.1 of the Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999) contains the main rule for consent. The Norwegian Directorate of Health has published an introductory course on consent to health care¹⁹. Four criteria are given which must be considered when assessing competence to give consent. An unofficial translation of these four criteria is as follows:

1. Does the patient have a general understanding of the type of decision this concerns, and of why it is necessary to take the decision?
2. Does the patient have a general understanding of the probable consequences of giving consent or of not giving consent in this situation?
3. Is the patient capable of understanding, remembering, applying or assessing the information that has been given on health care?
4. Can the patient communicate his/her decision – by speech, writing, body language or in other ways?

The principle of autonomy represents the starting point for drawing up Advanced Directives (AD) for use in issues on medical treatment and care when patients are not competent to give consent. In literature AD may be 1) A Durable Power of Attorney (DPA). That is a legal assignment document of a person who is given authority to perform treatment decisions on behalf of the signer and continues in effect when the signer becomes incompetent (Beauchamp and Childress 2009). In Norway a patient can choose a relative or a person to serve as an attorney, but this person cannot issue legally binding statements on behalf of the interest of the patient. AD as 2) a “living will” is a written document in which the patient – while he/she was competent to give consent – expressed his/her wishes regarding choice of treatment at the end of life. In Norway, so-called “living wills” are not legally binding documents. The Norwegian Medical Association is planning to compile a “living will” with the aim of enabling people to express their preferences regarding life-prolonging treatment. This is in accordance with Norwegian law and with Official Norwegian Report NOU 1999:2 [Help in life]²⁰ (Norwegian Ministry of Health and Care Services (HOD)(Roland 1999) in

¹⁹ Link to CD- and teaching programme:

<http://samtykkeitilhelsehjelp.helsedir.no/player/PlayerX.html?xmlid=../content/000000001926/000000001926&width=780&height=520&startloc=0:0:0:-1&flashver=10&useFS=true&langrec=nb&langmaster=nb&1299366065671>

²⁰ <http://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/19992000/stmeld-nr-26-1999-2000-.html?id=192850>

which the principles for refraining from treatment and for prescribing adequate pain medication are clearly expressed.

Competence to give consent may cease to apply wholly or partly if on account of dementia the patient is clearly not capable of understanding what consent entails. The grounds for the decision must be given in writing (Section 4.3 of the Patients' Rights Act -Norwegian Ministry of Health Care Services (HOD) July 1999).

The principle of non-maleficence is based on norms dictating that actions must not be taken that cause the patient harm, unnecessary discomfort or other burdens. Some philosophers consider non-maleficence and beneficence to be one and the same principle. Beauchamp and Childress (2009) distinguish between them, based on William Frankena's (1973) approach which sets out four obligations, the first of which refers to non-maleficence, the three remaining of which refer to beneficence. These are not provided in a hierarchical order (Beauchamp and Childress 2009: 151)

Nonmaleficence

1. One ought not to inflict evil or harm

Beneficence

2. One ought to prevent evil or harm
3. One ought to remove evil or harm
4. One ought to do or promote good

Rules of non-maleficence are negative prohibitions of actions, and by contrast rules of beneficence are positive requirements for action.

The principle of beneficence concerns the duty of physicians and nurses to act in the best interests of the patient and his/her next of kin. This is particularly important in situations where patients, for various reasons, are incapable of giving consent and are unable to make autonomous choices. At the same time, Beauchamp and Childress (2009) point out that morality is not restricted to respecting a person's autonomy, but equally to ensuring their well-being. In normative practices, such as medicine and nursing²¹ (Nortvedt and Grimen 2004), beneficence goes beyond the general moral approach of being altruistic and demonstrating love and humanity; it becomes instead a moral imperative to act for the benefit

²¹ Nursing care and medical practice are normative activities, which means that in deciding what should be done in specific situations related to treatment and care, health personnel encounter moral boundaries.

of others. Examples of mandatory forms of beneficence, according to Beauchamp and Childress (2009), are:

1. Protect and defend the rights of others
2. Prevent harm from occurring to others
3. Remove conditions that will cause harm to others (2009: 199)

Key to Beauchamp and Childress's (2009) explanation is the balance and delineation between beneficence and paternalism in professional practice. Hard paternalism should be avoided as the risk of abuse is significant. Even soft paternalism must be questioned.

The principles of beneficence imply:

- positive requirements for actions
- need not to be followed impartially
- do not provide reasons for legal punishment when agents fail to abide by them (Beauchamp and Childress 2009: 199)

The principle of justice, in brief, states that equal cases must be treated equally (Gillon 1986, Buchanan and Brock 1989, O'Neill 2002, Beauchamp and Childress 2009). Distributive justice is mostly relevant in our context, where shortage of resources might influence the decisions at end of life as there might be many competing needs among different patients to be satisfied. Beauchamp and Childress (2009) says that "*- someone has a fundamental need is to say that the person will be harmed or detrimentally affected in a fundamental way if the need is not fulfilled*" (2009:243). They discuss several approaches to justice according to different theories, but these will not be discussed in this empirical study.

3.1.2.3 The ethics of proximity

- are a relationship-oriented type of ethics, and emphasise the dyadic and relational features of moral relationships (Vetlesen and Nortvedt 1996). Closeness is related to literal physical proximity, but can also mean mental closeness through emotional or personal bonds between individuals (Vetlesen and Nortvedt 1996). Løgstrup and Levinas are key contributors to the ethics of proximity, and in their ontological approach the relationship to the specific other person constitutes the fundamental for ethics (Løgstrup 1999, Lévinas and Aarnes 2004). Vetlesen and Nortvedt (1996) present the following definition²²:

²² Unofficial translation

The ethics of proximity prescribe that only a participative approach to the other person makes a moral relationship with him possible: only by participating in the other's well-being can the 'I' act as a moral subject; and only as the addressee of such participation can the other appear as the moral addressee. The choice of approach is therefore defining for both parties simultaneously – for the party who takes the approach and for the party the approach is directed towards. The manner in which we view a situation decides what we see, decides the nature of the situation for us (Vetlesen and Nortvedt 1996:160).

Criticism levelled at the ethics of proximity has involved the fact that closeness and responsibility for the local patient can set aside considerations for other patient's with relevant needs as well as undermining our sense of global responsibility.

Nortvedt's own view is that the ethics of proximity cannot stand alone as an ethical perspective or theory, but must be supplemented by other and more traditional ethical approaches such as virtue ethics, deontology and consequentialism. He also claims that perhaps the most significant contribution of an ethics of proximity is to gain an understanding of the basic foundations of morality (Vetlesen and Nortvedt 1996).

3.2 Legislation and other official frameworks

Some extracts from and references to the most relevant statutes are given below to provide an overview of the legal provisions that are appropriate in issues of life-prolonging treatment and care. Public reports and documents that set guidelines for the treatment and care of elderly dying patients in nursing homes are also presented. The patient's next of kin, physician and nurses are part of this.

3.2.1 The Patients' Rights Act²³

The Act states the following on the role of the next of kin in cases where patients who are of full legal age and legal capacity are not competent to give consent (Norwegian Ministry of Health Care Services (HOD) July 1999)²⁴:

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 healthcare provider may make decisions concerning health care that is not of a highly invasive nature with regard to its extent and duration.

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/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 health care can be decided by the person who is responsible for the

²³ <http://www.lovddata.no/all/nl-19990702-063.html>

²⁴ The translation of the second paragraph of Section 4-6 is unofficial

health care following consultations with other qualified health personnel. The patient's record must contain any information from his/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.

Section 4-9. *The patient's right to refuse health care in special situations* (2nd and 3rd paragraphs)

A dying patient is entitled to object to life-prolonging treatment. If a dying patient is incapable of communicating his or her wishes as regards treatment, the health personnel shall refrain from providing health care if the patient's next of kin express similar wishes, and the health personnel, based on an independent assessment, find that this is also the patient's wish and that the wish should clearly be respected.

Health personnel must make sure that a patient as mentioned in the first and second paragraphs is of full legal age and legal capacity, and that he or she has been given adequate information and has understood the consequences of refusing treatment for his or her own health.

3.2.2 The Health Personnel Act²⁵

An extract on responsible conduct is quoted directly from the Act (Norwegian Ministry of Health Care Services (HOD) July 1999) as a significant point of reference for the discussion in Chapter 6:

Section 4. *Responsible conduct*

Health personnel shall conduct their work in accordance with the requirements for professional responsibility and diligent care that can be expected based on their qualifications, the nature of their work and the situation in general.

Health personnel shall act in accordance with their professional qualifications, and assistance shall be obtained and patients shall be referred on to others if this is necessary and possible. If the patient's needs so indicate, the profession shall act through co-operation and inter-action with other qualified personnel.

Upon cooperation with other health personnel, the medical practitioner and the dentist shall make decisions in matters concerning medicine or dentistry respectively in relation to examinations or treatment of the individual patient.

The fourth paragraph of this section related to this study's discussion addresses physicians' competence and their mandate to prescribe and provide medical treatment and to give information on such treatment:

The Ministry may determine in regulations that certain types of health care shall only be provided by personnel with special qualifications.

Distributing medication, including administering intravenous medicines, is a task for physicians. When nurses do this as part of their work, the physician delegates the task to them. Section 4 of the regulations relating to handling medicinal products governs the

²⁵ <http://www.lovdato.no/all/nl-19990702-064.html>

requirements regarding competence and training for delegated tasks and is based on Section 5 of the Health Personnel Act, *Use of assistants*. This can apply to administering intravenous antibiotics and intravenous pain-killing preparations etc. In hospitals these are everyday activities for nurses, whereas in nursing homes they may be tasks that are performed irregularly. Delegated responsibility encourages training and develops competence, and in nursing homes it is the duty of the enterprise director/administrator to ensure that this responsibility is safeguarded²⁶:

The enterprise manager must therefore ensure that health personnel possess and maintain the necessary qualifications for the nature of the tasks and the follow-up that is given. 'Qualifications' in this context means both formal and informal qualifications, i.e. professional health education, supplementary education and experience. This entails a dynamic competence requirement that totally depends on the task that is delegated.

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

In 2009 guidelines were published in Norway on the issue of limiting life-prolonging medical treatment (Norwegian Directorate of Health 2009). The need for such guidelines had come to light over time as a result of the medical development that makes it possible to prolong life beyond what was previously deemed natural and also achievable. The difficult ethical dilemma arose as a consequence of this development, and gradually drew attention to the need for such guidelines. Individual cases that were reported in the media led to professional debates and also revealed the need for common guidelines. The Centre for Medical Ethics at the University of Oslo and the Norwegian Medical Association have put considerable work into the guidelines, and various professional communities have been involved. The working group that compiled the guidelines was led by Reidun Førde. The target group is the specialist health service and the municipal health and care service, and the purpose is given as follows²⁷:

The purpose of the guidelines is to quality assure the decision-making process related to initiating or discontinuing the life-prolonging treatment of seriously ill patients who have a poor prognosis and who without such life-prolonging treatment will die within a short time, i.e. within days or a few weeks. The guidelines are intended to provide both frameworks for such decision-making processes and support for treatment personnel, patients and next of kin. Since the guidelines are aimed at the entire health service, the need may arise for more detailed guidelines within individual disciplines or institutions (2009:3).

²⁶ Unofficial translation

²⁷ Unofficial translation

The decision-making processes related to the issue of life-prolonging treatment are of central importance²⁸.

3.2.4 Long-term care – future challenges (Report no. 25 to the Storting: 2005-2006)

This document from the Ministry of Health and Care Services (HOD)(2005-2006) legitimates increased research and investment in competence in order to ensure the quality of services for the elderly. Significant and relevant topics for this study that are discussed in the report include a holistic dementia plan, a national standard for medical services in nursing homes, end-of-life care and palliative treatment.

3.2.5 The Coordination Reform – proper treatment – at the right place at the right time (Report no. 47 to the Storting: 2008-2009)

Patients, particularly elderly patients, are dependent on the various levels of treatment being conducted in a continuous chain to ensure that each individual receives good medical treatment and care. Poor collaboration has been revealed between the levels in the Norwegian public healthcare service, and in 2009 a report to the Norwegian parliament was issued (Ministry of Health and Care Services 2008-2009). This reform was aimed at ensuring better continuity in the treatment of patients across the various levels to prevent them being shuttled from one part of the health service to another. The term “collaboration” in this context entails professional collaboration among the various professions and across institutional borders (Orvik 2004, Wilson, Coulon et al. 2005).

3.2.6 Summary

As we have seen from this overview, ethical as well as legal and clinical oriented guidelines have in later years been established within the Norwegian health care contexts. This development of more structural and organised knowledge and research is a basis for the future quality of elderly care in which patient autonomy and shared decision-making will be important parts of medical treatment and nursing care.

²⁸ The guidelines give advice on including the next of kin of patients who are not competent to give consent. They also provide key definitions, as well as many references to relevant literature

4 Methodology and research process

The choice of methodology was made with a view to the nature of the topic and the research questions. Suhonen et al. (2010) found in their review study that international research on this topic is fragmented and there is a need for further research. Since I also found few studies on this delimited topic undertaken in Norway, there was a need to conduct a qualitative study in which I could ask open-ended questions of people who were familiar with the topic and had experience in dealing with it (Polit and Beck 2004). The aim was to map this topic, and discuss the findings in the light of medical ethics, Norwegian healthcare legislation and various official reports.

A key feature of the qualitative research paradigm is found in the complexity of its multiple approaches to epistemology and methodology (Denzin and Lincoln 2005).

In the following, I will position the study in a theoretical landscape, and describe and explain the chosen design. Furthermore, explanations will be provided for my choice of methods associated with sampling, recruitment and access to the research field, the process of collecting the data, ethical research considerations and the data analysis.

4.1 Theory of science

This study takes a hermeneutic interpretive approach based on qualitative in-depth interviews. The study is embedded in an understanding of a theory of science based on philosophical hermeneutics, and this chapter will briefly describe this basis. My preconceptions as a researcher will be discussed in line with key concepts connected to philosophical hermeneutics.

4.1.1 Hermeneutics

The word *hermeneutics* originates from Ancient Greek “hermeneuin”, which means “to interpret”. Palmer’s classic explanation (1969) states briefly about the purpose of interpretation:

” The task of interpretation must be to make something that is unfamiliar, distant, and obscure in meaning into something real, near, and intelligible (Palmer 1969:14)”.

The hermeneutic tradition associated with science and methodology developed from traditional hermeneutics into philosophical hermeneutics. In general, the former has an epistemological foundation and the hermeneutical method stresses objectivity and correct

interpretation (Thornquist 2003, Gadamer 2004). Philosophical hermeneutics developed as a criticism of a theoretical approach which focused on consistency, stressing instead the researcher's role as an interpreter. In this perspective, objectivity is not an issue, quite the contrary; the research pre-conceptions become central to the encounter with the interviewee (and by extension, to the data collected), thus necessitating an analysis of the researcher's own background. An exhaustive analysis is not possible, but it is important to raise the level of awareness in considering how one's own pre-conceptions may influence questions and the interpretation of the data. Becoming aware of one's own pre-conceptions is not only necessary; it is a condition without which understanding cannot be reached (Angen 2000). Familiarity with the object of research will enable an explorative study to be conducted. When the researcher encounters a study participant in an interview situation, both attend with their respective *horizons of understanding*. This means that any specific situation occurs in the light of history; we see what we see against the background of our own experience:

We always find ourselves within a situation, and throwing light on it is a task that is never entirely finished. This is also true of the hermeneutic situation – i.e. the situation in which we find ourselves with regard to the tradition that we are trying to understand. The illumination of this situation – reflection on effective history – can never be completely achieved; yet the fact that it cannot be completed is due not to a deficiency in reflection but the essence of the historical being that we are (Gadamer 2004:301).

Palmer (1969) refers to Gadamer when he describes an ideal situation in which life encounters life and there is a *horizontal merger*. The past and the present are unified through the process of understanding, thus giving rise to new knowledge. As an extension of this process, and based on the researcher's interaction with the interviewee, new knowledge emerges as a social construct (Rose and Webb 1998).

Interpretation and understanding of meaning is at the heart of the explorative study, which involves working in a continuous spiralling movement in order to achieve deeper understanding of a phenomenon. Alternately concentrating on the individual parts and then referencing them to the whole, is referred to as the *hermeneutic circle* (Gadamer 2004). A spiral is in fact a more useful concept, as the spiralling movement from part to whole is in constant development towards new understanding.

As a method, philosophical hermeneutics may also be considered to be ontological in character, because their philosophical foundation is based on the assumption that a given individual's consciousness has been developed through interaction between language, logic and traditions as historical, spiritual phenomena (Thornquist 2003).

4.1.2 The researchers' preconceptions

My epistemological assumption, based on the view that knowledge is subjectively constructed, thereby underscores the key role of the researcher (Fog 2004, Gadamer 2004, Graneheim and Lundman 2004, Silverman 2006, Kvale and Brinkmann 2009). Throughout the study, a continuously reflexive approach has been taken to my own experience and training. Awareness and thorough assessment of one's own role as a researcher may well constitute the most important qualities required for the validation of an interview-based study. The researcher is the actual instrument by which data collection is made possible (Angen 2000, Fog 2004, Silverman 2006, Kvale and Brinkmann 2009). This means that the researcher uses his or her own interaction with the interviewees in a process to which reflexivity is central. This reflexivity enables researchers to interpret their own perspectives based on their awareness of personal pre-conceptions in the encounter with the interviewee's perspective. In turn, this reflexivity will give cause for design adjustments en route in order to seek deeper understanding of the object of study. Interpretation is a key to this process. While conducting the interviews, I found on several occasions that the interviewee's understanding of the situation did not concur with mine. Clarifying follow-up questions uncovered new aspects which necessitated further exploration.

In my assessment, it was highly important to the study at hand that I was familiar with and had experience of the nursing home as an arena as well as the decision-making processes associated with life-prolonging treatment. This enabled me to convey and sharpen my focus during the interviews, and I was able to ask follow-up questions about topics which had not been talked about in order to retrieve important data (Reiter-Theil 2004). Experience from contact with next of kin during my clinical practice as a nurse in a nursing home spurred me to search for more in-depth knowledge of the experiences gained by the next of kin. I saw that justifications and explanations had to be requested. The next of kin provided important descriptions, which revealed that they understood situations in a manner which was different from what I had seen relatives do on earlier occasions. This proved to me that it is necessary to remain critical of one's own proximity to the research field, to prevent this preconception from threatening the validity of the study, by causing key aspects to be overlooked because they were taken for granted (Lykkeslett and Gjengedal 2007). In recent years I have been involved in competence-building in the municipal health services. When probing doctors and nurses on issues pertaining to well known questions of ethics, I revealed key reasons and a new understanding of why practices do not accord with ethics and law.

As seen above, part of our own preconception is associated with our personal experience. This is in turn tinged by the theoretical and epistemological understanding that I as a researcher have of my field of study. Chapters 2 and 3 form part of this whole.

4.2 Study design

The design has evolved as a result of continuous reflexivity throughout the research process. Descriptions and viewpoints that emerged during the interviews and in the course of the study have often provided new insights and led to an adaptation of the sample research questions and consequently the interview guide, as well as the scope and structure of the textual analysis (Patton 2002, Polit and Beck 2004). Thus, the study has been based on an exploratory design, and is thereby emergent in character (Pt. 4.3.2) (Polit and Beck 2004).

4.2.1 Sampling

Qualitative studies are concerned with seeking *understanding* of the phenomenon of interest (Patton 2002, Denzin and Lincoln 2005, Kvale and Brinkmann 2009). The difference between qualitative and quantitative studies can possibly be illustrated and explained in terms of the logic used to obtain their respective samples. Where quantitative studies seek to recruit a large sample in order to ensure statistical representativeness that can allow for generalisation to a larger population, - qualitative studies seek out information-rich participants who can provide maximum information about the research questions and then transfer this knowledge to a similar context (Polit and Beck 2004).

Purposive sampling, which has been used in this study, is characterised by an appeal made by the researcher to research areas and participants who are familiar with the topic of the study, but who also come from a variety of backgrounds, as this will allow for identification and elucidation of a maximum number of factors. In this study, this involved obtaining as much information as possible on the topic studied (Patton 2002; Graneheim and Lundman 2004; Kvale and Brinkmann 2009). On the basis of my own preconception, cooperation with nurses and doctors from a number of Norwegian nursing homes over the last years and a review of national and international research literature, I was able to form an impression of the various factors that may impinge on decision-making processes at the end of life.

The sampling was conducted in two steps - at 1) the nursing homes and among 2) the informants (relatives, physicians and nurses).

4.2.1.1 Nursing homes

Criteria for selection of nursing homes:

- Public nursing homes, including those that are part of the municipal health and care services in Southern Norway.
- Nursing homes in various geographical locations, in cities (>200 000), cities (<100 000), small built-up areas/small towns (>6000) and rural areas (<6000).
- Nursing homes with a minimum of one somatic unit and a minimum of one dementia unit.

Table 4.1: Nursing homes – demographic data

<i>Variable:</i>	<i>Location</i>	<i>Number of patients</i>	<i>Number of wards in the nursing home (dementia units)</i>	<i>Full-time equivalence - physicians` (1=100%)</i>	<i>Full-time equivalence - nurses` (1=100%)</i>
Nursing home 1	city (< 100 000)	72	3 (1)	0.6	15
“ 2	city (> 200 000)	108	5(1)	0.8	16
“ 3	small town	22	2 (1)	0.2	11
“ 4	rural area	62	3(1)	1.0	17.13
“ 5	small town	36	4 (1)	0.2	8.5
“ 6	small town	31	4 (1)	0.3	13
” 7	city (< 100 000)	59	7 (2)	0.6	19.5
“ 8	city (< 100 000)	40	2 (1)	0.6	13.27
“ 9	city (< 100 000)	58	3 (1)	0.4	15.75
“ 10	city (> 200 000)	96	6 (2)	0.9	19

A total of ten nursing homes in various communities in Southern Norway were contacted in line with purposive sampling as the setting for the study. These ten had a desirable geographical distribution. I took into consideration that certain cultural variations in terms of family traditions might occur, including the relationship to and experience of death according to the location of the nursing home. I also wanted to include nursing homes with varying distances to a hospital, since I assumed that this might have an effect on the propensity to hospitalise nursing-home patients. Furthermore, for nursing homes located in small rural

communities there is a greater probability that the children of elderly patients will live some distance away as a result of centralisation over the last centuries. I wanted to include this factor, because the geographical proximity of relatives to the nursing home may have an influence on the decision-making process.

The management of the health and care services in municipalities where relevant nursing homes were identified were contacted by telephone.

The table 4.1 shows the characteristics of the nursing homes, in terms of geographical location, the number of patients and their staffing by doctors and nurses.

4.2.1.2 Relatives

Criteria for selection of next of kin:

- Relatives of patients older than 75 years
- Relatives of patients with fully or partly absent competence to provide consent at the final stage of life (See Pt. 4.3.2)
- Relatives of patients for whom life-prolonging treatment at the final stage of life had been considered
- Son, daughter, son-in-law, daughter-in-law, spouse/partner
- Equal distribution of men and women
- Relatives who were resident in the same area as the patient (the nursing home) and relatives who were resident more than 100 km from the patient (the nursing home)
- Relatives from a variety of educational backgrounds
- Norwegian-speaking relatives
- Requirement for the interview to take place no less than two months and no more than one year after the death of the patient.

The sample of relatives was contacted deliberately to identify information-rich informants (purposive sampling)(Patton 2002, Denzin and Lincoln 2005). My goal was also to achieve a gender balance in the sample of relatives, and this could be ensured within the framework of ten nursing homes. Men and women might give different information about the topic due to social differences in family relations in care for the elderly. Table 4.2 shows the relatives' demographic data, linked to the patients.

Table 4.2: Relatives - demographic data, linked to patient data

Location of the nursing home	Relative		Patient				
	M/F *	Age	Relation to the informant	Age	Dementia Y/N **	Time in the nursing home	Hospitalisation from the nursing home
City (<100 000)	M	65	Father	96	N	Short	Admission, apoplexy
			Mother	88	Y	3 years	Admission, pneumonia
City (<100 000)	F	44	Mother	84	Y	3 years	Admission, fall x-ray
City (>200 000)	F	62	Mother	92	Y	2.5 years	Admission, apoplexy
Small town	F	69	Mother	95	Y	1.5 years	No
Small town	F	62	Father	85	N	5 months	No
			Mother	85	Y	Alive	
Rural area	M	41	Father	78	Y	6 years	No
Rural area	M	63	Father	83	N	10 days	No
			Mother	80	Y	3 years	Admission, acute abdominal pain
Small town	M	60	Father	90	N	3 years	Admission, apoplexy
Small town	M	55	Mother	88	N	1 year	Admission, pneumonia
			Father	90	Y	2 years	Admission, pneumonia
City (<100 000)	F	60	Mother-in-law	94	-language	10 days	No
			Mother	92	N	Short-term placement	Admission UVI (died in hospital shortly after)
City (<100 000)	F	62	Mother	90	N -language	2 months	Admission, apoplexy
City (<100 000)	M	60	Mother	89	N	1.5 years	No
City (<100 000)	M	77	Wife	76	Y	5.5 years	Admission, pneumonia
City (<100 000)	F	43	Father	83	N	5 months	No
City (>200 000)	M	55	Mother	78	Y	3 years	No

*M/F= Male/Female ** Y/N= Yes/ No

4.2.1.3 The sample of physicians and nurses

Criteria for the selection of physicians:

- At least two years of continuous employment as a physician in the nursing home

Criteria for the selection of nurses:

- At least two years of continuous employment as a nurse in the nursing home
- At least 50 per cent of a full-time equivalent position
- Clinical nurses on rota without management responsibility at the department level

Selecting the ten nursing homes on the basis of geographical criteria left certain factors uncontrollable with regard to the physicians and nurses. A factor which appears to be randomly distributed, and which can be seen as beneficial in terms of purposive sampling, is the age distribution among the physicians and nurses. The same observation applies to their respective years of experience as health workers in nursing homes. In eight of the ten nursing homes, the physicians' working hours were controlled by their General Practitioner (GP) contract with the local authorities, which required them to spend 20 per cent of their working week in the nursing home. Two of the physicians were employed in permanent positions at the nursing home, on a 60 per cent and 90 per cent basis respectively. This distribution reflects the staffing rate of physicians in Norwegian nursing homes (Statistics Norway SSB²⁹). None of the physicians were specialists in geriatrics, eight of nine were GPs. The last was a surgeon.

All nursing jobs were 0.7 full-time equivalents or above. Among the nurses, two had specialist training in palliation and one in geriatric nursing. Table 4.3 shows the demographic data of physicians and nurses.

Table 4.3: Physicians and nurses – demographic data

Variable	Physicians	Nurses
No.	9	10
Age (mean)	44	50.5
Experience (years)	11	9.8

(* = mean experience as an employee in a nursing home)

²⁹ http://www.ssb.no/helsetilstand_en/

4.2.2 Recruitment and access to the research field

All contacts with the **nursing homes** were established and maintained through the directors/administrators. Following a phone call providing outline information, written information on the project was sent if the director/administrator had consented (Appendix 3). After approximately one week I made renewed contact with the director/administrator to establish agreement on how to proceed further. Thirteen nursing homes were contacted. The administrator of one nursing home that I contacted declined to participate in the study, stating that the institution had not experienced situations that were relevant and useful for elucidating the research question. In two other nursing homes the administrators agreed to let their institutions participate in the study, but the information was never passed on to relevant informants. Lack of time was reported to be the reason. In one of these nursing homes, the administrator spontaneously stated that the local physician had expressed great interest in the research question. The final sample of nursing homes is shown in Table 4.1. Altogether ten nursing homes were included in the study.

Information letters describing the plan of progress were subsequently sent out by the director/administrator to encourage the nurses who were familiar with the daily routines to make contact with **relatives, physicians and other nurses**. Two relatives, one physician and one nurse were contacted from each nursing home. Five relatives and one physician declined to participate. The relatives had personal reasons for refusing, and the physician gave no reason for not participating. When relevant informants had agreed to participate, the director sent them information about the project and a consent form, including a pre-paid envelope (Appendix 4). My first contact with the informants occurred when they returned the consent forms with their phone numbers to my address. This was in agreement with the permission from The Regional Committee on Medical Research Ethics (REK)³⁰(Appendix 1).

4.3 Qualitative in-depth interviews

The study is inspired by Kvale and Brinkmann's explanation of the qualitative research interview (2009). Kvale and Brinkmann (2009) stress that the research interview is a tool characterised by its potentially pragmatic approach to epistemological and ontological questions. This means that the interviewer will need to make informed choices in such matters. I will be referring to the literature in order to justify my choice of method. The purpose of this chapter is primarily to clarify my choices and courses of action while

³⁰ Link: <http://helseforskning.etikkom.no>

providing my own definitions of concepts which appear ambiguous within the literature in line with Pope, Ziebland et al. (2000).

The researcher encounters the interviewee through a conversation, the objective of which is to increase the level of understanding of the interviewee's experience in connection with a given area or theme. The difference between an everyday conversation and a research interview is, according to Kvale and Brinkmann (2009), that the latter has a clear structure and purpose. Careful planning and knowledge about conversation as a tool is required to secure verifiable knowledge. The researcher is in control of the situation, which is therefore not a conversation between equal parties. Nevertheless, Kvale and Brinkmann (2009) uses the term "inter view" in order to explain that the researcher and the interviewee are talking about a topic of shared interest which generates an exchange of views. The researcher encourages the interviewee to describe his/her experience in as great detail as possible while also providing his/her reasoning in order to catch the interviewee's own horizon of understanding (Gadamer 2004). This is in accordance with a philosophical hermeneutic approach, as described above as a precondition for horizontal merger and a basis for new knowledge. The research interview forms the basis for a scholarly understanding and interpretation of the interviewee's experience. The interpretation takes place throughout the interviewing process, continues during the transcription process and throughout the further analysis.

My previous experience with qualitative research interviews has indicated to me that this is an appropriate instrument in situations involving vulnerable informants (Gjengedal 2000, Dreyer 2003, Dreyer and Nortvedt 2008). This methodology presupposes a focus on sensitivity and respect for the interviewee (Parahoo 1997, Silverman 2006, Kvale and Brinkmann 2009).

The contributions by Kvale and Brinkmann (2009) to interview-based research are thoroughly based in literature, and constitute significant insights that include the importance of communication, critical reflection on the role of the researcher and perspectives on data that emerge in an intersubjective context of this kind³¹.

An **interview guide** listing the questions to be answered is essential to keep the interview focused (Kvale 2009). A preliminary version of the interview guide was prepared on the basis of my experience with the field, conversations with physicians and nurses in various nursing

³¹ Kvale and Brinkmann's textbook: *Interviews: learning the craft of qualitative research interviewing* (2009)- provides a number of references for further reading

homes and reviews of national and international research literature (Appendix 5). An initial test of the coherence between the research questions and the interview guide was undertaken by coding the first interviews with a view to making the interview guide as appropriate as possible. This proved useful, because I became aware that I needed to take a more listening approach and let the participants speak more freely in the following interviews. I could see that with a view to the analysis it was essential to let the participants finish a topic (for example issues pertaining to intravenous fluids) without being tempted to continue prematurely. Relatives, for example, often had a need to talk, and often returned to topics they felt had been insufficiently described. I became aware that forcing the conversation could make the material unnecessarily incoherent.

Data saturation

Qualitative research uses the concept of data saturation. According to one definition that I find to be representative of the research literature, this means: “... *the collection of data in a qualitative study to the point where a sense of closure is attained because new data yield redundant information*” (Polit and Beck 2004:731). An editorial comment in the journal “Quality Health Research” points out that data saturation does not refer to a situation where I, as a researcher, have heard a participant refer to a phenomenon before; it describes how no further shades of meaning related to the phenomenon keep emerging (Morse 1995). The last interviews from the ten nursing homes produced little new material, and I concluded that further interviewing and inclusion of further nursing homes would be unlikely to add new aspects. This could be due to the fact that during the interviews I had made a considerable effort to focus on the relevant topics, and the focus was therefore quite a narrow one. Consequently, there is a risk of obtaining insufficient knowledge of specific areas (Morse 2000). This assessment was made in consultation with my supervisors and other health professionals from the nursing-home sector/institutions. I am also of the opinion that important information may be of a “latent” nature and might be left out.

4.3.1 Data collection

The interviews were conducted in the period from September 2007 to April 2008.

The very first interviews made it clear that it was essential to ask the physicians and nurses questions about their professional reasoning with regard to their practices, since they

described actions that were somewhat controversial in terms of ethics, but without giving any reasons. The hospitalisation of terminal nursing-home patients was one example.

From the very start I became aware that it was essential for coherence that I concentrated on the interviewing without too many other tasks to divert my attention. Furthermore, it was important to establish an interviewing frequency that could allow one interview to be transcribed and reviewed before I would go on to do the next one. A main purpose of the reviews was to include new questions in the interview guide if new topics came up (Pope, Ziebland et al. 2000).

To obtain the maximum benefit from a composite total sample of relatives, physicians and nurses I chose to mix the sequencing of the interviews. For example, when I had heard the statements from the relatives I could follow up on these in the interviews with the physicians and nurses in the same nursing home. In the same manner I could follow up on topics internally in the sub-samples (Kvale and Brinkmann 2009). As an example I followed up on an interview with one doctor from a small rural nursing home in an interview with a physician in a city nursing home. This gave some valuable data based on the impact of community differences and the physicians' familiarity with the patients and their families in the decision-making process.

The respective processes of interviewing medical professionals on the one hand, and the relatives of patients who had passed away on the other, were highly dissimilar. In order to learn about the medical professionals' experience while also seeking to shed light on their norms and values (grounds for action), it was important to accommodate reflection without posing questions that were too critical in order to make sure the interviewees did not take a defensive stance. Interviews with relatives were coloured by the fact that they had a genuine wish to share their experience with me as a researcher who was interested in listening to their experiences and post-event reflections. It was a challenge in these situations to ask questions which in addition to eliciting a description of their experiences, would uncover their reflections and their understanding of the decision-making processes.

4.3.1.1 The interview situation

The relatives were free to choose where to conduct the interview. In light of their recent bereavement, many respondents wished to be interviewed outside the nursing home. Physicians and nurses were interviewed at the nursing home in their working hours.

Prior to each interview I spent some time on focusing before meeting the interviewee. I retrieved the project description (with new comments added) and “calibrated” the focus for the interview. I also checked the updated interview guide.

Before switching on the digital recorder (in accordance with “written informed consent”), we would discuss the topic to establish a reasonably joint focus and I informed the participant that he or she was free to discontinue the interview at any time. I started the recorded interviews by asking the participants to describe their experiences. All the interviewees (physicians, nurses and relatives) started to give their descriptions. There were only two instances where these initial narratives diverted from the interview focus, “end-of-life decision-making processes”. In these situations I drew attention to previous statements to bring the interview back on track. In all other situations I refrained from interrupting with further questions. The interview guide was used to keep the interview focused. I followed up by asking questions that had not been fully described in the initial phase. The objective of the interview guide was to follow up participants with more elaborate questions wherever this felt natural, and also to ensure that the participants would describe topics that were central to my interest.

The atmosphere that prevails during the interview is important to enable the participants to come up with additional material and good descriptions rather than “censoring” their own statements thanks to a negative judgmental attitude, which would be reflected in the way the questions are asked (Kvale and Brinkmann 2009, Fog 2004). This is a part of the researcher’s important role in research interviews to secure the possible meeting of the interviewee participant’s horizon (Thornquist 2003).

Leading questions - were used deliberately in a number of different situations. In terms of methodology, this is a tool used to provoke the interviewee to elaborate on his or her own views. According to Kvale and Brinkmann (2009), deliberately leading questions are underused, since they can be utilised as a tool to increase the reliability of the respondents’ answers. The criticism raised against leading questions tends to emphasise that they may push the interviewee in a particular direction, although this is unlikely to be a problem in an in-depth interview, where knowledge and information are exchanged in an intersubjective relationship. Examples of leading questions that I asked the relatives with a view to obtaining

more detailed information included querying why one family had wanted to continue the intravenous hydration of their dying father:

Researcher: Your assessment after the hydration had been removed was that he needed it, then? That he would be thirsty, perhaps?

Relative: Sure, we had these infamous sponges, then – so we dipped them and moistened his mouth, and – we could see that he had saliva in his mouth, and – so we tended to his mouth and washed it, and he appeared to be very dry. So that was done, anyway, he was given some fluids. I cannot say whether he noticed, but we felt the need to do it (AS01P).

On other occasions I would receive negative/repudiating answers. Criticism of the use of leading questions is far more relevant with regard to questionnaires, in particular when pre-defined response categories are used.

Balancing the questions

In my interviews with physicians and nurses on topics such as competence to provide consent I was careful not to use leading questions. This could have induced them to answer “by the book”, and give a not entirely accurate description of their own practices. My assessment was that my oral and written presentation of the project would serve as sufficient introduction to the theoretical aspects of the research question. I was also aware that some interviewees might hold back some information or deliberately provide the answers that I expected. I assessed it to be ethically defensible to make an attempt to overcome these restrictions. I tried to focus on the use of different interview techniques. This involved, for example, maintaining a balance between being overly cautious so as not to offend the participant and ending up just “scratching the surface”, and asking more inquisitive questions in order to obtain more elaborate answers (Fog 2004).

The use of pauses - or waiting some moments before proceeding - could provide space for reflections that possibly could result in more elaborate answers. This is effective, but can be difficult when facing a stranger. The qualitative research interview is a “craft”, and awareness of this as well as of the need to conduct several interviews in order to develop the proper skills is required (Kvale and Brinkmann 2009).

I have discussed the content and the technique of the dialogue in the interviews (the process of collecting data) with one of my supervisors, who has also reviewed the full body of data in order to secure the necessary depth in the interviews.

4.3.2 Exploratory design as emergent and flexible

The project description focused on the next of kin as substitute decision makers in situations where the patients themselves were not competent to provide consent. The theoretical point of departure was primarily based on the principle of autonomy in relation to medical treatment as it has been discussed in medical ethics by, for example, Buchanan and Brock (1989); O'Neill (2002); Beauchamp and Childress (2009) and others. The working title was:

Relatives as substitute decision makers for the omission and (or) withdrawal of life-prolonging treatment in nursing homes – a study of current practices, in which focus is also put on the experiences and perceptions of relatives in situations involving the end of life.

Before I embarked on the interviewing process, I received a comment from a director of the first nursing home that I contacted, saying that the physician was reluctant to participate if focus was placed on the “omission” of treatment. This person perceived the title as provocatively negative, and claimed that it represented an erroneous approach to the topic. This input was valuable, and the title was rephrased: ... *experience of situations surrounding questions of life-prolonging treatment (including issues of withholding and (or) withdrawal).*

I deliberately chose not to include the dementia diagnosis as a criterion for inclusion, because a number of other conditions may alter a patient's competence to give consent (pain, depression, medications etc.), and I wanted a normative approach to the question of how life-prolonging treatment is handled in this type of situation. Given that close to 80 per cent of nursing-home patients suffer from some form of dementia (Ministry of Health and Care Services 2008-2009) and patients generally are very ill, I expected that patients' competence to give consent was assessed with reference to current issues. This expectation was based on the National Dementia Plan (Norwegian Ministry of Health and Care Services (HOD) (2007) as well as the educational material issued by the Norwegian Ministry of Health³² in relation to the assessment of competence to give consent. It was not until my interviews with relatives that I acquired an understanding of the patients' mental condition (cf. REK permission letter-Appendix 1).

³² Link to CD- and teaching programme:

<http://samtykkeitilhelsehjelp.helsedir.no/player/PlayerX.html?xmlid=../content/000000001926/000000001926&width=780&height=520&startloc=0:0:0:-1&flashver=10&useFS=true&langrec=nb&langmaster=nb&1299366065671>

The title of the study referred to *relatives as substitute decision-makers*. I therefore assumed that all relatives included in the study would have experience of patients who had not been competent to give consent.

It turned out, however, that many patients had remained fully or partly competent to provide consent and the interviews with relatives showed that close to half of the patients had been fully or partly competent to provide consent until shortly before their death. After a discussion with the supervisors on whether or not to exclude relatives of patients who had remained fully or partly competent to provide consent, we decided to include these relatives in order to capture various aspects of the understanding of patient autonomy and assessment of competence to provide consent. Consequently, questions relating to the assessment of competence to provide consent were added to the interview guides used for physicians and nurses.

A further example of the study characterised as emergent was provided by the first physician whom I interviewed, who talked at length about his collaboration with A&E and hospital colleagues. At the outset I had planned to study decision-making processes internally within the nursing home, but I realised that the interaction with the emergency services and the hospitals also had an effect on relatives and nurses. This seemed to engage all those interviewed and had an impact on the decision-making process at the end-of-life in nursing homes. The main focus was shifted slightly from the next of kin *as substitute decision makers* with regard to questions of life-prolonging treatment to concentrate more on the *processes* between relatives, physicians and nurses in questions of life prolonging treatment and care. Central to this was also the focus on their attitudes and reasons for their views, and last but not least the focus on the patient's role at their end of life. This shift is also a key component of the discussion chapter because it represents important findings from the processes of life-prolonging treatment in the ten nursing homes.

The examples mentioned demonstrate how an exploratory design can be emergent and flexible (Polit and Beck 2004).

4.3.3 Ethical research considerations

I would like to briefly comment on four of Parahoo's six points for assessing the ethical aspects of the qualitative research interview (Parahoo 1997).

Beneficence

Participants in a research project may well receive more attention and closer human contact than would otherwise be the case. The problem arises when this contact ceases. It is not unlikely that relatives who are given an opportunity to talk about their experiences with someone who is genuinely interested would like to resume contact with this individual. It is therefore important to explain that the objective is to gain knowledge about the experience of relatives, and that the contact is restricted to a single interview. The participants were made aware that my role was solely associated with my research and that the interview was restricted to a single conversation.

The ethical aspects of not forcing the conversation, or interrupting just to follow the interview guide, also involved showing respect for vulnerable relatives who had recently suffered bereavement (Gjengedal 2000). Physicians and nurses also stated that it felt good to talk about these topics, and the same consideration was valid for this group.

Non-maleficence

Research must not in any way be harmful to participants. Physical harm is of little relevance in this context, but it may be pertinent to look at psychological harm. Relatives who took part in the study were in a particularly vulnerable state which left them open to gaining new awareness through the interview process. I tried to be alert to this potential, and in two situations I encouraged relatives to contact ward staff in order to talk through what had happened while their relative was a patient there. I had explained in advance that the nurses had encouraged relatives to get in touch later on if there was anything they would like to talk about.

There is a risk of being too direct in interview situations, since the participants may arrive at new insights with regard to sensitive issues. This represents the core of the ethical dilemma of posing in-depth questions. An example from an interview with a relative as a substitute decision-maker shows a situation where the wishes of a dying father had been consistently overruled. It also emerged that this patient had been competent to consent to the matters at hand. I wished to obtain a reason for why the relatives had forcibly fed their dying father:

Researcher: You said that you tried to make him eat, even though he said he was full – why?

Relative: Well, it's just – you think that it is important to eat (laughs, appears surprised by the question). And then, you hear a lot about how elderly people just dehydrate. And nearly starve to death (BS02P).

Having asked this question I noticed that the relative looked pensive, and in the situation I interpreted this as an indication that he had not thought through this issue critically before. Having sensitivity to and experience of such situations is therefore essential to protect the participant and avoid doing harm in the name of research.

Veracity

Veracity relates to information provided about the research. I consider this point to be of the highest importance. It is essential that “the whole truth” be provided to enable the participants to consider whether or not they want to take part. Relatives were informed about the study in writing as well as by word of mouth. Veracity also relates to how the overall study is conducted. In addition to an assessment of the academic quality of the investigation, this is also a research ethical matter. At every stage of the process, it is necessary to demonstrate a search for results without manipulating outcomes in any direction, which would be ethically unjustifiable (Kvale and Brinkmann 2009).

Confidentiality

Even though a research scholar has obtained the participant's consent to include him or her in a study, the scholar is not entitled to seek information from the patient's medical records or from staff who were working on the ward where the participant's loved one was a patient. Neither is the scholar at liberty to share information provided by relatives with ward staff (Natvig 1997). Furthermore, it is essential to abide by general ethical principles with respect to the data at one's disposal.

4.3.4 Data analysis

The analysis and interpretation started with the planning of the study and continued throughout the process. This means that different choices were based on a general and pervasive analytical approach from beginning to end (Kvale and Brinkmann 2009).

A specific textual data analysis of the transcribed interviews will be described and discussed in Pt. 4.3.4.2.

Because the objective was to identify current practice with respect to decision-making processes, I conducted a content analysis (Polit & Beck 2004) of the transcribed interviews.

This meant that the data was interpreted and coded into units of meaning which in turn were categorised on a more general level. The objective was to provide a picture of the interviewees' own understanding. Polit and Beck (2004: 714) give the following as a definition of content analysis:

...The proper process of organizing and integrating narrative, qualitative information according to emerging themes and concepts

This is in line with the concept of “the analyses proper” that involve developing the meanings of the interviews, bringing the subject's own understanding to light as well as providing new perspectives from the researcher” (Kvale 1996:190).

As a further part of the normative analysis, the descriptive findings were considered in the light of medical ethics. In order to sharpen the focus, the findings were also considered in a legal and organisational context at this stage. In summary, the objective was to look at current practice through “an ethical lens”. The study thus provides an inductive contribution to empirical ethics. The normative analysis generally concurs with Kvale and Brinkmann's theoretical analysis (2009).

All the analyses have been reviewed by my supervisors.

4.3.4.1 Transcription

All the interviews were recorded on a digital audio device. In spite of the fact that transcription is a time-consuming task, I chose to do this myself. Experience from a previous study (Dreyer 2003; Dreyer and Nortvedt 2008) showed that the familiarity with, and proximity to, the data obtained through transcription is a major advantage when the textual analysis is undertaken. The transcripts were kept as accurate as possible - word for word. Also pauses, laughter were registered. Nothing was adjusted or changed to a written style. The interviews were transcribed verbatim in the participants' vernacular, to allow me to spend time with the content if something remained unclear. Translating the interviews into standard Norwegian could possibly alter the meaning of the spontaneous statements. The digital recorder had very good sound reproduction, and I rarely or never missed a word. One of my first informants read through my interview with him shortly after it had been conducted, as a validation of my transcription. With a view to ensuring anonymity, no names, locations or dates were recorded in the transcriptions. My supervisors compared the transcripts to the recorded interview.

I planned my time so as to be able to transcribe the recorded interview immediately. This allowed me to recall my thoughts and the emotional setting that could become important in the next interview. This worked well, and I soon discovered that the details of the interview were present in my memory when I did the transcription. This restricted the need to make extensive notes during the actual interview, a fact that I believe was beneficial for the atmosphere of the conversation with the participants. It kept my mind on the conversation, and the transcribed material was more than written text. This was essential for the analysis because my understanding of the topic discussed was linked to the mutual context in the interview situation and the social setting where my horizon of understanding met the interviewee's (Gadamer 2004). In addition, when doing the transcribing myself, the several hundred pages of transcript become more manageable (Rose and Webb 1998). Examples of issues that I captured during the interview and later could analyse during the transcription included several relatives stating that they had found it difficult to speak explicitly of the thoughts that had gone through their minds in the period immediately after the death of their loved one. It was essential for me to capture these thoughts, but this needed to be done in a way that would let the relatives turn to these issues as a natural development of the interview. On several occasions the transcription process brought more clarity, and the content of and responses to my questions emerged better when these were fresh in my memory. The next interview was planned in parallel with the transcription, on several occasions leading to adjustments to the interview guide, as described above. This stage of the study can thus also be related to the continuous process of analysis.

The transcription of the interviews is also a learning process that provides an opportunity to study the process of interaction with the participants from an analytical perspective (Kvale and Brinkmann 2009). I saw it as important not to be overly self-critical, and instead seek to identify the opportunities for learning from errors and omissions in order to become a better interviewer.

The interviews with physicians, nurses and relatives were analysed group by group. In the following presentation I will be including examples of these analyses (reviewing, condensing and coding) chosen solely from data collected during interviews with relatives. This is merely an effort to aid the accessibility of the presentation. In instances where there are discrepancies between the analyses of data collected from the different groups of participants, this will receive comment at a later point.

4.3.4.2 *Descriptive analysis, interpretation and findings*

This section presents the analysis and the process of interpreting the data in the light of the study's descriptive objective.

The research questions which formed the basis for my interview guide are fundamental to my analysis of data collected from physicians, nurses and relatives. My objective was to find an answer to these questions and to gain new insight based on them. Two new research questions were added during the data collection process, thus necessitating the incorporation of new questions in the interview guide and further analysis of my interviews with healthcare professionals (Figure 4.1).

The in-depth interviews were unstructured, bordering on narratives; the interviewees were *initially* invited to talk about their experiences. Even though the in-depth interviews took on a narrative character, I chose to carry out a descriptive content analysis³³ of the material associated with rich descriptions to make the material into a whole (Morgan 1993).

Due to the philosophical hermeneutics, the interpretation is central. The first and most important part of the interpretation was conducted, as previously mentioned, in the actual interviewing situation vis-à-vis the interviewees. My own understanding, based on clinical experience and knowledge (chapters 2 and 3), was challenged. The resulting realisations were made the subject of new questions which were formed in the interface between interpretation and deeper exploration.

Reviewing, condensing and coding

Once the interviews had been transcribed, they were all, in their entirety, inserted vertically into an analysis template. The adjacent column provided space for a condensed version of the interview. This was achieved without adding anything in order to make it simpler to retrieve particular descriptions during the analysis of a vast body of data, the number of pages expanding as a consequence of insertion into the analysis template. Then I always read the originally transcribed text to check the content. A third column provided space for the text to be coded into units of meaning (Patton 2002; Kvale and Brinkmann 2009). The textual analysis would balance between rigour and creativity (Rose and Webb 1998). I started by coding the units of meaning at a detailed level, but soon found that I had lost track of the

³³ Content analysis: The process of organising and integrating narrative, qualitative information according to emerging themes and concepts (Polit and Beck 2004:714)

overall picture, which I felt might impact negatively on my credibility (Graneheim and Lundman 2004). The column to the far right provided space for my own comments, notes and questions.

Table 4.4: Analysis template A – Condensing, coding and comments on the interview transcripts

Descriptions provided by physicians/nurses/ relatives (full transcription)	Condensed version	Units of meaning	Comments
Full transcription of interview	Abridged presentation of transcript	Coded transcript	Reference to literature, other interviews, contradictions internally within the interview etc

Nevertheless, statements and descriptions are clearly subject to interpretation. The following passage illustrates how a quote may need its content to be interpreted for it to be appropriately coded:

This is a question often raised by relatives. Yes, they are worried that the patient might be thirsty, or that they aren't receiving enough nutrition – which they are – often, towards the end, but – if I feel it's terminal and we're talking a few days or a week – perhaps a few weeks, I suppose I've learnt that liquids are really quite unimportant.

We try to have a good dialogue with the relatives. Often try to ring them before it's totally terminal, so we can get a discussion going ahead of time. If they have strong wishes I try to take account of these to a certain degree, but we're really rather restrictive when it comes to IV, - (ES05L).

This quote makes it clear that the physician takes account of the wishes of the relatives, despite the fact, according to the quote, that relatives have insufficient knowledge about the end of life. This also demonstrates that by accommodating the wishes of the relatives, the physician's actions are inconsistent with his own beliefs. By coding and grouping statements from the transcripts, the “technical” process incorporates a certain degree of interpretation of meaning and content in order to ensure that parts of transcripts from different interviews are grouped into joint categories (Braun and Clarke 2006).

Below (Textbox 4.1) is an example of the above template when used on a small coded excerpt of a transcribed interview.

Textbox 4.1: Analysis template A – Excerpt from coded transcript (of interview with relative)

Full transcript	Condensed version	Units of meaning	Comments
As I've said already, I feel it must be up to the doctors and nurses to consider what is for the best. She certainly had her own views on what she needed and what she didn't need.	Relative attaches great significance to the view that health professionals know what is best.	Opinion regarding the role played by health professionals in the decision-making process.	Graded competence to consent O'Neill (2004)
Yes, she was lucid in a way. She was lucid in that we could talk to her, and have a normal conversation with her. But then, all of a sudden, she would say something weird and rather - and she would forget a lot and repeat her questions and -. And she was reading a lot – right till the end. She was always fond of reading. Actually, she kept reading for quite a long time. She kept a newspaper, and then she had her Bible, which she would be reading regularly. So she kept herself occupied with this – and she was able to talk about the things she read in the paper. And we could look at the paper together – and I would say “Have you read that?” – and she would have, and -. We could talk about things she was interested in. In that sense she was lucid, but not in the sense that she was able to look after herself.	The mother was lucid “in a way” and was able to have a normal conversation, but might suddenly say something weird and repeat her questions. She remembered what she had read in the current newspaper and would talk about it. “But she was unable to look after herself”.	Competence to consent. Paternalism in relatives. Relatives' understanding of competence to consent.	Understanding competence to consent. The part played by relatives. Beauchamp and Childress Buchanan and Brock + Misc. papers What role may paternalism in relatives play with respect to the patient and the atmosphere of the decision-making processes? Inadequate knowledge and understanding of the dying process emerge earlier in the interview.

Analysis of units of meaning

The units of meaning I found while coding analysis A were extracted, analysed and grouped into various categories. Some categories were further divided in order to discern appropriately the nuances provided by the data. For example, in association with “relatives' reasoning regarding questions concerning life-prolonging treatment”, the objective was to record their end-of-life knowledge. The categories formed a template for the next step and were inserted into the far left column of analysis template B (Table 4.5).

The individual textual analyses are made subject to a spiral-shaped analysis which considers the units of meaning against the full interview – and subsequently against the other interviews in the same group. My analytical work was time-consuming. The systematic review of the units of meaning which formed the basis for analysis template B showed that virtually no parts of the transcripts, once they had been analysed, failed to be included in a category (Graneheim and Lundman 2004). This type of multi-stage content analysis is all about making a vast body of data accessible (Kvale and Brinkmann 2009). This part of the analysis formed

the basis for my identification of the decision-making processes, i.e. the descriptive analysis (Kvale 2009).

Table 4.5: Analysis template B (relatives) - Categories resulting from the analysis A coding process

The decision-making process in nursing homes		
<i>Categories</i>	<i>Own comments</i>	<i>Quote</i>
Conversation with relatives at the time of admission		
The decision-making process - Advance statement - Treatment - Hydration / nutrition - Hospitalisation		
Nature of communication Trust in healthcare staff throughout the process		
Knowledge about the end of life Grounds given for wanting life-prolonging treatment		
In retrospect		

Below are two examples of how categories were formed on the basis of research questions addressed to relatives. I have used an outline presentation in order to visualise the process.

Example 1:

What *role and involvement* do relatives have in decision-making processes associated with life-prolonging treatment and care? (Research question)

- How were they, as relatives, included in conversations about treatment and care?
 - What was the scenario with respect to time frame?
 - What kind of information did you receive?
 - Did you have an opportunity to confer with other family members?
- (Questions included in the interview guide for relatives – see appendix 5)

→ Category: The decision-making process

Example 2:

What *reflections and reasons* lie behind relatives' views on treatment and care in decision-making processes where the patient is not competent to give consent? (Research question)

- Were end-of-life issues discussed with the patient while he or she was still capable of consent, and if so, what was this experience like?
- To what degree were you in a position to assess what the patient would have wanted were he/she competent to consent?

→ Category: Autonomy

Categories are thus never formed by chance. They are carefully planned and provide – quite simply – the proof of the pudding; this is where I get the responses I have asked for (Braun and Clarke 2006). Despite the unstructured nature of the interviews, all questions included in the interview guide were answered in all interviews, even if the chronology would change from one interview to the next. The details and the level of variation within each category would depend on the informant's response.

Each interview was separately analysed and the associated transcript was pasted into the right-hand column of the appropriate category. When working with one interview at a time, this enabled me to validate the units of meaning by referring back to the text. I made a note of my own comments underway, linking them to a category and the associated text. The comments could relate to any contradiction there might be elsewhere in the interview, or provide a reference to other interviews, employing interview code.

As I progressed with the analysis of my interviews with relatives, the previous analysis was repeatedly reviewed and spontaneous notes were made. I would also return to the primary transcripts of each individual interview in order to re-consider each constituent part against the whole (Patton 2002; Kvale and Brinkmann 2009). This is not only a hermeneutically “correct phrase”, but a necessary “stage of the analysis. When units of meaning are “pasted” together from different parts of an interview, they are taken out of their context. By returning to the raw material provided by the transcripts, I ensured the reliability of the categorization (Kvale and Brinkmann 2009).

So far, my analysis had been largely motivated by a need to make the data accessible and manageable. I was now in a position to see, with ease, what all the interviewed relatives had

said with respect to each category. The categories from analysis template B were now inserted as headings into a Word document; quotes from all interviews were then inserted under the appropriate category. This enabled me to carry out an overall analysis, which led to the mapping of the participants' experience of the decision-making processes. Unadulterated quotes were retained as descriptions of each category. Again, repeated reviews became a key part of the process, during which I would continuously be making notes. For example, I found that relatives had insufficient knowledge about the end of life, including the importance of assessment and awareness with regard to competence to consent. Where patients were not competent to give consent, relatives were included only to a minor degree in decision-making processes concerning life-prolonging treatment. This is a serious infringement of the Norwegian Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999). It means that relatives are not given an opportunity to contribute with any knowledge they might have about the patient's presumed wish.

The following categories are presented in Paper 1, entitled: *Autonomy at the end of life: Life-prolonging treatment in nursing homes – relatives' role in the decision-making process* (Textbox 4.2).

Textbox 4.2: Categories from interviews with relatives

Categories

- Conversation at the time of admission
 - Relatives as participants in decision-making processes concerning life-prolonging treatment and care
 - Relatives' reason for their views on life-prolonging treatment and care
 - In retrospect
-

The interviews were not conducted in a set sequence; this was to allow information from relatives, for example, to feed into interviews with physicians and nurses. As mentioned above, this was a choice made after careful consideration because I felt this procedure would allow me to probe in greater depth during the interviews. My textual analysis would look at relatives, physicians and nurses as separate samples, thus allowing me to focus on descriptions from one group at a time.

Two rounds of analysis for interviews with physicians and nurses

My first analysis of the transcribed interviews with physicians and nurses was carried out in the same way as described above (relatives) and was based on my original research questions:

Textbox 4.3: Preliminary research questions (physicians and nurses)

- What *experience* do physicians and nurses have with decision-making processes concerning questions of life-prolonging treatment and care where the patient is not competent to give consent?
 - How do physicians and nurses describe their practice regarding life-prolonging treatment and care?
 - What reflections and reasons lie behind the professionals' actions in relation to life-prolonging treatment and care?
 - What role and involvement do relatives have in such issues?
-

The findings were presented in Paper 2 entitled: *Life-prolonging treatment in nursing homes: How do physicians and nurses describe and justify their own practice?* The following categories emerged:

Textbox 4.4: Categories from interviews with physicians and nurses

- Assessment of competence and securing patient autonomy
 - Beneficence and non-maleficence
 - Relatives as decision makers
-

Each of these categories covers descriptions of conversations at the time of admission, experience of decision-making processes, and grounds for course of action.

The findings showed that physicians and nurses generally agree with respect to attitudes and lines of reasoning associated with life-prolonging treatment; there is little talk of autonomy, instead they build on the principles of beneficence and non-maleficence. It was also evident that there are inconsistencies between current practice and the attitudes expressed by the healthcare professionals. I will not be discussing the findings here, merely pointing out that new findings give rise to new questions. While I was working on this analysis, I became aware that considerable attention was given to frustrations generated by the level of interaction between medical practitioners at nursing homes, A&E units and hospitals. These descriptions were forthcoming because my interview guide included questions about collaboration between nursing homes, A&E units and hospitals (Brazil, McAiney et al. 2004, Braun and Clarke 2006). While working to code the first analysis of interviews with physicians and nurses (A), these statements were categorised under “the decision-making process”. During analysis B, it became evident that the data provided “rich” descriptions of circumstances associated with collaboration. I would therefore have to choose whether my

data from physicians and nurses were to be presented collectively as a description of all aspects of the decision-making process (practical implementation, different experiences, reasoning behind current practice, experience of internal and external collaboration), or whether the category ought to be subdivided, allowing me to deal specifically with coordination and interaction in relation to frameworks and organisational factors. I chose the latter, and ended up conducting a supplementary analysis (Morgan 1993) of all interviews with physicians and nurses. In retrospect, I believe this to have been a sensible decision because the discussions regarding coordination and organisational factors address a wider audience, such as healthcare managers and bureaucrats. It is important to investigate these matters, as they influence the quality of treatment and care. Moreover, circumstances associated with the frameworks provided for clinical work have an impact on physicians and nurses as professional healthcare workers (Morse 2007). The table below illustrates the analysis of data set B from physicians and nurses under the following research questions (Textbox 4.5):

Textbox 4.5: New research questions formed on the basis of analysis of interviews with physicians and nurses

- How do physicians and nurses describe the level of coordination with regard to life-prolonging treatment and care within the nursing home and externally vis-à-vis hospitals and A&E units?
 - What consequences do internal and external professional organisation and coordination have for patients and relatives?
-

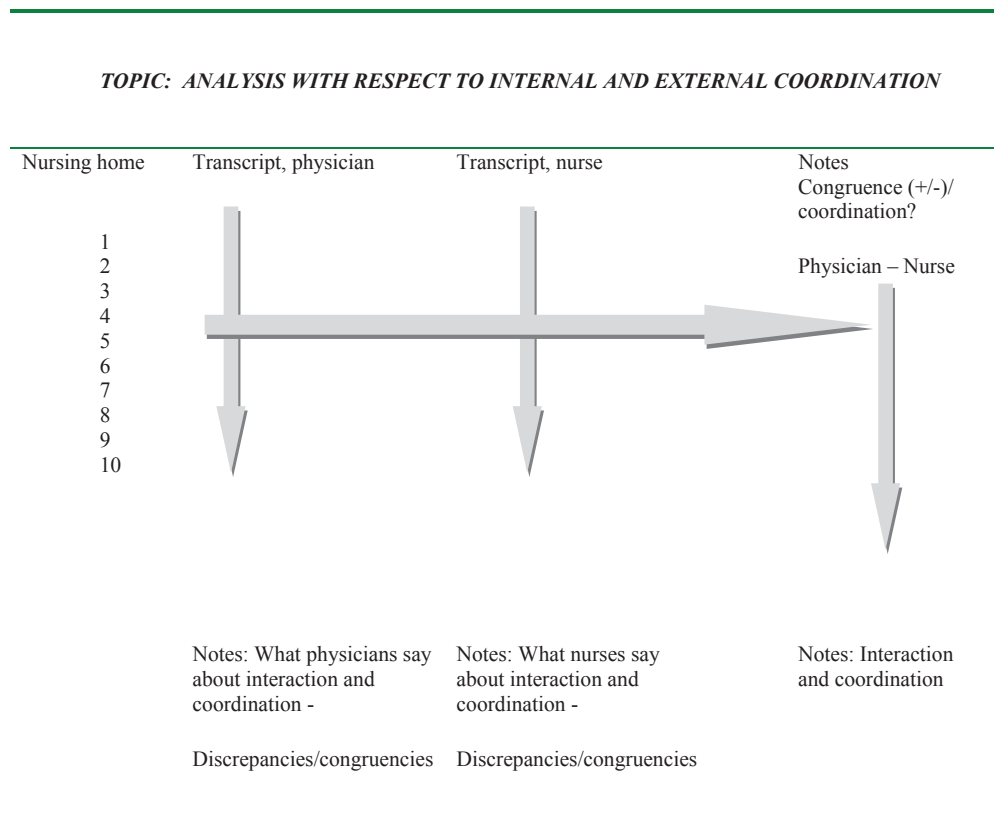
These new research questions were added *en route*, after some of the interviews had been completed. They were formed through an exchange process involving the reading of further literature on interaction within healthcare organisations (see Chapter 2) and the incorporation of new questions in the interview guide, thus providing a theoretical base (Patton 2002; Graneheim and Lundman 2004).

The key difference in this analysis is that the transcripts of interviews with physicians and nurses (analysis B) are laid out in parallel columns within the table, in which descriptions and quotes regarding interaction and coordination are sought in all categories (Appendices – enclose all templates). For example, the category labelled “assessing competence to consent” brought to light that failure to assess the competence to consent and deficient communication

with relatives at the hospital (external coordination) gave rise to a conflict-filled atmosphere between relatives and medical personnel at the nursing home.

The horizontal arrow in Figure 4.1 illustrates a further search for discrepancies or congruencies in quotes from physicians and nurses at the same nursing home with regard to the same category, based on the research questions (Textbox 4.5). The vertical arrows indicate a search through quotes under all topics for agreement or disagreement among physicians and nurses respectively, as separate groups.

Figure 4.1: Analysis of quotes from physicians/nurses with respect to internal and external interaction and coordination (hospital/ A&E unit)



The findings from this analysis point to circumstances worthy of criticism, for example with respect to the organisation of the nursing home service. These matters are presented in Paper

3, entitled: *Ethical decision-making in nursing homes – the influence of organisational factors*, which looks at the following categories (Textbox 4.6):

Textbox 4.6: Categories from the analysis of transcribed interviews with physicians and nurses

- Organisational and professional frameworks for interaction and coordination within the nursing home
 - Different patterns of professional interaction and coordination
 - Treatment responsibility
 - Coordination with hospitals
-

4.3.4.3 From descriptive to normative analysis

At an early stage, during the coding of the interviews, reflections pertaining to ethics and law were entered in a separate column (Textbox 4.1). I was also constantly making copious notes, the nature of which tended to be spontaneous rather than structured. I found that putting my immediate thoughts and ideas down on paper became part of the intellectual thought process: so-called reflection through writing (Dysthe, Hertzberg and Hoel 2010).

The normative analysis directs the research questions at *the content of the categories* resulting from the descriptive analysis. The questions were then directed at medical ethics and law. For example, wherever the findings point to organisational circumstances, these are discussed with respect to the relevant normative questions. This process constitutes a key part of the normative discussion within the thesis, running from the descriptive analysis through to the conclusion.

The description of the interview categories presented in the papers that form part of the thesis demonstrate that practice is not in line with ethical guidelines and the law. Text box (4.7) shows a highly simplified illustration of the connection between the categories of the descriptive analysis and the associated normative and legal aspects.

The normative analysis became exciting, albeit demanding. Based on the research questions, I compiled my findings in a combined layout. I repeatedly re-read my papers and returned, on several occasions, to parts of the data. The process took on the character of a lengthy dough-kneading session. My principal finding proved to be that the patient as an individual is virtually absent at the end of his/her life. Further reflection gave rise to the question: What is it that steals focus away from the patient, and what action can be taken to allow patients to

remain at the centre of their own departure from life? (Chapter 6). Parts of the “answer” were obvious and were discussed in my published papers; I kept on working on them. My work to systemise and outline the discussion was based on the core issue, of which *the decision-making processes* in questions pertaining to life-prolonging treatment are a key element.

Text box 4.7: From descriptive categories to related normative and legal aspects

Descriptive categories – Paper I	Normative and legal aspects for discussion
Conversation at the time of admission Relatives as participants in decision-making processes concerning life-prolonging treatment The relatives’ reasons for their views on life-prolonging treatment In retrospect	Principle-based ethics The Patients’ Rights Act The Health Personnel Act
Descriptive categories – Paper II	Normative and legal aspects for discussion
Assessment of competence and securing patient autonomy Beneficence and non-maleficence Relatives as decision makers	Principle-based ethics The Patients’ Rights Act The Health Personnel Act Professional ethics
Descriptive categories – Paper II	Normative and legal aspects for discussion
Organisational and professional frameworks for interaction and coordination within the nursing home Different patterns of professional interaction and coordination Responsibility for treatment Coordination with hospitals	Principle-based ethics Professional ethics, ethics of proximity The Patients’ Rights Act The Health Personnel Act

I worked for a while on compiling the discussion, put the work to one side and conducted another systematic literature review.

4.3.4.4 Final reflections

When my papers were submitted for review by international journals on medical and nursing ethics, I received good critical queries regarding the presentation and discussion of my findings. I re-visited these questions and the way in which they were posed. This process showed me how important it is to the methodology that reviewers, who come to the findings with fresh eyes, ask questions. At the end of a research project it is a challenge to handle material you have been working with over a long period of time while at the same time highlighting the issues and juxtaposing the findings through discussion. My supervisors have been asking important questions which have helped draw attention to the findings in the final phase of the analytical process. Others have also contributed. Discussion partners are essential to the process, and it is vital that readers ask critical questions.

4.3.5 Reporting

When seeking to *map* current practice, I will be presenting my findings by way of *descriptions* based on the analyses and found in quotes and their textual versions. The aim of the normative discussion is to invite clinicians and ethicists into a discourse about this theme.

Part of the moral responsibility associated with research is the responsibility to publish the results. My reason for choosing to present the findings in the form of a series of papers was a wish to contribute to the debate about end-of-life decision-making processes associated with life-prolonging treatment in nursing homes. By publishing the papers in international journals available in databases as PubMed, I made sure they would remain easily accessible. Two of the papers were published in the *Journal of Medical Ethics*, a cross-disciplinary publication within the field of medical ethics; the third paper was published in *Nursing Ethics*, a journal which addresses nurses more specifically. Nurses make up the largest professional group associated with the decision-making processes in nursing homes. In recent years, this group has experienced a far greater focus on research-based knowledge, partly thanks to the work undertaken by the Norwegian Agency for Quality Assurance in Education (NOKUT)³⁴ in order to raise the quality of nursing education.

³⁴ Link: <http://nokut.no/>

5 Results

Three papers have been published on the basis of the data collected and their textual analysis. These were the results of a research process which repeatedly provided new insights. The study's objective was to map current practice associated with life-prolonging treatment by conducting interviews with relatives, physicians and nurses when patients had lost their capacity to give consent. Significant focus was placed on examining the role played by relatives. The findings reveal fragmented practice with little targeted interaction between physicians, nurses and relatives. Whenever the concept of decision-making processes is used in my presentation of findings and discussions, the phrase would benefit from being put in quotation marks. Genuine processes were virtually non-existent. At an early stage of the study, a principal finding was that clinical practice failed to conform to key guidelines provided by the Norwegian Health Service and medical ethics.

5.1 Paper 1

Autonomy at the end of life: Life-prolonging treatment in nursing homes – relatives' role in the decision-making process (Journal of Medical Ethics 2009; Volum 35(11) s. 672-677)

The increasing number of elderly people in nursing homes with failing competence to give consent represents a great challenge for healthcare workers and their ability to protect patient autonomy with regard to life-prolonging treatment, hydration, nutrition and hospitalisation. Lack of national guidelines³⁵ and internal procedures may threaten patient autonomy. It is important to focus on patient autonomy safeguards in the decision-making process by examining how relatives experience their role. A qualitative descriptive design is presented with content analysis of transcribed in-depth interviews with relatives. The main findings reveal deficient procedures for the inclusion of relatives in decision-making processes. Relatives stated that they would be the party to initiate talks with physicians or nurses when they witnessed the patient's health deteriorating. Many said it came as a shock to them that the patient was in fact dying and they would have wished that a physician or nurse had told them at an earlier stage. Relatives have poor knowledge about end-of-life processes and there is little discussion about their role as substitute decision-makers for patients who are incapable of giving consent. Many relatives felt uncomfortable at being asked what *their wishes were* with respect to potential life-prolonging treatment for their loved ones. Neither

³⁵ National Guidelines were published after the paper had been written

were they asked if they knew what the patient's preferences were. Only few had discussed the end of life with the dying patient. Few relatives understood the concept of patient autonomy. In Norway, the treating physician is responsible for patient treatment. When relatives are included in discussions about treatment, the study shows that they perceive themselves as being responsible for the decision, which is a burden for them afterwards. Many relatives experienced doubt as to whether they had done and said the right thing, and whether their choices could have had an unfortunate outcome for the patient. Two relatives were later in doubt as to whether the physician's decision to withhold antibiotics in cases of pneumonia, thus bringing about the patients' deaths, was in fact a correct assessment. One of them later blamed himself for not having asked the right questions. There is an intrinsic dichotomy here: relatives prefer not to have the decision-making authority but later blame themselves for not having asked critical questions.

Poor information at the time of patient admission to the nursing home was referred to by many relatives as a source of prolonged conflict with healthcare staff. One of these individuals stated that their parents' move away from home and into nursing care represented a major crisis for the family. The focus was therefore shifted away from the patient and over to the conflict between relatives and staff. This qualitative study describes the experience of relatives, thus providing important information about the potential for improving patient autonomy safeguards and the level of care for relatives.

The study reveals failing procedures and thus uncovers a great potential for improvement with respect to decision-making and information procedures associated with treatment and patient care.

5.2 Paper 2

Life-prolonging treatment in nursing homes: How do physicians and nurses describe and justify their own practice? (Journal of Medical Ethics 2010 Jul;36(7):396-40)

Making the right decisions, while simultaneously showing respect for patient autonomy, represents a great challenge to nursing-home staff when it comes to life-prolonging treatment, hydration, nutrition and the hospitalisation of dying patients at the end of life. The aim of this study was to investigate how physicians and nurses protect the autonomy of nursing-home patients when making end-of-life decisions, and what grounds they give for their own practice. The study has a qualitative descriptive design with analysis of transcribed in-depth

interviews with physicians and nurses. Nine physicians and ten nurses at ten nursing homes in Norway were interviewed. The results show that assessment of the patient's competence to consent to treatment is virtually non-existent. When asked what an assessment of this competence entails, physicians and nurses used words such as: demented, conscious, awake, lucid, alert etc. Their appreciation of the meaning and practical consequences of the concept, however, was blurred. The nurses emphasised that they normally spend more time with the patients than the physician, and that they strive to uncover the patient's wishes and preferences. Nurses tend to trust the patients' rejection of life support, even when the patients have difficulty speaking or suffer from severe dementia. Except for two physicians who used ethical reasoning throughout the entire interview, it seemed to be difficult for the other physicians and all the nurses to *explicitly* describe their practice and the values and justifications on which this practice was built, even when asked directly.

Relatives were, according to healthcare personnel, included in decision-making processes to only a very limited extent. If relatives were included in discussions, the physicians had not considered whether this was in accordance with the patient's wishes. Only a single physician expressed the view that the next of kin might be someone other than a close relative, who may well be self-appointed. However, futile life support is sometimes provided contrary to the physicians' judgment of what constitutes the patient's best interest on occasions when they are pressurised by next of kin. Two of the physicians expressed the opinion that it was a good indication if relatives wanted the patient to be hospitalised. Eight physicians expressed a worry that relatives might contact the media. The ninth stated that relatives would never contact the media if there had been good communication from the outset.

This current study shows, however, that the patient's autonomy is not safeguarded in the manner required by the Norwegian legislation and according to key principles of medical ethics. Our findings reveal that physicians, to some extent, still pursue paternalistic ideals when they are searching in earnest for the best treatment for the patient, including palliative relief. Physicians and nurses appear to build their practice on the principles of beneficence and non-maleficence.

Further discussion is required to establish whether the concept of autonomy is applicable to situations in which the patient is impaired and dying.

5.3 Paper 3

Ethical decision-making in nursing homes – the influence of organisational factors (Nursing Ethics: 2011 Jul;18(4):514-25)

In this paper I study how medical staff in nursing homes describes their professional collaboration around dying patients, and how this may influence the treatment and care of patients and their relatives. Nine physicians and ten nurses at ten Norwegian nursing homes were interviewed about their experience of decision-making processes relating to life-prolonging treatment in nursing homes. Data from this part of the study were subjected to a second analysis of the data from physicians and nurses. The findings indicate that the organisational frameworks provided for professional collaboration between physicians and nurses hindered patient treatment and care from complying with ethical considerations and legislation.

All participants were concerned that the organisational framework within which they worked had a negative impact on the quality of the services they provided. The physicians who were responsible for nursing homes would work there in a part-time capacity only. At eight nursing homes each physician would work only a 20 per cent week, and many of these institutions would have three to five different physicians in attendance every week. This made it difficult to ensure high-quality processes vis-à-vis nurses and relatives. Questions associated with the end of life are demanding, and the organisational framework imposed on the medical professionals generated a feeling of falling short. At two of the nursing homes the physicians worked a 60 per cent and 90 per cent week respectively. At these institutions, statements from physicians, nurses and relatives demonstrated better processes and collaboration. The nurses here talked of far better job satisfaction than in nursing homes where physicians would work only one day a week each. The reason given was the abundant opportunity for collaboration and professional discussion.

With respect to qualifications, physicians insisted that specialised training in palliative or geriatric nursing care was highly important. This leads to better understanding of life-prolonging treatment among nurses. The physicians at many nursing homes also pointed out that sub-standard competence, for instance with respect to documentation, could undermine the decision-making process by making patient follow-up difficult. This was reinforced by the fact that there was little time for professional conferring. Uncertainty and deficient knowledge among nursing staff with respect to the administration of pain relief and intravenous therapy

meant that nurses would be pressing for hospitalisation. The physicians felt that this was something of a paradox, because nurses were basically opposed to such hospitalisations which they considered to be of greater harm than benefit to patients.

Furthermore, physicians felt indignant over the level of communication with their hospital colleagues, who would commence treatment without asking or informing the physician in charge at the nursing home. The documentation passed between first and second line services was described as censurable.

Despite insufficient time for professional conferring between physicians and nurses, staff at one nursing home said they had given priority to a discussion of futile life-prolonging treatment. They had arrived at a general consensus not to prolong life by administering futile treatment. Their focus was on pain relief. The problem arose when patients entered an acute phase and there was no scope for conferring between individual physicians and nurses. The findings indicate that in some cases this could lead to under-treatment of acute infections: treatment was not commenced because of a failure to assess the patient's condition properly. At five of the nursing homes where physicians worked a 20 per cent week, the physicians and nurses talked of little professional coordination and interaction, and when acute situations arose or patients were dying, little had been discussed in advance.

This study shows that clinical ethics do not develop in a social vacuum but are affected by external factors. The moral standard of medical treatment and care provided at the final stages of life in nursing homes is influenced by organisational factors. Practice is not in accordance with Norwegian legislation, which sets firm guidelines for collaboration. Ethical discussions must be viewed in the light of the clinical context in order to provide an understanding of why ethical principles are not followed.

5.4 Descriptions of the aspect of care in decision-making processes

Findings that may relate to the provision of care are insufficiently described in the various papers. The open in-depth interviews provided rich accounts of the care provided in situations where the question of life-prolonging treatment was raised. The descriptions of this point of interaction, or non-interaction, indicate that the care provided for patients and relatives may fail to conform to professional responsibility and diligent care practice.

Relatives are concerned about providing ill patients with food and drink, the reason being that they are worried their loved one is hungry or thirsty. This may increase the level of discomfort at the end of life. Nevertheless, it appears that nurses fail to intervene appropriately to explain what is happening with respect to a dying patients' need for food and drink. The findings include accounts provided by many relatives which clearly indicate that they have been force-feeding dying patients. Lack of care for relatives obviously has a negative impact on the patient. Quotes from physicians and nurses also indicate a lack of appreciation that relatives may experience grief and crisis. This matches statements from relatives about exclusion from discussions and about being treated in a manner which demonstrates a lack of understanding among healthcare staff.

5.5 Summary of findings

- The patient is almost absent from her/his own life in end-of-life situations (Papers 2,3)
- Inadequate holistic focus on the patient in questions concerning life-prolonging treatment in nursing homes (Papers 1, 2, 3)
- Inadequate routines (Papers 1, 2, 3)
- Inadequate care for patients and relatives (Papers 1, 2, 3)
- The role of relatives is vague (Papers 1, 2, 3)
- Physicians and nurses demonstrate good attitudes which appear to be built primarily on the principles of beneficence and non-maleficence, but these attitudes have little resilience against external pressures (Papers 2 and 3)
- Frameworks and organisational factors are sub-optimal, making it impossible for medical staff to implement their work in accordance with the requirements to professional responsibility and diligent care (Paper 3).

The next chapter goes on to discuss these findings through a comprehensive reflexive analysis.

6 Discussion

This study has focused on how end-of-life decisions are being made in Norwegian nursing homes as described by doctors, nurses and relatives. A special focus has been on how the interests and integrity of the patients were taken care of in these decisions.

Against the background of the in-depth interviews with relatives, physicians and nurses in nursing homes, and on the basis of the research questions, three main findings emerge (Dreyer, Forde et.al. 2009, Dreyer, Forde et.al. 2010, Dreyer, Forde et.al. 2011):

- The absence of the patient as main person
- The blurred role of the relatives
- The gap between medical ethics, legal guidelines and practice (organisational factors)

These findings are in sharp contrast to the current ideal concerning professional and ethical improvement in geriatric care, and not least to the fact that the patient is to be the focus of treatment, nursing and care (Norwegian Ministry of Health and Care Services (HOD) 2005-2006, WHO 2011). This constitutes a new question for the following discussion:

What is it that steals focus away from the patient, and what action can be taken to allow patients to remain at the centre of their own departure from life?

In this chapter, the role of the physicians and nurses and the justifications they provide for their actions are discussed and seen in relation to medical ethics and health legislation. The first two sections focus mainly on relational aspects of the decision-making process. The third section focuses on the context in which the decision-making process takes place. Finally, I discuss the possible implications of this study with regard to practices.

6.1 The absence of the patient as main person

Focus on the patient as a person and this person's values and preferences was often absent in the descriptions given by the relatives. Nor did the values and preferences of the patients play a major role in the healthcare personnel's descriptions of end-of-life decisions in the nursing homes. The patients' autonomy was not properly preserved due to non-existent or unsatisfactory routines.

6.1.1 Failing respect for elderly, ill people and their autonomy

The focus on patient autonomy has been assigned considerable priority in medical ethics in recent decades. Since my study reveals that the wishes of elderly, ill people were not

respected, nor were they demanded, it is of major interest to discuss the role of the patient in end-of-life decisions in a nursing home. How can respect for patient autonomy in a nursing-home context be practiced in the best way?

In reality, patients are often very ill when they are admitted to the nursing home, and questions pertaining to life-prolonging treatment may be a key issue to address. In such cases autonomy, defined as the patient's own decisions and opinions about the treatment, will need to be considered, including in cases where the patient is not competent to provide consent. In this context ethics and legal framework play a significant role. Knowledge of medical ethics and law provides an understanding of the patient and the next of kin's roles in good decision-making processes.

Most of the relatives said that the end of life and dying had not been a topic they had talked about within the family, and they therefore did not know the patient's wishes regarding the end of life. This concurs with studies that show that elderly people are concerned about death but nevertheless do not talk to their closest family about it because they are afraid that it may be a burden for the relatives (Lloyd-Williams, Kennedy et al. 2007, Malcomson and Bisbee 2009). Because the nursing home did not consult the relatives with regard to the patient's preferences, the physicians and nurses failed in their ethical and legal obligations and did not base their end-of-life decisions on the non-competent patient's presumed preferences. The same goes for competent patients: their views on life-prolonging treatment at end of life were rarely discussed with the patient. In the absence of knowledge of the patient's wishes the relatives were asked what they wished regarding end-of-life treatment. Although relatives will justify their preferences by saying that they are doing what they think is best at the particular point in time, it cannot be ruled out that relatives may have preferences that are difficult to regard as legitimate and which are not in the interests of the patient. Examples from the study indicate that next of kin could have a stronger wish for life-prolonging treatment than that expressed by the old people themselves. Other studies confirm this finding (Allen and Shuster 2002, Schaffer 2007). The fact is that elderly, ill people can be a burden, both financially and emotionally, and relatives may put their own interests before those of the patient (Harris 2003). In principle I am of the view that physicians and nurses must – to a far greater extent than the findings indicate – seek the reasons for different preferences among relatives when they demand treatment for elderly, ill people. This is important in order to reveal preferences that are not legitimate and are not based on the patient's wishes.

Since my interviews with physicians and nurses indicate that the patient's autonomy was violated by his/her closest relatives, it shows that the next of kin may have assumed a paternalistic position towards their elderly relative; it was assumed that the old person simply does not know what is best for him/her. The same paternalistic attitudes were also present among physicians, and partly also among nurses.

The study also reveals that the next of kin were given information about the patient and were included in issues of life-prolonging treatment, regardless of whether or not the patient was competent to consent. If this is against the wishes and interests of the patient, this is a serious violation of the autonomy of elderly, ill people (Reiter-Theil, Mertz et al. 2007).

It is, however, important to note, when the patient is no longer competent, that relatives can give some information which is a vital component in end-of-life decision-making: who is this person, how did he/she live, and what decision is it likely that he/she would make?

The relatives' knowledge of the patient as a human being throughout his/her life can then constitute a major contribution to a decision-making process, even if they are not aware of the patient's explicit statements and wishes regarding the end of life. This is an approach that is concurrent with a theoretical position that Beauchamp and Childress called the "pure autonomy standard" (Beauchamp and Childress 2009)³⁶.

Regardless, the goal of the actions that are chosen should be in the best interests of the patient and should not lead to harm or further discomfort (Beauchamp and Childress 2009, Happ, Capezuti et al. 2002). The choice of treatment and care in such situations concerns far more than self-determination: it concerns respect for the situation and for life and death (Randers, Olson et al. 2002, Randers and Mattiasson 2004, Rodriguez and Young 2006, Jones 2007). Respect for and knowledge about death may lead to sensitivity through reflection on the question of *what should be done and why*.

I give my support to Zuckermann who in 1994 said that "*A dogmatic emphasis on patient autonomy that dismisses other important issues often does more harm than good in the*

³⁶ Beauchamp and Childress' (2009) 3 standards: *The Substituted Judgement Standard* (1) concerns decisions made on behalf of the patient on the basis of knowledge of the patient. The person who knows the patient is enabled to make decisions in line with those the patient would have made if he/she had been competent. The *Pure Autonomy Standard* (2) is based on the fact that the patient made his/her wishes known when he/she was competent to provide consent. In brief, the *Best Interest Standard* (3) states that those who take on the substitute role assess carefully what will constitute the greatest benefit in relation to different alternatives in the situation. Each alternative is assessed in light of the patient's presumed wish, based on knowledge of the patient as an integrated human being.

context of geriatric patient care". In the article she stresses that it is thought-provoking that autonomy and self-determination are regarded as so important in a nursing-home context where old people have other human needs, such as closeness to their relatives and appropriate care. On the basis of such a problematisation, the principle of autonomy should be approached from a wider perspective than that of requests for consent for proposed treatments, by searching for the patient's own wishes for fulfilment at the end of life. This could apply to the patient's preferences regarding palliative treatment, spending time with the family and saying farewell as a natural element of a long life. As we have seen earlier, various studies also show that the elderly want the physician, nurses and relatives to make decisions for them rather than giving too much consideration to their previous statements (Puchalski, Zhong et al. 2000; Seymour, Gott et al. 2004; Laakkonen, Pitkala et al. 2005; Nolan, Hughes et al. 2005). Seemingly many elderly people do not want the freedom that self-determination may impose on them. In this context, the good and caring inclusion of the patient's next of kin in decision-making processes with physicians and nurses may satisfy the wishes of the elderly people, and it is the duty of health personnel to facilitate this. This may be in accordance with respect for the principle of autonomy. Still for some patients or residents self-determination is important and crucial for their wellbeing and feeling of respect. In this respect, proper assessment of decision-making competency is crucial.

6.1.2 Poor assessment of the patient's competence to consent

A patient's competence to provide consent is a precondition for respecting patient autonomy (Beauchamp and Childress 2009). There is often a gradual transition from what is understood as a fully competent patient to one who is permanently unconscious and who can in no way make his/her own choices (O'Neill 2002). A significant and troubling finding in my study is that although I asked the nursing homes to include relatives of non-competent patients, a significant proportion of patients actually were competent. Thus, relatives of almost half the patients in the study were of the opinion that the patient had been competent to consent right up to the final days before they died. This is thought-provoking and shows that there was a lack of both awareness of and focus on competence to provide consent among the nurses who selected and invited the relatives to take part in the study. Further, the findings indicate that physicians' and nurses' lack of understanding and focus on assessing competence to consent led to an erroneous foundation for decision-making processes regarding patient treatment and

care. This may also explain why doctors ignored competent patients and went directly to their relatives to discuss end-of-life decisions without the patient being involved.

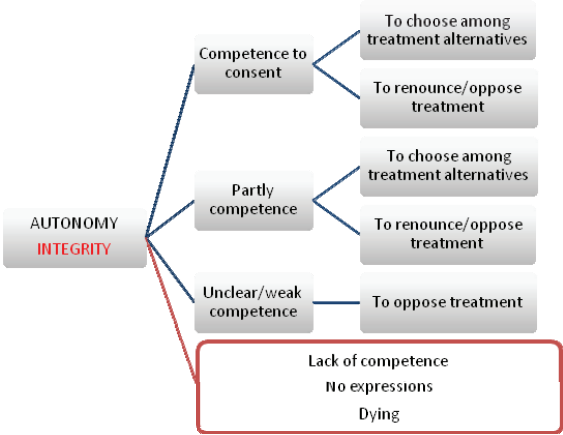
My study indicates that *if* physicians and nurses did address competence to consent it was often on the basis of a simplified dichotomy: dementia or no dementia. This approach is extremely inadequate. Ignoring statements because a patient is suffering from dementia or is otherwise cognitively impaired reveals an understanding of competence to provide consent that does not allow for significant nuances in the perception of competence. Even though patients in nursing homes may suffer from varying degrees of dementia, this does not mean that others should automatically take over all kinds of decisions for them (Hickman 2004, Tuckett 2006). One study indicates that nurses show less consideration for the integrity of patients with dementia, and these patients are included in issues and decisions on treatment to a far lesser extent than those who are in good mental health (Teeri, Valimaki et al. 2007). A review survey of 50 papers shows that obtaining such patients' views on their situation is far better than basing actions on biased assumptions of what it is like to live with dementia (de Boer, Hertogh et al. 2007). A new study shows that knowledge of methods for communicating with dementia patients is crucial for successful contact without the relationship breaking down (Alnes, Skovdal et al. 2011). Such knowledge of communication will be necessary when assessing the extent to which the dementia patient's statement can be regarded as competent in a specific situation. An assertion that a patient is competent to provide consent must be based on a careful assessment of the patient's clinical state and prognosis and of his/her ability to make decisions based on relevant information on the *current* treatment or care initiatives (Buchanan and Brock 1989; O'Neill 2002; Beauchamp and Childress 2009). It may be difficult to provide guidelines for assessment of the competence to provide consent on the basis of various stages of different diagnoses. In this case, the focus would be on the diagnosis rather than on achieving a real assessment of the patient in the here and now (O'Neill 2002). This is in line with the Norwegian Directorate of Health's guidelines for competence to provide consent³⁷.

Self (co)-determination and assessments of the competence to consent as they are currently described are largely based on patients' ability to think and express themselves rationally. An understanding such as this is narrow. The study indicates that it is necessary to extend the issue of self-determination to include an assessment of the competence to consent for patients

³⁷ <http://www.helsedirektoratet.no/kapittel4a>

with varying degrees of dementia (Hogan 2008). A study that raises the question of dementia patients’ consent for participation in research shows that they can be far more competent than was first presumed (Cahill , Begley et al. 2004). Then the question is whether a standard for assessing patients’ capacity for self (co) -determination can be applied without too great a focus on cognitive competence. If the right to decide is to be assigned real meaning for elderly, ill patients who are perhaps also suffering from dementia, traditional definitions of the competence to provide consent should be challenged (Figure 6.1).

Figure 6.1: Self (co) -determination understood as being able to choose or renounce/oppose treatment based on varying degrees of cognitive competence at the end of life



Buchanan and Brock (Buchanan and Brock 1989) present a definition that focuses little on rational competence, and the figure above is therefore in line with the following definition:

“Competence ... is a particular person’s capacity to perform a particular decision-making task at a particular time and under specified conditions.” (1989:18)

The Patients’ Rights Act Section 4.9 (Norwegian Ministry of Health Care Services (HOD) July 1999) gives dying patients the right to oppose life-prolonging treatment. This opposition should also be assessed by the physician on the basis of professional responsibility. An example of such treatment is when it prolongs a painful dying process (Norwegian Directorate of Health 2009). When patients with dementia refuse to accept more treatment in

the final phase of their lives, the physician could look at this as an expression of the patient's will and interests rather than totally ignoring the patient's statement or non-verbal expression because the patient is suffering from dementia. In addition to respecting patient autonomy, this action would also be according to the principles of beneficence and non maleficence.

The competence to consent can be affected by external or internal factors such as pain and depression (O'Neill 2002; Buchanan 2008; Beauchamp and Childress 2009). Pain in patients with dementia may, as we have seen, be insufficiently treated (Nygaard and Jarland 2005, Harris 2007, Husebø 2008, Kongsgaard, Wyller et al. 2008, Gran, Festvag et al. 2010, Slettebo, Kirkevold et al. 2010). To ensure that the patient has received proper pain relief should be a part of such assessment because untreated pain might influence patients' preferences and cognition. Depression can also be an internal factor among patients that affects competence to consent. More recent research shows that depression among dementia patients is under-diagnosed (Starkstein, Jorge et al. 2005, Teng, Ringman et al. 2008, Barca, Selbaek et al. 2009). As many as half the patients with varying degrees of dementia may be depressed (Teng, Ringman et al. 2008). This can have different causes, many of which are still unknown (Tuckett 2006, de Boer, Hertogh et al. 2007). Depression in dementia patients is shown by sadness, lack of interest, agitation and retardation (Engedal, Barca et al. 2010). Such symptoms are often exclusively assigned to a dementia diagnosis, but the fact that these are natural reactions to the loss of mental function and a lack of respect from the surroundings cannot be ignored (Bepthage 2005, Waugh 2006). Depression among elderly people with Alzheimer's disease can exacerbate a functional level that is already undermined (Starkstein, Petracca et al. 2001). Increased attention to and respect for dementia patients early in their stay at the nursing home is necessary in order to create the conditions for such patients to contribute their own viewpoints.

Beauchamp and Childress (2009) refer to the use of a "sliding-scale strategy":

...as the risk of a medical intervention increases for patients, we should raise the level of ability required for a judgement of competence to elect or refuse the intervention. As the consequences for well-being becomes less substantial, we should lower the level of capacity required for competence (2009:116)

If a *dying* patient opposes futile treatment it should be regarded as a consequence of the natural death process. Although a dying patient's treatment choice should be based on a minor degree of cognitive competence, I will nonetheless claim that in this context the patient has a partial form of competence to provide consent. This can be a matter of emotional and physical opposition that is expressed as a spontaneous and bodily – perhaps non-verbal – sign of a

feeling of fatigue and/or strong physical discomfort. When, after careful assessment, it is verified that a patient has reached the end of life and treatment will only lead to a minor form of improvement in his/her condition, it is meaningless not to take non-verbal and bodily utterances against such treatment into consideration (Jones 2007). Research shows that in the advanced stages of dementia the human body is unable to utilise nutrition – either by mouth, through a tube or by a drip. On the contrary, such treatment can cause nausea and lead to complications and considerable discomfort for the patient (Finucane, Christmas et al. 1999, Smith and Andrews 2000, Critchlow and Bauer-Wu 2002). In my study the participants have described situations in which some of the patients expressed their opposition to initiating treatment and care in precisely such situations. Initiating treatment then is not only violating the principle of autonomy, but it might be in conflict with the principles of beneficence and do-no-harm (Beauchamp and Childress 2009).

That a physician seeks the care providers' and relatives' knowledge of the patient may also be decisive for acquiring an overall assessment of the wishes of the dying patient (Valimaki, Leino-Kilpi et al. 2001, Steeman, de Casterle et al. 2006). Furthermore, full professional assessments should always be made to ensure that the patient's opposition to treatment and care does not have negative consequences for him or her.

Ethical judgement is based on knowledge of ethics that is applied in each individual case. An example of ethical judgement and ethically good and practical problem-solving from this study is the nurse who sees that an elderly patient who is in pain presses her lips together and refuses to accept medicines, thus telling the nurse that she does not have the strength to live any longer. By showing the patient which tablets are painkillers and by telling her that they do not prolong life, the nurse gives the patient a choice. In this case, the patient accepted only the pain-killing medication. The alternative could have been to accept the patient's refusal to take medicines, with the result that her pain and discomfort would not have been alleviated. The nurse would thus have respected the patient's choice, but without reflecting on the dilemma that was implicit in the situation and that presented possibilities for several choices of action.

Finally, a proper assessment of competence to consent might put the focus back on the patient as the main person at the end of life.

6.2 The blurred role of relatives in nursing homes

My study shows that relatives expressed a wish for information about the foreseen and imminent death and the dying process of the patient from health personnel, as well as a need to be acknowledged as grieving persons. They are seeking a place and a role as a caring relative and family member. The question is in what way and how can the next of kin contribute to a good process of dying for the patient? In decision-making processes in nursing homes, consideration for the role and situation of the relatives will be decisive with regard to maintenance of respect for the patient and for providing him/her with treatment and care in conformity with the principles of medical ethics in general. At the same time, care and consideration for the relatives should be a goal in itself. This is a key finding, which will be further discussed. Recommendations from the WHO (2011) underscore exactly this importance of care and inclusion of the patient's relatives.

I am of the view that there are grounds for discussing whether the place of the next of kin in the wording of Norwegian legislation is too weak and *unclear*. Currently, Section 4.6 of the Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999) states the following on the role of the next of kin: *Information may be obtained from the patient's next of kin in order to determine what the patient would have wanted*. A discussion of the place of the next of kin early in decision-making processes may strengthen their role so that both healthcare personnel and relatives are together seeking the benefit of the patient.

Still, as this study indicates, and as is confirmed by other studies, giving relatives *the final decision-making authority* may be a great burden for them afterwards (Forbes, Bern-Klug et al. 2000, Forbes-Thompson and Gessert 2005). Buchanan & Brock (1989) also emphasise that nobody should make decisions on life-prolonging treatment alone. This is also in line with Norwegian law (Norwegian Ministry of Health Care Services (HOD) Patients' Rights Act July 1999).

6.2.1 No starting point for cooperation with next of kin

It is a paradox that in nine nursing homes no routines for conversations at the time of admission had been established, particularly since physicians and nurses emphasised the importance of good introductory communication. The recurring explanation for this lack of routines was shortage of time. Better frameworks and more time are essential. Time spent on such introductory conversations need not constitute a substantial burden for the employees: surveys show that the result of good conversations is not exclusively dependent on time. Even

brief, planned conversations can give the recipient appropriate information and the experience of being taken care of (Hansson, Kihlbom et al. 2007). It is a matter of health personnel's awareness as well as the will to prioritise such conversations. The best starting point for further collaboration is provided if the responsible physician, nurse and others who are to share the responsibility for the care welcome the patient and relatives early in the process (Goldsteen, Houtepen et al. 2006, Jackson, Rolnick et al. 2009). The foundation is thus laid for the development of identities, for information-sharing as well as for the ability and the will to perceive others as unique and to ask who the old person is (Lamberg, Person et al. 2005, Goldsteen, Houtepen et al. 2006, Travelbee 1971). This might be an essential basis for key values such as respect and trust.

6.2.1.1 Trust and mistrust

We have found that poor communication on admission reduces trust between physicians/nurses and the patient/next of kin. When collaboration and dialogue are inadequate, it appears that high levels of frustration arise which easily culminate in conflicts between clinicians and relatives. The study indicates that the focus is easily shifted away from the patient when conflicts arise between relatives and health personnel. These conflicts may stem from the relatives' frustration at not being taken seriously. Further, Thompson, Menec et al. (2008) point out in an article that the next of kin are extremely concerned about how the health personnel treat the patient. My material indicates that the quality of the collaboration that took place between the health personnel and the next of kin also depended on the individuals involved. Four relatives described the contact they had with the staff as censurable. These people also reacted to the lack of respect shown in the treatment of the patient. There is no excuse for bad behaviour – neither lack of time nor lack of resources. Ethics and the law offer no protection against poor attitudes. Weeding out such undesirable conduct is also part of the managerial responsibility. Patients and next of kin must be able to rely on systems and to trust health care.

Trust is about *relying on* good treatment being given and about the physicians and nurses having the required knowledge. There has been little focus on trust in medical ethics, even though lack of trust has been a key topic in public debates (Onwuteaka-Philipsen, Pasman et al. 2001, O'Neill 2002). This also applies to Norwegian debates. Currently, next of kin express their criticism of the medical treatment and care of dying patients far more often than was previously the case, as is illustrated by media publicity in recent years. This is a sign of

negative experiences and accordingly reduced trust (O'Neill 2002). Scepticism of systems and individuals is not negative in itself – rather the opposite. Daring to be open towards the patient and next of kin by requesting feedback on how the relatives perceive the collaboration can (re)establish trust.

Trust is a basic element in a good relationship between physicians and nurses as well. Trust is also necessary for good decision-making processes (Fewster-Thuente and Velsor-Friedrich 2008), and the presence of trust, or the lack of such, may accordingly be decisive in the treatment and care of old, dying patients. Nurses can provide information to the relatives in a different way from the doctors and this might be clarified. Statements from the next of kin who were interviewed showed they wanted physicians and nurses to be clearer about what they stand for, to show professional self-assurance and to assume clearer responsibility for issues of life-prolonging treatment and care in their role.

The study shows that most relatives, physicians and nurses wanted the best for the patient. It is therefore vital to create the conditions for good communication in decision-making processes in which all those involved take part (von Gunten, Ferris et al. 2000, Mueller, Hook et al. 2004, Tulsy 2005, Hansson, Kihlbom et al. 2007). This request is in line with the Patients' Act (Norwegian Ministry of Health Care Services 1999) which places the treatment responsibility on the physician in cooperation with other professionals in the team.

6.2.1.2 Concealed reality of the coming death

The next of kin are important for dying patients, both practically and emotionally (Rabow, Hauser et al. 2004, Seymour, Gott et al. 2004, Nolan, Hughes et al. 2005). Knowledge about death does not occupy a place in the family as it did previously when old people died at home. Death was then a natural part of life, and the family and community were skilled in end-of-life care. For relatives, being present and close to a patient in the nursing home may be a way to re-instate the subject of death in close relationships (Emanuel, von Gunten et al. 2000).

Several of the physicians who were interviewed in this study were of the opinion that it was too early to talk about death at the beginning of the stay in the nursing home, while the next of kin expressed a need for the topic to be taken up before the patient was dying. This standpoint has also been communicated by a number of physicians at several large-scale conferences in the municipal health service in Norway in recent years. Various international studies reveal that physicians find it difficult to talk about death (Rurup, Onwuteaka-Philipsen et al. 2006,

Schaffer 2007). Although this can be challenging for health personnel and should not be taken too lightly (Elliott, Gessert et al. 2007), it is nonetheless important for health personnel to be qualified to communicate with both patients and their relatives at the end of life (Emanuel, von Gunten et al. 2000, von Gunten, Ferris et al. 2000). Talking about death should be taken up as soon as appropriate in order to provide a good starting point for collaboration and for treatment and care (Knops, Srinivasan et al. 2005, Rurup, Onwuteaka-Philipsen et al. 2006). It is a managerial responsibility to ensure that all physicians and nurses in nursing homes have undergone training to acquire the knowledge and skills necessary for talking about death. Providing competence in this area helps to ensure that health personnel can give responsible health care, and is thus part of good quality treatment and care. The fear that old people will react if the subject is broached is presumably exaggerated since various studies show that death is a topic old people are concerned about (Lloyd-Williams, Kennedy et al. 2007, Schaffer 2007). Most patients who today have a permanent place in a nursing home in Norway die there. Since they are old and suffer from numerous serious illnesses, the approach of death can be no surprise to anyone. It is important to break through the barrier to talking about death that may exist so that it becomes equally important to bring up subjects such as quality of life and farewells as it is to talk about the issue of life-prolonging treatment (Smith 2000, Steinhäuser, Clipp et al. 2000). This will be in line with the principle of beneficence for patients as well for their relatives, and with safeguarding respect for patient autonomy.

Poor communication about the death with the patient's closest relatives in such a vulnerable situation – where they are faced with an imminent loss – may at worst load the relatives with a burden that together with other experiences can ultimately have a negative health impact and generate a prolonged and pathological grieving process. The relatives of elderly, dying patients in nursing homes constitute a large group: almost 20,000 elderly people a year die in nursing homes in Norway (Norwegian Medical Association – Status Report (2001). The relatives of these perhaps amount to at least double that number. Quality in encounters with them may well be a primary form of prevention, thus providing social gains in the long term.

6.2.2 Poor care for relatives who are grieving

Several relatives in the study criticised the health personnel for not understanding that their situation was characterised by grief and loss. It may be possible that health personnel underestimate the grief of the next of kin of elderly, ill people because the situation is regarded as a natural departure from a long life. Regardless of age, the loss of a parent – either

a dementia patient or one who is mentally healthy – may well raise existential issues (Forbes, Bern-Klug et al. 2000, Bloche 2005). In the interviews, however, physicians and nurses stated that grief and imminent loss could be the reason for the relatives' demands for futile treatment when the patient was dying. Without taking this up with the relatives, they conceded to pressure and "treated" the patient to alleviate the relatives' feelings of crisis. My findings are confirmed by other studies (Brotherton and Carter 2007, Schaffer 2007). In some situations it may be justified and also morally acceptable to give the patient intravenous fluid to allow the relatives time for their grief processes. However, this should take place in a context where the physician and nurse explain the situation and listen to the next of kin, and it is above all important that a short postponement of the process of dying is not contrary to the wishes of the patient, nor leads to discomfort and suffering.

6.2.2.1 Recognition and degradation

The relatives in my study expressed their need to be kept continuously informed and to feel involved. This coincides with findings from other studies (Vohra, Brazil et al. 2006, Thompson, Menec et al. 2008). Including the next of kin early in the processes, with the physician and the nurse if this is in agreement with the patient's wishes, may well be a significant part of the care for the next of kin (Slowther 2006). If health personnel also concentrate on providing good care and pain relief, this could help elderly, ill people and their families to cope with the situation (Reynolds, Henderson et al. 2002, Hjort 2004).

I found that relatives who were not invited to a conversation, or who found that what they said was ignored, experiencing a lack of recognition, felt degraded. They had questions but were given no answers. This reveals a lack of respect. Descriptions given by several relatives showed that they had cared for and been responsible for their elderly, ill loved one before admission. When they crossed the threshold of the nursing home they no longer counted. Some of the core of the experience of degradation can be found in such situations. Equality does not lie in the level of professional knowledge but in the equal opportunity to express oneself on the basis of one's own position (Honneth 2008, Biola, Sloane et al. 2007). The study reveals various examples of degradation experienced by the next of kin where they fought for recognition. However, their need for recognition was not expressed explicitly, but could instead be expressed by them demanding treatment for their sick and dying family member – which again resulted in the focus being moved from the patient to a deadlocked relationship with the physician and nurse (Brotherton and Carter 2007). Recognition is thus

interesting from an ethical point of view, precisely because the degradation of the relatives may lead to a fight for recognition and a power balance in which the patient is not only a goal but becomes to some extent also a means. Showing positive curiosity for relatives and their history – recognising them as care providers and as grieving individuals – may well form part of an empathetic attitude (Halpern 2001), which in the long run enhances respect for the patient's autonomy.

Taking the relatives seriously does not mean that everything they say is complied with. For example, the physician asking critical questions is also a way of showing recognition for the next of kin. It is most probable that any conflicts that arose in such situations can also be attributed to other aspects, such as relatives' grief and their reactions to crisis. The fact that health personnel reflect on why conflicts with relatives become deadlocked may generate knowledge. Knowledge of what is important in recognition and what can be degrading for grieving relatives in crisis situations may unlock conflicts if the staff conjecture about what is happening and why (Cullberg 2007). Once again it is a matter of taking professional responsibility for communication, and the foundation of this should be incorporated into the various training programmes. Good collaboration between relatives, physicians and nurses based on clear roles enables focus to be placed on death and the dying (Rurup, Onwuteaka-Philipsen et al. 2006).

Morally defensible practices, as described in the legislation, are not an exclusively individual responsibility. The findings reveal that physicians and nurses are constricted between the frameworks and the organisation in their provision of compassionate treatment and care. In the following, I will discuss the organisational moral responsibility, and promote practice that is according to ethics and law.

6.3 The gap between ethical practice, legal guidelines and practice

An important finding of this study reveals inadequate routines and marginal frameworks with regard to both resources and organisational aspects for good collaboration between patients, next of kin, physicians and nurses in the nursing home. This also applies between the various levels in the health services such as nursing homes and hospitals. Insufficient knowledge and skills among physicians and nurses is a part of this picture. It appears that the consequences of relatively unplanned and unstructured processes for collaboration have been that relatives might have acquired power and responsibility on premises that have not always secured the best interest of the patient.

Clinical activities in nursing homes are governed by Norwegian health legislation (see Chapter 3). Section 2 of the Health Personnel Act (Norwegian Ministry of Health Care Services 1999) uses the term *responsible conduct*, where the quality of the health services entails basing medical provisions and treatment on diligent care. Responsible conduct sets requirements for professional qualifications and good collaboration between professionals. Proper treatment and care can easily be confused with the lowest acceptable quality but is a legal standard that is to be adjusted in accordance with professional advancement and ethical requirements (Norwegian Directorate of Health 2009). The ethical requirements that govern physicians' and nurses' activities in nursing homes demand knowledge and skills in medicine and nursing care. These skills are in turn based on ethical attitudes and on the ability both to identify values that are threatened in daily practice and to resolve these value conflicts by asking oneself what *should* be done (Vetlesen and Nortvedt 1996, Nortvedt and Grimen 2004, Slettebø and Nortvedt 2006). Reflection on actual practice will thus constitute a key component for assessing the best alternative for action in the relevant situation.

6.3.1 Poor practical and organisational frameworks for good decision-making processes

The study indicates that the opportunity for collaboration that would enable physicians and nurses together to carry out professionally responsible practice for seriously ill and dying patients in nursing homes is frequently non-existent. The study shows that practical frameworks and the provision of sufficient time do not meet the requirements for ensuring good information and decision-making processes. This is not unique to the nursing homes included in this study. The findings are also confirmed in other recent Norwegian studies (Husebo and Husebo 2005, Eriksen 2006, Bollig, Husebo et al. 2008, Nortvedt, Pedersen et al. 2008, Gjerberg, Forde et al. 2010, Jakobsen and Sorlie 2010, von Hofacker, Naalsund et al. 2010). Physicians in 20 per cent positions make continuity and collaboration difficult, which is particularly unfortunate when the patients are chronically and seriously ill and dying. Various studies show that the quality of collaboration affects the quality of the health facilities provided (Smith 2000, Sommers, Marton et al. 2000, Teno, Clarridge et al. 2004, Shield, Wetle et al. 2005, Wetle, Shield et al. 2005, Fewster-Thuente and Velsor-Friedrich 2008). Adequate competence in the treatment team is also a major prerequisite for responsible practice. When one-third of nursing home employees are unskilled (Norwegian Ministry of Health and Care Services (HOD) 2005-2006), professional discussions and training will be

absolutely necessary to ensure a certain quality internally in the nursing homes. The physicians in the study were concerned and worried about the fact that there were few qualified nurses on duty in the evenings and at weekends. This could have consequences for the choice of treatment measures, and could lead to undesired hospitalisation of dying patients. That qualifications and competence are important is confirmed in a report issued by SINTEF Health Research in 2004: [Staffing and services in nursing homes] (Bemanning og tjenestetilbud i sykehjem) (Paulsen B. 2004). The report reveals that there is no correlation between the number of employees and quality, which may indicate that qualified healthcare staffs are more important than the number of available hands³⁸.

Nursing-home staff express that discussions on demanding topics in the everyday clinical setting are necessary to strengthen the employees' chance of tackling ethical challenges (Gjerberg, Forde et al. 2010). Poorly qualified staff and inadequate routines make it difficult to ensure the quality of the treatment and care of patients in the final phase of life in nursing homes. This is not a phenomenon that applies uniquely to Norway; it is also described in international literature (Davies, Nutley et al. 2000, Bostick, Rantz et al. 2006, Carlson 2007, Collier and Harrington 2008, Maas, Specht et al. 2008). Since the number of elderly people is expected to increase sharply, and patients in nursing homes suffer from increasingly severe conditions (WHO 2011), it is necessary to ask why the provisions for elderly, ill people are characterised by poor staffing and therefore low quality (Oliver, Porock et al. 2004). One explanation may be that there has been considerable focus on medical treatment technology in recent decades, which has led to attention being drawn to hospitals rather than to nursing homes.

Research is a significant part of the quality work in the health service. In nursing homes, pain alleviation and care for the dying are far more natural areas of focus for research than curative treatment. Inadequate research and professional development may be among the reasons for the low status of geriatric care. Since this study commenced, however, more attention has been paid to these areas. The establishment of nursing homes specially devoted to training and more focus on ethics in the municipal health service are some of the programmes that underpin the improvement³⁹. These measures must be seen as a start-up phase for enhancing the quality for elderly, dying patients and their next of kin. Directing a clearer professional

³⁸ During the election campaign for the parliamentary election in 2007, a certain number of hands were promised as a metaphor for the establishment of more positions. No mention was made of the number of heads.

³⁹ Link: <http://www.undervisningssykehjem.no/>

focus on this sector may generate greater interest and thus provide better opportunities for the recruitment of well qualified health personnel. Documenting the conditions through research is not only a key component of the teaching but is also necessary to clarify the situation for the responsible authorities in order to ensure better care for elderly, dying patients and their families (WHO 2011).

Inadequate frameworks and routines for professional collaboration affect the quality of treatment and care not only internally in the nursing homes but also between the different levels such as nursing homes and hospitals (Paulsen B 2004, Ranhoff and Linnsund 2005, Garasen and Johnsen 2007, Bollig, Husebo et al. 2008, von Hofacker, Naalsund et al. 2010). More than half the relatives who were interviewed experienced that the patient had been hospitalised while he/she was a patient in the nursing home (Table 4.2). The physician, nurse and next of kin all regarded communication between these treatment levels as unsatisfactory. The coordination between the physicians in the hospitals and the nursing homes was often so weak that professional assessments were not exchanged. Since physicians in hospitals are highly focused on treatment, a careful assessment should be made as to whether the admission of nursing-home patients is appropriate (von Hofacker, Naalsund et al. 2010). Although nursing homes are well suited to treating and caring for dying patients if the staff are qualified (Husebo and Husebo 2004), it is nonetheless necessary to assess the need for hospitalisation of elderly, ill people where this is justified. One example is the provision of necessary palliative treatment in hospitals in cases where this cannot be given in the nursing home.

It is particularly important for the various treatment levels to be conducted as a continuous treatment chain (Brueckner, Schumacher et al. 2009, Norwegian Ministry of Health and Care Services (NOU) 2005:3). Collaboration as a concept currently used in the Norwegian health service is related to organisational quality, where emphasis is placed on coordinated measures as a prerequisite for the quality of patient treatment. Quality indicators of coordination as “organisational care” are shown in 1) quality experienced by the patient; 2) quality assessed professionally, 3) organisational quality and 4) quality experienced among professionals (Orvik 2004). My study is not an evaluation study but gives descriptions of all these indicators and refers to censurable aspects. The Coordination Reform, adopted in 2009, sets guidelines for communication between the various services (Norwegian Ministry of Health and Care Services 2008-2009). The prerequisites for achieving the intentions of such a reform are that the implementation of the reform is discussed in close cooperation with clinicians and

that the necessary resources are available to make professional discussions and collaboration across the various treatment and care levels possible.

6.3.2 Poor organisational ethical responsibility

It is important to focus on the consequences of how the welfare state handles responsibility for patient treatment and care. One main aspect that has been pointed out is that the assignment of system responsibility should be put on an equal footing with the assignment of individual responsibility (Vike, Brinchmann et al. 2002, Vike 2004). Ethics of proximity has set the trend with a view to rendering each health worker responsible in the encounter with the individual patient. Taken to its extreme, this approach can be politically abused, if the organisation of health services is regarded as exclusively depending on individual moral integrity, while the importance of the values among those who are making the decisions is ignored. Vike (2004) points out that a characteristic of the care groups is that they assume responsibility for maintaining quality in spite of inadequate resources, and that they do their utmost to keep the wheels turning. In my study the physicians also did all they could to secure patients the best treatment – for example by being available on the telephone for the nurses outside paid working hours. In this way they concealed the deficiencies in the primary health service, and thus contributed to making the sector functional and flexible (Vike 2004). The moral integrity of the health workers is challenged in their encounter with a clinical reality that is not in line with either professionally acceptable medical treatment or with the law and ethics. The consequence is the experience of moral stress, a condition that has been increasingly described in international literature and that concerns the gap between the ideal and the reality in the health sector (Bischoff, DeTienne et al. 1999, Kalvemmark, Hoglund et al. 2004, Vike 2004, McCarthy and Deady 2008, Gjerberg et al. 2010). The result can be emotional apathy and reduced moral sensitivity, and can culminate in high staff turnover and further reduction in quality. This can make good decision-making processes difficult to conduct (Gravel, Legare et al. 2006).

Responsibility for what is acceptable practice should not only be assigned to those who carry out direct and close patient treatment. The responsibility should be placed at a high political level so that the authorities are made accountable for ensuring that the frameworks and allocations for running nursing homes are morally acceptable. Furthermore, the managers at the various levels in each municipality also bear part of a joint responsibility for ensuring that

the service they lead is in line with morally professional responsibility and diligent care⁴⁰ (Norwegian Ministry of Health Care Services (HOD) The Health Personnel Act of July 1999). This means responsibility for sufficient framework conditions for mutual processes to ensure respect for and focus on the elderly dying patient and the next of kin. This applies to everything – from the recruitment of professionals and shift lists to staff training.

In England a so-called Gold Standard Framework (GSF) has been introduced in nursing homes⁴¹. The aims are to help the employees and their partners in hospitals to identify the patients' needs and symptoms, to support patients and relatives and to avoid undesired admissions to hospitals. An evaluation study shows that there were far fewer hospitalisations after the implementation of this standard (Hewison, Badger et al. 2009). Greater satisfaction was also revealed among those who were responsible for elderly, ill people in the final phase of life. One of the reasons is presumed to be that it encourages more discussion with patients and next of kin on end-of-life treatment. In addition, general communication with the A&E unit physician was improved. This shows that it may be necessary to introduce routines in nursing homes to improve quality. Evaluation studies of various initiatives have been published in recent years, and a key fact expressed in these is that a systematic approach is required to improve quality (Hanson, Danis et al. 1997, Hanson, Henderson et al. 2002, Miller and Han 2008). The reasons why end-of-life care is not good enough are complex (Emanuel, von Gunten et al. 2000), and the potential for improvement is substantial (Teeri, Valimaki et al. 2007). This is confirmed by this study.

My findings show that inadequate collaboration between physicians and nurses is the weakest and most fragile part of the decision-making processes on life-prolonging treatment and care. When physicians and nurses experience moral pressure, this must be taken seriously: they must prioritise professional conversations about their practice so that they can discuss and reach agreement on good treatment and care for patients and next of kin. This cooperation is necessary, and forms the basis of good decision-making processes.

⁴⁰Official translation of The Health Personnel Act § 4.2:Health personnel shall conduct their work in accordance with the requirements to professional responsibility and diligent care that can be expected based on their qualifications, the nature of their work and the situation in general.

⁴¹ <http://www.goldstandardsframework.nhs.uk/>

6.3.3 Insufficient knowledge and skills – a personal and managerial responsibility

The study indicates systematically insufficient knowledge and skills among the professionals. Professionals are responsible for keeping updated in their field. It is also a clear managerial responsibility to ensure that employees have the required training. Professional knowledge and training must include knowledge of ethics. Physicians and nurses must acquire far wider knowledge and skills about autonomy and assessing the patients' degree of competence to consent than my study shows they possess. This is a main premise for the patient to be placed in the central role at the end of their own life. Further, when nurses in my study did not provide adequate pain relief for dying patients for fear of giving them "the final injection", this shows a lack of both professional, legal and ethical competence in relation to palliative treatment and a lack of reflection on the various challenges linked to pain relief. Other studies confirm that pain relief in nursing homes is inadequate (Zwakhalen, Hamers et al. 2007; Hasson, Kernohan et al. 2008; Husebø 2008). To refrain from giving adequate palliative treatment is to disclaim responsibility and is unethical and against the principle of beneficence. This is thought-provoking – not least because the main task of nursing-home staff is to look after elderly, ill people and the dying. It may appear that nurses in particular are weak with regard to setting requirements for training. However, the study indicates that some of them had taken special education in palliative nursing, which the physicians greatly appreciated since it gave them greater ability to treat the patients in the nursing home. Various studies show that nursing home staff lacks knowledge about providing satisfactory end-of-life care. This can result in undesired but necessary hospitalisations (Happ, Capezuti et al. 2002, Lofmark, Mortier et al. 2006).

To provide good palliative care for patients in nursing homes is a clear managerial responsibility as much as a personal responsibility (Norwegian Ministry of Health Care Services (HOD) Community Health Act. 1982). Another example where the study reveals censurable conditions is where it emerged that many nurses had poor IT skills. Quality in nursing homes rests on communication between professionals and between systems. Other studies confirm that this can constitute a weak link in the chain (Obstfelder and Moen 2006, de Veer and Francke 2010). Good documentation is important when difficult ethical choices are to be made at the end of life – a fact that is emphasised in the National Guidelines (Norwegian Directorate of Health 2009).

The interviews with physicians and nurses revealed that the issue of values was seldom linked to theoretical ethics. The values were often implicitly expressed in discussions on specific situations. The absence of an “ethical language” makes normative reflection on practice difficult. A more recent doctoral thesis indicates that student nurses show little interest in the discipline of ethics during their studies (Tveit 2008). They found the discipline somewhat irrelevant. Such statements can hardly be exclusively restricted to students. Educational institutions should be made aware of the lack of motivation for learning about ethics so that the teaching of ethics is carried out in a way that is perceived as useful and meaningful for students. Knowledge of ethics and attention to handling values issues well form a significant part of the quality assurance of the health services, and deficiencies in this area can to some extent explain why current practice is unacceptable. Good attitudes alone are not an adequate starting point for necessary reflection on practice. One example is when the nurses described how they exerted pressure on patients with advanced dementia who did not want to eat, and that such daily situations in this department made the working day demanding for the healthcare personnel and the patients. This reveals a lack of knowledge of both ethics and dementia (Ersek, Kraybill et al. 2000, Wilmot, Legg et al. 2002, Solum, Slettebo et al. 2008).

Further, my material reveals that the relatives, physicians and nurses could struggle to understand each other because their perspectives were basically completely different. To ensure cooperation and understanding between the various parties in this complex group may be far more relevant than a unilateral focus on the patient’s right to self-determination (Zuckerman 1994). Sufficient routines and framework are a vital basis for good decision-making processes.

6.4 Possible contributions to and implications for improved practice

This last part of the discussion outlines the possible implications the findings may have for an improved practice. These implications are based on ensuring both that elderly, ill patients as individuals are included in decisions that concern their own life and that more attention is paid to the voice of the patient.

6.4.1 Shared decision-making (SDM)

The purpose of ethically sound decision-making processes is to make patients and their next of kin capable of making good choices together with health personnel with the aim of ensuring a good death for the patient (Lang and Quill 2004, Frank 2009, Hirsch, Keller et al.

2010). International literature describes such an approach as shared decision-making (SDM): seeking an understanding of what is best for the patient through a joint process of communication and deliberation (Rurup, Onwuteaka-Philipsen et al. 2006). This is not only relevant when the patient is not competent to provide consent, but also when the patient is still able and willing to make his/her own choices. Such a process may be a support for the patient, at the same time as it includes his/her close relatives if the patient does not oppose this. The process may prevent the patient and next of kin being isolated from each other when the end of life approaches, and may provide them with support for meeting death together.

There are various definitions and models of SDM (Moumjid, Gafni et al. 2007), and in this discussion I do not want to present suggestions for applying a specific model. On the contrary I challenge leaders at each institution to compile a model for decision-making processes in cooperation with the employees at the clinic, based on international literature on SDM. An important starting point is to ensure that the employees have a common understanding of what SDM should mean in their nursing home (Moumjid, Gafni et al. 2007). A general knowledge of decision-making processes, the ability to communicate, sound professional knowledge and not least good ethical judgement are necessary for such a model to succeed (Gravel, Legare et al. 2006).

6.4.2 Shared decision-making (SDM) organised through simple routines

Throughout this part of the thesis I have repeatedly emphasised the need for good routines for decision-making processes with patients and next of kin. Being in a relationship of mutual dependence where there is no trust can be an extremely negative experience for all those involved. Fixed routines can ensure that patients and next of kin rely on physicians and nurses. In his 2007 book, Vetlesen asks whether the contract (in this context the routine) threatens moral duty. He refers to the fact that obligations are triggered by the perception that the well-being of another person is something that concerns another individual (Vetlesen 2007). Is this awareness of other people threatened by an instrumental approach to others through a contract? I think it is important to have some guidelines. It prevents conflicts and increases transparency for relatives in the process. The Norwegian health service in the year 2011 cannot exclusively depend on individuals when it comes to quality of care and decision-making. Collaboration between professionals and patients and their next of kin that is governed by simple, efficient and necessary routines can ensure that the patient's or relative's basic need for information and attention are met. Simple routines can ensure that clinicians

who for several reasons lack sufficient awareness of the needs of patients and next of kin must nonetheless give and obtain the most important part of the most elementary information⁴².

Work on quality also concerns evaluating old established routines.

6.4.2.1 Admission conversations

Assessing the patients' competence to consent should represent a key starting point for a conversation when the patient is admitted, but should also be in focus among physicians and nurses from the first meeting with the patient. A more careful assessment shortly after admission may well make it possible for patients to communicate their preferences so that these are noted before he/she becomes too ill and loses the competence to provide consent (Allen and Shuster 2002, Meeker 2004, Slowther 2006). This may protect patients' autonomy when asking for preferences and searching for the patient as an integrated person. Relatives may also be satisfied when health personnel are curiously searching for the patient as a person (Dreyer and Nortvedt 2008).

Clarifying roles appears to be the key to preventing conflicts in communication on life-prolonging treatment. Relatives must be informed about their place in the nursing home to ensure that they can provide knowledge of the patient in line with Section 4.6 of the Patients' Rights Act (Norwegian Ministry of Health Care Services (HOD) July 1999). The study indicates that physicians and nurses internally should also clarify their roles for each other so that responsibility is clear.

The issue of life-prolonging treatment is thus not an isolated decision to be made the day the patient's condition deteriorates; the foundation for the decision is laid far earlier in the proceedings and should form part of a longer-term process rather than the decision being taken at the moment the patient becomes acutely ill.

An admission conversation in which both the patient and next of kin participate will allow physicians and nurses to form a significant picture of the collaboration between them (Lang and Quill 2004).

⁴² Some nursing homes have made considerable progress in establishing good professional quality. Examples of nursing homes that have introduced good routines are Bergen Red Cross nursing home www.brks.no, and the Church City Mission nursing home in Oslo www.bymisjon.no/Virksomheter/Sofienbergcenteret. As previously mentioned, the establishment of teaching nursing homes has also led to a greater focus on quality and routines in several municipalities <http://www.undervisningssykehjem.no/>

6.4.2.2 Drawing up an advanced care plan (ACP)

The admission conversation should form the starting point for drawing up an advanced care plan (Happ, Capezuti et al. 2002, Allen, DeLaine et al. 2003, Kahana, Dan et al. 2004). The ACP is described in international literature (Rosenfeld, Wenger et al. 2000; Happ, Capezuti et al. 2002, Allen, DeLaine et al. 2003, Kahana, Dan et al. 2004, Parker, Clayton et al. 2007). Basically, the patient should say who is to participate, and thus who can also represent him/her if the patient loses the competence to provide consent. This is in line with durable power of attorney (DPA) (Beauchamp and Childress 2009), hence not legally binding in Norway.

The content of such a plan should ensure focus on the patient through the discussion and documentation of preferences concerning the end of life, thus ensuring that the patient will not be exposed to treatment and care initiatives that he/she does not want (Happ, Capezuti et al. 2002, Engel, Kiely et al. 2006). An important point is also to include a short description of the patient's life events and wishes for the nursing home stay, as well as special requirements when death approaches (Rurup, Onwuteaka-Philipsen et al. 2006). This can form an appropriate foundation for discussing life-prolonging treatment when this becomes relevant, and keep the right focus on a good end of a long life in line with the main person. A new Australian study also shows that including the next of kin in the drawing up of an ACP reduces stress and depression afterwards among the closest relatives (Detering, Hancock et al. 2010). The next of kin will thus acquire knowledge and understanding, and can become more aware of their place and their role.

The Advanced Care Plan (ACP) can ensure that patients, relatives, physicians and nurses are familiar with the development and content of the mutual process.

6.4.2.3 Professional meetings between physicians and nurses

Adequate frameworks for collaboration entail nurses and physicians being able both to discuss the treatment level on a general basis and to continue such subjects in discussions on individual patients in the relevant situation (Gjerde, Førde et al. 2010). This need for regulatory measures is stressed by Zwakhalen, Hamers et al. (2007).

A plan of measures for dying patients has been introduced at six nursing homes in the county of Østfold. This is a cooperation project between these nursing homes and Østfold University

College, which started in 2008. They apply the Liverpool Care Pathway (LCP)⁴³, which is a plan of measures for dying patients and their next of kin. The plan is intended to be used in the cooperation between physicians and nurses when the patient has been assessed as dying, and conversations between the patient, next of kin, physician and nurse are key components of the plan. Experience shows that the nurses also find conversations on death demanding when they apply the LCP, and that it is important for the physician to take part in the cooperation (Watson, Hockley et al. 2006). Experience from these municipalities can provide input for other Norwegian nursing homes regarding learning about forms of cooperation between physicians and nurses.

Better collaboration between physicians and nurses in the first and second-line services should also be a major area of priority.

6.4.2.4 Systematic work on ethics

The establishment of reflection groups should be made possible, where employees can talk about difficult aspects of their practice so that they can become capable of taking responsibility and coping with demanding situations. Research shows that the opportunity to reflect on practice is a need that is not met in Norwegian nursing homes (Gjerberg, Forde et al. 2010; Gjerberg, Forde et al. 2011). All the occupational groups that are involved in direct patient treatment should be included, thus promoting greater interdisciplinary cooperation. One of the goals should be to adapt ethics in nursing homes to the unique aspects of the issues that arise in this setting rather than directly transferring ethics from a hospital context where the attention is often centred on curative treatment. Issues of life-prolonging treatment must not displace the focus on a good end to life in which pain relief and farewells are of key importance.

A search for knowledge and specially adapted teaching in nursing homes can lay the foundation for critical reflection (Molewijk, Stiggelbout et al. 2004, Grady, Danis et al. 2008, Molewijk, Abma et al. 2008, Gjerberg, Forde et al. 2010). An approach of this kind is currently being applied increasingly in clinical work on ethics in Norway, and has its foundation in systematic reflection on dilemmas that are experienced (Manual for the Clinical Ethics Committee⁴⁴) (Ruyter, Førde and Solbakk 2007, Eide and Aadland 2008, Leget, Borry

⁴³ <http://www.mcpcil.org.uk/liverpool-care-pathway/>

⁴⁴ <http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten/spesialisthelsetjenesten/manual/>

et al. 2009, Slettebø 2009). This is part of the core of clinical ethics (de Vries and Gordijn 2009, Leget, Borry et al. 2009).

When situations become complicated, utilising the National Guidelines for Decision-making Processes (Norwegian Directorate of Health 2009) can ensure that important facts, values, interests and assessments are not omitted, for example demands from the next of kin for treatment that is not in line with the physician's professional assessment.

Operative clinical ethics committees have been set up in some municipalities, and the committee at the local hospital can also be used in some places for questions concerning difficult ethical dilemmas on life-prolonging treatment in nursing homes. Relevant dilemmas in nursing homes often concern an assessment of whether elderly, dying patients can benefit from hospital treatment.

6.5 Methodological considerations

In retrospect I can see that I would have missed some important knowledge if I had chosen to conduct the study in the form of a survey. During the study, information was revealed which I would have been unable to include in a questionnaire, and this could have represented a systematic bias ("error") in the study because of my erroneous assumptions. One example of such information is the declaration by some relatives that they did not realise that the patient was dying, and that the health personnel should have informed them of this. Furthermore, it was revealed that assessments of the patients' competence to provide consent were only made rarely, and that relatives were occasionally included in decision-making pertaining to treatment while the competent patient was excluded. This turned out to be one of the main findings. These examples demonstrate the need for qualitative, exploratory research into situations characterised by traditions and routines, and where there is a dearth of research-based documentation. Case studies involving in-depth interviews with relatives, doctors and nurses with regard to the decision-making process were considered as a method. This method was not chosen because of the risk of missing important findings, especially from doctors and nurses, since the cases would concentrate on a specific situation involving a patient. Furthermore, conflicts associated with individual cases could have restricted the descriptions provided by doctors and nurses of their own attitudes and justifications in general regarding decision-making processes related to life-prolonging treatment.

6.5.1 Limitations of the study

Weakness of the sample includes the exclusion of informants from other national backgrounds than ethnic Norwegian. A critical inspection would also point out that the exclusion of Northern Norway fails to allow for maximum variation in the sample. The inclusion of only physicians and nurses from among the health workers in the nursing home was based on the nature of the research questions, which were associated with issues pertaining to life-prolonging treatment, and which made this choice the most relevant solution. Physicians are legally responsible for the provision of treatment (Norwegian Ministry of Health Care Services (HOD) The Patients' Right Act of July 1999). The nurses are delegated the task of providing most of the medical treatment prescribed by the physicians. In a nursing-home context, the physicians and the nurses tend to cooperate on these matters. One weakness of this study is that all the physicians in the selected nursing homes were men, and all the nurses were women.

6.5.2 Rigour and trustworthiness

The standards used for assessing the quality of research must be relevant to the research method applied. The knowledge arising from this study has been sourced from in-depth interviews and the data have been manually transcribed and interpreted; consequently, the study shows clear signs of subjectivity. From the outset till the very end, it has therefore been important to focus on validation. I have tried to provide clear reasons for my various choices of method at all stages in order to ensure transparency (Malterud 2001). Kvale and Brinkmann (2009) use the concepts of reliability and validity when dealing with the validity assessment of qualitative studies. Reliability is the standard against which the study's handling of data is gauged, whereas a study's validity tells us whether it investigates what it is meant to investigate. Furthermore, transferability is an understandable concept which measures a study's applicability within similar contexts; in my opinion, this is a more appropriate concept than generalisation in a qualitative setting (Reiter-Theil 2004).

6.5.2.1 Process validation

Critical awareness of the researcher's own role is important throughout all stages outlined above, also because the choices made are associated with the role of the researcher. Tranøy (1986) writes that if we assume the moral calibre of researchers to be on a par with that of everybody else, then openness to opposing views and criticism is imperative. Self-criticism plays a key role in this respect.

Whilst the continuous *practical process* of this study is based on Kvale and Brinkmann's seven stages of an interview investigation, I present a summary process assessment of the consistency (reliability) of the results and whether the study has investigated the issues it was intended to investigate (validity). This process validation is inspired by Kvale's sixth phase (Kvale & Brinkmann 2009).

Textbox 4.7: The seven stages of validation – a summary

1. *Thematisation.* At this stage, validity is linked to the correlation between the topic studied and the theoretical basis, and also to the derivation of the research questions. Medical ethics and the autonomy principle formed the theoretical points of departure. However, although this was a relevant starting point, the data collection process introduced a need to draw on other aspects of medical ethics in order to enable discussion of the findings in the light of theory beyond the autonomy principle. Norwegian legislation also represented a key framework for these discussions, as well as literature on frameworks and organisational factors.
 2. *Planning.* My choice of method and design was based on the research question. In order to gain knowledge about the decision-making processes experienced by physicians, nurses and relatives while mapping what was happening, qualitative in-depth interviews emerged as a natural choice. The application of emergent design, which was developed in pace with the data collection process and the textual analysis, proved to be important for my ability to uncover new knowledge and to continue probing in further depth.
 3. *Interviewing.* At each of the nursing homes, participants were selected through "purposive sampling" by a nurse who was familiar with potential participants with experience of the research question. By personally transcribing the interviews, I was in a position to listen to my own interviews and the responses I received. Combined with interview guidance, this process was useful in allowing me to probe sufficiently deeply, thus improving the quality of my interviews.
 4. *Transcribing.* All interviews were transcribed verbatim. This was in order to capture all the content as accurately as possible. When reviewing the material it was easy to read and detect nuances in a holistic way. Nothing was added or subtracted. The transcripts were further validated by a participant reading through them and confirming their accuracy. My supervisor also checked my transcripts against the audio files.
 5. *Analysing the data.* Large chunks of my work with the data involved making them accessible from within the context of the research questions and their textual presentation. Three separate analyses resulted in a descriptive presentation of the findings. My primary task in interpreting the findings was to "sort" the participants' various statements to ensure they were put into the correct category. Furthermore, textual presentation will always be coloured by interpretation. This was checked and discussed with my supervisors.
 6. *Validation.* I have sought to question the study's reliability and validity at every stage. I have constantly stopped to focus on the core questions in order not to lose the "thread" throughout the study. Because the interviews provided a rich source of information, it was tempting to include other associated topics. I noted these associated topics as proposals for further research (Appendix 6). This was helpful in putting associated topics to one side in order to maintain my focus on "end-of-life decision-making processes in questions pertaining to life-prolonging treatment in nursing homes".
 7. *Reporting.* I have chosen to present my findings in the form of multiple papers in the hope that this will facilitate the communication of knowledge about the study to other interested parties in a nursing home context, nationally and internationally. The presentation of my findings is kept in a descriptive format, interspersed with selected quotes which I find to be particularly illustrative of the various findings.
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Textbox 4.7 presents a brief validation summary for all stages (Kvale and Brinkmann 2009). Please refer to the descriptions of the various stages of my work for a more detailed assessment of the quality of the study.

6.5.2.2 Pragmatic validation and transferability

My epistemological position and my declared view that the development of knowledge is a social construction (Rose and Webb 1998), will inevitably affect my attitude with respect to quality assessment of this study in a wider context. When I set out to map decision-making processes at end-of-life in nursing homes, my presentation of the findings was never meant to constitute a correct reflection of an isolated situation within the ten specific nursing homes. The objective was for the descriptions provided by representative participants (purposive sampling) with experience of this particular situation to shed light on as many factors as possible associated with end-of-life decision-making processes in nursing homes. From there on, the aim is for audiences in other nursing homes to consider the findings in the light of their own setting. My critical and normative discussion of the findings can be further assessed and discussed and may stimulate improved practice. Kvale and Brinkmann (2009) refer to this process as pragmatic validation, a method by which the social sciences provide input to an ongoing dialogue about quality in society, rather than isolated questions about verified knowledge. This makes it possible for the present qualitative study to be considered by physicians and nurses in similar settings, allowing the findings to be used as potential working hypotheses for further work rather than absolute truths (Malterud 2001). One objective is to draw attention to subjective descriptions of practice based on relevant experience. Another objective is to stimulate further research into the issues raised (Angen 2000). In this way the outcome becomes a continual validation of research beyond the individual studies.

7 Conclusion

The results of this study are derived from in-depth interviews with next of kin, physicians and nurses from ten nursing homes, and the analysis is based on hermeneutic interpretation. The aim of the study was to map the practice regarding decision-making processes between relatives as substituted decision-makers, physicians and nurses related to issues of life-prolonging treatment and care in nursing homes. During the study, focus was also directed towards patients who had this competence. The original question concerned the role elderly patients in nursing homes play in their own lives when death draws near.

One main finding is that little focus is placed on the patient as the main person in decision-making processes. Little focus is placed on the patient's competence to provide consent. This also leads to an inadequate basis for the decision-making processes between the patient, next of kin, physician and nurse. The study shows that the view of competence to provide consent was insufficient.

Poor routines for admission conversations and on including next of kin as care providers also lead to an inadequate basis for the decision-making processes. The relatives' role was blurred. Conflicts can arise in such situations, and the end-of-life phase for the old person can be reduced to a question of treatment decisions taken by others. Physicians and nurses may be pressurised by relatives into taking actions that are not in keeping with their convictions with regard to giving more proactive life-prolonging treatment than they find appropriate.

Perhaps a dogmatic view of autonomy does not ensure respect for elderly, ill patients in issues of life-prolonging treatment and care. Patients in nursing homes can be in a situation where a desired dependence on others can supercede the need to make self-determined decisions. Although changes have taken place in recent decades, the family is still a natural basic unit of society. The next of kin should be given a far clearer position in nursing homes if this is in line with the patient's wishes. Since many old people die in nursing homes, and since death in many ways has been alienated from society, physicians and nurses should create the conditions for farewells and solidarity within the family when the patient is in a nursing home. This will help to give the next of kin a more important place, although not as independent decision makers. The study shows that none of the relatives interviewed wanted to take sole responsibility for issues of life-prolonging treatment.

The study reveals a practice that is not in line with ethics and the law. It can partly be explained by the practical and organisational frameworks, but also by the fact that physicians and nurses do not fulfil their professional responsibility in their encounters with patients and next of kin. Physicians and nurses describe good attitudes based on values such as beneficence and non-maleficence, but there is little focus on the patient's co-determination and the understanding of relatives' role.

The material shows little collaboration – not only between the patient, next of kin, physicians and nurses internally in the nursing home but also between the various treatment levels.

Some proposals for routines are discussed on the basis of the results from the study. Decisions on treatment must be taken, and Shared Decision-Making (SDM) based on the Best Interest Standard is recommended as an arena for decision-making processes on life-prolonging treatment and care. For the relatives who experienced doubt and frustration afterwards, SDM can form part of good preventive health work by clarifying roles and responsibilities.

My discussion of the findings can be assessed and examined further so that employees in other nursing homes will view the findings in light of their own setting. The hope is that the study will provide input to a continuous dialogue about quality in nursing homes rather than to verified knowledge.

7.1 Further research⁴⁵

Competence enhancement in the field of ethics is assigned priority today in the municipal health service where the medical treatment and care of elderly, ill people is central. The goal must be to ensure that this important work is continued as part of a continuous development of ethical awareness and competence in the sector. Evaluation research may point to further directions for this work.

Norway is a multi-cultural country. To ensure that all patients and relatives have an appropriate experience of death in nursing homes, research into decision-making processes in which the focus is directed towards culture and language is of importance.

⁴⁵ Associated topics as proposals for further research emerged under this research process, see Appendix 6

To ensure the fulfilment of dementia patients' wishes in issues of life-prolonging treatment and the various care initiatives when life approaches its end, further research is necessary to acquire more knowledge of how such patients can be cared for in situations of this kind.

Research that has been carried out in Norwegian nursing homes must be coordinated in order to make significant findings more available than they currently are.

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PAPER I

Dreyer, A., Forde R., Nortvedt P. (2009). "Autonomy at the end of life: life-prolonging treatment in nursing homes- relatives' role in the decision-making process." Journal of Medical Ethics **35**(11): 672-677

PAPER II

Dreyer, A., Forde R., Nortvedt P. (2010). "Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice?" Journal of Medical Ethics **36**(7): 396-400

PAPER III

Dreyer, A., Forde R., Nortvedt P. (2011). "Ethical decision-making in nursing homes: influence of organizational factors." Nursing Ethics **18**(4): 514-525

Appendix 1



Cand. san Anne Dreyer

Saksbehandler
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St.Olavs Hospital

Vår dato:
07.06.2007

Vår ref.:
4.2007.974

Deres dato:

Deres ref.:

Pårørende som stedfortredende beslutningstakere ved behandlingsunntattelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem.

Komiteen vurderte prosjektet i møte 25. mai 2007 med følgende merknader og tilråding.

Hensikten er å gjøre en undersøkelse av dagens praksis av prosessene rundt behandlingsunntattelse i sykehjem der fokus rettes mot erfaringer og opplevelser hos pårørendes i forhold til situasjoner knyttet til livets slutt. Hovedfokus i denne undersøkelsen er pårørendes rolle knyttet til behandlingsunntattelse; -i hvilken grad de inviteres til en prosess sammen med behandlende lege og evt. sykepleier og hvordan denne foregår. Få sykehjem har retningslinjer i forhold til denne type beslutningsprosesser, og det er ikke funnet forskning på dette knyttet til norske forhold. Internasjonal forskning gir inntrykk av at fenomenet "stedfortredende beslutningstaker" er et vanskelig etisk område, der mye ikke er godt nok håndtert. Et viktig etisk spørsmål er om pårørende vet at deres medbeslutning skal bygge på hva de mener og tror den syke ville ha ønsket selv i situasjonen om vedkommende hadde vært samtykkekompetent. Det er planlagt å ta utgangspunkt i 10 sykehjem, der lege og sykepleier intervjues sammen i fokusintervju. Hensikten med de intervjuene er å kaste lys over beslutningsprosessene der pårørende deltar. Videre er det tenkt retrospektive dybdeintervju med 20 pårørende.

Komiteen har følgende merknader til prosjektet:

- Komiteen viser til prosjektprotokollen og er usikker på om man kan forvente ærlige svar fra helsepersonellet, på de aktuelle spørsmål om behandlingsunntattelse, når lege og sykepleiere skal intervjues sammen? Det er mulig at separate intervjuer vil være bedre i denne situasjonen.
- Komiteen bemerker at det finnes omfattende lovreguleringer på dette feltet og disse burde vært bedre gjennomgått i bakgrunnsbeskrivelsen av studien. Det henvises til at det finnes lite kunnskap om praksis for beslutninger om behandlingsunntattelse, men det finnes altså et lovverk (Pasientrettighetsloven) som gir klare føringer for hva som her skal gjøres. Dette må innarbeides bedre i prosjektet. Komiteen anbefaler f eks. Aslak Syses kommentarer til Pasientrettighetsloven.
- Studien må meldes til må meldes til Norsk Samfunnsvitenskapelig Datatjeneste (NSD) og det må stå i informasjonsskrivet at dette er gjort.

- Komiteen viser til informasjonsskrivet og ber om at setningene *Kjære...* strykes da dette kan virke appellerende.
- Avsnittet om at det er planlagt en artikkelbasert avhandling skal strykes i sin helhet da dette er irrelevante opplysninger for eventuelle studiedeltakere.
- Bruken av fremmedord bør reduseres.
- Det må stå at alle data vil bli behandlet konfidensielt, og at alle som skal ha kontakt med de innsamlede data er underlagt taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonellovens § 21. Det må presiseres om dataene skal anonymiseres eller aidentifiseres. Dette kan erstatte det som er skrevet om taushetsplikt og konfidensialitet i skrivet.
- Det skal stå at studien er godkjent av Regional Komité for Medisinsk Forskningsetikk, Midt-Norge.
- Kontaktinfo, telefonnummer til prosjektleder må oppgis.
- I samtykkeerklæringen skal det kun stå at man har lest informasjonsskrivet og at man samtykker i deltakelse.
- Komiteen ber om at revidert informasjonsskriv sendes til sekretariatet. Komiteens leder får fullmakt til å gi endelig vurdering, og prosjektet må ikke settes i gang før slik vurdering og godkjenning foreligger.

Tilråding:

”Komiteen godkjenner at prosjektet gjennomføres med de merknader som er gitt.”

Med hilsen



Arne Sandvik
Professor
Leder i komiteen



Jacob C Hølen
Seniorkonsulent



Cand. san Anne Dreyer

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St.Olavs Hospital

Vår dato:
11.06.2007

Vår ref.:
4.2007.974

Deres dato:

Deres ref.:

Pårørende som stedfortredende beslutningstakere ved behandlingsunntakelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem.

Vi viser til e-post med reviderte informasjonsskriv og tar disse til etterretning uten ytterligere merknader.

Med hilsen

Arne Sandvik
Professor
Leder i komiteen

Jacob C Hølen
Seniorkonsulent

Appendix 2



Anne Dreyer
Seksjon for medisinsk etikk
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Org.nr. 985 321 884

Vår dato: 29.06.2007

Vår ref: 16824/KH

Deres dato:

Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 26.04.2007. All nødvendig informasjon om prosjektet forelå i sin helhet 18.06.2007. Meldingen gjelder prosjektet:

16824

Pårørende som stedfortredende beslutningstakere ved behandlingsunntakelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem. En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

Behandlingsansvarlig
Daglig ansvarlig

Universitetet i Oslo, ved institusjonens øverste leder
Anne Dreyer

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

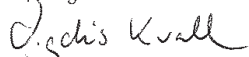
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

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/endringskjema>. 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, 31.07.2011, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Kjersti Håvardstun

Kontaktperson: Kjersti Håvardstun tlf: 55 58 29 53

Vedlegg: Prosjektvurdering

Appendix 3

Pårørende som stedfortredende beslutningstakere ved behandlingsunntatelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem

- En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

Dette er en forespørsel om deltakelse i en undersøkelse som er en del av et doktorgradsarbeid. Hensikten med undersøkelsen er å kartlegge

1. - dagens praksis i forhold til pårørendes deltakelse ved behandlingsunntatelse i norske sykehjem. Fokus rettes mot sondeernæring , PEG (percutan enteroskopisk gastrostomi) og intravenøs væskebehandling. Det er også en hensikt med undersøkelsen å få mer kunnskap om hva som skjer i forkant av avgjørelse om behandlingsunntatelse. Sentralt i dette er å kartlegge lege og sykepleier sine erfaringer med beslutningsprosesser ved livets slutt.
2. - pårørendes *opplevelser og erfaringer* med situasjoner der det besluttes å ikke sette i gang medisinsk behandling eller der livsforlengende behandling blir avsluttet

Kunnskap om disse spørsmålene vil kunne føre til bedre praksis og mer informerte retningslinjer med hensyn til behandlingsunntatelse i omsorgen for syke gamle som ikke er samtykkekompetente. Å ha kunnskap om pårørendes opplevelser av dette, kan gi bedre grunnlag for informasjon og omsorg som reduserer stress og ubehag.

Dersom det gis tillatelse til å gjennomføre prosjektet i sykehjemmet, betyr det at doktorgradsstudent Anne Dreyer som er ansatt ved Høgskolen i Ålesund og tilknyttet Seksjon for medisinsk etikk Universitetet i Oslo, får anledning til å samtale med/intervjue 1 lege, 1 sykepleier og 2 pårørende tilknyttet sykehjemmet om deres erfaringer i forhold til behandlingsunntatelse i sykehjemmet. Det gjøres lydopptak av samtalene.

10 sykehjem er utgangspunktet for denne undersøkelsen. Alle som skal ha kontakt med de innsamlede data er underlagt taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonellovens § 21. Alle data anonymiseres ved prosjektslutt 31.07.2011. Det samme gjelder båndene/datafilene med intervjuene som makuleres når avhandlingen er slutført. Enkelt personer vil ikke kunne gjenkjennes i publikasjoner. Studien er godkjent av Regional Etisk Komité for Medisinsk Forskningsetikk (REK), Midt-Norge og Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datatjeneste (NSD). Universitetet i Oslo er behandlingsansvarlig institusjon.

Du kan få mer informasjon om prosjektet ved å kontakte undertegnende på telefon eller e-post.

Med vennlig hilsen

Anne Dreyer, doktorgradsstudent
45664806/ aod@hials.no

Pårørende som stedfortredende beslutningstakere ved behandlingsunntakelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem

- En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

INFORMASJON OM PRAKTISK GJENNOMFØRING

Takk for positivt svar!

Jeg har lagt ved informasjonsskriv til de som skal intervjues; - en sykehjemslege, en sykepleier og to pårørende.

Noen opplysninger om gjennomføringen:

- Det er du/dere som må ta den første kontakten med de som vurderes som aktuelle. Det ønskelige er om lege og sykepleier har erfaring fra sykehjem over noe tid. Pårørende skal intervjues minst 2 måneder etter dødsfall. Det skal være i forbindelse med naturlig død som en del av høy alder/sykdom. Hensikten er å få deres erfaring fra situasjoner der spørsmål om videre behandling/væske og ernæring har vært tema. Dette trenger ikke å ha vært konfliktfylt. Pårørende skal være ektefelle, barn eller søsken av den døde.
- Når aktuelle personer sier ”ja” til å bli intervjuet, gir du/dere vedkommende konvolutt med informasjon om prosjektet. I konvolutt ligger også et samtykkeformular som de må skrive under og returnere i vedlagt frankert konvolutt til meg. Det er viktig at du/dere ber dem svare raskt når de har bestemt seg for å delta.
- Jeg vil kontakte deg eller eventuelt en annen sykepleier som du delegerer ansvar til innen 14 dager for å høre om du /dere har fått positivt svar fra aktuelle personer.
- Jeg kan gjøre intervjuene fortløpende uten at alle har svart. Når jeg får skriftlig svar fra de du/dere har spurt, tar jeg selv kontakt med dem for å avtale tid for intervjuet/samtalen.

Enkelte har stilt spørsmål til begrepet ”behandlingsunntakelse”. Ordet er mye benyttet innenfor medisinsk etikk, og er mye brukt i situasjoner der det diskuteres om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avbrytes. Begrepet brukes også relatert til medisinsk behandling i sykehus. Ordet ”behandlingsunntakelse” kan ha en noe negativ klang, men det er et mye brukt som norsk oversettelse for ”withholding” og ”withdrawing” relatert til behandling i internasjonal sammenheng.

Ta gjerne kontakt om det er noe som er uklart.

Anne Dreyer
Doktorgradstudent/stipendiat
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Vedlegg:
Informasjon om prosjektet , 4 informasjonskonvolutter

Appendix 4

Pårørende som stedfortredende beslutningstakere ved behandlingsunntak og (eller) tilbaketrekking av livsforlengende behandling i sykehjem

- En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

Til pårørende

Dette er en forespørsel om å delta i en undersøkelse som er en del av et doktorgradsarbeid. Hensikten med undersøkelsen er å kartlegge

3. - dagens praksis i forhold til pårørendes deltakelse i situasjoner der det stilles spørsmål om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avsluttes. Fokus rettes mot sondeernæring og intravenøs væskebehandling
4. - pårørendes *opplevelser og erfaringer* med situasjoner der det stilles spørsmål om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avsluttes.

Kunnskap om disse spørsmålene vil kunne føre til bedre praksis og mer informerte retningslinjer med hensyn til væske- og ernæringstiltak i omsorgen for syke gamle som ikke er samtykkekompetente. Å ha kunnskap om pårørendes opplevelser av dette, kan gi bedre grunnlag for informasjon og omsorg som reduserer stress og ubehag.

Dersom du sier ja til å delta i denne undersøkelsen, betyr det at doktorgradsstudent Anne Dreyer som er ansatt ved Høgskolen i Ålesund og tilknyttet Seksjon for medisinsk etikk, Universitetet i Oslo, får anledning til å intervju deg om hvordan du har opplevd tiden i sykehjemmet i tilknytning til livets slutt hos en av dine nærmeste. Intervjuet vil finne sted i sykehjemmet. Skulle du av ulike grunner ønske å gjennomføre intervjuet et annet sted, kan vi avtale det. Det gjøres lydopptak av samtalen.

10 sykehjem er utgangspunktet for denne undersøkelsen. Lege og sykepleier intervjues også. De intervjues om deres generelle opplevelse av beslutningsprosesser knyttet til livets slutt (de skal ikke uttale seg om konkrete pasienter).

De som skal ha kontakt med de innsamlede data er underlagt taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonellovens § 21. Alle data anonymiseres ved prosjektslutt 31.07.2011. Det samme gjelder båndet/datafilen med intervjuet som makuleres når avhandlingen er slutført. Enkelt personer vil ikke kunne gjenkjennes i publikasjoner. Studien er godkjent av Regional Etisk Komité for Medisinsk Forskningsetikk (REK), Midt-Norge og Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datatjeneste (NSD). Universitetet i Oslo er behandlingsansvarlig institusjon.

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Med vennlig hilsen

Anne Dreyer, doktorgradsstudent/stipendiat
45664806/ aod@hials.no

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Pårørende som stedfortredende beslutningstakere ved behandlingsunntakelse og (eller) tilbaketrekking av livsforlengende behandling i sykehjem

- *En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørendes i forhold til situasjoner knyttet til livets slutt*

Telefonnummer der jeg kan treffes for å gjøre avtale om intervju: _____

Dato: _____

Navn: _____

Dette skjema returneres i den frankerte konvolutten

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- En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

Til sykehjemslege

Dette er en forespørsel om å delta i en undersøkelse som er en del av et doktorgradsarbeid. Hensikten med undersøkelsen er å kartlegge

5. - dagens praksis i forhold til pårørendes deltakelse i situasjoner der det stilles spørsmål om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avsluttes. Fokus rettes mot sondeernæring, PEG (percutan enteroskopisk gastrotomi) og intravenøs væskebehandling. Det er også en hensikt med undersøkelsen å få mer kunnskap om hva som skjer i forkant av slike avgjørelser. Sentralt i dette er å kartlegge lege og sykepleier sine erfaringer med *beslutningsprosesser* ved livets slutt.
6. - pårørendes *opplevelser og erfaringer* med situasjoner der det stilles spørsmål om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avsluttes.

Kunnskap om disse spørsmålene vil kunne føre til bedre praksis og mer informerte retningslinjer med hensyn til væske- og ernæringstiltak i omsorgen for syke gamle som ikke er samtykkekompetente. Å ha kunnskap om pårørendes opplevelser av dette, kan gi bedre grunnlag for informasjon og omsorg som reduserer stress og ubehag.

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- En undersøkelse av dagens praksis der fokus rettes mot erfaringer og opplevelser hos pårørende i forhold til situasjoner knyttet til livets slutt

Til sykepleier

Dette er en forespørsel om å delta i en undersøkelse som er en del av et doktorgradsarbeid. Hensikten med undersøkelsen er å kartlegge

7. - dagens praksis i forhold til pårørendes deltakelse i situasjoner der det stilles spørsmål om det skal settes i gang væske- og/eller ernæringstiltak ved livets slutt, eller der det stilles spørsmål om slik behandling skal avsluttes. Fokus rettes mot sondeernæring , PEG (percutan enteroskopisk gastrotomi) og intravenøs væskebehandling. Det er også en hensikt med undersøkelsen å få mer kunnskap om hva som skjer i forkant av avgjørelse om behandlingsunntatelse. Sentralt i dette er å kartlegge lege og sykepleier sine erfaringer med beslutningsprosesser ved livets slutt.
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10 sykehjem er utgangspunktet for denne undersøkelsen. Sykehjemslege og pårørende intervjues også. De intervjues om deres opplevelse av beslutningsprosesser knyttet til livets slutt.

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Appendix 5

Aktuelle spørsmål i en intervju – guide på bakgrunn av forskningsspørsmålene:

Hvordan *opplever* pårørende beslutningsprosesser ved spørsmål om livsforlengende behandling der pasienten ikke er samtykkekompetent?

Samtalen/intervjuet starter med en oppfordring til pårørende om å fortelle

- hvordan de opplevde å skulle være med å diskutere behandlingen når pasienten ikke lenger var samtykkekompetent
- om egne erfaringer og opplevelser knyttet til situasjoner rundt behandlingsavslutning i sykehjem. Fokus her vil være prosessen både i forkant av aktuelle situasjoner, situasjonen der beslutningene tas og tiden etter dødsfallet.

Kan du fortelle meg.....Jeg er interessert i din opplevelse.....
(Her kommer den pårørende med *sin* fortelling/opplevelse.)

Deretter stilles spørsmål (som det ikke allerede er gitt utfyllende svar på i første runde). Målet er å følge pårørende med disse utfyllende spørsmålene der det faller naturlig. Fokus for samtalen må holdes: beslutningsprosessen der pårørende deltar:

Hvilke *rolle og medvirkning* har pårørende i beslutningsprosesser knyttet til avgjørelser om livsforlengende behandling?

- Hvordan ble de som pårørende inkludert i beslutningsprosessen?
- Hvordan var rammene i situasjonen i forhold til tid?
- Hva slags informasjon ble du gitt?
- Hadde du mulighet til å konferere med andre i familien?

Hvilke *refleksjoner og begrunnelser ligger bak* pårørendes standpunkt i beslutningsprosesser om livsforlengende behandling der pasienten ikke er samtykkekompetent?

- Var spørsmål rund livets slutt diskutert sammen med pasienten mens han eller hun var samtykkekompetent, og hvordan opplevdes eventuelt det?
- I hvilken grad var du i stand til å vurdere hva pasienten ville ha ønsket i situasjonen om han/hun hadde vært samtykkekompetent?

Intervjuguiden skisserer aktuelle spørsmål/områder som skal belyses gjennom forskningsintervjuet. Ser jeg at noen av disse er uehdige å diskutere, vil de justeres. Likeledes kan erfaringer fra pårørende som kommer fram føre til at nye spørsmål legges til for å få mer kunnskap fra de resterende i utvalget. Dette er i tråd med en hermeneutisk tilnærming og bruken av det kvalitative forskningsintervjuet.

Aktuelle spørsmål i en intervjuguide på bakgrunn av forskningsspørsmålene:

Hvilke erfaringer har leger og sykepleiere i forhold til beslutningsprosesser ved spørsmål om livsforlengende behandling der pasienten ikke er samtykkekompetent?

Fokusintervjuet starter med en oppfordring til lege og sykepleier om å fortelle

- om egne erfaringer og opplevelser knyttet til situasjoner rundt spørsmål om livsforlengende behandling (inkludert spørsmål om tilbakeholding eller tilbaketrekking) i sykehjem (hva skjer i slike situasjoner). Fokus her vil være prosessen både i forkant av aktuelle situasjoner, situasjonen der beslutningene tas og tiden etter at pasienten er død

Kan dere fortelle meg.....Jeg er interessert i deres erfaring.....
(Her kommer lege og sykepleier med *sine* fortellinger/erfaringer)

Deretter stilles spørsmål (som det ikke allerede er gitt utfyllende svar på i første runde). Målet er å følge legen og sykepleieren med disse utfyllende spørsmålene der det faller naturlig. Fokus for samtalen må holdes: beslutningsprosessen der pårørende deltar:

Hvilke rolle og medvirkning har pårørende i beslutningsprosesser knyttet til avgjørelser om livsforlengende behandling?

Hvordan inviteres pårørende til en prosess/samtale om spørsmål rundt livsforlengende behandling?

- Hvem av pasientens pårørende deltar?
- Hvem tar initiativet til å diskutere spørsmål rundt livsforlengende behandling (i utgangspunktet)?
- Hvilke preferanse gir pårørende uttrykk for når det gjelder behandling ved livets slutt?
- På hvilken måte sikres det at pårørende tar en stedfortredende rolle på vegne av pasienten?
- Hva med tidsperspektivet – gis det rom/ oppfordres pårørende til å diskutere seg imellom?
- Ble pårørende invitert til samtale sammen med pasienten mens pasienten var samtykkekompetent, og ble eventuelt dette dokumentert?

Hvilke refleksjoner og begrunnelser ligger bak legens/ sykepleieres standpunkt i beslutningsprosesser om livsforlengende behandling der pasienten ikke er samtykkekompetent?

Intervjuguiden skisserer aktuelle spørsmål/områder som skal belyses gjennom forskningsintervjuet. Ser jeg at noen av disse er uheldige å diskutere, vil de justeres. Likeledes kan erfaringer fra pårørende som kommer fram føre til at nye spørsmål legges til for å få mer kunnskap fra de resterende i utvalget. Dette er i tråd med en hermeneutisk tilnærming og bruken av det kvalitative forskningsintervjuet.

Hvordan beskriver du relasjonen til legevakt og sykehus i situasjoner knyttet til spørsmål om livsforlengende behandling der disse er involvert?

Appendix 6

Forslag til videre forskning

Gjennom alle stadiene i denne forskningsprosessen har jeg notert ideer til videre forskning knyttet til livets slutt i sykehjem på bakgrunn av

- manglende forskning å bygge studien på relatert til norske forhold (også internasjonale reviews),
- funn fra intervjuene av pårørende, leger og sykepleiere som ansporet til videre undersøkelser som grenset til mitt prosjekt
- fordypning i medisinsk etikk og lovverket som reiste nye spørsmål (lesing og diskusjoner i fagmiljøet)
- diskusjoner med helsepersonell under konferanser som førte til spissing av nye spørsmål
- mediedebatter som avdekket mulig manglende kunnskap i samfunnet
- statistikk fra ssb som ansporet til uoppdaget kunnskap bak tallene

Informanter	Survey	Observasjon/dybdeintervjuer	Aksjonsforskning
Eldre	Preferanser om livets slutt Døden	Preferanser om livets slutt Døden	Samtaler i helsestasjon for eldre som intervensjon
Pasienter	-	Væske og ernæring Smertelindring Eksistensielle spørsmål Relasjoner ved livets slutt Hvordan oppleves behandling i sykehjem der det besluttes å ikke legge pasienten inn i sykehus Utarbeide redskap for å fastlegge demente pasienters samtykkekompetanse som gradert størrelse	Væske og ernæring Smertelindring Eksistensielle spørsmål Relasjoner ved livets slutt Innkomstamtaler med fokus på livets slutt Beslutningsprosesser Utarbeide redskap for å fastlegge demente pasienters samtykkekompetanse som gradert størrelse
Pårørende	Kartlegging av kunnskap om livets slutt Kartlegging av preferanser for egen rolle og ansvar knyttet til beslutningsprosesser	Hvordan oppleves behandling i sykehjem der det besluttes å ikke legge pasienten inn i sykehus	Innkomstamtaler med fokus på livets slutt Beslutningsprosesser
Leger	Kartlegging av kunnskap om livets slutt	Dybdeintervjuer av leger i sykehus ad innleggelse av sykehjemspasienter	Implementering av "Veilederen" i sykehjem Beslutningsprosesser
Sykepleiere	Kartlegging av kunnskap om livets slutt	Dybdeintervjuer av sykepleiere i sykehus ad innleggelse av sykehjemspasienter	Implementering av "Veilederen" i sykehjem Beslutningsprosesser
Organisasjon	Kaste ballen til fagmiljøet	Deltakende observasjon i sykehus og sykehjem knyttet til mellomledernivå	

Appendix 7

Preliminary plan

Framdrift	H 2007	V 2008	H 2008	V 2009	H 2009	V 2010	H 2010	V 2011	Kommentar
Div. søknader									
Dybdeintervju									
Dataanalyse									
Artikkel 1									Publisering
Artikkel 2									Publisering
Artikkel 3									Publisering
Forskerkurs									Egen plan utarbeides
Teoretisk ”kappe”									Ferdigstilles september-10

ERRATA

Page 29: Reference to Søren Holm is (Part VI in: Harris 2001).

Page 104: Textbox 4.7 should be Textbox 6.1

