Ethical challenges, decision-making and end-of-life care in nursing homes

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Ethics is nothing other than reverence for life.

Albert Schweitzer

Figure 1: Occhio (eyes)

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Different perspectives and views

Investigating the different perspectives of all stakeholders can provide us with a more detailed and diverse picture of any topic, and thus enhance knowledge and understanding. According to Thorne (2008: p.74), an important presumption of interpretive description is that there is not one true 'reality', but that human experience consists of multiple constructed realities that may even be contradictory.

Examples of different viewpoints on ethical challenges in nursing homes, as presented in this thesis from the research, are:

A resident:

> It is so good to be able to talk to someone…old fashioned comfort…To comfort, that is what has been lost. They (the staff) have forgotten how to comfort…That is what I feel. The only thing they (the nurses) do is wash people, not comfort them.

A member of the nursing home staff:

> In my opinion lack of time for every patient is a big problem because of lack of resources. Some patients do get too little stimulation. Just to be with them more often and to take the patients to activities can give them a better quality of life.

A relative:

> It is not clear if she wants the same that we want…I do not want to…I cannot decide.

A member of the nursing home staff:

> I think we have to be careful that what the relatives say or want is the residents will. If the staff and the relative do not agree and stand against each other…probably one should hear what the resident themselves wants.

A researcher:

> There was one nurse who had to feed four residents. The nurse felt that this was an ethical dilemma because she did not know who to feed first or whether it was appropriate to feed four people at the same time.

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List of abbreviations

ACP	Advance care planning
ADLs	Activities of daily living
CPR	cardiopulmonary resuscitation
CS	Caritas Socialis
EOL	end-of-life
KS	Kommunesektorens organisasjon (The Norwegian Association of Local and Regional Authorities)
NHS	National Health Service
PEG	percutaneous endoscopic gastrostomy tube
PPC	preferred priorities for care
REM	resident ethics meeting
WHO	World Health Organisation

Definitions

Advance Care Planning

- "ACP is the process of discussion between an individual and their care provider, and this may also include family and friends." (Thomas, 2011: p. 9).
- "Advance care planning (ACP) aims to help patients establish decisions about future care that take effect when they lose capacity." (Mullick et al., 2013: p. 2).
- "ACP is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future. If they wish, they can put on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for that care or treatment (whether professional staff or family carers) in the event that they lose the capacity to decide as their illness progresses. ACP has three possible outcomes: - a verbal or written advance statement of wishes and feelings, beliefs and values - a verbal or written advance decision to refuse treatment. (ADRT) (must be written with specific requirements if refusing life-sustaining treatment) - a lasting power of attorney."
  (NHS England, 2014: p. 4).
- "ACP is defined as a process of discussion between an individual and their care provider, irrespective of discipline. If the individual wishes, their family and friends may be included." (Holman and Hockley, 2010: p. 10).

Decision-making

- "The action or process of making important decisions." (Oxford Dictionaries, 2016).

End-of-life care

- "End-of-life care is support for people who are in the last months or years of their life." (NHS Choices, 2015).

Ethical challenge

- "An 'ethical challenge' arises when there is doubt, uncertainty or disagreement about what is right or good." (Hem et al., 2014: p. 1).

Ethical dilemma

- "By definition, an ethical dilemma involves the need to choose from among two or more morally acceptable options or between equally unacceptable courses of action, when one choice prevents selection of the other." (Ong et al., 2012: p. 11).

Ethics

- "Ethics is nothing other than reverence for life." (Albert Schweitzer).
- Ethics can be summarised as the question what is good. (Heller, 2009: p. 158).
- Ethics is the science or foundation of morality. (Maio, 2012: p.2).
- Ethics is the moral responsibility that we have for others. (Clancy, 2007: p. 72).

Nursing home

- "A nursing home is a facility with a domestic-styled environment that provides 24 hour functional support and care for persons who require assistance with activities of daily living (ADLs) and who often have complex health needs and increased vulnerability. Residence within a nursing home may be relatively brief for respite purposes, short term (rehabilitative), or long term, and may also provide palliative/hospice and end-of-life care." (Sanford et al., 2015: p. 183).

Shared decision-making

- "Shared decision-making is an approach where clinicians and patients make decisions together using the best available evidence…Shared decision making respects patient autonomy and promotes patient engagement." (Elwyn et al., 2010: p. 1).

Systematic ethics work

- "…includes an organisation's systematic use of different measures, tools and places to enhance ethics discussions and ways to handle ethically difficult situations and choices in nursing homes, e.g. ethics education, ethical deliberation, different arenas for ethics discussions, ethics consultants and ethics committees." (Paper III: p.2).

Scientific environment

The work presented in this thesis was carried out from 2009 to 2016 at the Department of Clinical Medicine, University of Bergen, Norway, Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital Bergen, Norway and the Department of Anaesthesiology, Intensive Care, Palliative Medicine and Pain Therapy, HELIOS Klinikum Schleswig, Germany.

The research project was mostly carried out part-time, in addition to clinical work as a consultant in palliative medicine and nursing home medicine. The PhD candidate was employed in the project's starting phase at Bergen Red Cross Nursing home and later at the Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital Bergen, Norway.

The PhD candidate was admitted to the Department of Clinical Medicine, University of Bergen and followed the organised research training programme in doctoral education at the Faculty of Medicine and Dentistry, University of Bergen. As part of the research training the PhD candidate attended PhD courses and regular PhD meetings at the University of Bergen, the Bergen University College, the University of Oslo and the Faculty for Interdisciplinary Research and Further Education, Faculty of University Klagenfurt, Vienna, Graz, Austria.

The main supervisor was Professor Jan Henrik Rosland from the Department of Clinical Medicine, University of Bergen and Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital Bergen, Norway.

Co-supervisors were Professor Eva Gjengedal from the Department of Global Public Health and Primary Care, University of Bergen, Norway and Molde University College, Molde, Norway and Professor Andreas Heller from the Institute of Palliative Care and Organisational Ethics, IFF (Faculty for Interdisciplinary Research and Further Education), Faculty of University Klagenfurt, Vienna, Graz, Austria.

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Acknowledgements

A research project is like a journey to explore a foreign country and previously unknown territory. According to Kvale´s *traveller metaphor* (Kvale, 1996: p. 4) the interviewer can be seen as a traveller who tells the story of his journey and his conversations with the people met during this journey. In the years of this research project I felt like a traveller on a journey to various parts of the nursing home world and I have learned more about the unknown territories of this world through encounters with different people with differing views.

First of all I want to express my deep gratitude to the nursing home residents, relatives and staff for sharing their thoughts and stories with me. They provided me with new insights into the nursing home world through their perspectives. It was a pleasure and an honour that many of the residents shared their thoughts about life and death in nursing homes with me.

As a successful research project is based on good ideas, hard work and good supervisors, I am very grateful for my excellent supervisors who supported my work in the best way possible.

My main supervisor, Jan Henrik Rosland, was always available and brilliant in giving advice and help whenever needed. With his kind, calm, friendly and humorous manner he encouraged me to continue the project over the years. We had many interesting discussions not only about science and the research project but also about the important things of life in general.

Co-supervisor Eva Gjengedal guided me through the jungle of qualitative enquiry and encouraged critical reflection on our findings. She was outstanding as a co-worker and counterpart for scientific reflections.

Co-supervisor Andreas Heller influenced my way of thinking about ethics in general and especially my view on the role of ethics in palliative care and elderly care. With his expertise in ethics he questioned the work from the start, and thus helped me to reflect the framework and the findings of the studies critically.

I am very thankful to my co-workers Gerda Schmidt and Arnd May for their support and our useful discussions about the study design, the data collection, the data analysis and the revision of the manuscripts. Many thanks also to Kristina Nordstrønen, Karoline Nordstrønen and my sister Henny Bollig for help with the transcriptions of the interviews.

I am especially thankful to the Norwegian Extra Foundation for Health and Rehabilitation, which made the whole research project financially possible through EXTRA funds (grant nr. 2008/2/0208).

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I also thank the University of Bergen which made open access publishing possible by funding the fees for all the four papers included in this thesis.

I am thankful that the Norwegian Red Cross and the management and staff of Bergen Red Cross Nursing Home supported the research project even before its official start. The idea for the research project was born in and grew through discussions with many colleagues from the Bergen Red Cross Nursing Home. Thank you as well to my colleagues from the Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital Bergen, Norway for inspiring discussions and helpful support.

A warm thank you goes to my former colleagues, co-workers and supporters, Reidun Førde, Reidar Pedersen, Elisabeth Gjerberg and Ole Frithjof Norheim, who encouraged me to start the project and with whom the first literature searches, publications on related topics and the first draft of the research proposal were created.

Last but not least many thanks also to all the people who are not addressed personally who encouraged and supported me by different means and who provided me with important information or inspiration during discussions and meetings connected to the topics of my research.

Without the support, the patience and the understanding of my wonderful family, my wife Kirsten and my sons Peer and Nils, the project would not have been possible. Although they had to endure me being absent from home and the family life due to research and journeys to conferences they encouraged me to finish the work on this thesis over the years. I am really very grateful for their love, understanding and for being with me.

Summary (Abstract)

Background: Many nursing home residents suffer from multimorbidity, frailty and dementia. A number of ethical challenges are connected to living and dying in nursing homes.

Objective/purpose: This thesis investigates ethical challenges, decision-making and end-of-life care in nursing homes. The research focuses on the views of residents, relatives and staff on these topics.

Materials and methods: The studies relied on a mixed methods approach. Qualitative research was based on qualitative description and interpretive description. In-depth interviews with nursing home residents and focus group interviews with relatives and nursing home staff were conducted. Questionnaires were used to collect data on ethical challenges in nursing homes and to document ethics discussions in five institutions in Austria, Germany and Norway.

Results: From the perspective of residents and relatives, ethical challenges in nursing homes are mostly connected to everyday ethical issues. Residents trust relatives, physicians and nurses to make important decisions on their behalf, but many relatives do not know the resident's wishes, and experience decision making as a burden. Many staff members describe ethical challenges as a burden and appreciate systematic ethics work. The most frequent ethical challenges are lack of resources, end-of-life issues, advance care planning and coercion. Ethics meetings can help to reach consensus in over three-quarters of cases. To implement systematic ethics work in nursing homes, time for reflection, ethics education and support from the management are needed. Residents were entirely absent in the documented ethics meetings.

Conclusion and consequences: Both end-of-life issues and everyday ethical challenges are important in nursing homes. As relatives are often insecure about the wishes of residents, preparatory conversations about treatment preferences and advance care planning should be offered. Systematic ethics work should be implemented in all nursing homes. The regular participation of relatives, physicians and residents in ethics discussions should be encouraged. The participation of residents may strengthen their feelings of autonomy and dignity.

Future perspectives: Further research should aim to investigate strategies to improve the participation of residents in ethics discussions. Research into the views of residents with cognitive impairment is lacking, due to methodological and ethical barriers. The advantages and disadvantages of different models for systematic ethics work in nursing homes need to be explored in more detail.

List of articles

This thesis is based on the following papers.

Paper I

Bollig G, Gjengedal E, Rosland JH. Nothing to complain about? – Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing Ethics* 2016, 23(2): 142-53. doi: 10.1177/0969733014557719. Epub 2014 Dec 8.

http://nej.sagepub.com/content/23/2/142.full.pdf+html

Paper II

Bollig G, Gjengedal E, Rosland JH. They know! - Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine* 2016, 30(5): 456-70. doi: 10.1177/0269216315605753. Epub 2015 Sep 22.

http://pmj.sagepub.com/content/30/5/456.full.pdf+html

Paper III

Bollig G, Schmidt G, Rosland JH, Heller A. Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives. *Scandinavian Journal of Caring Sciences 2015,* 29(4): 810-23. doi: 10.1111/scs.12213. Epub 2015 Apr 28.

http://onlinelibrary.wiley.com/doi/10.1111/scs.12213/epdf

Paper IV

Bollig G, Rosland JH, Gjengedal E, Schmidt G, May AT, Heller A. A European multicenter study on systematic ethics work in nursing homes. *Scandinavian Journal of Caring Sciences 2016.* doi: 10.1111/scs.12373. Epub 2016 Aug 26.

http://onlinelibrary.wiley.com/doi/10.1111/scs.12373/epdf

1. Introduction

> "Most decisions in the nursing home are made by someone other than the resident."
> (Hayley et al., 1996: p. 250)

1.1 Background

Worldwide, the population is ageing and the number of people more than 65 years old, and people in need of long-term care are increasing (Robinson and Reinhard, 2009; Nowossadeck, 2013, Kolb and Weissbach, 2015). Life expectancy is increasing and the number of people over 85 years of age, and even those who will reach an age of 90 or 100 years, is rising (Christensen et al., 2009; Vaupel and Kistowski, 2005). According to Christensen et al. (2009), there is evidence that people will live longer, with fewer disabilities and functional limitations (Christensen et al., 2009). In contrast, a recent study of 112 German centenarians showed that they had a average of five diseases; many had impaired vision or hearing (94%), decreased mobility (72%), and cardiovascular diseases (57%), and 36% suffered from pain that they themselves rated as unbearable (Jopp et al., 2016). Demographic change will lead to an increase in people suffering from dementia, multimorbidity and frailty, with a high demand for nursing home care and end-of-life care (Ferri et al., 2005; Peters et al., 2010; Clegg et al., 2013; Cesari et al., 2016). The number of people with dementia has been estimated to reach 81.1 million worldwide by the year 2040 (Ferri et al., 2005). This demographic change is sometimes addressed negatively in the media and in the scientific literature, and has, for example, been called a "silver tsunami" (Dunn and Alici, 2013; Bartels and Naslund, 2013) Other negative and even discriminating expressions are also used. This can be seen as an "ageism" that is connected to the neglect and mistreatment of older people (Stevens et al., 2013; Band-Winterstein, 2015). Butler (1990) called ageism a disease. He reminds us that we should not discriminate against older people:

> "Old age is dynamic, not static. Aging is not inevitably associated with the devastation of mind and body. It is necessary to develop and apply the conceptual strategy of extracting

> aging as such from the host of variables associated with growing older and with older people. Dispelling the myths of age, sameness, senility, unproductiveness, dependence, inflexibility, sexlessness - also forges a more positive set of images of age. On the other hand, we see a minority - but a most significant minority, indeed – of those who are in great need of both our humanity and our science."
>
> (Butler, 1982)

"Ageism" and the current existing "gerontophobia", anxiety about old-age, are probably connected to "thanatophobia", an anxiety about death and dying, in our modern society (Jacobsen, 2013).

All human beings have to die, and will go through a period that can be called "the end of life" (Loewy and Springer Loewy, 2000), where they need help and will depend on others. At present many elderly people live in nursing homes that will be the place of death for many of them. Many nursing home residents are multimorbid, suffer dementia and also suffer from a variety of symptoms within their last year of life. According to the World Health Organisation, palliative care for older people should be prioritised in public health care, and available to all people in need, including those with non-malignant diseases, and older people (World Health Organisation, 2004; World Health Organisation, 2011; Dalkin et al., 2016).

In order to meet the future care needs of the so-called "baby boomers", which will be required from the year 2030, the organisation of community services and insurance systems has to adapt to the challenge of caring for large numbers of frail elderly people (Knickman and Snell, 2002). Older people need personal care (Knight, 2001) and a balance between specialised and general healthcare approaches, based on justice and patient perspectives (Pedersen et al., 2008). Kojer and Schmidl (2011) demand that the basic communication needs of (older) people be recognised as a human right. With the increase in the total number of nursing home residents, there will be an increasing shortage of resources and an increase in the number of ethical challenges. Another concern is that, together with the increase in life-expectancy, the dying process may become longer, and may take years, as with dementia, for example (Gronemeyer and Heller, 2014; Kojer and Schmidl, 2011).

Unfortunately, the potential for care within individual families will not increase in the future. This may lead to an even higher demand for professional carers, in contrast to the expectation that there will be fewer available health care personnel, such as geriatricians, in the future (Nowossadeck, 2013; Lee and Sumaya, 2013).

In order to meet the future challenges of this demographic change, a public debate about ethical challenges and the prioritisation of elderly care is needed on all levels, in countries, in communities, in neighbourhoods and in the health care services, and ethics discussions in nursing homes should be a part of this discourse. This scientific and public discourse must include ethical challenges, decision-making and end-of-life care in nursing homes.

Structure of this thesis

The theoretical background and existing results from empirical research are presented under their respective headings in the following sections. Part 1 provides an overview of the philosophical background and the theoretical framework, and depicts current practice and existing scientific literature, sorted thematically. The literature search was last updated in June 2016. In order to enable the reader obtain basic information about the sources while reading the thesis, the references are marked in the text with the author names and publication year. The reference list is sorted in alphabetical order for easy access.

1.2 Ethics and its importance in the nursing home world

Many different definitions of morality and ethics have been suggested by different philosophers, theologists, ethicists, etc. throughout history. Today, autonomy is very important in biomedical ethics and principal-based ethics. The principle-based approach to biomedical ethics, as described by Beauchamp and Childress (2009), has become widespread in many countries. Their detailed definition of ethics is:

> “Ethics is a generic term covering several different ways of examining and understanding the moral life. Some approaches to ethics are normative, others nonnormative…General normative ethics attempts to answer the question, “Which general moral norms for the guidance and evaluation of conduct should we accept, and why?” Ethical theories attempt to identify and justify these norms, which are often called principles…There are two types of

> nonnormative ethics. The first type is descriptive ethics, which is the factual investigation of moral beliefs and conduct. It uses scientific techniques to study how people reason and act…The second type is metaethics, which involves analysis of language, concepts, and methods of reasoning in normative ethics. For example, metaethics addresses the meanings of terms such as right, obligation, virtue, justification, morality, and responsibility… Descriptive ethics and metaethics are nonnormative because their objective is to establish what factually or conceptually is the case, not what ethically ought to be the case or what is ethically valuable."
>
> (Beauchamp and Childress 2009, pp. 1-2).

Other definitions of ethics are listed on page 10. Although many people use morality and ethics synonymously, there is a differentiation between morality and ethics. Whereas morality is the sum of an individual's beliefs, such as about good and bad, wrong and right; ethics is reflection about good and bad, moral beliefs and how to act towards others (Springer Loewy, 2008). To act can mean both to act in the sense of doing something, but also can mean to let others do. This may include letting others decide. Ethics deals with the great questions of human life, such as "How should we live a good life?", "What is right and what is wrong?". The question of how to live a good life goes back to Aristotle, who saw it as most important to strive for a lucky life and to aim to live well together with others (Aristotle, 1999; Düwell et al., 2006). One major problem with moralities is that they are not universal but are often only shared among a certain group or culture (Beauchamp and Childress, 2009). Beauchamp and Childress therefore introduced their principles of biomedical ethics in 1977, which may be used across different countries and cultures (Beauchamp and Childress, 2009).

Although the main theme of reflection on ethics from ancient times has been how a person could live a good life, these days organisations have become very important and powerful, and therefore ethical reflection has to include ethics in organisations and between different organisations. Organisational ethics is the systematic reflection of moral questions and ethical analysis of decisions that are relevant tor the organisation. There has been a shift from individual ethical reflection to collective ethical reflection within organisations, and a focus on the ethical culture of an organisation as a whole (Heller and Krobath, 2010; Springer Loewy, 2008).

Applied ethics plays a role both in the healthcare service and the community (Worthington, 2005). This applies especially to health care personnel and nursing home staff. Although daily life is full of ethical elements and ethical challenges, most people are unaware that we have to deal with ethical issues in many everyday situations. A feeling of discomfort can be a sign of an ethical dilemma situation (Slettebø and Bunch, 2004). An awareness of ethical issues is important, and is the first step to handling ethical challenges - or as Peile (2001) noted “you don't perceive what you don't perceive.” It thus seems to be important that both the public and nursing home staff have knowledge of ethics and participate in ethical reflection. Time, places and suitable approaches to ethics reflection are also needed, adapted to local needs in nursing homes (Bollig et al., 2009; Hallwirth-Spörk et al., 2009; Bollig, 2010a; Gjerberg et al., 2010; Bockenheimer et al., 2012; Lillemoen and Pedersen, 2012; Bollig et al., 2016). Several authors have provided overviews and different practical approaches to implementing ethics in the health care system and nursing homes (Jonsen et al., 2002; Ruyter et al., 2007; Steinkamp and Gordijn, 2010; Heller and Krobath, 2010; Bockenheimer et al., 2012)

Ethics is often reduced to decisions that have to be made with an amount of uncertainty, but it is also about the everyday questions of leading a good life, and has moved from clinical ethics to political ethics (Schuchter and Heller, 2016). Ethics is also about care for others in need, as defined by Levinas (2006) as the “humanism of the other” and in care-ethics, as described by Gilligan (1988) and Conradi (2001). Other concepts such as “care-ethics” (Conradi, 2001) or Levinas’ concept of the “other” (2006) and the “ethical claim” (Løgstrup, 1956) probably also need to be discussed and integrated in order to establish a concept of nursing home ethics dealing with many residents with cognitive impairment and complex problems and dilemmas, and the need for assistance to make important decisions, such as in end-of-life decision-making. According to Heller and Schuchter (2013) the ancient picture of the ethics of a good life is that of people living well together in the world. People without orientation, such as people suffering from dementia, need support from others who have an ethical orientation on how to live a good life, and probably also how to die well.

In summary, ethics has many elements and definitions, and plays an important role in everyday life. Reflection on ethics is therefore useful and needed, both in everyday life and in the nursing home world.

1.2.1 Ethical challenges and problems in nursing homes

Chichin and Olson (1995, p. 183) stated more than 20 years ago, that

> "The incidence of ethical dilemmas in long-term care settings is likely to increase."

Ethical issues in long-term care include the placement of people, allocation of scarce resources, autonomy issues, informed consent, privacy and dilemmas around end-of-life treatment (Olson et al., 1993). A survey of ethical dilemmas from 225 U.S. nursing homes showed that the most common problems encountered were: assessing a resident's decision-making capacity (79%), do not resuscitate decisions (78%), do not hospitalise decisions (77%), tube feeding issues (74%), implementing advance directives (70%), ascertaining resident health care preferences (68%), identifying surrogate decision-makers (59%) and withholding/withdrawing life sustaining treatments (48%) (Weston et al., 2005). Initiating and/or withdrawing (or) withholding tube feedings was the most frequent reason for case consultation requests (Weston et al., 2005). According to a review of the literature, two major groups of ethical issues in nursing homes can be identified. The first group can be described as "everyday ethical issues", such as autonomy, informed consent, use of restraints, offensive behaviour and refusing medication, food and bathing. The second group consists of "big ethical issues" mostly dealing with life or death matters, including decisions to sustain or withdraw life-sustaining treatment (including artificial nutrition and hydration), to hospitalise a patient or not, to treat or not (e.g. with antibiotics), to provide curative or palliative care (Bollig, 2010a; Bollig et al., 2009). When the research project presented in this thesis began, in 2009, some nursing homes had already established ethics committees and pilot projects with ethics reflection and ethics consultation in nursing homes were ongoing in some countries (Reitinger et. al., 2007; Bockenheimer-Lucius, 2007; Bockenheimer-Lucius and May, 2007; Hallwirth-Spörk et al., 2009; Schmidt, 2009).

1.2.2 Decision-making and nursing home end-of-life care

Nursing home physicians describe the importance of consensus about prognosis and the development of a palliative care plan as the most important features in end-of-life care (Bern-Klug, 2004).

Decision-making for patients in stages of terminal disease should include communication and the discussion of possible treatment options with patients, relatives and colleagues (Hermsen and ten Have, 2005). Dialogue and communication with the patient are crucial in care that protects dignity among nursing home patients (Chochinov, 2007). The preservation of dignity may even lead to less suffering in terminally ill patients (Chochinov et al., 2002). Dignity-conserving care can thus contribute to relief distressing symptoms.

It has been said that physicians often show a paternalist attitude, and act as surrogates for incompetent patients, although relatives are available and are able to make decisions on behalf of the patients (Buchanan and Brock, 1998). Living wills, advance directives and proxy appointments can be used to ascertain a patient's wishes (Olson, 1993). In addition, to aid treatment decisions for future events, advance care planning can also help a patient and their family to prepare for death and dying. Both the patient and their relatives should therefore be involved in advance care planning (Martin et al., 2000). More than 75% of people living in Norwegian nursing homes suffer from dementia (Engedal and Haugen, 2004). In advanced dementia patients cannot make decisions on their own anymore, and so physicians, nurses and relatives have to make difficult decisions for these patients, often without knowing the patient's will. Ethics consultation and ethics committees can be useful tools for decision-making in advanced dementia (Gerhard and Bollig, 2007; Bollig, 2010a).

About 70% of elderly patients want their family and physicians to make decisions about resuscitation if they were to lose decision-making capacity (Puchalski et al., 2000). Elderly patients prefer shared decision-making about CPR preferences (Frank et al., 2003). A model of collaborative surrogate decision-making has been suggested by Rosenfeld et al. (2000). In contrast, health professionals have complained that they have to make decisions without input from the patients (Schaffer, 2007). Disagreement between relatives of incompetent patients and staff members in nursing homes about the medical treatment of life-threatening disease is common. This was shown in a study including interviews with nursing home residents (101 competent and 106 incompetent), 142 relatives and 207 staff members where it was concluded that treatment preferences should be discussed before an acute situation occurs, especially in incompetent patients (Moe and Schroll, 1997). In discussions with patients and relatives, physicians should focus on acceptable outcomes rather than only discussing life-sustaining treatment options (Rosenfeld et al., 2000).

1.2.3 The resident's perspective

The patient's perspective on end-of-life care has been studied by Singer et al. in 38 long-term care patients who participated in in-depth, open-ended, face-to-face interviews (Singer et al., 1999). They identified five domains of quality of end-of-life care:

- "receiving adequate pain and symptom management,
- avoiding inappropriate prolongation of dying,
- achieving a sense of control,
- relieving burden,
- strengthening relationships with loved ones"

A qualitative study involving interviews about ethical problems in the end-of-life care of elderly people, their relatives and health care professionals from Norway showed that all participant groups experienced ethical problems involving the adequacy of healthcare care for elderly Norwegians (Schaffer, 2007). All three groups reported ethical problems concerning communication and conflicts between patients, relatives and health care professionals. Although elders in this study were concerned about decision-making for end-of-life care, none had talked about this with their physician (Schaffer, 2007). A methodological weakness in this study was that the English language was used to interview Norwegian patients. English is a foreign language for Norwegians, and Norwegian elders may have struggled to explain their feelings and emotions. The elderly who were interviewed lived at home and not in nursing homes. The perspective of elderly people living in nursing homes might be different.

Nursing home ethics committees seldom involve residents or their relatives as participants. A study from the U.S. showed that only 8% of nursing home ethics committees included patients, and 15% included family members, whereas 93% included administrators and 82% included medical directors as members of the committees (Glasser et al., 1988). From a palliative care ethics perspective, important choices should be discussed early with both patient (nursing home resident) and family (see chapter 1.3.2).

1.3 Palliative care and patient-centred care

The subject of this thesis cannot be discussed from the perspective of ethics and medical ethics alone but has to take the demographic change and the palliative care perspective into account. Therefore palliative care and patient-centred care are addressed in the following chapter.

Two names are strongly connected with the international development of the hospice movement and palliative care: Cicely Saunders and Balfour Mount.

Cicely Saunders: Hospice movement and total pain concept

Dame Cicely Saunders (1918 - 2005) is the main founder of the modern hospice movement. She established St Christopher's Hospice in London in 1967, participated in research in the field of palliative care, and described the "total pain" concept. Saunders was educated as a nurse, social worker and physician. The hospice movement is based on hospice philosophy. Hospice philosophy accepts death as a normal part of life and neither aims to postpone nor to hasten it. It focuses on the person, not on only the disease of a patient, and is family-centred in including both the patient and their family in decision-making. A central aspect of hospice philosophy is "death with dignity" and to provide humane and compassionate care to patients at the end of life, aiming to enable them to live as fully as possible until death (Saunders et al., 2003; American Cancer Society, 2016). Hospice philosophy is strongly connected to values of autonomy and individuality (Thoresen, 2003). Cicely Saunders' idea was that people should have an autonomous life with dignity until the end-of-life, and she stands for a patient-centred approach and multi-professional teamwork in palliative care. Saunders' work was based on her Christian belief (Saunders et al., 2003; Pleschberger, 2007a, Cicely Saunders Institute, 2016). The "total pain" concept includes physical, emotional, social, and spiritual aspects of distressing symptoms, and acknowledges the human being in a holistic way with all existing facets of human life. Saunders reminded healthcare workers to also consider the care of needs of the family:

> "How people die remains in the memory of those who live on." (Saunders, 2016).

Balfour Mount: Palliative care

Balfour Mount (b 1939) has been called the father of palliative medicine in Canada. He founded the first palliative care ward in Canada in 1973. Mount focused on patient needs and whole-person palliative care for body and soul, instead of simply curing the patient's disease. As he was a cancer survivor himself, this probably inspired his later work. He introduced the term "palliative care" to the world based on the idea that a term should be applicable and understandable both in English and French. (McGill News, 2016; Pleschberger, 2007a).

The World Health Organisation (WHO, 2016) has defined palliative care as follows:

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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:
>
> - provides relief from pain and other distressing symptoms;
> - affirms life and regards dying as a normal process;
> - intends neither to hasten or postpone death;
> - integrates the psychological and spiritual aspects of patient care;
> - offers a support system to help patients live as actively as possible until death;
> - offers a support system to help the family cope during the patients illness and in their own bereavement;
> - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
> - will enhance quality of life, and may also positively influence the course of illness;
> - is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."

One main feature of palliative care is a radical patient-centred approach (Heller and Knipping, 2006). The needs of both patient and family are the very centre of all palliative care efforts. This is illustrated in Figure 2.

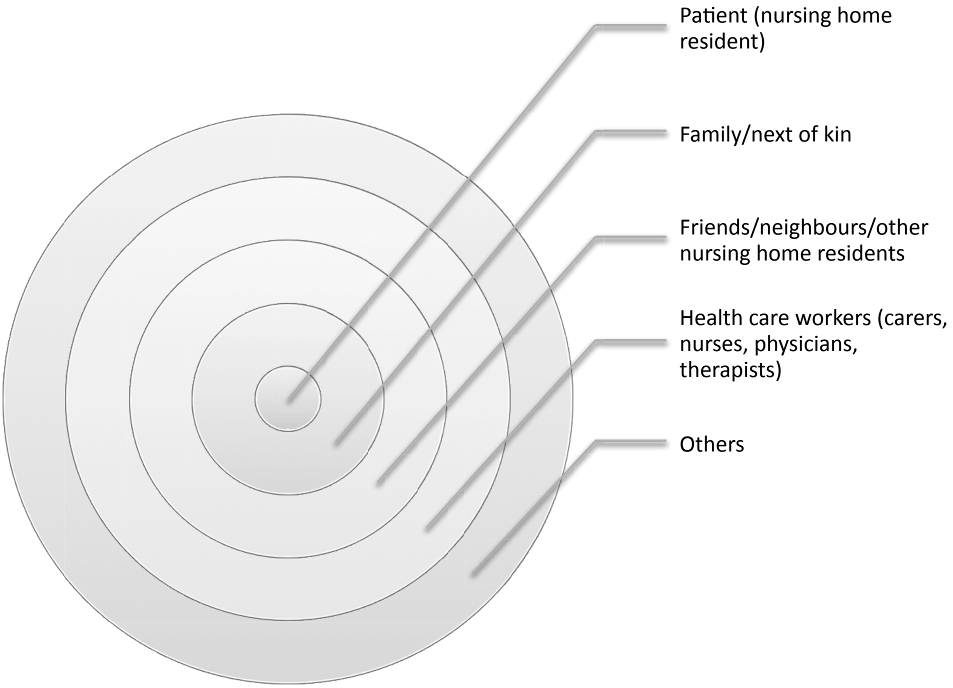

Figure 2: The patient (nursing home resident) and their social network

An important part of palliative care is ethical decision-making. Palliative care comprises nine dimensions (as described by Gomez-Batiste et al., 2009):

1. Care of patients and families: evaluation of needs
2. Care of patients and families: comprehensive therapeutic plan
3. Teamwork
4. Ethical decision making
5. Monitoring of clinical and organisational results
6. Education and training
7. Research
8. Continuous quality evaluation and improvement
9. Links to society

Palliative care is based on a multidimensional team approach, including both professionals and lay people, such as relatives, neighbours and volunteers. This is illustrated in Figure 3 (adapted from Bollig, 2010d).

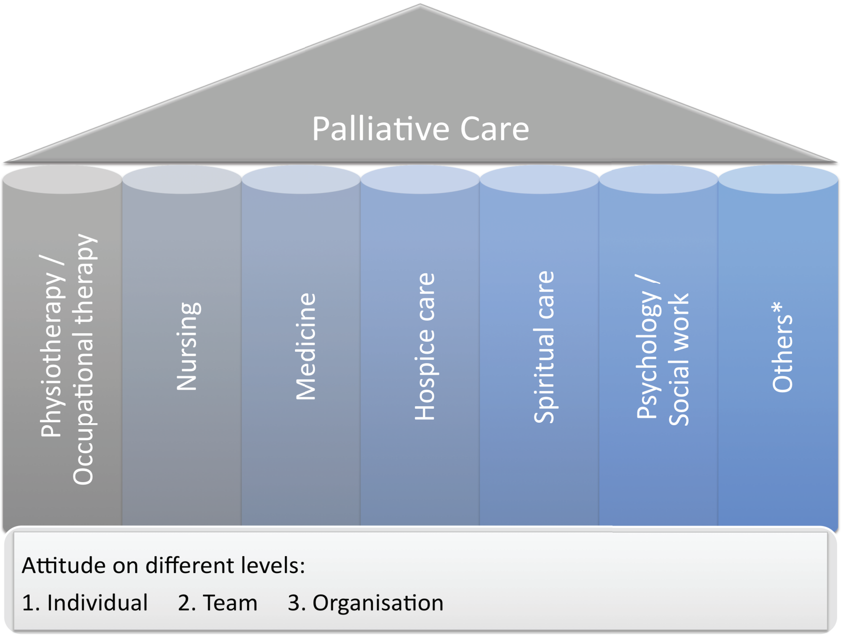

Figure 3: The foundation of palliative care

*Volunteers, administration, other professions and relatives/next of kin

The terms 'palliative care', 'end-of-life care' and 'terminal care' are often used as synonyms, although they have differing meanings. The term 'terminal care' should be restricted to the relatively short lifespan before death, whereas 'palliative care' has a broader meaning, including care for patients with chronic illnesses and a life expectancy of months, or even years. Accordingly the term 'palliative care including end-of-life care' might in general be more appropriate for nursing home residents. The main requirements of palliative care are to support the patient to live to the end with as much quality of life as possible and to enable a "good death" as far as possible.

The American Institute of Medicine defined a good death as follows:

> “a decent or good death is one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients and families wishes; and reasonably consistent with clinical, cultural and ethical standards”
>
> (Institute of Medicine, 1997).

The concept of “orchestrating death” has been described by Loewy and Springer Loewy (2000). This sees professionals (nurses, physicians, etc.) as having the role of conductors, and means that they must know and understand a patient in order to arrange their death.

The concepts of patient-centred care and patient-centred medicine stand for the acknowledgement of, and respect for, the patient’s perspectives, and involves the patient’s needs, preferences and unique values. Patient-centred medicine aims to ensure that “the patient remains the true focus” (Laine and Davidoff 1996, p.155). Care must be patient-centred, but research should also be patient-centred (Pignone, 2012). This means that research should aim to improve a patient’s life and to focus on what is important from the patient’s perspective. According to Pignone (2012, p. 2) patient-centred research should become the “norm rather than the exception”. A patient-centred quality improvement strategy has shown potential to improve the quality of end-of-life care (Powis et al., 2004). Palliative care and hospice philosophy are based on patient-centred care and aim to include the patient and their next of kin in a more “holistic” approach.

Other people have made important contributions with particular impact on patient-centred care and palliative care, and thus on the framework of this thesis. These are summarised briefly.

Alexander Romanowitsch Lurija: Romantic science

Alexander R. Lurija (1902 - 1977) was a Russian neuropsychologist and physician, and the founder of modern neuropsychology. He worked with patients with traumatic brain injuries and published famous case studies about them (Lurija, 1987; Lurija, 1993). The individual human being was important to him:

> “In the care for sick people we must not forget that we face an individual human life, and not a statistical abstraction that can confirm or disprove our theories.” (Lurija, 1993).

Oliver Sacks: The whole patient in the centre

Oliver Sacks (1933 - 2015) was a neurologist and researcher who became famous for his case studies of patients with neurological syndromes, whom he described in detail and with great compassion (Sacks, 2016a). His stories introduced many people to the patient’s life-world and are really patient-centred. Through his books and films he has given a voice to vulnerable people and addressed many of the topics that are important in patient-centred care:

> “It was not just a question of diagnosis and treatment; much graver questions could present themselves—questions about the quality of life and whether life was even worth living in some circumstances.” (Sacks, 2015).

In his last book, “Gratitude”, which Sacks wrote while seriously ill and suffering from cancer, he gave a summary of the individuality that is the basis of patient-centred care and palliative care:

> “It is the fate of every human being, to be a unique individual, to find his own path, to live his own life, to die his own death.” (Sacks, 2016b).

Eric Cassell: The person and suffering

Eric Cassell is a retired physician (born 1928) who specialised in internal medicine and palliative medicine, and is an ethicist. Cassell highlights the fact that all patients are different and have to be treated differently, based on their individual personhood and needs (Cassell, 2013). Suffering and the feeling of sickness are related to the patient’s person. Disease and sickness destroy the wholeness of a person and sickness can even impair a patient’s thinking (Cassell, 2001; Cassell, 2013). Suffering and loneliness are related (Cassell, 2009). Cassell differentiates between disease and sickness: a person can have a disease without being sick or suffering:

> “Just because you are dying there is no reason to be sick.” (Cassell, 2013).

This highlights that a person’s coping strategies may help to endure even life-threatening disease and may reduce the feeling of sickness or suffering. This model is similar to the main elements of Saunders “total pain” concept. According to Cassell, medicine in general lacks knowledge about very important aspects of human health (Schei, 2011). In connection to getting old, Cassell stresses the importance of the tiny everyday aspects of life (Schei, 2011). According to Cassell, a person lives at all times in relationships to others. Listening itself can thus be healing and can change a sickness (Cassell, 2013). Cassell has published many articles and books with discussions about the person in medicine, suffering and doctoring. (Cassell, 1999; Cassell, 2001; Cassell, 2004; Cassell, 2009; Cassell, 2010; Cassell, 2016). His work underlines the importance of patient-centred and whole-person palliative care to address the different issues needed to improve patient conditions based on their personhood and their individual needs.

Harvey Chochinov: Dignity and respect

Harvey Chochinov introduced dignity-conserving care and dignity therapy to the field of palliative care. Through dialogue and communication, dignity for nursing home residents can be conserved (Chochinov, 2002; Chochinov et al., 2004; Chochinov, 2007). He established the A,B,C,D of dignity-conserving care: A = Attitudes, B = Behaviours, C = Compassion and D = Dialogue. This framework can help to maintain dignity in vulnerable nursing home residents (Chochinov, 2007) and may even lead to less suffering (Chochinov et al., 2002).

> “One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.” (Chochinov 2007, p. 186)

Dignity therapy is currently used in many countries, such as Canada, Denmark and Germany (Schramm et al., 2014). Nursing home staff can support a resident's feeling of dignity by creating conditions in which residents can feel to in control and be seen as "a worthwhile person" (Oosterveld-Vlug et al., 2013a). Unfortunately it seems to be difficult to tailor dignity-conserving care for an individual nursing home resident (Oosterveld-Vlug et al., 2013b).

Historically, palliative care has generally been associated with cancer. In recent years palliative care for people with non-cancerous diseases, such as progressive neurological diseases, dementia, COPD, heart-failure, AIDS, multimorbidity and frailty has been carefully addressed and recommended (World Health Organisation, 2004; Bollig, 2010b; World Health Organisation, 2011; Dalkin et al., 2016).

1.3.1 Palliative care and end-of-life care in nursing homes

In Norway, an increasing number of people die in nursing homes and need palliative care at the end-of-life (Husebø and Sandgathe Husebø, 2005, Husebø and Husebø, 2005). According to statistics from the Norwegian Institute of Public Health (folkehelseinstituttet 2016) the percentage of deaths in long-term care facilities in Norway has changed from 43% in 2009 to 47 % in 2014. Although there is a growing culture of palliative care in nursing homes, a combination of education of all staff members, support from the management and a change in the culture within organisations themselves are needed (Bollig, 2010 b). Nurses in elderly care need competence in many areas, including palliative care, ethics and communication (Bing-Jonsson et al., 2015). A palliative care culture has to be established in all nursing homes (Heller et al., 2003; Bollig, 2010b). In recent years the importance of palliative care has been recognised and the implementation of instruments and standards for the provision of palliative care in nursing homes has begun (Kinley et al., 2013; Hermans et al., 2014, Frogatt and Parker, 2014; Handley et al., 2014; Goodman et al., 2015). There are active working groups to improve palliative care at a national level, such as in England (Gold Standards Framework, 2016) and Germany (Deutsche Gesellschaft für Palliativmedizin and Deutscher Hospiz- und Palliativverband, 2012, Hospiz- und Palliativverband Schleswig-Holstein, 2016), as well as on the European level. The European Association for Palliative Care (EAPC) has established a taskforce on palliative care in long-term care settings for older people (European Association for Palliative Care, 2016).

In Norway the parliament introduced the so-called “verdighetsgaranti” (“dignity guaranty”) in 2010, which will enable all elderly people to live a meaningful life with dignity and assist with their individual needs. This guarantee includes palliative care, and end-of-life care with the opportunity for death with dignity (Helse- og omsorgsdepartementet, 2010). In Germany a new law to enhance hospice and palliative care was passed in the Bundestag in November 2015 (Bundesministerium für Gesundheit, 2015). This law includes the provision of palliative care and the right to receive treatment from specialised palliative care teams at home or in nursing homes (Bundesministerium für Gesundheit, 2015). Unfortunately, there are currently still many nursing homes without adequate availability of palliative care for residents.

1.3.2 Resident or patient?

Terms such as ‘resident’ or ‘user’ are being used in many nursing homes in order to underline the autonomy of residents and the fact that the nursing home serves as a home for disabled persons. In contrast, Hjort (2002) suggests that people living in nursing homes should be called ‘patients’ based on the fact that they have different diseases and are in the last phase of their life. This opinion is supported by the fact that nursing home residents are often multimorbid and vulnerable. ‘Clients’, ‘users’ or ‘customers’ have been suggested as alternative terms for patients, but by using these terms, responsibility is transferred to the people in need. Being a customer would remove the most central element of health care, that is the public’s responsibility and help, for someone who is sick or vulnerable (Hem, 2013). People living in nursing homes are often both residents and patients. On one hand they are often multimorbid and do need regular medical care and treatment by a physicians, which means they are patients. On the other hand they actually live in the nursing homes and are thus residents. As people have a variety of roles throughout life, the term used should be adapted to the actual context. When talking about people living in nursing homes the term ‘resident’ is appropriate and if treated by a physician the term ‘patient’ is applicable.

1.3.3 The physician’s role in the nursing home

The role of nursing homes, the type of assistance and treatment offered, and the understanding of the term ‘nursing home’ shows great variability between different countries (Sanford et al., 2015). Whereas all nursing homes provide support for people who need assistance with the activities of daily life, not all are staffed with health care professionals. Whether palliative care or hospice care is provided on a regular basis depends on the country (Sanford et al., 2015). Across different countries the role of physicians in nursing homes ranges from treating the nursing home residents as a general practitioner or family doctor, with visits to the nursing home on request, to full-time work as a nursing home physician, as in Norway and the Netherlands. In Norway a sub-specialisation in nursing home medicine (kompetanseområdet alders- og sykehjemsmedisin) has been possible since 2011, and the first two physicians were approved in 2013 (Johannessen, 2013). According to Hjort (2002), a physician may choose between two different roles in the nursing home: limiting their participation to giving medical treatment to the patients, or engage in creating the culture of the nursing home. Hjort (2002) noted that a physician has an important impact on nursing home culture. Hjort also defined four important goals in nursing home end-of-life care:

- Good treatment of distressing symptoms
- Good nursing care
- Good human care for both patient and relatives
- Good spiritual care for both patient and relatives

These goals are in accordance with the goals of palliative care. The terms "care" or "caring" are often associated with nursing. Different authors have noted that caring is an important aspect not only of nursing, but also of a physician's work (Maio, 2009; Dyste, 2013; Bollig, 2015a). Maio has stated:

> "Caring should be understood as a prerequisite for autonomy. Autonomy without caring is not medicine." (Maio, 2009)

Care should thus be enabled through autonomy, rather than autonomy provided instead of care (Maio, 2009). To care and to comfort patients/nursing home residents and to provide psychosocial support is part of the physician's healing art and belongs among their routine tasks (Bollig, 2015a). This is true for all physicians, but might be more obvious in palliative medicine and nursing home medicine.

1.4 Advance care planning

Advance care planning (ACP) is important for people who want to make autonomous decisions about their future care, especially for situations when they may not be able to decide themselves, and important decisions have to be made for them. There are many different definitions of ACP (see under definitions), and ways and methods to ascertain that one's wishes will be respected in the future, and these can, for example, be found in existing handbooks (Thomas and Lobo, 2011; Coors et al., 2015). These can be summarised in an "Advance Statement of Preference", which documents a patient's preferences and aspirations. Such a statement is not usually binding, but may be guidance for the treating physician. An "advance decision" that relates to a specific treatment is legally binding. It usually states what a patient does not want to happen (for example refusing life-prolonging treatment with artificial nutrition through a percutaneous endoscopic gastrostomy tube) (Thomas, 2011).

ACP is a process, and more than a one-time consultation. It presupposes repeated discussions about making an individual's wishes and preferences known (Thomas and Lobo, 2011; Mullick et al., 2013; NHS England, 2014; Brinkmann-Stoppelenburg et al., 2014; Coors et al. 2015). According to Singer et al. (1998) patients often involve loved ones in advance care planning, and physicians are infrequently involved. Preparing for death is an important element of advance care planning (Martin et al., 2000).

A major challenge may be lack of communication between patient, relatives and physician about advance directives and the patients wishes at the end-of-life. Very few elderly people express their wishes for end-of-life care, and many people seem unable to talk openly about death (Lloyd-Williams et al., 2007). Important strategies to enhance conversations about end-of-life are a physician's communication skills, a patient-centred approach, a focus on quality of remaining life and early discussions about the end-of-life (Larson and Tobin, 2000).

Discussions about ACP can be begun by physicians or other staff members in nursing homes, and communication is central (Holman et al., 2011). Due to the frequency of cognitive impairment and dementia in nursing home residents, discussions about ACP and treatment preferences should be offered as early as possible (Dening et al., 2012; Robinson et al., 2012a).

Ethical challenges and problems with decision-making and communication are often described in the literature, and ACP may help to reduce these (Kayser-Jones, 2003; Schaffer, 2007; Dreyer et al., 2009; Dreyer et al., 2010; Gjerberg et al., 2010; Fromberg et al., 2013). It has been shown that ACP can improve the quality of end-of-life care (Brinkman-Stoppelenburg et al., 2014). Despite these positive effects, ACP is not yet implemented widely in nursing homes (Gjerberg et al., 2010; Friis and Førde, 2015). An important aspect of ACP in nursing homes is the prevention of unnecessary hospital admission of frail nursing home residents at the end of life (Holman et al., 2011). ACP may even save costs (Klingler et al., 2016). Advance care planning in nursing homes leads to respect for the resident's choices and improves care and treatment at the end-of-life (In der Schmitten and Marckmann, 2012; Lücke, 2015). A simple approach that can be used to introduce ACP is a conversation about preferred priorities for care (PPC), which has been used in England since 2007, and can be used in almost every setting (Storey and Betteley, 2011). It is based on three questions:

1. "What has been happening to you in relation to your health?"
2. "What are your preferences and priorities for your future care?"
3. "Where would you like to be cared for in the future?"

(Storey and Betteley, 2011).

In Germany a law called "Gesetz zur Patientenverfügung" (Law on Living Wills) has strengthened patients rights and made it clear that physicians have to respect a patient's documented choices (Borasio et al., 2012). Unfortunately a living will often is not enough to aid decision-making in complex situations, and therefore ethics discussions in nursing homes may serve as additional supportive measures to aid decision-making (Gerhard and Bollig, 2007; Steinkamp and Gordijn, 2010; Hallwirth-Spörk et al., 2009)

1.5 Ethical reflection and systematic ethics work in nursing homes

When the work in this thesis started in 2009, systematic ethics work was rare in Norwegian nursing homes and the ethics project of the Norwegian Association of Local and Regional Authorities (KS in Norwegian) was still in its initial phase. The Bergen Red Cross Nursing Home had established its own ethics committee for the nursing home in 2006 (Husebø, 2006).

In Oslo a clinical ethics committee in primary care (klinisk etikk-komité i kommunehelsetjenesten, KEKK in Norwegian) was established and serves as joint ethics committee for 25 nursing homes in Oslo (Oslo kommune sykehjemsetaten, 2010). In Germany and Austria different organisations and institutions are engaged in the implementation of systematic ethics work in nursing homes. This includes organisations such as the Diakonie Bavaria (Dinges and Kittelberger, 2016) and the Malteser (Heinemann, 2005) in Germany, and the two models of good practice from the Caritas Socialis in Vienna, Austria (Hallwirth-Spörk et al., 2009) and the network for ethics in elderly care 'Frankfurter Netzwerk Ethik in der Altenpflege' from Frankfurt, Germany (Bockenheimer-Lucius et al., 2012; Frankfurter Netzwerk Ethik in der Altenpflege, 2016) that were included in the studies presented in this thesis (Papers III and IV). A Norwegian pilot study and literature review showed that ethics support in nursing homes and home-based health care was fragmented, and needed to be improved (Bollig et al., 2009). Knowledge and the literature on systematic ethics work in nursing homes from Europe is still relatively limited, although a number of studies have been made, and articles, reviews and books published (Husebø, 2006; Bockenheimer and May, 2007; Bollig et al., 2009; Bockenheimer et al., 2012; Hallwirth-Spörk et al., 2009; Heller and Krobath, 2010; Lillemoen and Pedersen, 2012; Lillemoen and Pedersen, 2015; Van der Dam et al., 2014; Bollig et al., 2016). Ethics support in nursing homes is today diverse and different approaches to discuss and handle ethical challenges in nursing homes have been proposed (Van der Dam et al. 2014, Bollig et al. 2016). Current methods include reflection groups (ethics peer groups), ethics consultant/ethics team, ethics committees and ethics cafés (Bollig et al., 2016).

Important factors in the implementation of systematic ethics work are ethics education, the organisation of time and places for ethics reflection, and support from management (Lillemoen and Pedersen, 2012; Neset et al., 2012; Gjerberg et al., 2014; Lillemoen and Pedersen, 2015). As local needs and resources may show great variation a three-step model of systematic ethics work has been proposed (Bollig, 2010a; Bollig et al., 2016)

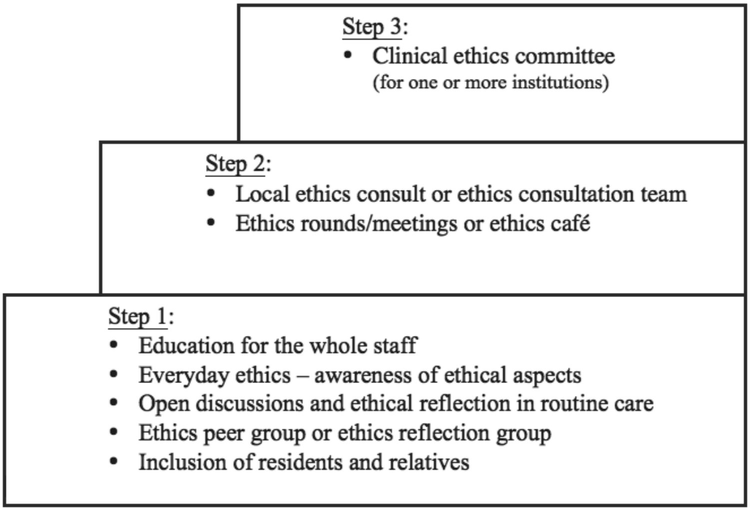

Figure 4: A three-step approach to systematic ethics work in nursing homes
(from Bollig et al., 2016)

1.6 Resident autonomy in the nursing home

Although the concept of autonomy has its roots more than 2000 years ago, it is central in modern ethics (Düwell et al., 2006). Beauchamp and Childress (2009) have described the four principles of biomedical ethics: respect for autonomy, non-maleficence, beneficence and justice. The approach of the four principles has been widely adopted in medical ethics to discuss ethical dilemmas, and is used in ethics committees and in ethics consultations in hospitals. Gillon (2003) suggested the principle of respect for autonomy as "first among equals". One reason for this is that it is a necessary component of elements of the three other principles. Linked to the concept of autonomy is the concept of competence in terms of decision-making. In order to make an autonomous decision one has to be competent. Competence can vary over time, however, and there is no definition or standard of competence (Beauchamp and Childress, 2009). As long as a patient is competent and can make decisions on his own, the concept of autonomy seems useful in medical practice, but things are complicated when a patient is no longer competent. Dementia is a disease in the course of which a patient gradually loses his competence and ability to decide. Taking into account the fact that many nursing home residents suffer from dementia and are incompetent, it is clear that many patients are not able to practice their autonomy, and that strategies have to be implemented to respect a patient's will, even if there is no ability to question them in an actual situation. In order to ensure that the patient's view and values will be taken into account in decision-making, advance directives, proxies, moral deliberation and ethics committees are used in nursing homes. There are three general standards for surrogate decision-making: substituted judgement, pure autonomy and the patient's best interest (Beauchamp and Childress, 2009). Due to the high number of residents without the capacity to decide on their own, ethics discussions are needed on a routine basis in nursing homes, but, as pointed out in the introduction of this thesis, medical ethics and the four principles approach might not be the only possible approach with which to deal with ethical challenges in nursing homes. Other concepts such as "care-ethics" (Conradi, 2001) or Levinas' (2006) concept of the "other" and the "ethical claim" (Løgstrup, 1956) need to be integrated to establish a concept of nursing home ethics dealing with many incompetent residents with complex problems and dilemmas, including the need for important end-of-life decision-making for residents without the capacity to decide.

1.7 The residents and their family's involvement in decision-making and ethics discussions in nursing homes

Although the principle of autonomy is of utmost importance in biomedical ethics, this does not imply that it is seen as important in daily nursing home care. Most decisions in nursing homes are made without the participation of the residents (Hayley et al. 1996, p. 250) although autonomy and participation in decision-making are humanistic care indicators for nursing homes (Lee and Wang, 2014). It is important for nursing home residents to have a voice and to be heard (Walent and Kayser-Jones, 2008). Autonomy is important to older people living in long-term care (Rodgers and Neville, 2007). Residents appreciate a perception of choice and control of everyday issues (Kane et al., 1997). The resident's choice of, and control over food, for example, is limited and could be improved (Winterburn, 2009). Ways to improve a resident's self-determination include participation in resident committees, participation in quality-of-life or dietary surveys and care planning (Lewis, 1995). Competent nursing home residents can decide whether their relatives should be included in ACP and decision-making for them (Holman and Hockley, 2010; Friis and Førde, 2015).

Regular meetings with residents and relatives, as introduced in the Bergen Red Cross Nursing Home in Bergen, Norway, can help to explore the views and preferences of residents and relatives (Ester, 2009). Nevertheless, there are inadequate procedures with which to address ethical aspects of patient autonomy and include relatives in decision-making in many Norwegian nursing homes (Dreyer et al., 2009). A resident's participation in medical decision-making still seems to be limited in long-term care settings (Garcia et al., 2016). The inclusion of residents is feasible, however, if residents are able to set the agenda (Baur et al., 2013). Surrogate decision-making is a source of stress for family members of nursing home residents with advanced dementia (Givens et al., 2012). According to Reiter-Theil (2003) a patient's perspective has often been neglected in clinical ethics consultations. This may lead to a lack of balance in ethics consultations. The patient (nursing home resident), or at least their perspectives, should also thus be included in clinical ethics consultations in nursing homes.

1.8 The need for more research

The need to improve elderly care in general, and especially systematic ethics work in the primary health care service and in elderly care including nursing homes, has been recognised by Norwegian clinicians and politicians. The Norwegian Medical Association declared in 2001 that it should be a national aim to integrate research in nursing homes (Den Norske Lægeforening, 2001). The Norwegian government agreed on a national plan for better care for the elderly, including the aim to improve care in nursing homes in 2006 (Norwegian Government St.meld. nr. 25, 2006). Cooperation between the Ministry of Health and Care Services and the Norwegian Association of Local and Regional Authorities (KS in Norwegian) has been established, and educational courses on ethics and different tools to enhance ethics reflection in nursing homes and primary care have been started (Kommunesektorens organisasjon, 2015 and 2016). In 2006 systematic ethics consultation and ethics support were relatively rare in community care and nursing homes in Norway although hospitals already had well established clinical ethics committees (Pedersen and Førde, 2005; Førde and Pedersen, 2011). Results from a Norwegian pilot-study from 2007-2008 showed that lack of resources and ethical challenges in end-of-life care were frequently mentioned ethical challenges in nursing homes and home-based health care in Norway, and that more research on ethics work in nursing homes was needed (Bollig et al., 2009). KS drove a project to improve ethics reflection from 2007-2013 (Kommunesektorens organisasjon, 2015). The evaluation of that project showed that systematic ethics work led to enhanced quality of work and that ethics became a part of everyday work. The biggest challenges described were lack of time, lack of motivation and the need for organisational foundation (Kommunesektorens organisasjon, 2015).

The research project presented in this thesis is about ethical challenges, decision-making and end-of-life care in nursing homes. Its main focus was on the experiences and views of residents and their relatives, regarding ethical challenges in nursing homes and decision-making using different approaches to ethics counselling in nursing homes. The project has its origin in Norway, and its main focus was the situation in Norway. Scientific knowledge about ethical problems and ethical decision-making in nursing homes is currently still limited for Norway and Europe. Knowledge about the inclusion of nursing home residents in medical decision-making and ethics discussions is lacking in general. The project may therefore have relevance for societies in all countries.

The theoretical framework and background to all the studies and papers presented in this thesis are the principles of biomedical ethics as described by Beauchamp and Childress, palliative care ethics and hospice-philosophy, where the concept of autonomy is central and the wishes and needs of patients (residents) and their relatives are paramount (Loewy and Springer Loewy, 2000; Heller and Knipping, 2006; Düwell et al., 2006; Beauchamp and Childress, 2009). Respecting a resident's autonomy in nursing homes includes the obligation to let residents and relatives participate in decision-making (Dreyer et al. 2009). It is necessary to improve end-of-life decisions and reduce unwanted life-prolonging treatment and hospitalisation (Pedersen et al., 2008).

As most previous studies on end-of-life care use health-care professionals as nurses and physicians as informants there is a lack of the patient's perspective, both in ethics consultation and research. But how can one know what the residents themselves think and want? More knowledge is needed about this from qualitative studies involving residents living in nursing homes and their relatives. This PhD project aimed to add the perspective of nursing home residents and relatives on ethical challenges, decision-making and end-of-life care in nursing homes. Nursing homes and models of good practice from the different healthcare systems in

Norway, Germany and Austria were also included as different experiences of ethical challenges and systematic ethics work, and to provide a richer picture of the topic from a European perspective.

Inclusion of all stakeholders and to give them a voice

The artwork “Occhio” (eyes), created by Verena Staggl (p. 3) can be interpreted as a symbol of the different perspectives held by stakeholders connected to the nursing home world, the nursing home residents, their relatives, health care personnel and other members of the nursing home staff, on ethical challenges in nursing homes and end-of-life care. In order to understand each other better it is useful to get to know other perspectives, and to use “another pair of glasses” in order to focus on particular issues from a different point of view. This is the aim of ethics reflection and ethics discussions.

The views of the different stakeholders from the nursing home world, the residents, relatives, nurses, physicians and other members of the nursing home staff, will be explored further and presented in this thesis.

2. Objective/purpose

2.1 Overall aims

The overall aims of this thesis were to study ethical challenges in nursing homes and the current practice of ethics discussions and decision-making in nursing homes. A specific major aim was to explore the views of nursing home residents and relatives regarding ethical challenges, decision-making and end-of-life care in nursing homes. Another important aim was to determine which ethical challenges were discussed in nursing home ethics discussion arenas and which experiences the staff have with systematic ethics work. It was also an aim to find out whether prospective ethics discussions may lead to consensus and related actions.

The questions that we aimed to answer were:

1. What do nursing home residents, relatives and staff members perceive as ethical problems in nursing homes?
2. How do nursing home residents and relatives think decisions for the residents should be made?
3. What are the most frequent ethical challenges discussed in ethics meetings in nursing homes in Norway, Germany and Austria?
4. What are the staffs experiences with systematic ethics work and ethics discussions in nursing homes in Norway, Germany and Austria?

2.2 Aims of each paper

The work presented in this thesis can be divided into two main parts: Part One (Papers I and II) which is mainly about the views held by residents and relatives on a “good life”, ethical challenges, decision-making and end-of-life care in nursing homes, and Part Two (Papers III and IV) which is mainly about the views of nursing home staff on ethical challenges in nursing homes and their experience with ethics discussions, including the documentation of ethics meetings in different countries and different approaches to implementing systematic ethics work.

Paper I

The aim of Paper I was to explore what nursing home residents and relatives perceive as a "good life" and as ethical challenges in nursing home care including end-of-life care.

The research question addressed was:

1. What do nursing home residents, relatives and staff members perceive as ethical problems in nursing homes?

Paper II

The aim of Paper II was to explore the views of cognitively able residents and relatives from Norwegian nursing homes on advance care planning, decision-making and end-of-life care. We were particularly interested in views on participation in decision-making in end-of-life care.

The research question addressed was:

1. What are the views of nursing home residents and relatives on advance care planning, decision-making and end-of-life care in nursing homes?
2. How do nursing home residents and relatives think decisions should be made for the residents?

Paper III

The main aim of Paper III was to investigate the opinions and experiences of ethical challenges of the nursing home staff and to identify which types of ethical challenges and dilemmas occur and are being discussed in nursing homes. Detailed aims were:

- To explore the opinions and experiences with ethical challenges of the staff of a large Norwegian nursing home, including both health care personnel and non-medical personnel.
- To find out which types of ethical challenges and dilemmas occur and are being discussed in nursing home ethics meetings.
- To investigate whether results of ethics meetings were put into practice. The inclusion of the residents' views through the participation of the residents themselves, or their next of kin, was of special interest.

The research questions addressed were:

1. What are the opinions and experiences of ethical challenges of the staff of a large Norwegian nursing home, including both health care personnel and non-medical personnel?
2. Which types of ethical challenges and dilemmas occur and are being discussed in nursing home ethics meetings?
3. Do residents or their relatives participate in ethics discussions?
4. Was consensus reached after the ethics discussion?

Paper IV

The main aims of Paper IV were to investigate which types of ethical challenges are discussed and to study the approaches to implementing systematic ethics work that were used in daily practice in nursing homes in Norway, Germany and Austria.

The research questions addressed were:

1. Which ethical challenges are discussed in nursing homes?
2. What are the staff's experiences with the implementation of systematic ethics work?
3. Were residents and relatives included in ethics discussions?

3. Materials and methods

The studies in this thesis are based on a mixed methods approach and rely mostly on qualitative research. Paper I and Paper II are based on qualitative in-depth interviews of nursing home residents and focus group interviews with relatives of nursing home residents. Paper III includes a questionnaire with an open question to describe a recent ethical challenge faced by staff members in their own words, which constitutes qualitative data. The staff descriptions were analysed using qualitative methods. Paper IV uses focus group interviews with nursing home staff about their experiences with ethical challenges and systematic ethics work in nursing homes. Paper III and Paper IV collected quantitative data about ethical challenges and ethics discussions through questionnaires for nursing home staff members.

3.1 Study sample: setting, participants and sample selection

Setting

Nine Norwegian nursing homes in different regions were chosen to participate in the studies for the four papers of this thesis. Figure 5 shows the location of the nine participating nursing homes in Norway. Documentation of ethics discussions was collected from five centres in Norway, Austria and Germany.

Participants

Twenty-five nursing home residents and 18 relatives of nursing home residents participated in depth-interviews and focus groups interviews for Papers I and II. An overview of the participants is been provided in the appendix of this thesis (from Paper I for the relatives, and from Paper II for the residents, including background information about the resident's health).

The data used in Paper III was from 93 staff members of a big Norwegian nursing home who participated by completing a questionnaire about ethical challenges in nursing homes. Of these, 80 were healthcare professionals and 13 were from other professions, such as a priest, economist, and technical and cleaning personnel.

Forty-three nursing home staff members or nursing home ethics committee members with experience in the implementation of systematic ethics work or ethics discussions from five institutions in Norway, Austria and Germany participated in focus groups about systematic ethics work. An overview of the participants is provided in the appendix of this thesis (from Paper IV). The documentation sheets of the ethics discussions were collected by Georg Bollig and Gerda Schmidt in cooperation with contact persons appointed by the management of the five institutions.

The appendix provides tables with information about all three groups of informants: residents, relatives and nursing home staff members.

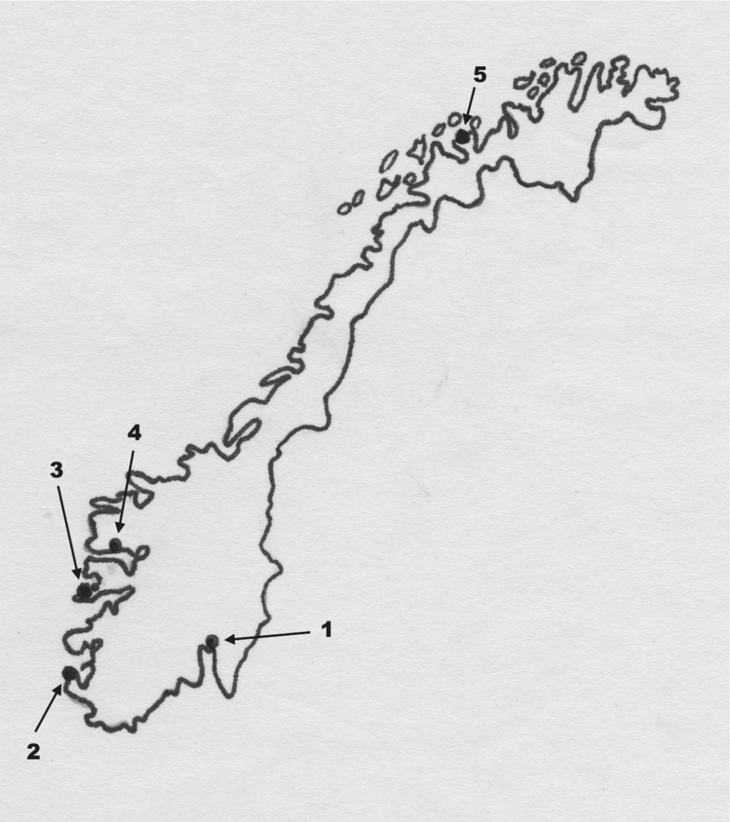

Figure 5: Participating Norwegian regions: 1= Oslo, 2= Rogaland, 3=Hordaland, 4= Sogn og Fjordane, 5= Troms

Sample selection

Purposeful sampling (Palinkas et al., 2015) was used to ensure the maximum possible variation in the data collected for Papers I and II. The aim was to recruit participants from a wide geographical spread and location. Inclusion criteria for participating residents were the capacity to provide informed consent and living in long-term care in a nursing home. Participants were included as relatives if they had one or more relatives living in a nursing home on a long-term care ward. All participants were recruited by nursing home staff or members of the management (Papers I and II).

The whole staff of a big Norwegian nursing home was invited to participate by filling out a questionnaire for the data collection for Paper III. A model of good practice from Austria was used to document experiences from ethics discussions. When the study started it was not possible to include a Norwegian model of good practice in this field due to restricted experience with systematic ethics work in Norwegian nursing homes (Paper III).

Purposeful sampling (Palinkas et al., 2015) was used for collection of the data for Paper IV, and five centres from three countries were included, that had introduced or started programs to increase their staff's ethical competence. Three of these were models of good practice, one from each participating country (Norway, Austria and Germany). As there is no existing gold standard for systematic ethics work, we chose to include models of good practice that had, to our knowledge, a wide experience with systematic ethics work in nursing homes (Paper IV).

3.2 Mixed methods

Mixed methods approaches combines qualitative and quantitative data and have been used in different scientific fields, such as in evaluation research in palliative care (Pope and Mays, 2006; Ingleton and Davies, 2007; Plowright, 2011). A mixed methods approach was used to investigate systematic ethics work in nursing homes (Paper III and Paper IV) with a combination of quantitative data from questionnaires on ethics discussions in nursing homes and qualitative data from an open question asked in the questionnaire, and focus group interviews about systematic ethics work. The main reason to use mixed methods in these studies was the intention to provide a richer picture of systematic ethics work in nursing homes.

Often this combined approach is used to access a wider range of data or to “expand the scope of enquiry” (O´Cathain and Thomas 2006, p.102). The combination of qualitative and quantitative methods to provide a bigger or richer picture is one of the reasons for using mixed-methods, as described by O´Cathain and Thomas (2006).

3.3 Qualitative methods

The four papers included in this thesis used qualitative methods to collect and analyse the data. The data were collected by using well described methods, in-depth interviewing, and focus groups interviews (Britten, 1995; Kvale, 1996; Crabtree and Miller, 1999; Malterud, 2001; Krueger and Casey, 2009; Malterud, 2011; Malterud, 2012). Analysis was based on interpretive description (Thorne, 2008; Thorne et al., 1997; Thorne et al., 2004) and qualitative description, (Sandelowski, 2000; Neergaard et al., 2009; Sandelowski, 2010). The COREQ guidelines (Tong et al. 2007) were applied for reporting the qualitative research. This is described extensively in Paper II.

Interpretive description is a qualitative method developed by Thorne, Reimer Kirkham and MacDonald-Emes, and is “a qualitative approach to clinical description with an interpretive or explanatory flavor” (Thorne et al., 1997). Interpretive description was used in Paper I and Paper II. Thorne (2008, p. 74) described the foundational underpinnings as follows:

“Interpretive description studies

- are conducted in as naturalistic a context as possible in a manner that is respectful of the comfort and ethical rights of all participants,
- explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of clinical insight,
- capitalize on human commonalities as well as individual expressions of variance within a shared focus of interest,
- reflect issues that are not bounded by time and context, but attend carefully to the time and context within which the current expressions are enacted,
- acknowledge a socially “constructed” element to human experience that cannot be meaningfully separated from its essential nature,

- recognize that, in the world of human experience, “reality” involves multiple constructed realities that may well be contradictory, and
- acknowledge an inseparable relationship between the knower and the known, such that the inquirer and the “object” of that inquiry interact to influence one another.”

> “Interpretive description…creates the context in which engagement with the data extends the interpretive mind beyond the self-evident – including both the assumed knowledge and what has already been established – to see what else might be there. As such it offers the potential to deconstruct the angle of vision upon which prior knowledge has been erected and to generate new insights that shape new inquiries as well as applications of “evidence” to practice.” (Thorne 2008, p. 35).

According to St. George (2010) interpretive description can be characterised by two words: applied and interpretive. It has a close connection to practice, therefore it is applied. Questions arise from the practice field and the researcher engages in meaning-making (St. George, 2010).

Interpretive description was chosen as a method with respect to the patient-centred approach. This strategy allows close attention to the data and the participant descriptions without too much interpretation. Another reason to use interpretive description was the aim to investigate the differing views of nursing home residents, relatives and nursing home staff from various angles and to look at the topic through different glasses in order to explore new insights. Interpretive description was the methodological basis of the qualitative approach used in data collection and analysis in Paper I and Paper II.

Qualitative description aims to provide a comprehensive description and summary of experiences or events in everyday terms. It is the method of choice for a straight description of phenomena (Sandelowski, 2000). Qualitative description is a qualitative method that is close to the data and is less interpretive than other qualitative methods, such as interpretive description (Sandelowski, 2000; Neergaard et al., 2009; Sandelowski, 2010). Nevertheless “all description entails interpretation” (Sandelowski, 2000). Qualitative description was used in Paper III and Paper IV.

Data collection

All interviews were performed and data collected by Georg Bollig. Qualitative data from the in-depth interviews of nursing home residents, and the focus group interviews with relatives and nursing home staff, were recorded digitally.

In-depth interviews

Paper I used two opening questions to the interviews:

- "How can you live a good life in the nursing home?"
- "Can you please describe a common day in the nursing home?"

After using the opening questions an interview was performed with follow up questions related to the patient's answers and responses.

Key themes that were explored include:

- A good life in the nursing home
- Daily life in the nursing home
- Ethical challenges related to daily life and end-of-life care in the nursing home

If residents did not mention ethical challenges in the interview, the interviewer asked about the resident´s view of ethical challenges, which were reported in the literature.

Paper II used different opening questions for residents and relatives, as described in the paper. Opening questions for the resident semi-structured interviews are described in detail in Paper II. After the first eleven interviews with nursing home residents, the interview guide for the in-depth interviews was revised and adapted based on the first preliminary codes and results.

Focus group interviews

The interview guide for the focus group interviews of relatives was prepared after preliminary coding and discussion of the first eleven interviews with the co-authors. The methods for the focus group interviews were based on the descriptions of Malterud, Krueger and Casey (Malterud, 2001; Krueger and Casey, 2009; Malterud, 2011; Malterud, 2012). The opening questions for relative focus group interviews are described in detail in Paper II.

Transcription and Data analysis

The PhD candidate Georg Bollig and three trained assistants transcribed the digital interview recordings using the transcription software f4, from Audiotranskription (Dresing and Pehl, 2012; Audiotranskription, 2012). The interview records were transcribed verbatim. The software QSR NVIVO 9 (QSR International, 2011; Bazeley and Jackson, 2013) was used to support the process of transcription, systematic coding and analysis of the interview transcripts. Analysis of the qualitative data was performed using qualitative content analysis with data-derived themes, and was based on interpretive description (Papers I and II) and qualitative description (Papers III and IV) (Miller and Crabtree, 1999; Sandelowski, 2000; Thorne, 2008; Sandelowski, 2010; Malterud, 2011). A detailed description of the analysis process used in all studies is shown as an example from Paper II:

1. GB, EG and JH read the transcripts and familiarised themselves with the data
2. GB and EG independently identified preliminary codes and themes
3. GB, EG and JH compared and discussed the preliminary codes and themes
4. GB coded all the material according to the preliminary codes and themes
5. GB revised the preliminary codes and themes and compared them to his field notes
6. GB, EG and JH discussed the revised codes and themes and agreed on the final codes and themes
7. GB, EG and JH checked the transcripts in order to question the findings
8. GB, EG and JH discussed the findings and themes and agreed about the interpretation of the data

During the analysis process the text was read several times, themes coded and codes revised after repeated discussions between the co-authors. This approach was used throughout the whole analysis process in order to validate the findings. Reflexivity was sought through repeated discussions with all co-authors about alternative interpretations, critical reflection and meta-positions (Malterud, 2011).

3.4 Quantitative methods

Questionnaires were used to collect quantitative data about ethical challenges and ethics discussions (Paper III and Paper IV). The questionnaire about ethical challenges for nursing home staff was an adapted version of a questionnaire used in a previous pilot study (Bollig et al., 2009). The questionnaire about ethics meetings was designed and revised with the help of the co-authors of Paper IV. The questionnaires are included in the appendix. Nursing home staff and members of ethics committees or ethics discussion groups filled out the questionnaires. The PhD candidate Georg Bollig collected the data with help of Gerda Schmidt. Descriptive statistics are usually used describe “the basic features of the data in a study” (Research Methods Knowledge Base, 2006). Descriptive statistics were used to describe and summarise the data from the questionnaires and to give an overview of cases and topics from the ethics consultations in participating nursing homes.

3.5 Research Ethics and Ethics approval

The studies in this thesis were reported to, and approved by, the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a. The studies included nursing home residents, relatives of nursing home residents and nursing home staff (nurses, physicians and other staff members from different professions, including non-medical professions and participants in ethics committees and ethics discussion groups).

All participants were recruited to participate by the management or nursing home staff from the different locations. All participants received both oral and written information prior to their participation in the study and had the ability to contact the researcher if they had any questions or concerns. Written informed consent was obtained from all participants. All participants received information about their right to end the interview at any time without the need to provide a reason and without any consequences for them. Participants of the in-depth interviews and focus groups were informed that they did not have to answer any question if they did not feel comfortable doing so. Before and during the interviews with nursing home residents, the interviewer (GB) was attentive for clinical signs of cognitive impairment.

Residents with signs of cognitive impairment or dementia were excluded from the study. Only one patient had to be excluded, and no interview had to be ended upon the patient’s request. In a few cases, patients did not answer a question and the interviewer changed the subject. The information documented about the residents who participated in the in-depth interviews included gender, age and an overview of important medical diseases. All residents gave their informed consent to publish this data in scientific articles. The resident cases from the ethics meetings were documented using a questionnaire with a description of the case discussed, but without personal data concerning the resident, relatives, or other participants. No resident data other than gender and age were documented.

4. Results/summary of papers

4.1 Paper I

Nothing to complain about? – Residents' and relatives' views on a "good life" and ethical challenges in nursing homes.

The aim of this study was to discover what nursing home residents and their relatives perceive as a "good life" and what they see as ethical challenges in Norwegian nursing homes.

Past studies about ethical challenges in nursing homes have mostly included staff members as informants. A few studies have focused on the views of relatives, but knowledge about the perspective of residents is lacking.

Our research used a qualitative design with in-depth interviews with 25 nursing home residents from nine nursing homes, and three focus group interviews with 18 relatives of the nursing home residents from three of these nursing homes. Analysis was based on interpretive description.

Our research identified four main themes. Ethical challenges in Norwegian nursing homes from the resident and relative perspectives were: (a) acceptance and adaptation, (b) well-being and a good life, (c) autonomy and self-determination, and (d) lack of resources. Relationships with the staff was an important topic frequently reported by our informants and was experienced as both rewarding and problematic. None of the residents from our study described ethical challenges connected to end-of-life care. Most informants did not feel autonomous or self-determinant.

In summary, residents and relatives both experience ethical challenges in Norwegian nursing homes, mostly connected to everyday ethical issues. Participation in daily life, social contact and self-determination were important factors for a good life for the residents.

4.2 Paper II

They know! - Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes.

Nursing homes are places where many people die, and therefore palliative care and end-of-life decision-making is an integral part of nursing home care.

The aim of this study was to investigate the views that cognitively able residents and relatives have of advance care planning, end-of-life care, and decision-making in nursing homes.

A qualitative study design with in-depth interviews with nursing home residents and focus group interviews with relatives of nursing home residents was used. 43 informants from nine nursing homes participated in the study (25 nursing home residents and 18 relatives). The interviews and locations were the same as in Paper I. Analysis was based on interpretive description.

The study results showed that residents and relatives have different views about decision-making and advance care planning. Most residents want the relatives and staff to make important decisions for them and trust them to be capable of that, but many relatives are not aware of the concrete wishes of the residents and feel that decision-making is a burden. Advance care planning is not yet standard and most residents had not had preparatory conversations or written advance care plans. Many residents pointed out that they knew they would die in the nursing home but none of them reported challenges connected to end-of-life care or mentioned any wish for euthanasia.

In summary, most residents from this study seem to be satisfied with decision-making and end-of life care as it is at present. Many relatives are not aware of the resident’s wishes for future treatment and care, and therefore there is a need for systematic advance care planning and that all residents should be offered preparatory conversations and advance care planning. Talking about a resident’s wishes for care and medical treatment may ease decision-making for the relatives, physicians and the whole staff.

4.3 Paper III

Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives.

The aims of this study were to explore the opinions and experiences that the nursing home staff had of ethical challenges and to provide a description of the different types of ethical challenges and dilemmas that exist and were discussed in nursing homes.

The research used a mixed-methods approach combining quantitative and qualitative methods. A questionnaire on ethical challenges and systematic ethics work in Norway and a registration of systematic ethics discussions from an Austrian model of good clinical practice were used. Both healthcare personal and staff from other professions were included as informants in Norway.

We found that ninety per cent of the participating nursing home staff members experienced ethical problems in their daily work and ninety-one per cent saw ethical problems as a burden. The most frequently mentioned ethical challenges were lack of resources (79%), end-of-life issues (39%) and coercion (33%). Most employees suggested ethics education (86%) and time for ethics discussion (82%) as measures to improve systematic ethics work. Twenty-nine out of 33 documented ethics meetings were prospective resident ethics meetings, where decisions had to be made for a resident. In all 29 cases consensus could be reached in the resident ethics meeting and the result was put into practice. No residents participated in the meetings. Relatives of the residents participated in the majority of case discussions. The main topics of the resident ethics meetings were end-of-life care and life-prolonging treatment.

In summary, lack of resources, end-of-life issues and coercion were the ethical challenges most frequently reported by nursing home staff. Resident ethics meetings were helpful in reaching consensus in decision-making for nursing home patients. There was a lack of resident participation in the ethics discussions. The staff members appreciated systematic ethics work as an aid to ethical reflection and decision-making in general.

4.4 Paper IV

A European multicenter study on systematic ethics work in nursing homes.

The aims of this study were to document which ethical challenges were discussed in nursing home ethics discussion meetings in Austria, Germany and Norway, and to explore the staff's experiences with different approaches and methods to implementing systematic ethics work in nursing homes.

The study was based on a mixed-method two-tiered study approach. Five institutions in Austria, Germany and Norway were chosen for data collection from ethics discussions in nursing homes. Qualitative interviews from focus groups with nursing home staff, regarding the implementation of systematic ethics work, were used. Systematic ethics discussions in nursing homes were documented through a questionnaire.

The results of the first part of the study included 105 documented ethics meetings. The main topics of the ethics discussions were advance care planning, challenges associated with the use of a percutaneous endoscopic gastrostomy tube (PEG), as well as questions about hospitalisation and end-of-life decision-making. Thirty three per cent of the meetings focused mainly on everyday ethical challenges. In 29% of discussions no residents or relatives participated. In 76% of prospective case discussions, agreement about a solution could be reached. Results from the focus group discussions showed a greater ethical awareness, enhanced openness and dialogue in general as advantages of the implementation of systematic ethics work. Many informants voiced a need for structure and support from the administration. Some informants from the focus groups reported that the participation of physicians was too rare, although physicians actually participated in 76% of the documented meetings.

In summary, systematic ethics work is greatly appreciated by the staff. Systematic ethics discussions can help to reach a consensus in the majority of prospective case discussions. Unfortunately, no residents participated in the documented ethics discussions. Many staff members would appreciate the regular participation of physicians and relatives. The residents themselves should be encouraged to participate in ethics discussions in order to strengthen their autonomy and feelings of dignity.

4.5 Main findings and synopsis of the papers

The most important findings of this thesis are:

- Participation in daily life, social contact and self-determination are important factors for a good life from the residents' perspective (Paper I).
- Preserving their dignity is important for the residents and is a major challenge for them. Interaction with the staff can both ensure and endanger a resident's feelings of autonomy and dignity (Paper I).
- Most informants reported that they did not feel autonomous or self-determinant (Paper I).
- Residents and relatives in Norwegian nursing homes mostly experience ethical challenges connected to everyday ethical issues (Paper I).
- The lack of resources associated with too few nursing home staff members was frequently described as an ethical challenge. From the perspective of residents and relatives the lack of resources leads to a lack of time to talk and care, long waiting times to get help and sometimes even coercion (Paper I).

- Most nursing home residents trust their relatives, physicians, and nurses to make decisions for them (Paper II).
- Unfortunately many relatives do not know their resident's wishes and feel decision-making as a burden (Paper II).
- Resident wishes for end-of-life care were: not to be alone, pain relief, and no life-prolonging treatment. (Paper II).
- Some residents said that they were waiting to die, but none of them expressed the wish to hasten death by euthanasia or physician-assisted suicide (Paper II).

- 90% of the nursing home staff reported ethical problems in their daily work (93% of the healthcare workers vs. 77% of employees from other professions) and 91% described ethical problems as a burden (Paper III).
- The most frequently described ethical challenges were lack of resources (79%), end-of-life issues (39%), coercion (33%), communication (31%), lack of professional competence (31%) and issues about resident autonomy (29%). Everyday ethical issues

are important in nursing homes (Paper III).

- Nursing home staff would prefer ethics education (86%) and time for ethics discussion (82%) in order to improve systematic ethics work (Paper III).
- Out of a total of 33 documented ethics discussions 29 were prospective resident ethics meetings where decisions had to be made for a resident. Consensus could be reached in all of these and the result was put into practice (Paper III).
- Relatives participated in 26 of 29 resident ethics meetings (90%), but no resident participated (Paper III).

- The main topics of the 105 documented ethics meetings were ACP (46%), PEG-insertion or ethical challenges associated with PEG use (43 %), hospitalisation (33 %) and end-of-life decision-making (27 cases, 26 %) (Paper IV).
- 33% of the meetings focused mainly on everyday ethical challenges. When systematic ethics work is implemented, a change of focus in ethics discussions from end-of-life themes to everyday ethical challenges, including respect for resident autonomy and dignity, was described (Paper IV).
- In 25 of 87 prospective case discussions (29 %), no residents or relatives participated (Paper IV).
- In 76% of prospective case discussions, agreement about a solution could be reached (Paper IV).
- Focus group participants described enhanced openness and dialogue in general, and a greater ethical awareness as advantages of systematic ethics work. Many stated a need for structure and support from the administration (Paper IV).

The combination of results from the four papers showed that ethical challenges in nursing homes are experienced frequently by residents, relatives and staff members (including both health care personnel, such as nurses, nurse assistants, physicians and the non-medical staff). Unfortunately many of our informants from the resident group did not feel autonomous. The results highlight the importance of everyday ethical challenges in nursing homes. Everyday ethical issues are often hidden under the surface, as shown in Figure 6. Systematic ethics work is appreciated by the staff and leads to an enhanced awareness of ethical challenges and to a change in the focus of the ethics meetings from big ethical issues, such as end-of-life decision-making to everyday ethical challenges as questions related to autonomy or others (see Fig. 6 and 7).

Figure 6: Ethics iceberg

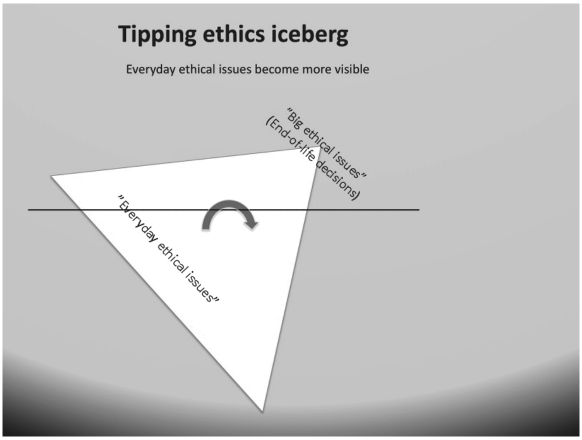

Figure 7: Tipping ethics iceberg

Our results indicate that ethics discussions can help to reach consensus about important decisions that have to be made for the residents. Although relatives and physicians participated in about three-quarter of ethics meetings some informants suggested that they were missing the participation of physicians. Support from the management and structures are needed to implement systematic ethics work according to our informants.

Reflection on the combined results from all four studies led to Figure 8, which represents the different stages of human autonomy in the course of a lifetime. Autonomy and the capacity to decide should probably not be seen as an on or off phenomenon which is present or not, but as a continuum that changes throughout the course of life. Autonomy is very restricted at birth and grows during childhood. Adulthood represents a period and the state of real or true autonomy, and a kind of legal autonomy that is reached at the age of 18 (this age may differ between different countries and cultures, and the young adults may still be dependent of their parents for several years), and may last for many years, if not endangered by losing cognitive function through accidents or diseases. At the end-of-life, the ability to use one’s autonomy usually diminishes gradually until death occurs. This is shown in Figure 8.

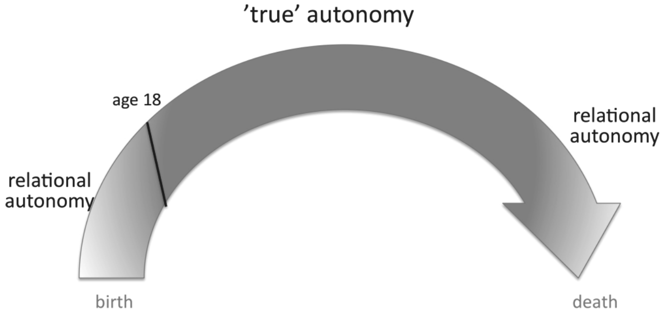

Figure 8: The natural course of autonomy throughout life

The natural course of autonomy throughout life could also be called “the five stages of autonomy”, which includes: 1. childhood, 2. adolescence, 3. adulthood, 4. seniority, and 5. vulnerability and frailty. One may thus question how autonomous we really are as human beings in the course of a lifetime, and ask what the role of relational autonomy is. Figure 8 shows that it is normal that in the course of a lifetime as a human being, there are periods at the beginning and often at the end of life, were one is dependent on the support of others.

The implications of the study and future perspectives will be addressed in Chapter 7, on future perspectives and implications (p. 84).

5. Discussion

An overview of the background and the current literature on the topics of this thesis has been provided in Part 1. introduction. A discussion of the results following the different topics and presented under different thematic headings, followed by a discussion of the methodological aspects and considerations of the studies, is given below.

The theoretical framework and background to all the studies and papers presented in this thesis are the principles of biomedical ethics as described by Beauchamp and Childress (2009), palliative care ethics and hospice-philosophy where the concept of autonomy is central and the wishes and needs of patients and their relatives are paramount (Loewy and Springer Loewy, 2000; Heller and Knipping, 2006; Düwell et al., 2006; Beauchamp and Childress, 2009). Principlism is based on four moral principles: respect for autonomy, nonmaleficence, beneficence and justice (Beauchamp and Childress, 2009). It is a frequently used ethical framework of moral norms in modern bioethics (Düwell et al., 2006). Palliative care is patient-centred and based on an orientation towards the needs of the individual patient (or nursing home resident) and their relatives. In order to provide good patient-centred and palliative care it is thus necessary to explore the views and lived experiences of nursing home residents, their relatives and the staff.

5.1 Discussion of main findings

5.1.1 Ethical challenges in nursing homes from the viewpoint of residents and relatives

Ethical challenges are experienced differently depending on the viewpoint of the stakeholder involved. The views of nursing home residents and relatives were explored in Paper I. Residents and relatives experience ethical challenges connected to everyday ethics most frequently. These are often about autonomy and self-determination but also about resources to enable social contact and help with activities of daily life (Paper I). Factors associated with “a good life” from the residents point of view are, for example, to be able to participate instead of sitting passively in a chair, the possibility of being trained by a physiotherapist, individualized mealtimes and human contact with other people (Paper I).

Unfortunately most residents reported that they do not feel autonomous or self-determinant (Paper I). The findings from our study are in contrast to previous findings from Norway that showed that most residents were satisfied with nursing home care (Sørbye et al., 2011). Many residents in our study started by saying that they had nothing to complain about, but then mentioned ethical challenges and told the interviewer their criticisms or complaints in the course of the interview. This was probably in part due to fear that complaining may have consequences for them. As some residents are afraid to offer critique, their relatives seem to have to do the "complaining". This shows that interaction with staff can both strengthen or endanger a resident's feeling of control and dignity. Goffmans' term "total institution" has been applied to nursing homes, as nursing home residents are vulnerable and depend on the nurses and staff members (Goffman, 1961; Bockenheimer et al., 2012). When living in an institution, a major challenge for the residents is to preserve their feeling of dignity. Their relationship and interaction with the staff is of the utmost importance for both residents and relatives. This may be another reason that residents rarely complain (Paper I). Pleschberger has shown that nursing home residents are highly vulnerable with regard to their dignity (Pleschberger, 2007b). Dignity-conserving care is based on kindness, respect and humanity (Chochinov, 2007), and therefore to maintain and enhance the residents feeling of control and dignity, as well as respecting resident autonomy, is a major task for the nursing home staff (Kane et al., 1997; Chochinov, 2002; Chochinov, 2007; Andersson et al., 2007; Moser et al.,2007; Brandburg et al. 2013). Nursing home staff should focus on the resident as a person (Ory 2015), an individual with rights who deserves respect. To see and to address the residents as individual persons and to enable them to be in control as much as possible, may therefore strengthen the residents feelings of dignity, and promote well-being.

A commonly described ethical challenge by both residents and relatives was the lack of resources associated with too few nursing home staff members, and a lack of time to talk and care, as well as long waits to get help. According to the informants, lack of resources can sometimes even result in the use of coercion (Paper I). Lack of resources is frequently raised as an ethical challenge connected to nursing home care (Olson et al., 1993; Kayser-Jones et al., 2003; Bollig et al., 2009; Gjerberg et al., 2010; Bollig, 2010a; Bollig, 2010c; Bockenheimer et al., 2012; Lillemoen and Pedersen, 2012; Gjerberg et al., 2013) and has also been connected to coercion in nursing homes (Gjerberg et al., 2013).

As mentioned above, big ethical issues as decision-making at the end-of-life, do not seem to be important for the residents themselves (Paper II). Interestingly, none of the residents in our study addressed ethical challenges in end-of-life care (Paper I). Although some residents mentioned a desire to die, none expressed a wish for euthanasia. It is important for residents that their will is respected, and that they are allowed to die, and also that they do not feel as if they are being a burden to others (Pleschberger, 2007b). Residents from our study described a wish for a natural death (Paper II) but not for euthanasia. Patients who make a request for hastened death often want their caregivers to listen to them, but do not expect the caregivers to actually provide assisted suicide (Pestinger et al., 2015). Sometimes this may be interpreted as a cry for help or an invitation to talk about death with the caregivers. A recent study about dying from Germany showed that many people fear a prolonged dying process (62%), suffering pain or dyspnoea (60%) and being a burden to others (54%) (Ahrens and Wegner, 2015). Ahrens and Wegner (2015) showed that the numbers of opponents of assisted suicide increases with age (53% of the informants were over 80 years of age). A palliative care approach, and dignity-conserving care, thus not only have the potential to enhance a resident's feeling of dignity, but might also reduce the wish for euthanasia. The implementation of palliative care and systematic ethics work can help to deal with distressing symptoms at the end-of-life, and at the same time include a patient-centred and dignity-conserving way of caring, and so this could be beneficial in all nursing homes (Gerhard and Bollig, 2007; Schaffer, 2007; Bollig, 2010c). One of the authors has formed the following sentence:

> "Health care services for the growing frail older population need to be reframed to integrate a palliative care philosophy that supports patient and family goals for cure or prolongation of life, while promoting peace and dignity during illness and the dying process." (Schaffer 2007, p. 255).

In contrast to the residents and relatives who mostly perceived everyday ethical challenges (Paper I), the nursing home staff and ethics committees are often engaged with ethical challenges connected to end-of-life issues, also termed 'big ethical issues' (Weston et al. 2005, Paper III; Bollig et al.,2009; Bollig, 2010a; Gjerberg et al., 2010). For some of the relatives, ethical challenges and decision-making in end-of-life care is a burden (Paper II). Advance care planning should be encouraged to improve communication about a resident's wishes and preferences, and it can enhance the autonomy of residents, and reduce conflicts and burden around end-of-life decision-making (Paper II; Kayser-Jones, 2003; Schaffer, 2007; Thomas and Lobo, 2011; Dening et al., 2012; In der Schmitten and Marckmann, 2012; NHS England, 2014; Coors et al., 2015).

ACP is a strategy to prevent ethical dilemmas and to deal with ethical challenges. ACP can enhance quality of life (Brinkmann-Stoppelenburg et al., 2014) and may even save costs (Klingler et al., 2016), and can therefore be seen as a win-win situation for all stakeholders.

5.1.2 Ethical challenges in nursing homes from the staff view

Lack of resources (79%), end-of-life issues (39%), coercion (33%), communication (31%), lack of professional competence (31%) and issues about resident autonomy (29%) were the most frequently described ethical issues from our data (Paper III). Our data indicate that both big ethical issues and everyday ethical issues are important in nursing homes. These findings are in accordance with the international literature, where lack of resources, communication, autonomy, coercion, decision-making about treatment at the end-of-life, withholding or withdrawal of artificial nutrition and hospitalisation are often described as ethical issues and dilemmas in nursing home care (Weston et al., 2005; Glasser et al., 1988; Bollig et al., 2009; Bollig, 2010a; Slettebø, 2004; Bollig et al., 2016). The data presented in Paper III suggests that ethics reflection in nursing homes focuses mostly on big ethical issues, and that everyday ethical issues are hidden under the surface. This has been shown graphically in the ethics iceberg (Figure 6, p. 60).

Ethics committees deal mostly with big ethical issues, such as treatment and decision-making at the end-of-life (Chichin and Olson, 1995; Weston et al., 2005). The main topics of 105 documented ethics meetings in Norway, Germany and Austria were advance care planning, ethical challenges associated with artificial nutrition, hospitalisation, and end-of-life decision-making. About a third of all meetings focused mainly on everyday ethical challenges (Paper IV). Our findings are similar to other findings from the literature that have explained that ethical challenges in nursing homes are mostly about end-of-life care, decision-making and other big ethical issues, and seldom about everyday ethics (Aroskar, 1989; Olson and Chichin, 1993; Sansone, 1996; Slettebø and Bunch, 2004; Weston et al., 2005; Schaffer, 2007; Bockenheimer-Lucius and May, 2007; Reitinger et al., 2007; Bollig et al., 2009; Dreyer et al., 2010; Bollig, 2010a; Gjerberg et al., 2010). Our data shows a difference, however, with a higher reported frequency and importance of everyday ethical issues. Lack of resources was not as prominent in our data as reported in previous studies (Bollig et al., 2009; Gjerberg et al., 2010).

From the residents point of view, the everyday ethical challenges deserve more attention (Paper I), whereas the nursing home staff experience both big ethical issues and everyday ethical issues as important, although big ethical issues are more frequently addressed in the documented ethics discussions. Everyday ethics is probably more often discussed informally, and thus rarely documented by our informants. A reason for this could be an underreporting of everyday issues because they are not acknowledged as important and thus remain under the surface (Figure 6, p. 60).

Slettebø (2004) has reported that it is most important for nurses in nursing homes to strive for the patient's best interests. In order to handle ethically challenging situations, nurses use four strategies: awareness, negotiation, explanation and coercion (Slettebø, 2004). This highlights the importance of the awareness that a given situation does have ethical aspects. Awareness is the first step to handling ethical challenges (Peile, 2001). Striving for the residents best interests should probably include striving to strengthen the residents feeling of dignity and autonomy (Kane et al., 1997; Chochinov, 2002; Slettebø, 2004; Chochinov, 2007; Andersson et al., 2007; Brandburg et al., 2013; Moser et al., 2007). As described by the residents in Paper I, the small things in daily life are very important in giving residents a feeling of control and dignity. In making comparisons to big ethical issues and everyday ethical issues, one may use terms like "big dignity" versus "everyday dignity", emphasising that it is not just big decisions or issues that strengthen dignity and autonomy, but also the control of smaller details, like the ability to choose what and when to eat, or the time one would like to go to bed.

5.1.3 Decision-making in nursing homes

An overview of the scientific literature suggests that decision-making in nursing homes is often done by people other than the residents themselves (Hayley et al., 1996) and can lead to conflicts between nursing home staff, physicians and relatives (Aroskar, 1989; Olson et al., 1993; Weston et al., 2005; Schaffer, 2007; Bollig et al., 2009; Gjerberg et al., 2010). Advance care planning (ACP) may help to reduce ethical dilemmas and ethical challenges in decision-making, communication and conflicts that are described frequently (Kayser-Jones et al., 2003; Schaffer, 2007; Dreyer et al., 2009; Dreyer et al., 2010; Gjerberg et al., 2010, Fromberg et al. 2013). ACP is described in detail under Chapter 1.4. Residents and relatives should be included in decision-making in order to respect the autonomy of residents (Dreyer et al., 2010). This is what ACP aims for, but unfortunately ACP is not yet standard in all nursing homes; only few people have written ACP documents and a systematic approach to ACP and documentation of the patients will is often lacking (Royal College of Physicians, 2009; Cox et al., 2011; Robinson et al., 2012b).

One major finding of our work is that most nursing home residents trust their relatives, physicians, and nurses to make decisions for them, but that unfortunately many relatives are insecure about doing this, or do not know the resident's wishes (Paper II). This difference is striking, and needs to be taken into account both in ACP and decision-making for nursing home residents. Many relatives experience decision-making as a burden (Paper II). The lack of preparatory conversations can cause problems in the decision-making process, be experienced as burden, and even cause moral distress for relatives, physicians and nursing home staff (Paper II, Hansen et al., 2005; Dreyer et al., 2009; Givens et al., 2012). This indicates the need to offer systematic ACP to all nursing home residents who want to participate. Preparatory conversations and advance care planning can both support a resident's feelings of autonomy and dignity and be helpful in reducing moral distress for the relatives and staff (Paper II). To know that most residents trust relatives, nursing home staff and physicians to make important decisions on behalf of them is positive, but it does not relieve the whole burden of decision-making for another person, without knowing the person's will and preferences. As many residents appreciate participation, being heard and having a feeling of control (Lewis, 1995; Kane et al., 1997; Walent and Kayser-Jones, 2008; Ester, 2009) a systematic approach to including residents in ACP and ethics discussion might help and be beneficial for all involved stakeholders. Residents could use their autonomy and thus enhance their feeling of control and dignity, and the relatives, physicians and nursing home staff might learn more about a resident's true will and preferences for care, which might lead to reducing the burden which they feel is connected to decision-making.

Another concern is that physicians have been shown to recommend different treatments for patients than those they would choose for themselves, and that people who have to decide for others may tend to choose the option which is easiest to defend or would be preferred by most people (Kray and Gonzalez, 1999; Kray, 2000; Ubel et al., 2011). Decision-making in end-of-life care may be even more complicated as there are cultural differences between ethnically different groups, with a variety of different values and preferences (Kwak and Haley, 2005; Johnstone and Kanitsaki, 2009). It might be in the residents best interest to talk about living and dying in the nursing home, their individual preferences for treatment and care, and to engage in ACP, in order to ensure that others act according to their will, in case they are no longer able to make decisions themselves. ACP has also been said to have a positive impact on quality end-of-life care (Teno et al., 2007; Detering et al., 2010). The first results from ongoing work suggest that resident participation in decision-making and ethics discussions is possible, although nursing home staff in general seem too reluctant to encourage residents to participate (Bollig et al., 2015b). Talking with patients about end-of-life decisions has been described as an ethical obligation for healthcare providers:

> "Discussing and preparing (the patient) for an end-of-life decision early enough, is a prerequisite of good palliative care. It is an essential obligation on the side of the healthcare professionals to support openness, respect for autonomy, and dignity by addressing issues of dying and death with the patient, in order to help facilitate advance care planning." (Lenherr et al., 2012).

Although the individual wishes of nursing home residents can differ from what others may want, it is good to know what most nursing home residents wish and prefer for end-of-life care in general. The resident's wishes for end-of-life care according to our data are:

1. not to be alone,
2. good pain relief, and
3. no life-prolonging treatment

(Paper II).

Many informants in our study expressed the wish for a natural death without life-prolonging treatment or artificial nutrition (Paper II), and that they do want pain relief and company. These findings are in accordance with previous findings from the literature (Singer et al., 1999).

5.1.4 Autonomy and self-determination

In Paper I we have shown that many residents and relatives experience issues connected to autonomy and self-determination as ethical challenges in nursing homes. These challenges are often about everyday ethical issues and self-determination in everyday life, and not only autonomy issues in end-of-life care and big ethical issues. Autonomy, participation and a feeling of choice and control are important for nursing home residents (Kane et al., 1997; Rodgers and Neville, 2007; Walent and Kayser-Jones, 2008), and are also used as humanistic care indicators for nursing homes (Lee and Wang, 2014). Unfortunately, the participation of residents in medical care was rated as important but low (Garcia et al., 2016). Different authors have contributed to acknowledging the patient and their next of kin as central, and to giving patients a voice and making their views and experiences known, as described in Chapter 1.3 (Lurija, 1993; Saunders et al., 2003; Cassell, 2001; Chochinov et al., 2002; Chochinov et al., 2004; Pleschberger, 2007b; Chochinov, 2007; Cassell, 2013; Sacks, 2015; McGill News, 2016). In order to enable autonomy in nursing homes one must listen to the wishes of the residents.

Autonomy in connection to medical treatment has some important presuppositions. First, there has to be a reason to provide a medical treatment. A decision about whether medical treatment is indicated and needed, has to be made by a physician. Medical treatment can not be demanded by a patient if there is no indication for it (Bollig, 2014). The medical indication for a particular treatment or measure is the core of medical ethics (Maio, 2014). Second, the patient has to be informed about different treatment options and possible risks. Third, the patient has to give informed consent, which means that the patient should understand the information given by the physician, and have the opportunity to ask clarifying questions prior to making their decision. To obtain informed consent can thus be a complicated matter, even if patients do have normal cognitive function, and are capable of making decisions on their own. One major problem with the application of the concept of autonomy, as used in current biomedical ethics in nursing homes, is its limitation to adult and cognitively able people. In the care of vulnerable nursing home residents, including many residents with cognitive impairment, it is important to enable the residents to be as far autonomous as possible, and to let them participate in shared decision-making as far as possible. It should also be remembered that caring is a prerequisite for autonomy, as suggested by Maio (2009):

> "Today the physician is often reduced to a mere technician who fulfils the wishes of the patient. Such a concept lacks the caring aspect that is essential for the physician´s identity, and which is important for patients in need. It is suggested that caring should be understood as a prerequisite for autonomy. Autonomy without caring is not medicine."
> (Maio 2009)

It could be argued that many nursing home residents have an impaired capacity to decide, or suffer from dementia. In Norway about 80% of nursing home residents suffer from cognitive impairment or have been diagnosed with dementia (Ferri et al., 2005; Selbæk et al., 2007), and therefore relational autonomy has to be taken into account. Relational ethics is about ethical actions in relationships. Important aspects of relational ethics are mutual respect, engagement, embodied knowledge, environment and uncertainty (Pollard, 2015, p. 364). Relational autonomy is based on the social nature and interaction of people where autonomy emerges *within* and *because* of relationships (Ells et al., 2011; Sherwin and Winsby, 2011). According to Ells et al. (2001) relational autonomy is a central component of patient-centred care. Relational ethics includes advocacy in nursing (MacDonald, 2007) as well as ethically reflective healthcare decision-making, where nurses "must care *with* the patient" (Pollard, 2015). Care ethics (Gilligan et al., 1988; Conradi, 2001) is based on relationships, and the reflection of nursing practice. Care ethics does not focus on autonomous rational individuals who subsequently cooperate in the form of contract relationships, and reminds us that through many phases of life we are anything but reasonable, autonomous, or independent individuals: in childhood, adolescence, old age, sickness, and weakness. This refers to the change of autonomy throughout life as shown by the results in Chapter 4 and illustrated by Figure 8 (p. 60). From a care ethics perspective, it is indispensable to be able to understand ourselves as fundamentally connected beings (Gilligan et al., 1988; Conradi, 2001). Other ethical ideas and concepts, such as Levinas' concept of the "other" (2006), and the "ethical claim" (Løgstrup, 1956), may help staff when dealing with residents with cognitive impairment and complex problems and dilemmas, when important decisions have to be made on behalf of residents who can not participate in shared-decision-making by verbalising their wishes or preferences.

The triangular model of suffering (Cherny, 2005) shows that patients, families and health care providers are inextricably connected, and that the distress of any of these people influences the distress of the others. On this basis, a model of relational autonomy can be constructed, where autonomy, in terms of being capable of making decisions and stating them verbally, should influence the other partners. This means that a shared decision-making approach should be applied where the nursing home staff and relatives have to take over a greater part of the decision-making, if a residents loses more and more of their capacity to decide on their own, and to verbalise their wishes.

Another important aspect of autonomy that has emerged from our data in Paper I and II is the fact that some older nursing home residents do not want to make decisions for themselves, but prefer decision-making by others; mostly by relatives, but also by physicians or nurses or all of these together (shared decision-making). This suggests that an autonomous decision can also be not to use one’s autonomy, and therefore, the use of one´s own autonomy does include the decision not to use it; that means to let others decide. The definition of autonomy should thus include the right not to choose. Such a decision should be respected. Respect is an important aspect of preserving dignity for nursing home residents.

5.1.5 Experiences with systematic ethics work in nursing homes

As pointed out already, there are many ethical challenges experienced by the staff, the relatives and the residents of nursing homes every single day, and they need to be addressed and discussed. Our data shows that 90% of nursing home staff reported ethical problems in their daily work, and 91% described ethical problems as a burden (Paper III). This indicates a strong need for systematic ethics work in nursing homes, and supports previous findings and suggestions (Bollig, 2010a; Bollig et al., 2016). Today, many different approaches and methods are used to implement systematic ethics work in practice; and these are often adapted to local needs (Bollig, 2010a; Van der Dam et al., 2014; Bollig et al., 2016). Although the need to discuss and handle ethical challenges in nursing homes is widely recognised, there is no gold standard for systematic ethics work.

The results of Paper IV showed that the main topics of the 105 documented ethics meetings were ACP (46%), PEG-insertion or ethical challenges associated with PEG use (43 %), hospitalisation (33 %) and end-of-life decision-making (27 cases, 26 %). Not all results from the 105 documented ethics meetings could be included, to cover all details, in Paper IV. A more detailed presentation of the data is therefore included in the appendix in a table describing types of meetings, participants, themes discussed, reason for meeting, ethical challenges and results and conclusions.

In accordance with other studies, our findings show that ethical challenges about decision-making and end-of-life care are frequent, and have to be dealt with on a regular basis (Weston et al., 2005; Bollig et al., 2009; Dreyer et al., 2009; Bollig, 2010a; Gjerberg et al., 2010). The implementation of palliative care and patient-centred care, including advance care planning and systematic ethics work, can help to address and handle these challenges.

Thus, both big ethical issues and everyday ethical issues seem to be important in nursing homes and deserve to be addressed (Weston et al., 2005; Glasser et al., 1988; Bollig et al., 2009;, Bollig, 2010a; Slettebø ,2004; Bockenheimer et al., 2012; Bollig et al., 2016). Thirty three per cent of the meetings noted in our data focused mainly on everyday ethical challenges (Paper IV). Our informants from Paper IV reported that the implementation of systematic ethics work led to a change of focus in ethics discussions, from end-of-life themes to everyday ethical challenges (shown in Figure 7, p. 59). It seems that big ethical issues are often addressed first in the implementation process of systematic ethics work and that everyday ethical issues are addressed later in the process. This is probably connected to a raised awareness of ethical issues in daily life, after staff members started to look more closely at ethical aspects of their work. This supports the importance of ethics education and the implementation of systematic ethics work in general.

It has to be noted that neither residents nor their relatives participated in 25 of the 87 prospective case discussions (29 %) (Paper IV). One may thus speculate about whether the resident’s view was really included in these discussions. Nevertheless, an agreement about a solution was reached in 76% of prospective case discussions (Paper IV). In general the participation of residents and relatives is not common in ethics committees or other ethics discussion arenas.

Data from the U.S. showed that patients were included in 8%, and relatives in 15% of nursing home committees (Glasser et al. 1988). In a survey from Germany residents were seldom proposed as members of a nursing home ethics committee (Bockenheimer et al., 2012). Glasser et al. (1988) demanded the broader inclusion of patient perspectives in ethics committees. Our results show that the inclusion of relatives probably has become more common in ethics discussion but that the residents themselves are missing in these meetings. This is probably due to a reluctance in the staff to encourage residents to participate (Bollig et al., 2015b). To include residents in ethics discussions is a major task for the future. Ethics meetings that aim to explore the different views of all stakeholders, must include the views of all stakeholders, which means residents and relatives in addition to all staff members, and including physicians. As many nursing home residents do not feel that their will is respected, or that they are autonomous (Paper I; Wetle et al., 1988), the inclusion of residents in ethics discussion may improve their feeling of autonomy and dignity. The benefits of dignity-conserving care to enhance a resident's feeling of dignity and well-being, have already been described above (Kane et al., 1997; Chochinov, 2002; Slettebø, 2004; Chochinov, 2007; Andersson et al., 2007; Moser et al., 2007; Brandburg et al., 2013).

Focus group participants who were nursing home staff described enhanced openness and dialogue in general, and a greater ethical awareness, as advantages of systematic ethics work. They described ethics meetings as places for differing views. Many stated a need for structure and support from the administration (Paper IV). Important key factors for implementing systematic ethics work are ethics education, support from management and a structure giving time and a place for ethics reflection. These findings are similar to other findings in the literature (Lillemoen and Pedersen, 2012; Gjerberg et al., 2014; Lillemoen and Pedersen, 2015). It has been shown that ethics reflection is beneficial and may improve practice (Lillemoen and Pedersen, 2015).

Based on the fact that many ethical challenges in nursing homes are about life-prolonging treatment and decision-making in end-of-life care, the regular participation of physicians in ethics meeting in the nursing home seems necessary, and has been advocated by our informants (Paper IV). The results from Paper IV suggest that ethical reflection may be implemented using different places or arenas for ethics discussion. This finding supports existing models as the three-step approach, shown in Figure 4 (Bollig, 2010a; Bollig et al., 2016) and the model used by the Caritas Socialis in Vienna (Hallwirth-Spörk et al., 2009; Schmidt, 2009). Both models have in common that they support the use of different types of meeting places to discuss ethics within the organisation, suggesting that there is no single solution that fits all.

To implement systematic ethics work in nursing homes, different approaches and methods can thus be chosen and may be adapted to local needs (Van der Dam et al., 2014; Bollig et al., 2016). One future perspective will probably be the formation of a special framework called "nursing home ethics" (Bollig, 2013a) that could be based on a combination of the principles of biomedical ethics proposed by Beauchamp and Childress (2009), care ethics (Gilligan et al., 1988; Conradi, 2001), palliative care ethics and hospice-philosophy (Loewy and Springer Loewy, 2000; Heller and Knipping, 2006), and the ideas of Levinas (Levinas, 2006; Floriani and Schramm, 2010) and Løgstrup (1956).

5.2 Methodological considerations

5.2.1 General methodological considerations for all papers

Both the Norwegian Parliament (Norwegian Government. St.meld. nr.25, 2006) and the Norwegian Medical Association have stated that more research in the field of elderly care is needed (Den norske legeforening, 2001). To explore the views of nursing home residents, qualitative interviews with residents can help give this vulnerable group a voice and to ensure that their point of view is heard (Hall et al., 2009; Rogers and Addington-Hall, 2008; Bollig et al., 2013b). As one main aim of this thesis was to explore the views and experiences of nursing-home residents and relatives we chose to use qualitative interviews as our method (Papers I and II). Residents were in-depth interviewed and relatives focus group interviewed. In-depth interviews with nursing home residents were chosen to account for the fact that many suffer from multimorbidity, have problems with vision or hearing, have problems with concentration, and need more time to think and answer in an interview situation. In-depth interviews enable the researcher to adapt the pace of interviewing to the individual resident. The relatives were interviewed in focus groups, which gave them the opportunity to talk to each other and to exchange their views in the group. This led to open and free discussion about the interview topics.

Within a palliative care and patient-centred care framework interpretive description was chosen as qualitative method because it includes a description and interpretation of the described phenomena. We wanted to stay close to the informant's descriptions, to let them be the true focus of our interest. Interpretive description also "recognizes that the clinical mind tends not to be satisfied with "pure" description, but rather seeks to discover associations, relationships and patterns within the phenomenon that has been described." (Thorne (2008, p. 50). As residents and relatives often tend to embed their views and experiences in narratives, an interpretive part was needed as the results may have been more diffuse with a pure description only.

Purposeful sampling and the inclusion of informants from locations with a geographical spread and the different surroundings of the included institutions, were used for the greatest possible variation in the data. This was done to include the views of people with different backgrounds in origin, education and living circumstances.

Due to ethical and legal concerns and requirements in Norway, we chose to include only residents who were able to give informed consent, and did not show signs of cognitive impairment. As many residents in nursing homes do have cognitive impairment, this is an obvious limitation of the studies.

To explore the frequency of ethical challenges in nursing homes and the results of systematic ethics work, we chose to use mainly quantitative methods. The frequency of different ethical challenges experienced by nursing home staff was documented through questionnaires given to nursing home staff, and the moderators of the ethics discussions or ethics committees (Paper III and IV). The effect of prospective ethics discussions was assessed by using the frequency of reaching consent in these meetings (Paper III and IV). Descriptive statistics were used to give an overview over the frequency and type of ethical challenges and ethics meetings documented.

As a measure of the respect for the autonomy and self-determination of nursing home residents, their participation and the participation of their relatives as substitute decision-makers in the ethics discussions, was documented. To assess the degree of moral stress that is created by ethical dilemmas, the nursing home staff was asked about the degree to which they experienced ethical challenges as a burden in their daily work (Paper III). Qualitative description was also used to provide a straight description and summary of the experiences (Sandelowski, 2000) of nursing home staff with ethical challenges in nursing homes, and the implementation of systematic ethics work (Papers III and IV).

As different authors have already investigated the experiences of nursing home staff from the viewpoint of managers, leaders and nurses with leader functions, we chose a “spotlight-approach” to explore the views of the whole staff, including both healthcare-personnel and staff from other non-medical professions. This approach gave us a picture of the staff experience across the whole nursing home. Although this approach can not be seen as statistically representative for all nursing homes in Norway, it provides information from a Norwegian nursing home that may serve as an example of a typical nursing home.

As many ethics meetings are about prospective decision-making for the residents, we used the frequency of "consensus agreed on" after the meeting, as a measure of meeting success. This assumption has a limitation, as there are certain cases where it might not be possible to reach consensus with all involved parties.

The autonomy and self-determination of residents is important, and therefore their participation in ethics discussions was used as a measure of the inclusion of the residents perspective in the ethics meetings.

5.2.1.1 The researchers initial understanding and basic ideas

As the researchers initial understanding may influence the results of a study it will be addressed in the following paragraphs. When work on the studies presented in this thesis started in 2009 the principal researcher Georg Bollig was working as nursing home physician and consultant in palliative medicine and nursing home medicine on a specialised palliative care department in the Bergen Red Cross Nursing Home. He had a lot of experience talking about living and dying, decision-making and advance care planning with elderly people and their relatives. One presupposition was that the experience of talking with people about these topics might help to obtain open and honest answers from interview participants.

There was no relationship between the researcher/interviewer and the participants. No participants were recruited from Bergen Red Cross Nursing Home, where Georg Bollig was working as nursing home physician, in order to avoid ethical problems and bias based on dependence issues. All study participants were informed that the interviewer was a researcher from the University of Bergen and that the goals of the research were to investigate the views of residents and relatives on living in nursing homes, including ethical challenges and their opinion on ACP, end-of-life care and decision-making in nursing homes. When the residents asked, he told them more about his background as both a researcher and nursing home physician.

The basis and starting point for the scientific studies in this thesis was Georg Bollig's previous work on ethical challenges in primary health care and nursing homes in Norway, which was done in connection with the project on "ethics in primary health care" at the Section of Medical Ethics in the University of Oslo were he worked 50% as a nursing home physician and 50% as a researcher from September 2007 to April 2008, funded by the Norwegian

Department of Health (Helse- og Omsorgsdepartementet) and by a grant from the Norwegian Medical Association (Den norske lægeforening). This work, which was finished in part in connection with the work on this thesis, included a review of the literature on ethical challenges, decision-making and end-of-life care in nursing homes and primary health care and led to several presentations and publications (Bollig et al., 2008a; Bollig et al., 2008b; Bollig et al., 2009; Bollig, 2010a; Bollig, 2010c).

The professional experience of the principal researcher, Georg Bollig, as a nursing home physician and consultant in palliative medicine may be considered both as a strength and as a weakness. On one hand, it may ease communication with both residents and relatives regarding difficult and sensitive subjects. On the other hand, the researcher's presuppositions may colour and direct discussions to his way of thinking. The ability to talk to nursing home residents and relatives in an empathic way about their fears, losses, diseases and death, however, hopefully allowed an honest description of the informant's experiences. During data analysis the researcher's presuppositions were reflected via meta-positions, reflection and discussions with the supervisors.

International cooperation with colleagues in Germany and Austria was sought to help to obtain an overview of ethical problems in nursing homes in these countries and to be able to compare the results with the situation in the U.S. as described, for example, by Glasser et al. (1988), Weston et al. (2005) and others.

5.2.1.2 Ethical and legal aspects of research in nursing homes

The ethical and legal framework for research in Norway includes the Declaration of Helsinki of the World Medical Association, the "Norwegian law on research" and the "Norwegian law on ethics and integrity in research" (Lovdata, 2006; Lovdata, 2008; World Medical Association, 2013). To include nursing home residents in research means to include members of a vulnerable group and therefore close attention must be paid to ethical research considerations. Vulnerable groups deserve special protection when included in research projects. There are a number of things that have to be taken into account:

- Research in nursing homes should aim to improve the situation of the residents.
- Due to the high percentage of residents with cognitive impairment and dementia it is necessary to assess the resident's capacity and their ability to provide informed consent.

- Nursing home physicians should be aware that the residents are dependent on them, and therefore they should avoid including residents from their own workplace in research projects.
- Residents with cognitive impairment and lacking the capacity to provide informed consent should only be included in research if absolutely necessary and with a sound reason for the need for their participation.
  (Hall et al., 2009; Malterud, 2011; World Medical Association, 2013; Bollig et al., 2013b)

Based on the experiences of other research projects, where the inclusion of residents with cognitive impairment and dementia was criticised by the Norwegian Directorate for Health and Social Affairs (Sandgathe Husebø 2008, p. 32) we decided to exclude people with cognitive impairment from our studies. As many residents in Norwegian nursing homes suffer from cognitive impairment, this is an obvious major limitation of our studies. One may argue that we have also excluded the views of residents with mild cognitive impairment who might be able to participate in interviews, due to legal and ethical reasons. We decided that with reference to the Norwegian law, this was the most correct option at the time the study began.

The experiences from the interviews in our studies suggest that it might be possible to include residents with cognitive impairment in future research. Most residents who participated in the interviews were very thankful for the attention and ability to present their views to the researcher. No negative reactions during or after the interviews were observed. The researchers' experience as nursing home physicians probably made it easier to interview nursing home residents and to talk with them about life and death without causing anxiety or fear.

5.2.1.3 Methodological aspects of research in nursing homes

An important aspect of research in nursing homes is the recruitment of residents, relatives and staff members for participation. It may be seen as introducing biased that we used the management and nursing home staff members to recruit participants. Gatekeepers may only recruit residents and relatives that are supposed to present a positive picture of a nursing home, and those who are expected to provide criticism may not be asked to participate. The experience from the interviews suggested that many of the residents and relatives described both positive and negative experiences, and the informants defined several areas of ethical challenges and the need for improvement, and therefore the results can be seen as representative for other nursing homes and other nursing home residents and relatives.

An important methodological aspect of qualitative research is to ask good questions that lead to rich descriptions of the informant's views, experiences and their life world. A good interview question should be short, clear, easy to understand, and open (Malterud 2012, p. 71). There is a difference between a good research question and a good and dynamic interview question. A good introductory question allows for the informant's descriptions and narratives and can then be followed by different types of questions, such as follow-up questions and also silence (Kvale, 1996; Kvale and Brinkmann, 2009). Kvale has described the impact that silences and pauses may have as follows:

> "…by allowing pauses in the conversation the subjects have ample time to associate and reflect, and then break the silence themselves with significant information."
>
> (Kvale 1996, pp. 134-135)

Using pauses is even more important when interviewing old people, because they often react more slowly, and do need more time to think, before they respond. If a researcher is not attentive, and does not provide long enough pauses, useful and important information might be missed.

As one main aim of our studies was to explore ethical challenges in nursing homes from the perspectives of residents and relatives, a good question was paramount when asking them about ethical challenges, and therefore much time and discussion was spent on exploring how to ask the informants about ethical challenges. It was a major challenge to find suitable interview questions for the research question: What do nursing home residents perceive as ethical problems in nursing homes? This question is difficult to use as interview question, because it demands that the informant has already reflected on what ethics is about, and knows how to define ethics. We assumed that a direct interview question like "What do you experience as ethical challenges in the nursing home?" would not be useful at all. Repeated discussions with supervisors and colleagues from multi-professional research courses in Norway, Germany and Austria were used to find suitable questions to ask residents living in nursing homes, and relatives, about ethics. In addition the literature was reviewed. The search and repeated discussions led to the question “How can you live a good life in the nursing home?” (Bollig, 2012). The question was inspired by Aristotle’s definition of ethics as the reflection of how people can live good lives together (Aristotle, 1999; Düwell et al., 2006). All participants easily understood the question. Many informants reacted with direct and spontaneous answers, and a variety of other comments, some even with laughter. The use of this simple question led to rich descriptions of ethical challenges and problems by the residents and relatives.

6. Conclusions

The contribution of the work presented in this thesis to scientific knowledge is in explaining that ethical challenges in nursing homes include both big ethical issues and everyday ethical challenges for all stakeholders, including residents, relatives and staff. One main conclusion is the need to talk together about everyday ethical challenges, decision-making and end-of-life care in nursing homes. This includes residents, relatives and nursing home staff members, such as nurses and physicians. Advance care planning and preparatory conversations can help residents to be as autonomous and self-determinant as possible, may reduce the burden of decision-making without knowing the true wishes of the residents for relatives and staff, and may thus help to reduce conflict, especially conflict about decision-making in end-of-life care.

The overall aims of this thesis were to study ethical challenges in nursing homes and the current practice of ethics discussions and decision-making in nursing homes. Major aims were to explore the views of nursing home residents and relatives on ethical challenges, decision-making and end-of-life care in nursing homes, and also to document which ethical challenges were discussed in nursing home ethics discussion arenas, what experience the staff had with systematic ethics work, and whether ethics discussions contribute to reaching consensus.

The following conclusions are answers to the four main research questions raised in the thesis:

1. ***What do nursing home residents, relatives and staff members perceive as ethical problems in nursing homes?***

Everyday ethical issues are most important for the residents and relatives. They frequently mentioned autonomy and a lack of time to get help and social contact (lack of resources). None of the residents mentioned ethical issues in end-of-life care. Important factors for a good life, from the residents perspectives, were social contact, participation in daily life and self-determination (Paper I).

Most staff members experienced ethical challenges in daily work. The most commonly described ethical challenges were a lack of resources, end-of-life issues, coercion, communication, lack of professional competence and issues about resident autonomy. Everyday ethical issues are important in nursing homes, including from the staff perspective (Paper III). ACP, PEG-insertion or ethical challenges associated with PEG use, hospitalisation and end-of-life decision-making were the most important topics in the 105 documented ethics meetings (Paper IV). About a third of the meetings focused mainly on everyday ethical challenges.

2. ***How do nursing home residents and relatives think decisions should be made for the residents?***

Differing views about decision-making and advance care planning between residents and relatives, was one of the main findings. Most residents trust relatives and staff to make important decisions for them, and believe that they would know their wishes. The majority of the residents had not participated in advance care planning. They seem to be satisfied with decision-making and nursing home end-of-life care in general. Many residents want their relatives to make decisions for them, and appreciated shared decision-making by relatives, nurses and physicians if unable to decide for themselves. In contrast, many relatives are insecure about a resident's wishes, and experience decision-making as a burden (Paper II). Most relatives prefer shared decision-making with physicians and nurses (Paper II).

3. ***What are the most frequent ethical challenges discussed in ethics meetings in nursing homes in Norway, Germany and Austria?***

Lack of resources, end-of-life issues and coercion were the ethical challenges most often reported by nursing home staff from Norway. Although everyday ethical issues play an important role in the daily work, topics discussed in resident ethics meetings mostly involve ACP, the withholding or withdrawing of life-prolonging treatment and other big ethical issues. Everyday ethical issues are often hidden under the surface as illustrated by the ethics iceberg (Paper III).

Of the 105 documented ethics meetings in Norway, Germany and Austria, the main topics were advance care planning, ethical challenges associated with artificial nutrition, hospitalisation, and end-of-life decision-making. About a third of all meetings focused mainly on everyday ethical challenges.

Agreement about a solution was reached in ¾ of prospective case discussions. Unfortunately in about a third of these, no residents or relatives participated (Paper IV).

4. *What are the staff experiences with systematic ethics work and ethics discussions in nursing homes in Norway, Germany and Austria?*

Nursing home staff members appreciate systematic ethics work to aid decision-making. Resident ethics meetings helped to reach consensus in all documented prospective ethics discussions (Paper III) Relatives participated in most ethics discussions, whereas participation of residents was totally absent. The results of the study support the value of a systematic approach to resolving ethical dilemmas in nursing homes (Paper III).

The advantages of systematic ethics work described by the staff were enhanced openness and dialogue, overall, and a greater ethical awareness. Many voiced a need for structure and support from the administration (Paper IV).

Systematic ethics work is greatly appreciated by the staff and helps to reach a consensus in the majority of case discussions. Attention to everyday ethical challenges is important. The participation of relatives and physicians could be improved (Paper IV).

The implementation of systematic ethics work leads to a change of the focus in ethics discussions from end-of-life themes to everyday ethical challenges,, such as dignity, resident autonomy and self-determination (Paper IV). This is illustrated by the tipping ethics iceberg.

For the staff, systematic ethics work and ethics discussion arenas may help to reduce the burden of ethical challenges, and serve as tool to aid decision-making for residents without the capacity to decide.

7. Future perspectives and implications

The results of the scientific studies presented in the four papers in this thesis suggest that there are several pieces of advice that could improve practice in handling ethical challenges, ACP, decision-making and end-of-life care in nursing homes.

Ethical challenges and dilemmas are common in nursing homes and thus need attention. Everyday ethical issues need to be addressed in systematic ethics work in nursing homes and daily routines in nursing homes should be adapted to meet these challenges. As many residents in our studies did not feel autonomous it is suggested that efforts are made to meet the resident's wishes as far as possible in order to strengthen their feeling of autonomy and dignity. Routines in nursing homes should enable a resident's social contact and participation, and the staff should strive to include residents in decision-making as far as possible, in order to strengthen their feeling of autonomy and dignity. Talking about death and dying in general, and especially about resident preferences for everyday care, as well as advance care planning, treatment and decision-making in end-of-life care are paramount, and should be addressed by the staff in order to maintain self-determination and dignity.

Although most residents in our studies seemed to be satisfied with decision-making and end-of life care, there is a definitely a need for a systematic approach to advance care planning. Advance care planning could help to explore future wishes for care and ease decision-making for the relatives, physicians and staff, and should thus be offered to all cognitively able nursing homes residents. Communication about ACP should be routine in all long-term care facilities. Unfortunately most residents and relatives are reluctant to start conversations about life and death, and their preferences for treatment and place of care at the end-of-life, although most residents and relatives are willing to talk about ACP and these questions in general. Most nursing home residents are not aware that ACP is an option to use their autonomy, and to make sure that their personal preferences are known both to the relatives and nursing home staff. It often seems that a third person,, such as a physician or member of the nursing staff, is needed to initiate these important conversations, and therefore nursing home staff and physicians should offer residents opportunities for these discussions, engage in ACP, and offer the opportunity to discuss death, dying and wishes for care and treatment at the end of life, with nursing home residents, and when the resident agrees, their next of kin.

One relatively new option to improve the discussion about death and dying, ACP and preferences at the end-of-life is the “last aid course”, an educational effort to teach the public about palliative care, end-of-life care and ACP (Bollig, 2010b: pp. 72-73).

Systematic ethics work with both ethics education and ethics meetings that include the residents and relatives should be implemented in all nursing homes, and should be routine, instead of something special for the few. Ethics education and systematic ethics work in nursing homes should probably focus more on everyday ethical issues, instead of focussing solely on end-of-life care and decision-making conflicts. All stakeholders should participate in ethics discussions in nursing homes. This includes nursing staff, physicians, relatives and, of course, the residents. The participation of physicians and relatives should be improved. Residents should be encouraged to participate in ethics discussions in order to use their autonomy and right of self-determination, as far as possible.

Further research should focus on how to improve the autonomy and participation of residents in nursing homes, and to include them in decision-making in everyday life and advance care planning. Research into the views of residents with cognitive impairment and dementia is interesting, but ethically problematic. There needs to be discussion about whether this vulnerable group should be excluded, in order to protect them, or included, in order to give them a voice, and make them heard. More knowledge about the different types of ethics meetings and ethics discussion arenas, such as resident ethics meetings, ethics discussion groups, ethics cafes and ethics committees, is needed. The advantages and disadvantages of different models for systematic ethics work in nursing homes need to be explored in more detail.

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9. Appendix

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Papers I-IV

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Overlege dr.med Georg Bollig
Bergen Røde Kors Sykehjem
Ellerhusensvei 35
5043 Bergen

Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst A (REK Sør-Øst A)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 66
Telefaks: 22 85 05 90
E-post: jorgen.hardang@medisin.uio.no
Nettadresse: http://helseforskning.etikkom.no

Dato: 04.11.09
Deres ref.:
Vår ref.: 2009/1339a

2009/1339a Etiske problemer og avgjørelser rundt livets slutt i sykehjem

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional forskningsetisk komité for medisinsk og helsefaglig forskningsetikk i møtet 19. oktober 2009. Søknaden er vurdert i henhold til lov av 20. juni 2008 nr. 44, om medisinsk og helsefaglig forskning (helseforskningsloven) kapittel 3, med tilhørende forskrift om organisering av medisinsk og helsefaglig forskning av 1. juli 2009 nr 0955.

Prosjektleder : Overlege Georg Bollig
Vitenskapelig tittel : dr.med
Arbeidssted : Bergen Røde Kors Sykehjem

Forskningsansvarlig : Universitetet i Bergen , HDS og Institutt for kirurgiske fag

Dette er et delvis norsk, delvis utenlandsk empirisk prosjekt som blant annet skal lede frem til doktorgrad. 20 medlemmer av etiske refleksjonsgrupper og etiske komiteer samt 20 sykehjemsbeboere og 40 pårørende intervjues med sikte på å få frem hyppighet av etiske problemer (spørreskjema for den førstnevnte gruppen) og opplevelse, holdninger og tanker(dybdeintervju og fokusgruppeintervju for de to sistnevnte gruppene).

Rekruttering av forskningsdeltakere skjer via sykepleier og leger fra sykehjem.

Komiteens vurdering

Det forutsettes at Universitetet i Bergen er forskningsansvarlig i prosjektet.

I søknadens punkt 5h opplyses det om at data i form av lydbåndopptak fra samtaler med forskningsdeltakere skal lagres. REK forutsetter at lydbånd slettes eller anonymiseres ved prosjektets sluttdato, og at det opplyses om dette i informasjonsskrivene.

Når det gjelder innhenting av samtykke til deltakelse i forskning hos beboere i sykehjem, forutsetter komiteen at helseforskningsloven § 17 fjerde og femte ledd følges i forhold til vurderingen av samtykkekompetanse og fremgangsmåte i de tilfeller hvor en sykehjemsbeboer blir funnet å være i en tilstand hvor vedkommende enten bare har delvis samtykkekompetanse, eller mangler samtykkekompetanse.

Ut fra det ovenstående oppstiller komiteen følgende vilkår til søknaden:

1. Lydbåndopptak slettes eller anonymiseres ved den fastsatte sluttdato for prosjektet.

2. Det forutsettes at vurderingen av samtykkekompetanse og innhenting av stedfortredende samtykke innhentes etter gjeldende bestemmelser i helseforskningsloven

Vedtak

Prosjektet godkjennes under forutsetning av at de vilkårene som er anført ovenfor blir innarbeidet før prosjektet settes i gang.

Godkjenningen av prosjektet gjelder til 31.12.2012. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2017. Opplysningene skal deretter slettes eller anonymiseres, senest innen 30.1.2018.

Opplysningene skal lagres avidentifisert, det vil si adskilt i en nøkkel- og en opplysningsfil.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK Sør-Øst A på fastsatt skjema senest 1.6.2013

I tillegg til vilkår som fremgår av dette vedtaket, er tillatelsen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Hvis det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene er "vesentlige", må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK REK Sør-Øst A. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no
Vennligst oppgi vårt saksnummer/referansenummer i korrespondansen.

Med vennlig hilsen

Gunnar Nicolaysen (sign.)
Professor
Leder

Øyvind Grønlie Olsen
Fungerende komitésekretær

Regional komité for medisinsk og
helsefaglig forskningsetikk
Sør-Øst-Norge

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

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Nettadresse: http://helseforskning.etikkom.no

Dato: 6.1.2010
Deres ref.:
Vår ref.: 2009/1339a

2009/1339a Etiske problemer og avgjørelser rundt livets slutt i sykehjem

Vi viser til e-post av 26.11.09 med tilbakemelding komiteens spørsmål til prosjektopplegget med følgende vedlegg: informasjonsskriv med samtykkeerklæring til sykehjemsboende og pårørende og informasjonsskriv med samtykkeerklæring til deltaker i refleksjonsgrupper.

Komiteen tar til orientering at vilkår for godkjenning er oppfylt.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no

Vennligst oppgi vårt saksnummer/referansenummer i korrespondansen.

Med vennlig hilsen

Gunnar Nicolaysen (sign.)
Professor
Leder

Jørgen Hardang
Jørgen Hardang
Komitésekretær

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Anne S. Kavli	22845512	15.09.2015	2009/1339/REK sør-øst A
			Deres dato:	**Deres referanse:**
			04.09.2015	

Vår referanse må oppgis ved alle henvendelser

Georg Bollig
Flensburger Str. 60

2009/1339 Etiske problemer og avgjørelser rundt livets slutt i sykehjem

Forskningsansvarlig: Universitetet i Bergen
Prosjektleder: Georg Bollig

Vi viser til søknad om prosjektendring datert 04.09.2015 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

REK har vurdert følgende endring i prosjektet:
-Ny sluttdato. Prosjektet søkes forlenget til 31.12.2016.

REK har vurdert søknaden og har ingen innvendinger til endringen som er beskrevet.

Vedtak

Komiteen godkjenner med hjemmel i helseforskningsloven § 11 annet ledd at prosjektet videreføres i samsvar med det som fremgår av søknaden om prosjektendring og i samsvar med de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom det skal gjøres ytterligere endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende ny endringsmelding til REK.

Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Opplysningene skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK, se helseforskningsloven § 12, senest 6 måneder etter at prosjektet er avsluttet.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10 tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst A. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Med vennlig hilsen

Knut Engedal
Professor dr. med.
Leder

Anne S. Kavli
Seniorkonsulent

Kopi til: *post@uib.no;*

Forespørsel om deltakelse i forskningsprosjektet
”Etiske problemer og avgjørelser rundt livets slutt i sykehjem”

Intervju av sykehjemsbeboere og pårørende

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å få frem sykehjemsbeboernes og deres pårørendes syn på etiske problemer og avgjørelser på sykehjem i sammenheng med omsorg og behandling i livets slutt. Personer som bor fast på sykehjem og pårørende av sykehjemsbeboere er valgt ut til å delta i intervju. Ansvarlig for prosjektet er prosjektleder og forsker Georg Bollig ved Bergen Røde Kors Sykehjem. Prosjektet er knyttet til Universitetet i Bergen og Universitetet Klagenfurt/Wien, Østerrike.

Hva innebærer studien?

Det skal gjennomføres intervju med enkeltpersoner som bor på sykehjem og gruppeintervju av pårørende. Tidsbruk for disse intervju vil variere og vil ca. ta en halv time til en time. Intervjuene skal tas opp på bånd. Opptakene vil bare bli tilgjengelig for prosjektleder/forsker Georg Bollig og andre medvirkende forskere. Disse vil bli analysert og skal brukes til å skrive vitenskapelige artikler. Lydbånd vil bli anonymisert etter prosjektets sluttdato 31.12.2012.

Mulige fordeler og ulemper

Intervju vil gå inn på spørsmål om etikk, om behandling og ønsker rundt livets slutt. Å snakke åpent om disse emner oppleves av de fleste mennesker ikke som belastende. Det kan derimot ikke utelukkes at enkelte vil føle det belastende å snakke om forhold rundt livets slutt. Derfor er det fullt mulig å trekke seg fra intervju eller å ikke svare på enkelte spørsmål til en hver tid uten nødvendighet for å begrunne dette.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og prøver gjennom en navneliste. Det er kun prosjektleder knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektleder Georg Bollig, tlf. 48892254.

Spørsmål om studien? Ta kontakt med prosjektleder Georg Bollig tlf. 48 89 22 54

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse:

Deltakere skal bo på sykehjem og være samtykkekompetente, d.v.s. at det kan gjøre selv rede for seg og kan ta egne avgjørelser selvstendig. Pårørende som deltar i studien skal ha en pårørende som bor på sykehjem.

Bakgrunnsinformasjon om studien:

Det er beskrevet en del etiske problemer i sammenheng med avgjørelser i livets sluttfase på sykehjem. Den tilgjengelige litteraturen bruker som regel fagpersonal som informanter. Denne studien skal sette fokus på pasientens og pårørendes egne formeninger, opplevelser og ønsker.

Hva skjer og hva innebærer deltakelse i prosjektet?

Deltakelse vil innbefatte et intervju med forsker Georg Bollig som vil ta en halv time til en time. Intervju vil foregår med deltaker og forsker en til en for beboere på sykehjem og i gruppeintervju sammen med flere andre pårørende (ca. 8-12). Deltakerne vil være med en gang og behøver ikke å gjøre noe mer utover det. De står fritt til å ta kontakt med prosjektlederen dersom de har spørsmål eller behov for kontakt også etter intervju. Det gis ikke godtgjørelse for å delta i studien eller dekning av utgifter i forbindelse med oppmøte til intervju. Det regnes ikke med at intervju vil føre til ubehag men man gjør oppmerksom på at man under intervju vil komme inn på livets slutt og død som del av livet. Tidspunkt for intervju vil bli avtalt med sykehjemmet og deltakerne i god tid på forhånd og vil forgår i perioden fra høst 2009 til sommer 2011.

Kapittel B - Personvern, biobank, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er navn, fødselsdato og boadresse. Medisinske opplysninger om deg vil ikke bli registrert. Båndopptakene fra intervju oppbevares adskilt fra persondata og det er bare prosjektleder som har tilgang til begge deler. Anonymiserte båndopptak vil brukes av medvirkende forskere i prosjektet. Bergen Røde kos Sykehjem ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre

Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til medvirkende forskere fra andre EU-land som for eksempel Tyskland og Østerrike.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Helse- og Rehabiliterings rolle

Prosjektet er finansiert med Extra-midler fra Helse og Rehabilitering. Det finnes ingen interessekonflikter i sammenheng med prosjektet.

Forsikring

Studien omfatter ingen risiko for deltakere og derfor finnes det ingen forsikringsordninger.

Informasjon om utfallet av studien

Alle deltakere har rett til å bli informert om resultatet fra studien. Alle som ønsker dette vil få tilbudt om å få tilsendt skriftlig informasjon etter at studien er avsluttet i løpet av 2012.

Samtykke til deltakelse i studien

”Etiske problemer og avgjørelser rundt livets slutt i sykehjem”

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i et forskningsprosjekt
*om e*tiske problemer og utfordringer i sykehjem

Spørreskjemaundersøkelse om etikk i sykehjem

Bakgrunn

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å finne ut mer om etiske problemer og avgjørelser på sykehjem.

På sykehjem er det mange etiske valg som må tas hver eneste dag. En del handler om hverdagsetiske utfordringer som f. eks. om det er riktig å bruke tvang eller å blande medisiner i syltetøy mot pasientens vilje. Etiske utfordringer rundt livets slutt er f. eks. spørsmål om å fortsette eller avbryte livsforlengende behandling eller innleggelse på sykehus versus behandling på sykehjem. I de fleste norske sykehjem er over 70 % av beboerne demente. Disse vil ikke lenger være i stand til å ta livsviktige avgjørelser for seg selv. Allerede i dag er det en stor utfordring for personalet i helsevesenet å finne ut hva pasientene ville ønsket selv dersom de ikke var dement og kunne fortsatt gi uttrykk for sin vilje. Ofte må derfor etiske avgjørelser tas av sykepleier, leger, og pårørende. Etiske veiledningsgrupper eller etikkomiteer startes nå opp på flere sykehjem i Norge. Det finnes bare få vitenskapelige studier på dette området.

Hensikt:

Målsetting er å undersøke hvilke etiske utfordringer eksisterer i sykehjem og hvilke tiltak de ansatte ønsker for å styrke systematisk etikkarbeid i sykehjem. Fordeler og ulemper av forskjellige tiltak som etikk diskusjonsgrupper, etiske komiteer eller etikk råd på sykehjemmene skal belyses.

Hva innebærer studien?

Deltakelsen foregår gjennom å besvare det vedlagte spørreskjema. Spørreskjemaene skal leveres til forsker Georg Bollig og vil bare bli tilgjengelig for prosjektleder/forsker Georg Bollig og andre medvirkende forskere. Resultatene vil offentliggjøres i form av en eller flere vitenskapelige artikler og evt. omtale i andre media. Det vil ikke være mulig at enkelte deltakere blir kjent igjen i publikasjonene.

Frivillig deltakelse

Det er frivillig å delta i studien. De som ønsker å delta skal fylle ut spørreskjemaet og kan levere det til Georg Bollig i en lukket konvolutt. Personlige opplysninger vil bli behandlet konfidensielt.

Kriterier for deltakelse:

Alle som jobber på sykehjemmet kan delta, dette gjelder også ikke-medisinsk personell som for eksempel i kjøkken, teknisk avdeling eller ansatte i administrasjon, etc.

Bakgrunnsinformasjon om studien:

Det er beskrevet en del etiske problemer i sykehjem. Det handler om forskjellige etiske utfordringer i hverdagen og også ved livets slutt. En pilotstudie fra Norge av Bollig, Pedersen og Førde er publisert i Sykepleien forskning og kan finnes på nettet:

http://www.sykepleien.no/ikbViewer/page/sykepleien/vis/artikkel-forskning?p_document_id=279903

Det er mulig å få kopi av denne pilotstudien ved henvendelse til Georg Bollig.

Personvern og økonomi

Personvern

Opplysninger som registreres om deg er bare alder, yrke og kjønn. Spørreskjemaene oppbevares låst og det er bare prosjektleder og medarbeidere i prosjektet som har tilgang til disse.

Økonomi og Helse- og Rehabiliterings rolle

Prosjektet er finansiert med Extra-midler fra Helse og Rehabilitering. Det finnes ingen interessekonflikter i sammenheng med prosjektet.

Informasjon om utfallet av studien

Alle deltakere har rett til å bli informert om resultatet fra studien. Alle som ønsker dette vil få tilbudt om å få tilsendt skriftlig informasjon etter at studien er avsluttet i løpet av 2012.

Spørsmål om studien?

Ta kontakt med prosjektleder Georg Bollig tlf. 48 89 22 54

Samtykke til deltakelse i spørreskjema-undersøkelse om etikk i sykehjem

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Forespørsel om deltakelse i forskningsprosjektet
”Etiske problemer og avgjørelser rundt livets slutt i sykehjem”

Intervju av deltaker i etikk refleksjonsgrupper / etikk komitteer

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie finne ut mer om etiske problemer og avgjørelser på sykehjem i sammenheng med omsorg og behandling i livets slutt. Personer som har deltatt i etiske reflekjsonsgrupper eller etikkomiteer er valgt ut til å delta i et gruppeintervju. Ansvarlig for prosjektet er prosjektleder og forsker Georg Bollig ved Bergen Røde Kors Sykehjem. Prosjektet er knyttet til Universitetet i Bergen og Universitetet Klagenfurt/Wien, Østerrike.

Hva innebærer studien?

Det skal gjennomføres intervju med medlemmer av etikk refleksjonsgrupper eller etikkomiteer på sykehjem. Tidsbruk for disse intervju vil variere og vil ca. ta en til to timer. Intervjuene skal tas opp på bånd. Opptakene vil bare bli tilgjengelig for prosjektleder/forsker Georg Bollig og andre medvirkende forskere. Disse vil bli analysert og skal brukes til å skrive vitenskapelige artikler. Lydbånd vil bli anonymisert etter prosjektets sluttdato 31.12.2012.

Mulige fordeler og ulemper

Intervju vil gå inn på spørsmål om etikk, om behandling og ønsker rundt livets slutt. Å snakke åpent om disse emner oppleves av de fleste mennesker ikke som belastende. Det kan derimot ikke utelukkes at enkelte vil føle det belastende å snakke om forhold rundt livets slutt. Derfor er det fullt mulig å trekke seg fra intervju eller å ikke svare på enkelte spørsmål til en hver tid uten nødvendighet for å begrunne dette.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og prøver gjennom en navneliste. Det er kun prosjektleder knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.
Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektleder Georg Bollig, tlf. 48892254.

Spørsmål om studien? Ta kontakt med prosjektleder Georg Bollig tlf. 48 89 22 54

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse:
Deltakere skal være med medlemmer av etikk refleksjonsgrupper eller etikkomiteer på sykehjem og har deltatt i etikkarbeidet på sykehjem.
Bakgrunnsinformasjon om studien:
Det er beskrevet en del etiske problemer i sammenheng med avgjørelser i livets sluttfase på sykehjem. Den tilgjengelige litteraturen bruker som regel fagpersonal som informanter. Denne studien skal sette fokus på hvilke etiske utfordringer diskuteres finnes på sykehjem og hva deltakerne synes er fordeler og ulemper med deres metode (veiledningsgruppe, etikkkomoitee, eller lignende) å reflektere etiske problemer på.

Hva skjer og hva innebærer deltakelse i prosjektet?
Deltakelse vil innbefatte et intervju med forsker Georg Bollig som vil ta en til to timer.
Intervju vil foregå med deltaker og forsker i gruppeintervju sammen med flere andre (ca. 8-12). Deltakerne vil være med en gang og behøver ikke å gjøre noe mer utover det. De står fritt til å ta kontakt med prosjektlederen dersom de har spørsmål eller behov for kontakt også etter intervju. Det gis ikke godtgjørelse for å delta i studien eller dekning av utgifter i forbindelse med oppmøte til intervju. Det regnes ikke med at intervju vil føre til ubehag men man gjør oppmerksom på at man under intervju vil komme inn på livets slutt og død som del av livet.
Tidspunkt for intervju vil bli avtalt med sykehjemmet og deltakerne i god tid på forhånd og vil forgår i perioden fra høst 2009 til høst 2010.

Kapittel B - Personvern, biobank, økonomi og forsikring

Personvern
Opplysninger som registreres om deg er bare alder, yrke og kjønn. Båndopptakene fra intervju oppbevares adskilt fra persondata og det er bare prosjektleder som har tilgang til begge deler. Anonymiserte båndopptak vil brukes av medvirkende forskere i prosjektet. Bergen Røde Kors Sykehjem ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre
Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til medvirkende forskere fra andre EU-land som for eksempel Tyskland og Østerrike.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Helse- og Rehabiliterings rolle

Prosjektet er finansiert med Extra-midler fra Helse og Rehabilitering. Det finnes ingen interessekonflikter i sammenheng med prosjektet.

Forsikring
Studien omfatter ingen risiko for deltakere og derfor finnes det ingen forsikringsordninger.

Informasjon om utfallet av studien
Alle deltakere har rett til å bli informert om resultatet fra studien. Alle som ønsker dette vil få tilbudt om å få tilsendt skriftlig informasjon etter at studien er avsluttet i løpet av 2012.

Samtykke til deltakelse i studien

”Etiske problemer og avgjørelser rundt livets slutt i sykehjem”

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Spørreskjema etikk i sykehjem

Personalia/bakgrunnsopplysninger (vennligst kryss av eller skriv inn)

Alder i år: ☐ under 20 ☐ 20-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60-69

Kjønn: ☐ Mann ☐ Kvinne

Profesjon: ☐ Lege ☐ Sykepleier ☐ Hjelpepleier ☐ Annet, spesifiser:________________

Stillingsbetegnelse, (skriv):____

Avdeling: ☐ Langtidsavdeling ☐ Korttidsavdeling ☐ Palliativ avdeling ☐ Annet

1. Opplever du etiske utfordringer eller problemer i ditt arbeid i sykehjem?
   ☐ Ja ☐ Nei
   Hvis svaret er ja:
   a) Hvilke etiske utfordringer eller problemer dette er?
   (kryss av)
   ☐ Ressursmangel / prioriteringsproblem
   ☐ Etiske utfordringer ved livets slutt
   ☐ Kommunikasjon og taushetsplikt
   ☐ Pasientautonomi / samtykkekompetanse
   ☐ Manglende faglig kompetanse
   ☐ Tvang mot pasienter
   ☐ Annet? (beskriv evt. med egne ord) ____

   b) Hvordan håndterer du/dere etiske utfordringer eller problemer i hverdagen?
   (kryss av)
   ☐ Uformelle diskusjoner med kolleger
   ☐ Samtale mellom lege, pleiepersonalet, pasienter og/eller pårørende
   ☐ Veiledning- /refleksjonsgruppe
   ☐ Etikk-råd
   ☐ Vet ikke
   ☐ Annet? (beskriv evt. med egne ord) ____

2. I hvilken grad opplever du/dere etiske problemer som en belastning i hverdagen?

☐ ikke i det hele tatt ☐ i liten grad ☐ i noen grad ☐ i stor grad ☐ i svært stor grad

3. Er det behov for å jobbe mer systematisk med etiske utfordringer og øke etikk-kompetansen på din arbeidsplass/innenfor ditt arbeidsområde?
☐ Ja ☐ Nei
Hvis ja, hvordan:
a) Kompetanseheving i etikk?
☐ Ja ☐ Nei ☐ Usikker
Hvis svaret er ja: kompetanseheving i etikk, for hvem? (kryss av)
- For ressurspersoner?
  ☐ Ja ☐ Nei ☐ Usikker
- For ledere?
  ☐ Ja ☐ Nei ☐ Usikker
- For hele personalet (inkl. ufaglærte og andre)?
  ☐ Ja ☐ Nei ☐ Usikker
- Nettbasert undervisning?
  ☐ Ja ☐ Nei ☐ Usikker

b) Refleksjonsmodeller og verktøy til å diskutere etiske utfordringer?
☐ Ja ☐ Nei ☐ Usikker

c) Retningslinjer for etiske vanskelige områder, for eksempel avslutning av livsforlengende behandling?
☐ Ja ☐ Nei ☐ Usikker

d) Kjerneverdier for arbeidsplassen?
☐ Ja ☐ Nei ☐ Usikker

e) Møteplasser/fora hvor etiske utfordringer blir diskutert?
☐ Ja ☐ Nei ☐ Usikker

f) Noen å henvende seg til for å kunne få råd og veiledning?
☐ Ja ☐ Nei ☐ Usikker

Hvis ja;

- Ansatt med etikk-kompetanse?
  ☐ Ja ☐ Nei ☐ Usikker
- Etikk-komite for arbeidsplassen?
  ☐ Ja ☐ Nei ☐ Usikker
- Jurist?
  ☐ Ja ☐ Nei ☐ Usikker

g) Bør man avsette tid og ressurser til etikkarbeid?
☐ Ja ☐ Nei ☐ Usikker

h) Trengs det interkommunale/nasjonale møteplasser og eller plasser for erfaringsutveksling (for eksempel fagdager, konferander, eller lignende?
☐ Ja ☐ Nei ☐ Usikker

i) Trengs det faglig veiledning/påfyll utenfra (for eksempel fra Universitet/høyskole)
☐ Ja ☐ Nei ☐ Usikker

j) Trengs det forskning omkring hvordan etiske utfordringer håndteres i sykehjem og kommunehelsetjenesten?
☐ Ja ☐ Nei ☐ Usikker

Annet? (beskriv evt. med egne ord) ____

4. Kan du beskrive med egne ord det siste etiske dilemma eller utfordring som du har opplevd på sykehjem? (evt. bruk eget ark i tillegg dersom det ikke er nok plass)

Spørreskjema om etikk diskusjons- og/eller veiledningsgrupper / møte i etikk komite angående etiske utfordringer i sykehjem

1. **Institusjon og sted:**

2. **Dato:**

3. **Antall deltaker:**

4. **Type etikk diskusjon/veiledning** – vennligst kryss av

   ☐ Uformell samtale om etiske utfordringer

   ☐ Etikk diskusjons- /veiledningsgruppe

   ☐ Etikk komite

   ☐ Andre (skriv):______________________________

5. **Deltakernes yrke/funksjon** – vennligst kryss av

   ☐ Sykepleier
   evt. med ledelsesfunksjon ☐ Sjef-/oversykepleier ☐ avdelingssykepleier/avdelingsleder

   ☐ Hjelpepleier eller pleiemedhjelper

   ☐ Lege

   ☐ Fysioteraput

   ☐ Ergoterapeut

   ☐ Sosionom

   ☐ Prest

   ☐ Frivillig medarbeider

   ☐ Andre: (skriv)______________________________

6. **Var beboeren / pasienten selv eller en stedfortreder (pårørende, venner, hjelpeverge, etc.) tilstede?**
   - vennligst kryss av

   ☐ Beboeren / pasienten selv var tilstede

   ☐ Pårørende, venner, hjelpeverge, etc.- evt. antall personer:_____________

7. **Fantes det et skriftlig livstestamente eller lignende?**

   ☐ Ja

   ☐ Nei

   Evt. kommentar:____

8. **Gjaldt møtet en beboer / pasient (drøfting av pasient kasus)?**

☐ Prospektiv – en avgjørelse for beboeren / pasienten måtte tas i framtiden

☐ Retrospektiv – etter at en avgjørelse for beboeren / pasienten måtte tas; beboeren/pasienten er muligens ikke lenger i institusjonen

☐ Diskusjon av vanlige etiske utfordringer (f. eks. Bruk av tvang, avslutning av livsforlengende behandling, etc.)

9. **Hva var grunnen for møtet?** – vennligst beskriv kort med egne ord

10. **Hvem har ønsket at møtet fant sted?** - vennligst beskriv kort med egne ord

11. **Hva var det / de etiske problemet / problemer?** - vennligst beskriv kort med egne ord

12. **Ble man enige om en løsning eller avgjørelse?**

☐ Ja

☐ Nei, fordi (skriv)____

Hvis ja, ble løsningen fulgt i virkeligheten?

☐ Ja

☐ Nei, fordi (skriv)____

Mange takk for hjelpen og utfylling av dette spøreskjemaet!

Prosjektleder Dr. med. Georg Bollig, MAS (Palliative Care), DEAA

Kirurgisk institutt, Universitetet i Bergen

Kontakt: E-post: bollig.georg@gmx.de / mobil: +47 - 48 89 22 54

Informants – nursing home residents

Nr.	Age (years)	Gender	Main medical diagnoses	Number of nursing home residents in the nursing home
1	66	Male	Multimorbidity Chronic pain Heart disease Depression Stroke	50-100
2	70	Male	Multimorbidity Parkinson disease Angina pectoris Depression	100-150
3	74	Female	Multimorbidity Rheumatoid disease Diabetes COLD Basalioma Arteriosclerosis	100-150
4	75	Male	Stroke (several times)	100-150
5	77	Female	Multimorbidity Heart disease Atrial fibrillation Chronic pain Osteomyelitis	100-150
6	79	Male	Multimorbidity Rheumatoid disease Prostate cancer Intestinal diverticulum Ileocolostomy	< 50
7	81	Male	Osteoporosis Rheumatoid arthritis	100-150
8	81	Female	Multimorbidity Diabetes type II Hypertension Depression Renal insufficiency	100-150
9	83	Male	Multimorbidity Parkinson disease Hypertension Hyperlipoproteinemia Depression	< 50
10	87	Female	Multimorbidity Stroke COLD Atrial fibrillation	< 50
11	88	Female	Rheumatioid disease	50-100
12	89	Female	Multimorbidity Hypertension Depression Biological aortic valve Bypass operation	100-150
13	89	Female	Multimorbidity Heart disease Atrial fibrillation Chonic muscle pain	50-100
14	89	Female	No information provided	150-200
15	91	Female	Multimorbidity Intestinal diverticulum Intestinal cancer Ileocolostomy Coxarthrosis Angina pectoris Intervertebral disc disease	100-150
16	92	Female	Multimorbidity heart failure hypertension osteoporosis pulmonary embolism thrombosis	100-150
17	92	Male	Multimorbidity Prostate cancer Macular degeneration Intestinal cancer Paroxysmal tachcardia	100-150

18	93	Male	Multimorbidity Stroke Hypercholesterolemia Vertebral canal stenosis Cataract Deafness	100-150
19	94	Female	Multimorbidity Stroke Diabetes	50-100
20	94	Female	Multimorbidity Atrial fibrillation Stroke Heart disease Intestinal diverticulum Ileocolostomy	100-150
21	95	Female	Basalioma Arthrosis	100-150
22	96	Female	Multimorbidity Hypertension Depression Stroke	100-150
23	97	Male	Multimorbidity Depression Chronic muscle pain Deafness	50-100
24	99	Female	Multimorbidity Hypertension Stroke Angina pectoris Atrial fibrillation Esophageal reflux	50-100
25	100	Female	Multimorbidity Deafness Aortic stenosis Chronic pain Compressionfracture of lumbar vertebrae Glaucoma Esophagitis Coxarthrosis	100-150

In order to protect the residents' privacy and to ensure that they can stay anonymous the resident numbers in the table do not correspond with the numbers of the citations. One informant was excluded during the interview because of cognitive impairment.

Informants – relatives of nursing home residents

Nr.	**Age**	**Gender**	**Number of nursing home residents in the nursing home**	**Community size – inhabitants**
1	41	Female	< 50	< 1.500
2	45	Male	100-150	> 250.000
3	53	Female	< 50	< 1.500
4	58	Female	< 50	< 1.500
5	59	Female	100-150	> 250.000
6	60	Female	100-150	> 250.000
7	66	Female	< 50	< 1.500
8	67	Female	100-150	> 250.000
9	67	Female	100-150	> 250.000
10	71	Female	100-150	> 250.000
11	72	Female	100-150	> 250.000
12	73	Female	100-150	> 250.000
13	74	Female	100-150	> 250.000
14	77	Male	100-150	> 250.000
15	77	Female	100-150	> 250.000
16	80	Male	100-150	> 250.000
17	86	Male	100-150	> 250.000
18	91	Male	100-150	> 250.000

In order to protect the relatives' privacy and to ensure that they can stay anonymous the resident numbers in the table do not correspond with the numbers of the citations.

Informants – Nursing home staff members or nursing home ethics committee members with experience in the implementation of systematic ethics work or ethics discussions

Focus group participants (n=43)

Focus group nr.	**1**	**2**	**3**	**4**	**5**
Number of participants	11	9	10	4	9
Nursing staff	5		4	3	3
Spiritual care	2			1	2
Management (incl. Nursing managers)	2	9	3		
Physician	2				1
Ethicist			3		1
Researcher					2
Ethics committee member	4		10		9

*Some of the participants had more than one profession/functions

Complete results from 105 documented ethics discussions from 5 centers in 3 countries

Nr.	Part.	Type of meeting	Profession of participants * (if documented)	Number of next of kin	Discussion prospective=1 retrospective=2 common challenges=3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment	Agreement about a practical solution reached and put into practice? (for prospective cases only; yes or no)
1	6	EC	N,PC,P	0	3	education planning, participation in research projects, palliative medicine and multiple sclerosis, end-of-life care in dementia	regular meeting		discussion of common ethical challenges, no case discussion	
2	6	EC	N,PC,P	0	3	guidelinepain treatment, education planning, participation in research projects, end-of-life care in dementia	regular meeting		discussion of common ethical challenges, no case discussion	
3	3	REM	N, PC	1	1	artificial nutrition and PEG	head nurse	benefit and burden of starting artificial nutritionand PEG insertion.		yes
4	4	REM	N, PC	2	1	hospitalisation versus palliative care in the nursing home	head nurse	palliative care in the nursing home apporiate and according to the residents wish?		yes
5	5	REM	N, PC	1	1	artificial nutrition and PEG, Do not resuscitate (DNR)-order, hospitalisation and moving to another nursing home ward	head nurse	benefit and burden of starting artificial nutritionand PEG insertion. DNR-order. Hospitalize or not?		yes
6	6	REM	N, P, PC, AN	1	1	death of the residents wife	head nurse	breaking bad news and ACP		yes
7	9	REM	N, P, PC, AN	1	1	resident refuses food, drink and medication	nursing team	Shall the residents behaviour be respected?		yes
8	4	REM	N, P	1	1	ACP, DNR? No communication possible	head nurse	Residents wish? DNR-order. Hospitalize or not?		yes
9	4	REM	N,PC,P	1	1	resident refuses nutrition, ACP	head nurse	ACP, PEG insertion, DNR		yes
10	6	REM	N,PC,P	2	1	ACP, PEG use in the future	head nurse	ACP. Future PEG use (no reeinsertion if functional failure)		yes
11	8	REM	N,PC,P, PSY	1	1	refusal of food and drink	head nurse	Accept of the natural will? letting die		yes
12	8	REM	N, P, PC, AN	1	1	hospitalisation vs Palliative Care in the nursing home	head nurse	ACP, Hospitalisation		yes
13	6	REM	N, P	1	1	ACP, hospitalisation?, assumed will	head nurse	respecting the residents natural will, hospitalisation, ACP		yes
14	6	REM	N, P, AN	1	1	assumed will, ACP	nursing team	ACP, PEG insertion, DNR		yes
15	4	REM	N, P	2	1	ACP, PEG?	physician	ACP, PEG insertion, DNR		yes
16	4	REM	N,P,SW	1	1	Daily care adequate?	head nurse	place of Care: nursing home vs. hospice		yes
17	8	REM	N,AN,P	1	1	resident with dementia, ACP?	head nurse	ACP, PEG insertion vs nutrition		yes
18	4	REM	N,P	2	1	artificial nutrition and PEG?	head nurse	life-prolongig treatment, ACP, DNR	no decision was made	no

Complete results from 105 documented ethics discussions from 5 centers in 3 countries

19	4	REM	N,P	2	2	limitation of therapy as documented in another nursing home / residents condition improved	head nurse	treatment limitation or not?		yes
20	4	REM	N, P	2	1	ACP, hospitalisation?	ass. head nurse	hospitalisation, PEG insertion		yes
21	4	REM	N, P	1	1	overweight in a resident with dementia	head nurse	Restriction of nutrition?		yes
22	3	REM	N, P	1	1	nutrition, weightloss	ass. head nurse	ACP, PEG insertion, DNR		yes
23	4	REM	N, P	1	1	coercion to enable pacemaker control in a patient with dementia?	head nurse	use of coercion?		yes
24	3	REM	N	1	1	place of care, ACP, life-prolonging treatment	head nurse	ACP, PEG insertion,	no decision was made	no
25	9	REM	N,AN,P	2	1	hospitalisation, PEG-insertion?	nursing team and relatives	PEG-insertion and hospitalisation		yes
26	3	REM	N, P	1	1	PEG-insertion in the hospital against the residents written will. Afterwards removal of the PEG by the resident himself.	physician	new PEG or respect for the residents will?	no decision was made	no
27	3	REM	N, P	1	1	ACP, Palliative Care planning	nursing team	ACP, PEG insertion, hospitalisation DNR		yes
28	4	REM	N, P	2	1	medical diagnostic or treatment	head nurse	resident with not properly diagnosed condition. Medical diagnostic or treatment needed?		yes
29	4	REM	N, P	2	1	life-prolonging treatment, PEG	ass. head nurse	ACP, PEG insertion, hospitalisation DNR		yes
30	3	REM	N, P	1	1	ACP	physician	ACP, PEG insertion, hospitalisation DNR		yes
31	8	REM	N, P, PC, AN	1	1	ACP,PEG,resuscitation	nursing team and relative	ACP, PEG insertion, hospitalisation DNR		yes
32	4	REM	N, P	1	1	nutrition, weightloss, PEG-insertion?	head nurse	ACP, PEG insertion, hospitalisation DNR		yes
33	3	REM	N, P	2	1	wish to die, ACP, Palliative Care	head nurse	ACP, PEG insertion, hospitalisation		yes
34	4	REM	N, P	2	1	resident with dementia and PEG-insertion after hospitalisation	nursing team	ACP, PEG insertion, hospitalisation		yes
35	6	REM	N,AN,P	1	1	resident with dementia and partial refusion of nutrition, ACP	nursing team	ACP, PEG insertion, hospitalisation		yes
36	4	REM	N, P	1	1	resident with dementia, ACP?	nursing team	ACP, PEG insertion, hospitalisation DNR		yes
37	3	REM	N, P	1	1	resident with dementia, ACP?	nursing team	ACP, hospitalisation, Palliative Care		yes
38	5	REM	N,AN,P	1	1	resident with dementia, ACP?	head nurse	ACP, PEG insertion, hospitalisation		yes
39	5	REM	N,AN,P	1	1	resident with dementia and partial refusion of nutrition, ACP	head nurse	ACP, PEG insertion, hospitalisation		yes
40	4	REM	N, P	2	1	resident with dementia, ACP?	head nurse, physician	ACP, PEG insertion, hospitalisation		yes
41	3	REM	N, P	1	1	resident with dementia, ACP?	head nurse, physician	ACP, PEG insertion, hospitalisation		yes
42	4	REM	N, P	2	1	resident with cancer, hospitalisation, Palliative Care	nursing team	ACP, PEG insertion, hospitalisation, transfer to a hospice?		yes
43	3	REM	N, P	2	1	resident with dementia, ACP?	head nurse	ACP, hospitalisation		yes

Complete results from 105 documented ethics discussions from 5 centers in 3 countries

44	4	REM	N, P	1	1	resident with dementia, ACP, hospitalisation, PEG?	head nurse	ACP, PEG insertion, hospitalisation DNR		yes
45	7	REM	N, P	2	1	ACP, PEG, Palliative Care planning	head nurse	ACP, PEG insertion, hospitalisation		yes
46	4	REM	N, P	1	1	ACP, PEG, DNR, Palliative Care planning	nursing team, physician	ACP, PEG insertion, hospitalisation DNR	resident died in an ambulance on the way to a hospital	no
47	3	REM	N, P	1	1	resident with dementia, ACP?	head nurse, physician	DNR	concrete ACP-planning was postponed to a new meeting	yes
48	5	REM	N,PC,P	2	1	resident with dementia, ACP?	head nurse, physician	ACP, PEG insertion, hospitalisation	second meeting about ACP	yes
49	4	REM	N, P	2	1	resident with dementia, ACP?	nursing team	ACP, PEG insertion, hospitalisation		yes
50	9	REM	N,AN,PC,P, PSY	1	1	resident refuses food, weightloss	nursing team and relative	residents will, nutrition, ACP		yes
51	3	REM	N, P	1	1	nutrition, depression	head nurse	nutrition, medical treatment of depression needed?, PEG?		yes
52	4	REM	N,AN,P	0	1	nutrition, PEG, ACP	nursing team	ACP, PEG insertion, DNR		yes
53	6	REM	N, P	2	1	ACP, PEG, Palliative Care planning	head nurse	ACP, PEG insertion, hospitalisation DNR		yes
54	3	REM	N, P	1	1	PEG, life-prolonging treatment	head nurse	PEG-insertion, nutrition, life-prolonging treatment?	PEG-insertion against the consensus found in the meeting	no
55	7	REM	N,AN,PC,P	1	1	resident with dementia, ACP?	nursing team	PEG-insertion, nutrition		yes
56	4	REM	N, P	2	1	ACP, PEG, DNR, hospitalisation?	physician	ACP, PEG, hospitalisation, Palliative Care		yes
57	4	REM	N, P	2	1	ACP, PEG, DNR, Palliative Care planning	nursing team and relatives	ACP, PEG insertion, hospitalisation DNR		yes
58	5	REM	N, P	2	1	nutrition, weightloss, PEG-insertion?,ACP	nurse	ACP, PEG, hospitalisation, Palliative Care	resident received subcutaneous fluid against the consensus found in the meeting	no
59	5	REM	N, P	2	1	resident with cancer, hospitalisation, PEG-insertion, Palliative Care	nursing team	ACP, PEG insertion, hospitalisation DNR,Palliative Care		yes
60	5	REM	N,AN,P	2	1	resident with dementia, ACP?	nursing team	ACP, PEG insertion, hospitalisation DNR,Palliative Care		yes
61	4	REM	N, P	2	1	resident with dementia, ACP?	nursing team	ACP, PEG insertion, hospitalisation DNR,Palliative Care		yes
62	3	REM	N, P	1	1	nutrition, weightloss, PEG-insertion?,ACP	nurse	residents will, nutrition, PEG?		yes
63	12	EC	N,AN,P,O,PC,ET	0	3	economical challenges and risk for ethical dilemmas	regular meeting		discussion of common ethical challenges, no case discussion	
64	12	EC	N,AN,P,O,PC,ET	0	3	educational effeorts, ethical challenges of poltical reforms	regular meeting		discussion of common ethical challenges, no case discussion	
65	12	EC	N,AN,P,O,PC,ET	0	3	alcohol in nursing homes, confidentiality	regular meeting		discussion of common ethical challenges, no case discussion	

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66	12	EC	N,AN,P,O,PC,ET	0	3	documentation of cases discussed im the ethics committee, documentation of the residents will in the journal in the nursing home	regular meeting		discussion of common ethical challenges, no case discussion	
67	12	EC	N,AN,P,O,PC,ET	0	3	celebration of feasts in nursing homes in a multicultural society	regular meeting		discussion of common ethical challenges, no case discussion	
68	9	EC	N,P,PC,ET	0	1	future PEG use in a resident with multiple sclerosis	regular meeting	ACP, withdraw PEG ,	case discussion without consensus due to lack of information	no
69	12	EC	N,AN,P,O,PC,ET	2	1	resident had removed a PEG several times, PEG-insertion?	case discussion on request of the nursing team and the relatives	PEG-insertion, residents will?	case discussion without consensus	no
70	12	EC	N,AN,P,O,PC,ET	0	2	coercion, withdrawal of life-prolonging therapy	case discussion on request of the relatives	coercion, withdrawal of life-prolonging therapy	case was taken to court	no
71	12	EC	N,AN,P,O,PC,ET	0	2	young resident with small children who neeedd a lot of resources for Palliative Care within the holiday periode, extra personnel was hired, adequate use of resources?	case discussion on request of the nursing home leader	use of resources for residents with terminal care vs. other nursing home residents, dignity, relatives role		no
72	3	Ethics Case-discussion	N	1	1	Medical condotion, Resident does not coorporate	nursing manager	diet against the residents will, coercion?		yes
73	3	Ethics Case-discussion	N	1	1	resident with dementia and fear, ACP	nursing team	moving into a dementia care group?		yes
74	3	Ethics Case-discussion	N	2	3	relatives complain about insufficient care	nursing manager	worsening condition or lack of adequate care?		yes
75	8	Ethics Case-discussion	N,SW	0	1	resident with dementia and depression, How to improve quality of life?	nursing manager	medical treatment needed? Improvement of quality of life		no
76	2	Informal discussion	N	1	1	resident with diabetes mellitus and lack of compliance to medical treatment, autonomy	nursing manager	autonomy vs medical recommendations		yes
77	9	Ethics discission forum	nursing home staff,professions not documented	0	2	sexual abuse of a resident by a staff member	nursing home staff member	How to deal with sexual abuse in the nursing home?		no
78	9	Ethics discission forum	nursing home staff,professions not documented	0	1	resident with dementia who believes to be able to move home	nursing home staff member	shall one always tell the truth?		no
79	9	Ethics discission forum	nursing home staff,professions not documented	0	1	Resident suicidal?	nursing home staff member	autonomy and selfdetermination vs law	a consensus how to handle the case was found in the group	not known
80	9	Ethics discission forum	nursing home staff,professions not documented	0	3	autonomy, non-compliance of a resident	nursing home staff member	autonomy vs care	a consensus how to handle the case was found in the group	
81	9	Ethics discission forum	nursing home staff,professions not documented	0	1	resident with PEG and written advance directive that states no life-prolonging treatment	nursing home staff member	To use the PEG in the future or not?	a consensus how to handle the case was found in the group	not known

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82	9	Ethics discission forum	nursing home staff,professions not documented	0	1	resident in a vegetative state, parents and husband have different opinions about the residents will	nursing home staff member	different views between parents and husband of a resident, Residents will?	a consensus how to handle the case was found in the group	not known
83	9	Ethics discission forum	nursing home staff,professions not documented	0	1	relative withextreme high expectations of the care of the resident	nursing home staff member	How to handle the relatives demands, protection of the resident needed?	a consensus how to handle the case was found in the group	not known
84	9	Ethics discission forum	nursing home staff,professions not documented	0	1	optimal care for a chronic wound	nursing home staff member	What is good wound care for the resident?	a consensus how to handle the case was found in the group	not known
85	8	EC	N,P,SW,PC,ET	0	1	resident refuses palliative care after being moved from the hospital	nursing home manager	residents right to refuse care. autonomy		yes
86	8	EC	N,P,SW,PC,ET	0	1	aggressive behaviour of a resident	pastoral care	adequate care, need for medication / Hospitalisation?		not known
87	5	EC	N,P,SW,PC,ET	0	1	Residents will? Inadequate nutrition	nursing home manager, relatives	Autonomy and residents will? PEG-insertion?		no
88	9	EC	N,P,SW,PC,ET	0	1	resident has financial problems and problems with his insurance company, oxygen equipment	nursing home manager	optimal medical care (oxygen equipment) residents right for optimal medical treatment		nursing home manager
89	9	EC	N,P,SW,PC,ET	0	1	resident shal receive palliative care at the end-of-life, nutrition via PEG?	head nurse	Sufficient palliative care possible in the nursing home?		yes
90	10	EC	N,P,SW,PC,ET	0	1	resident refuses hospitalisation although urgent medical need (bowel obstruction)	head nurse	Sufficient palliative care possible in the nursing home?		no
91	12	EC	N,PC	0	2	staff sees a decision made bu the residents guardian as not appropriate	member of the ethics committee	Decisions are not transparent for the staff, residents will?		
92	10	EC	N,PC	0	1	residents guardian alcoholic? Residents autonomy and will?	member of the ethics committee	residents autonomy, duty to care of the staff		yes
93	12	EC	N,PC,SW	0	2	resident with the need for ampuatation and shifting will	nursing home manager	residents autonomy		yes
94	10	EC	N,PC	0	2	death of a resident due to inadequate medical care	member of the ethics committee	Different suggestions from different physicians. Who shall decide? Residents will?	a consensus found in the group	
95	10	EC	N,PC	0	1	sexual abuse of a resident by a staff member	member of the ethics committee	How to deal with sexual abuse in the nursing home?		yes
96	10	EC	N,PC	0	1	problems with adcance care planning, recommendation from a judge to write a new ACP	member of the ethics committee	duties of the staff, Duty to care?		yes
97	11	EC	N,PC,SW	0	1	decision to hospitalise a resident by the guardian	member of the ethics committee	duty to care vs guardians rigt to decide, What is best for the resident? To hospitalize or not?		yes
98	11	EC	N,PC,SW	0	1	treatment withdrawal, conflict between physician and nurses	member of the ethics committee	duty to care, residents quality of life		no
99	5	EC	N,PC	0	1	to withhold or withdraw artificial nutrition, resident was not asked about his opinion although he was able to communicate	member of the ethics committee	to withhold or withdraw life-prolongig treatment, resident autonomy		yes
100	9	Informal discussion	N	0	2	placement of a young resident in a closed area	member of the ethics committee	autonomy, coercion		not known

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101	9	EC	N,PC,SW	0	1	lacking information of the resident by a physician concerning palliative surgery, informed consent?	member of the ethics committee	written living will vs the residents actual will, Capacity to consent?		yes
102	12	EC	N,PC,SW	0	1	physicians behaviour: the resident was not included in a conversation about the treatment (although this might have been possible), hospitalisation?	member of the ethics committee	to withhold or withdraw life-prolongig treatment, resident autonomy		not known
103	8	EC	N,PC,SW,ET	0	2	hospitalisation of a resident, the written living will was not send to the hospital with the patient, therefore he received maximal acute therapy in the hospital	pastoral care	residents living will was not taken into account, acute therapy against the patients will		yes
104	7	EC	N,P,SW,PC,ET	0	1	insufficient care of a resident by his wife	nurse	Acceptance of subotimal care? Nurses duty to care?		yes
105	5	EC	N,PC	0	1	residents consent to artificial nutrition?	nursing manager	autonomy, Residents will?	residents will not clear	no

*Profession of participants N=Nurse AN=Assistant nurse P=Physician PC=Pastoral Care SW=Socialworker
O=occupational therapist PSY=Psychologist ET=ethicist

Paper I

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Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes

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Abstract

Background: Nursing home residents are a vulnerable population. Most of them suffer from multimorbidity, while many have cognitive impairment or dementia and need care around the clock. Several ethical challenges in nursing homes have been described in the scientific literature. Most studies have used staff members as informants, some have focused on the relatives' view, but substantial knowledge about the residents' perspective is lacking.

Objective: To study what nursing home residents and their relatives perceive as ethical challenges in Norwegian nursing homes.

Research design: A qualitative design with in-depth interviews with nursing home residents, and focus-group interviews with relatives of nursing home residents. The digitally recorded interviews were transcribed verbatim. Analysis was based on Interpretive Description.

Participants and research context: A total of 25 nursing home residents from nine nursing homes in Norway, and 18 relatives of nursing home residents from three of these nursing homes.

Ethical considerations: This study was reported to and approved by the Regional Ethics Committee in Oslo, Norway.

Findings and discussion: The main ethical challenges in Norwegian nursing homes from the residents' and relatives' perspective were as follows: (a) acceptance and adaptation, (b) well-being and a good life, (c) autonomy and self-determination, and (d) lack of resources. The relationship with the staff was of outmost importance and was experienced as both rewarding and problematic. None of the residents in our study mentioned ethical challenges connected to end-of-life care.

Conclusion: Residents and relatives experience ethical challenges in Norwegian nursing homes, mostly connected to "everyday ethical issues."

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Older people, ethics, nursing homes, relatives' view, residents' view

Introduction

People living in nursing homes are vulnerable. The term nursing home in this study includes long-term care facilities for older people. In Norway, usually only older people with a high need of care and need for medical assistance are admitted to nursing homes. Many nursing home residents in Norway suffer from multimorbidity; more than 80% have dementia and more than 70% show psychiatric and behavioral symptoms.[1]

A review of the literature revealed two major groups of ethical issues in nursing homes. The first group of issues consists of "everyday ethical issues," such as autonomy, privacy, informed consent, use of restraints, offensive behavior, refusal of medication, food, placement of people, and lack of resources. Second, "big ethical issues," mostly in regard to life or death matters including decisions to sustain or withdraw life-sustaining treatment, to hospitalize or not, and other similar matters.[2–9] Most case consultations by nursing home ethics committees in the United States were about end-of-life issues and tube feeding.[5] In a Norwegian nursing home survey, the most frequently reported ethical challenges were inadequate care due to lack of resources and violation of the patient's autonomy and integrity. Many staff members also described conflicts with relatives and dilemmas concerning end-of-life care.[7] Conflicts between healthcare personnel and relatives were often mentioned in the literature.[7,10] Another major ethical problem in nursing homes is the lack of participation of the residents and their next of kin in decision-making. According to Dreyer et al., there are inadequate procedures to include the relatives and to address ethical and legal aspects of patient autonomy in decision-making in Norwegian nursing homes.[11]

A methodological weakness of research in this field is the fact that most research is based on questionnaires and interviews aimed at the staff or managers. At present, there is a lack of research on ethical challenges from the perspective of residents and their next of kin. The aim of this study was to explore what patients and their relatives perceive as a "good life" and ethical challenges in nursing home care including end-of-life care.

Method

This study had a qualitative design using semi-structured, in-depth interviews with nursing home residents and focus-group interviews with their relatives. The methods used to collect and analyze the data were based on the descriptions by Kvale[12] and Malterud[13] and especially on Interpretive Description as provided by Thorne.[14] Studies using this method have according to Thorne some common features: they are conducted in a naturalistic context, use subjective and experiential knowledge as a source of clinical insight, acknowledge a socially constructed element to human experience, presume that there is not one true "reality," but that human experiences consist of multiple constructed realities that may even be contradictory. Interpretive Description acknowledges that researcher and participant influence each other by interaction.[14]

Participants and research field

Purposive sampling was used to ensure the greatest possible variation of the data. Therefore, sampling aimed for geographical spread and different sizes and locations of the included nursing homes. An overview of the participating residents and relatives and characteristics of the nursing homes, including their size and location (urban vs rural area), is given in Tables 1 and 2. A total of 25 nursing home residents participated in in-depth interviews. All residents were living on long-term wards, and older people with short-time or

Table 1. Informants—nursing home residents.

No.	Age (years)	Gender	Interview duration in minutes	Number of nursinghome residents in the nursing home	Community size—inhabitants	Comment
1	66	Male	20	50–100	>50,000	
2	70	Male	71	100–150	>600,000	
3	74	Female	43	100–150	>250,000	
4	75	Male	22	100–150	>250,000	
5	77	Female	43	100–150	>600,000	
6	79	Male	36	<50	<1500	
7	81	Male	47	100–150	>250,000	
8	81	Female	41	100–150	>600,000	
9	83	Male	12	<50	<1500	
10	87	Female	30	<50	<1500	
11	88	Female	30	50–100	>600,000	
12	89	Female	18	100–150	>250,000	
13	89	Female	38	50–100	>50,000	
14	89	Female	33	150–200	>600,000	
15	91	Female	44	100–150	>100,000	
16	92	Female	10	100–150	>250,000	Excluded during the interview because of cognitive impairment
17	92	Male	49	100–150	>100,000	
18	93	Male	16	100–150	>250,000	
19	94	Female	15	50–100	>600,000	
20	94	Female	46	100–150	>600,000	
21	95	Female	22	100–150	>600,000	
22	96	Female	39	100–150	>250,000	
23	97	Male	23	50–100	>50,000	
24	99	Female	18	50–100	>50,000	
25	100	Female	33	100–150	>250,000	

In order to protect the residents' privacy and to ensure that they can stay anonymous, the resident numbers in the table do not correspond with the numbers of the citations.

rehabilitation residence were excluded from the study. The residents came from nine Norwegian nursing homes in five regions, public and private owners and communities with a varying number of inhabitants. In addition, three focus-group interviews were undertaken with a total number of 18 relatives of nursing home residents from three different nursing homes. Both participating residents and relatives were selected by nursing home staff or nursing home physicians. All participants received written information about the study and had the opportunity to ask questions prior to signing written informed consent.

Data collection

All interviews were undertaken by the first author (G.B.) in the patient's room or another private room. The focus-group interviews with relatives were conducted in a suitable room within the nursing home. In order to enable open communication and discussion of critique, staff members were not permitted.

The individual interviews started with two opening questions: "How can you live a good life in the nursing home?" and "Can you please describe a usual day in the nursing home?" in order to open up for the patients' own descriptions. Most of the interviews were open, with follow-up questions related to the

Table 2. Informants—relatives of nursing home residents.

No.	Age (years)	Gender	Number of nursing home residents in the nursing home	Community size—inhabitants
1	41	Female	<50	<1500
2	45	Male	100–150	>250,000
3	53	Female	<50	<1500
4	58	Female	<50	<1500
5	59	Female	100–150	>250,000
6	60	Female	100–150	>250,000
7	66	Female	<50	<1500
8	67	Female	100–150	>250,000
9	67	Female	100–150	>250,000
10	71	Female	100–150	>250,000
11	72	Female	100–150	>250,000
12	73	Female	100–150	>250,000
13	74	Female	100–150	>250,000
14	77	Male	100–150	>250,000
15	77	Female	100–150	>250,000
16	80	Male	100–150	>250,000
17	86	Male	100–150	>250,000
18	91	Male	100–150	>250,000

In order to protect the relatives' privacy and to ensure that they can stay anonymous, the resident numbers in the table do not correspond with the numbers of the citations.

patient's answers and responses. If no ethical challenges were mentioned, the interviewer asked about ethical challenges, which were reported to exist in nursing homes in the literature.[2–9] Key themes in the interview guide were as follows: a good life in the nursing home, daily life in the nursing home, and ethical challenges in daily life as well as in end-of-life care.

The focus groups were based on preliminary results from the analysis of the individual interviews. The interviews began with questions about a good life and ethical challenges in the nursing home, followed by an open group discussion, where the interviewer asked clarifying questions. All interviews were digitally recorded and transcribed verbatim by the first author and two trained assistants. Transcription was aided by the software f4 from Audiotranskription.[15]

Analysis

The analysis of the transcripts was conducted in multiple phases.[12,14] Analysis and coding were supported by the computer program NVivo 9.[16,17] The text was read several times, and meaning units and preliminary themes were coded by different researchers (G.B. and E.G.). To control the analysis, all authors reviewed the data material on their own. Coding was then discussed, revised, and approved repeatedly to ensure agreement on the main themes and meanings. After a preliminary coding of the first 11 participant transcripts, an interview guide for the focus-group discussions was prepared based on the initial results from these interviews. Source triangulation was used to discover different perspectives or agreement on the topic from different angles. Therefore, the preliminary results from the individual interviews could be questioned and deepened in the group interviews in addition to investigating the relative's views. Further analysis of the themes found in the data material and the coded text was done repeatedly and was supplemented by the interviewer's (G.B.) field notes. Validation of the results was sought by repeated reading of the interviews in order to question the findings in the interview transcripts and repeated discussions with the co-workers of the study. The analysis of both the individual and focus-group interviews led to four main themes that are presented in the ‘‘Results’’ section.

Research ethics

This study was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a. Written informed consent was obtained from all participants. All participants were informed of their right to end the interview at any time without reason or consequence. Participants were informed that they did not have to answer any question if they did not feel comfortable doing so. Patients with signs of cognitive impairment or dementia were excluded from the study. Only one patient had to be excluded, and no interview had to be ended upon the patient’s request. In few cases, patients did not answer a question and the interviewer changed the topic.

Results and interpretations

Many of the informants from the individual interviews began by saying that they had no complaints. In contrast to that statement, the findings revealed that there were several ethical issues in nursing homes, and four main themes were defined. Each theme is illustrated with one describing sentence and will be described and discussed further. Most themes have both positive and negative aspects. The main findings from the group discussions, which will be described at the end of each section, were similar to the findings from the residents’ interviews.

Acceptance and adaptation: “To become a nursing home resident”

There are profound ethical challenges when people have to move into a nursing home. One major challenge is to preserve dignity. For most people, it will be their last place of residence until they die. The informants told the interviewer about the process of acceptance of their own situation and seeing death as a normal part of life, but they also told about hope. This showed the ambiguity of living in the nursing home in an ambivalent situation between life and death. Most informants did not want to complain and said that they were offered good care and that they were grateful to receive care in the nursing home:

> I think it is very good like it is at present. (Resident 8)

Although many residents experience the transition as troublesome, some reported a homelike feeling after living in the nursing home for a while:

> I think differently [about being in the nursing home] than I did in the beginning when I came here . . . because I now feel more connected [to the nursing home] than I did when I came here. I do feel more at home. (Resident 5)

Acceptance and adaptation play a role for both residents and relatives. The relatives have to accept the fact that they have to move their loved-ones into the nursing home. Some relatives described a feeling of guilt or failure because of the fact that they could not take care of their loved-ones at home anymore:

> Relative 2: Yes it is hard to be a relative.
>
> Relative 4: We probably all have the same feelings about it. That we should have endured it a little bit longer, we should have endured [caring for relatives at home]. And the most difficult [part] was to sign the papers [for

> admittance to the nursing home]. But, on the other hand, we do know that we could not have managed [caring for relatives at home] much longer. (Focus group 1)

Well-being and a good life: "To participate instead of sitting in a chair"

Participation in daily life and social contact are the two main dimensions of well-being from the residents' perspective. Interestingly, to sit in a room and watch people on the street and at a nearby supermarket through a window was described as taking part in the lives of other people. Well-being was not just created by the surroundings, contact with the staff and the other residents alone, but was described to be achievable by active behavior of the residents themselves. It is the resident's own attitude that mattered. To think positively and to do something on one's own seemed to be important:

> And I do as much as I can. I do the cleaning and make my bed myself. And I do what I am able to participate in life. You can participate in life and not just sit on your butt . . . (Resident 17)

Dimensions of a good life and well-being described by the informants were often about normal aspects of everyday life, such as participating in activities (including training with a physiotherapist), eating, and communicating with others. As there are many patients suffering from dementia in nursing homes, the residents without cognitive impairment only have a few people with which to communicate:

> I usually sit together with a nice lady, she is old, more than 90. But she is quite clear in her head. We talk together and eat together . . . otherwise, most people in here are in bad condition in their heads. (Resident 15)

Food was often described as being important. Mealtimes were the main structure of the day. A bad meal could lead to the experience of a bad day overall:

> And you know, you just sit and wait for mealtime. Lunch at one o' clock, coffee at four and so on. This is what happens during the day. There is nothing else going on. (Resident 20)

From the interviews, it was evident that to be seen as a human being and to be engaged in some kinds of social interaction were crucial factors for well-being and the preservation of their dignity as described by the residents. Ethical problems could arise from lack of contact. For the relatives, activities and participation were the most important dimensions of well-being. Often, relatives participated in the daily life in the nursing home by feeding the residents, singing, or reading for them.

From the residents' point of view, the relationship to the nurses is crucial to live a good life in the nursing home:

> Everything depends on how the nurses are. Their way to behave, their face . . . counts very much, their attitude. (Resident 3)

The relatives shared the resident's opinion that the relationship to the nurses is a very important factor for well-being. They defined a good nurse as somebody who would *see the resident and show that she cares*, which illustrated the two dimensions of well-being described above. To be a good caregiver is, according to the relatives, not connected to formal training but depends on attitude:

> Relative 4: They sit down and seem to be interested [in the residents]. They have to look at them and to show that they have time.
>
> Relative 3: These are not just professionals but also unskilled care givers. The ones who have an inborn radar . . . I must admit they are caring. "Care" or "thoughtfulness" might be the right words for it. (Focus group 2)

Autonomy and self-determination: "Striving to keep one's own autonomy"

The opinions of the nursing home residents on the extent of autonomy and self-determination that they experienced in daily life varied greatly between different residents and different wards, even within the same nursing home. Many participants mentioned this theme embedded in stories of the relationship to the nurses. While some felt that they could decide most things (e.g. having breakfast in bed at the time they wanted), the majority of informants reported that they did not have much to decide at all and did not feel autonomous or self-determinant. Informants talked about problems inviting guests to share their meal, obstacles to smoke, being controlled around the clock, and that daily routines were in deep contrast to their desired level of self-determination. The following examples focus on the informants who mentioned problems with autonomy:

> You lose a big part of your freedom. Everybody who comes into a nursing home will discover that. For example, you cannot just take your bag and tell them that you will go shopping. You can not do that. (Resident 22)

A problem can be the lack of respect that can influence the feeling of dignity. One resident spoke about a young assistant who was watching TV while feeding her:

> I have told them These are young girls who are not used to this . . . and if the television is on . . . they concentrate on the film and forget to feed me. (Resident 3)

To be respected is of great importance in order to be able to practice self-determination:

> When they (the nurses) enter the room . . . they shall knock on the door. This is my room! Sometimes I choose to be quiet and not to say anything. (Resident 3)

The relatives stated that lack of resources could also be experienced as an offense and, thus, endanger autonomy. For example, some residents have to go to bed at six o' clock in the evening because there are too few nurses on duty in the evening.

Another important finding was the description of a problematic relationship to the nurses. The relatives often had to complain about things because the residents themselves were afraid to face consequences if they would complain themselves. The relatives could be labeled as troublemakers by the staff. Therefore, many relatives do not complain "too much":

> It is not always easy to be a relative [of a nursing home resident] . . . I have always let them know, from the very first day. I had to talk about it . . . then you are labeled as a relative who . . . [is difficult to deal with]. When I came in, I felt someone [the nurses] saying—"There she is." When they were in the corridor, I just saw them stepping away into a room. (Relative 6, focus group 1)

Locked doors were acceptable for most relatives in order to prevent demented residents from leaving the nursing home. Otherwise, the relatives refused coercion (e.g. in order to give medication or food). As mentioned above, some stated that early bedtime due to lack of personnel was unacceptable coercion.

Lack of resources: "More hands and more time for social contact are needed"

The residents believed that they received too little help from the staff and had little social contact with the staff:

> They are too few staff members . . . they do not have enough staff. They cannot be everywhere, these ladies. So, I understand their situation. (Resident 3)

Most of the residents did not want to complain, and many stated that they did not have anything about which to complain. However, stories from their daily life showed that lack of resources was a problem:

> We do have much waiting time . . . if there is something [you need] . . . they tell you that you just have to call, just call . . . so everything will be done, but it is not like that . . . it takes time. For example, if I sit here and eat breakfast, I just need to call when I am done. Then you may sit a long time . . . a very long time before they think that I am done, and I have to wait for them to come . . . (Resident 5)

Many residents would appreciate more activities, and some would like to have the possibility to train regularly with a physiotherapist:

> The only thing that I miss, which I think they can do something about . . . is a physiotherapist. This would be good to have here . . . but they do not have money. When I was in the hospital we had physiotherapists . . . I had to take medicine, but when the physiotherapist came . . . he managed to make my limbs move again . . . (Resident 7)

> You know, they [the other residents] are placed in a chair and then they sit there. With more personnel, we could come out more often . . . and not just sit in a chair in the living room and be half asleep. (Resident 12)

Activity options, such as a sewing room, had been closed down in some places due to lack of resources:

> It has been there before, they told me it has. A sewing room and other things which one could work with, but this offer does not exist anymore. They cannot afford it anymore. It has been removed from all nursing homes: there is nothing. We just sit in the chair . . . that is what we do. There is not a set of cards to play with. I believe this has to do with the local government, costs and payments. (Resident 20)

Some of the residents would like to have better, healthier food, or simply more options when dining:

> There is one thing I do miss very much, that is fresh fruit. (Resident 15)

The relatives see the lack of resources as being a serious problem. According to their description, this deficiency leads to lack of contact with the residents. Too few staff members were also named as cause of coercion.

> Relative 4: We do need more hands.
>
> Relative 1: They don't have time. There are at least too many residents per staff member. (Focus group 3)

Discussion

The informants in our study described factors associated with a good life and the preservation of their dignity and several ethical challenges in Norwegian nursing homes that could be categorized as everyday ethical issues. The main findings of the study were that residents and relatives experienced challenges with acceptance and adaptation, well-being and a good life, autonomy and self-determination, and lack of resources. Adaptation to living in the nursing home often led to feeling as though complaining was inappropriate. Preserving their dignity is important for the residents. Many residents were aware that they would die in the nursing home, but none of them specified ethical challenges connected to end-of-life care.

Our findings were contrary to another Norwegian qualitative study on quality of life of nursing home residents published by Sørbye et al.[18] in 2011, which concluded that most residents enjoyed themselves in the nursing home and were satisfied with the offered care. Nevertheless, most of the 20 residents in that study that was performed as quality assurance measure wanted more time to talk to the staff about challenges in daily life and more serious themes.[18] In order to preserve the residents' dignity, time for dialogue and communication is crucial. It has been emphasized that the assessment of the nursing home residents' satisfaction was difficult due to cognitive impairment and vulnerability and that qualitative and ethnographic methods could help to provide a more balanced picture than using surveys.[19] Our informants did not want to complain too much, probably because of the fear of consequences. The balance between ensuring autonomy and dignity has been described to be an ethical challenge for nursing home staff because they have had to use weak restraints. Such a behavior disrespected patients' autonomy.[20] The term "total institution" was introduced by Goffman and has also been applied to the nursing home world where vulnerable residents were dependent upon the nurses.[9,21] This term seems to cover the views of some of our informants who felt that there was no autonomy in a nursing home because residents were under observation at all hours. Kindness, humanity, and respect are core values of medical professionalism and dignity conserving care.[22] Respecting the residents' autonomy could enhance their satisfaction, although shortcomings of self-determination were often mentioned by the residents.[23] In order to enhance self-determination, the staff could help the resident understand that certain areas could be controlled by the residents themselves.[24]

Brandburg et al.[24] described 21 facilitative resident strategies for "making a life in a nursing home." The main strategies were to take one day at a time, to seek supportive relationships, to be patient, and to make the best out of it. "To take one day at a time" seems to be a frequently used strategy in our material. Our informants told the interviewer about the process of acceptance and adaptation, which was similar to the facilitative strategy "learn the nursing home system and how to get what you need."[24] The relation to and the behavior of the nursing home staff influenced the feeling of dignity. Our results showed that the relationship to the staff was of utmost importance and that dignity could be protected or endangered by the staff's behavior. Nursing home residents are highly vulnerable with regard to dignity, and their dignity is challenged by illness and care needs.[25] In order to be able to live a good life in the nursing home, a safe surrounding with enough space, nursing care around the clock, enjoyable food, self-determination, regular activity, and social contact were necessary. Interestingly, both residents' and staff members' attitudes and behaviors could help to create a good life and preserve dignity. The description of a good nurse in our material was similar to a recent literature review: good nurses were understanding, caring, and recognized the patients' needs promptly. Good nurses built trust-based relationships with the residents.[26] Our material showed that trust-based relationships between the staff and relatives were important for the relatives as well. Inactivity and too little contact were major challenges in nursing homes at present. The residents need to communicate with other people; talking had been described to be the most important activity for them.[23] To meet communication needs means to show respect and can thus strengthen the feeling of dignity. According to Kojer and Schmidl,[27] to receive contact and empathic communication should be a human right for nursing home residents. Therefore, basic care should include taking care of communicational needs, in addition to the need of being dry, clean, and fed.

A qualitative review on living well in care homes discussed the lack of autonomy and difficulties in forming relationships with others and summed up four key themes: acceptance, adaptation, connectedness with others, and a homelike environment.[28] The authors concluded that a relationship-centered approach was wanted by the residents but "requires the well-being of both staff and residents, and an examination of the philosophy and values of the administration as these will undoubtedly affect the psychological milieu (or well-being) of all who live and work there."[28] It seems that well-being regularly included both residents and staff, and that the well-being of both groups was influenced by their behavior. Therefore, the well-being of the staff should be taken into account when aiming for enhancement of the residents' well-being, but must not be prioritized at the expense of the residents.

The residents want both physical and psychosocial care; being able to receive help when needed was important.[29] Unfortunately, lack of resources in terms of too few staff was crucial because there was too little time for social contact. In Norwegian primary healthcare, inadequate attention, the need for social contact, and physical activity or self-determination were ethical challenges experienced most frequently by healthcare workers.[30] Staff working closest with the patients reported ethical challenges more often than those working further away.[30] Although lack of resources did not necessarily cause lack of contact with the nurses, it restricts the time frame in which nurses could use their spare time for contact with the residents. Lack of resources has been named an ethical challenge in many studies from the literature.[2,6–9,30–32] That lack of resources and staffing could result in inadequate care had been observed in one of the participating nursing homes and was recorded in the researcher's field notes. In that situation, there was one nurse who had to feed four residents. The nurse felt that this was an ethical dilemma because she did not know whom to feed first or whether it was appropriate to feed four people at the same time. Lack of resources and the frequent use of "suboptimal staffing" may be the cause of avoidable coercion in nursing homes.[32] For the residents in our study, lack of resources was almost synonymous with lack of time to get help from or to have contact with the staff. Dignity and quality of life are endangered by both lack of resources and disrespect of the residents' autonomy. Early bedtime because of too few nurses is not only lack of resources but a violation of the residents' autonomy and an offense to dignity. Sufficient resources and nursing home staff seem to be the crucial factor in order to meet the residents' and relatives' communication and care needs and to preserve their dignity. These findings were in accordance with research where nursing home staff have been informants.[6,7,30]

This study addressed the views of nursing home residents and relatives on ethical challenges in nursing homes in addition to former knowledge of the views of nursing home staff. The views of the residents and relatives from our study agreed on most aforementioned themes. Many informants from both groups mentioned problems with self-determination, lack of factors associated well-being (e.g. food and staffing), lack of resources, and the importance of the relationship to the staff. The interaction with the care givers was of outmost importance because the staff needed to know the residents and to be sensitive to the residents' needs in order to ensure their autonomy and dignity.[33] Residents and relatives were found to have different strategies when complaining. It seems that the relatives often complained about certain issues to the staff because some residents were afraid to complain due to fear of consequences.

Limitations and strengths of the study

One possible limitation is the selection of participants. Due to ethical concerns, all nursing home residents with cognitive impairment or dementia were excluded from the study. Another possible limitation of the study could be that the nursing home staff selected the participants. However, our results show that there were both positive and negative comments, and the informants defined several areas with ethical challenges and the need for improvement. The experience of the first author (G.B.) as a physician from working in a nursing home and palliative medicine may be considered both strength and weakness of the study. Being able to talk to nursing home residents about their losses, diseases, and death enabled the interviewer to ensure empathic communication. To avoid "going blind" by own presumptions and the researcher's own point of view from working as a nursing home physician and the danger to try to verify own hypotheses about possible results, the interviewer reflected his preconceptions during the whole process. This was done using meta-positions and team reflections with the coauthors and supervisors.

It could probably be seen as a weakness that our study did not identify ethical challenges in end-of-life care from the residents' point of view. Although the residents were especially asked about end-of-life care, they did not report ethical challenges in this area. It seems that everyday ethical issues are most important for the residents. It could be considered to be the strength of the study that the interview atmosphere was open enough to talk about problems and negative aspects as well as death and dying. Although most participants stated in the beginning that they had nothing to complain about, they allowed themselves to utter critiques during the interview. Most of the informants in our study were grateful and thanked the interviewer for the talk and the time spent together. Some of the informants stated that they never before had talked to another person about some of the issues mentioned during the interview. For the relatives, the group discussion seemed to be a place where they could share their feelings and problems related to being a relative of a nursing home resident with others in the same situation.

Conclusion and implications

Residents and relatives did experience ethical challenges in Norwegian nursing homes, mostly connected to "everyday ethical issues" including lack of resources to meet their basic communication and care needs. None of the residents did mention ethical issues in end-of-life care. Social contact, participation in daily life, and self-determination were important factors for a good life for the residents.

Implications of the study for practice are as follows: the results of our study suggest that daily routines in nursing homes should be adapted to these challenges, and that one should strive to meet the residents' wishes as far as possible in order to strengthen their feeling of autonomy and dignity. Ethics education and systematic ethics work in nursing homes should probably focus more on everyday ethical issues instead of focusing solely on end-of-life care and decision-making conflicts.

Further research could focus on how to improve the resident's autonomy in nursing homes and to include them in decision-making in everyday life. Research on the views of residents with cognitive impairment and dementia is interesting though methodologically and ethically problematic.

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Conflict of interest

All authors declare that there is no conflict of interest.

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Paper II

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They know!—Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes

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Abstract

Background: Residents living in long-term care facilities are a vulnerable population. For many residents, a nursing home is their place of death. Palliative care and end-of-life decisions are important components of their care provision.

Aim: To study the views of cognitively able residents and relatives on advance care planning, end-of-life care, and decision-making in nursing homes.

Design: A qualitative study with in-depth interviews with nursing home residents and focus group interviews with relatives of nursing home residents. Analysis is based on interpretive description.

Setting/participants: In total, 43 informants from nine nursing homes participated in the study (25 nursing home residents and 18 relatives). All included residents had capacity to provide informed consent and lived in long-term care.

Results: The main findings of this study were the differing views about decision-making and advance care planning of residents and relatives. Residents do trust relatives and staff to make important decisions for them. The relatives are in contrast insecure about the residents' wishes and experience decision-making as a burden. The majority of the residents had not participated in advance care planning. None of the residents stated challenges connected to end-of-life care or mentioned the wish for euthanasia.

Conclusion: Although most residents seem to be satisfied with decision-making and end-of life care, there is a need for systematic advance care planning. Advance care planning could help to explore future wishes for care and ease decision-making for the relatives, physicians, and staff and should be offered to all cognitively able nursing homes residents.

Keywords

Nursing homes, long-term care, residential facilities, end-of-life care, decision-making, palliative care, advance care planning, family

What is already known about the topic?

- Many people die in nursing homes.
- Nursing homes provide palliative care at the end of life.
- Systems for advance care planning (ACP) and inclusion of residents and relatives in end-of-life decision-making are unsatisfactorily implemented in many nursing homes.

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What this paper adds?

- Residents trust their relatives, physicians, and nurses to make decisions for them, but in contrast many relatives do not know for sure what their next of kin really wants.
- Talking about death and dying in general and especially about the residents' preferences for treatment and decision-making in end-of-life care are paramount and should be addressed by the staff in order to maintain autonomy and dignity.
- Although some nursing home residents stated a wish to die, none expressed the wish for euthanasia or physician-assisted suicide.

Implications for practice, theory, or policy

- Physicians and nursing home staff should engage in ACP and offer the opportunity to discuss death, dying, and wishes for care and treatment at the end of life with nursing home residents and when the resident agrees with their next of kin.
- Although most residents and relatives are willing to talk about ACP, they are reluctant to start a conversation on that topic.
- Most nursing home residents are unaware that ACP is an option; thus, staff should ensure to offer residents opportunities for these discussions.

Introduction

Older people often need nursing home or home-based care due to multimorbidity and frailty.[1] Across different countries, similar issues need to be addressed. For example, about 70%–80% of nursing home residents in the United Kingdom and Norway suffer from cognitive impairment or dementia.[2,3] For many people, a nursing home is their place of death. In the United Kingdom, 35% of the people died in care homes or at home in 2006.[4] In the United Kingdom, between 2001 and 2010 55% of people suffering from dementia died in care homes.[5] In Norway, 48% of all deaths occurred in long-term care facilities and 15% at home in 2012.[6] There are numerous ethical challenges in nursing homes.[7–9] Nursing homes are places where end-of-life care is provided. Providing end-of-life care involves overcoming various challenges. One such challenge is advance care planning (ACP). ACP is a process with discussion between an individual and a carer (relative, nurse, and physician) to ensure that the individuals' wishes and preferences are known.[10–13] Definitions of ACP are provided in Box 1. The practice and legal framework of ACP differs between countries and may include repeated discussions with relatives, nurses and physicians; appointment of a substitute decision maker; and use of written advance directives. The use of ACP has a positive influence on the quality of end-of-life care.[11] Unfortunately, ACP is not yet widely used in nursing homes, and decision-making in end-of-life care may therefore lead to conflicts between the staff and relatives.[8,14] Norwegian legislation allows relatives to consent to medical treatment if a patient is unable to make decisions.[14] Residents with capacity can decide whether their relatives shall be included in ACP and decision-making.[15,16] Although some elderly Norwegians do have their wishes for future care and participation of relatives in decision-making, ACP is not standard.[15]

Aim

The aim of this study was to explore the views of cognitively able residents and relatives from Norwegian nursing homes on ACP, decision-making, and end-of-life care. We were particularly interested in the views on participation in decision-making and in end-of-life care.

Box 1. Advance care planning—definitions.

- "Advance care planning (ACP) aims to help patients establish decisions about future care that take effect when they lose capacity." (Mullick et al.)[12]
- "ACP is a process of discussion between an individual and their care provider, and this may also include family and friends." (Thomas and Lobo)[10]
- "ACP is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future. If they wish, they can set on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses. ACP has three possible outcomes: a verbal or written advance statement of wishes and feelings, beliefs and values—a verbal or written advance decision to refuse treatment (ADRT) (must be written with specific requirements if refusing life-sustaining treatment-see below)—a lasting power of attorney." (NHS England)[13]
- "ACP is defined as a process of discussion between an individual and their care provider, irrespective of discipline. If the individual wishes, their family and friends may be included." (Holman and Hockley)[16]

Methods

Ethics approval and ethical considerations

This study was approved by the Regional Ethics Committee (REK Sør-Øst A, Norway, reference 2009/1339a). All participants gave their written informed consent after receiving both oral and written information about the study. All participants were informed about their right to end the interview at any time without the need to explain the reasons for doing so and without consequences.

Design

A qualitative study design based on interpretive description described by Thorne[17] was used. An interview setting with semi-structured in-depth interviews[18,19] with Norwegian nursing home residents and focus group interviews with relatives of nursing home residents were conducted by the first researcher (G.B.). The focus group interviews with relatives were undertaken after primary analysis of the first 11 resident interviews. Box 2 provides an overview over the opening questions used. Reflexivity was sought through repeated comparison of the researchers' presuppositions with the results, using critical reflection and metapositions[19] as well as repeated discussions with the co-authors about alternative interpretations of the results. We followed the consolidated criteria for reporting qualitative studies (COREQ) guidelines for reporting qualitative research (details in Table 1).

Setting, participants, and sample selection

In order to ensure that the greatest possible variation of data was obtained, a purposive sampling technique was utilized. This aimed to recruit participants from a wide geographical spread and location. The participants were the same as in a previous study.[9] Tables 2 and 3 provide an overview of the participants.

Inclusion criteria for residents were as follows:

- Capacity to provide informed consent;
- Living in long-term care.

Residents with cognitive impairment were excluded. Inclusion criterion for relatives was to have a relative living in long-term care.

Nursing home staff (e.g. nurses or physicians) chose and recruited relatives and residents who were able to give written informed consent as study participants. The staff assessed cognitive function clinically without formal cognitive testing. G.B. (a specialized nursing home physician) made a secondary assessment of the resident's capacity to give informed consent. One patient was excluded because of cognitive impairment.

The interview technique was open-ended with follow-up questions related to the participant's answers and responses. Key themes in the interview guide were ACP, decision-making, and ethical challenges in end-of-life care in the nursing home. Data were collected from April 2010 to November 2011.

Transcription and analysis

Verbatim transcription of the digital interview recordings was supported by the transcription software f4 from audiotranskription and undertaken by G.B. and two trained assistants. Analysis and coding of the transcripts were conducted systematically, in different phases, aided by the software QSR NVivo 9. A detailed description of the analysis process is provided in Table 4. Analysis of the themes found

Box 2. Opening questions for the interviews.

Opening questions for resident semi-structured interview

- Have you thought about death and dying?
- Have you talked about critical illness, death, and preferences for care at the end of life with your relatives?
- Have you talked about critical illness, death, and preferences for care at the end of life with the nursing home staff (nurses or nurse aids) or your family doctor?
- Have you been involved in planning for care in critical medical situations or the end of life (advance care planning (ACP))?
- If you were not able to decide for yourself anymore due to disease or loss of consciousness …
    - Who shall make decisions for you?
    - Are your relatives/next of kin able to decide for you?
    - Do your relatives know what you would want?

Opening questions for relatives focus group interview

- Have you talked critical illness, death, and preferences for care at the end of life (ACP) with your relative who lives in the nursing home?
- Do you know what your relative would want if he or she would become critically ill?
- Do you know which type of care or treatment your relative would want at the end of life?
- Are you able to explain/define your relatives' wishes if they will not be able to do it themselves anymore?

Table 1. Report on accordance with the COREQ guidelines—checklist for reporting qualitative research.

No item	Description
Domain 1: research team and reflexivity	
Personal characteristics	
1. Interviewer/ facilitator	G.B. conducted all interviews and focus groups.
2. Credentials	The first author and researcher G.B. was a PhD student, medical doctor (MD), and Master of Advanced Studies (MAS) in Palliative Care specialized in Palliative Medicine and Nursing home medicine; E.G. and J.H.R. hold both a PhD and work as professors at the University of Bergen, Norway.
3. Occupation	G.B. was working both as nursing home physician and consultant in Palliative Medicine at Bergen Red Cross Nursing Home in Bergen, Norway, and as PhD student at the University of Bergen, Norway.
4. Gender	G.B. and J.H.R. are male and E.G. is female.
5. Experience and training	The main investigator G.B. was a MD specialized in Anesthesiology, Palliative Medicine, and Nursing Home Medicine and had experience in research from different areas including quantitative and qualitative research. He received a German doctoral degree (Dr. med.) from the University of Cologne, Germany, in 2000. In addition, he underwent additional formal PhD education in Norway in qualitative research and medical ethics.
Relationship with participants	
6. Relationship established	There was no relationship between the researcher/interviewer and the participants. No participants were recruited from the nursing home where G.B. was working as nursing home physician in order to avoid ethical problems and bias grounded on dependence issues.
7. Participant knowledge of the interviewer	The participants did get information that the interviewer was researcher from the University of Bergen and that the goals of the research were to investigate residents and relatives views on living in nursing homes including ethical challenges and their opinion on ACP, end-of-life care, and decision-making in nursing homes. When the residents asked, G.B. told more about his background being both researcher and nursing home physician.
8. Interviewer characteristics	The article includes information about the professional background of the interviewer. The main interest of G.B. in the topic was grounded in his daily work in Nursing Home Care and Palliative Care with experience of challenges related to ethical problems and end-of-life care in the nursing home.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation	The framework of the study was Palliative Care and Hospice philosophy. The basis for the qualitative methods used was interpretive description as described by Thorne.
Participant selection	
10. Sampling	Purposive sampling aiming for geographical spread and different sizes and locations of the included nursing homes was used in this study. All approached nursing homes agreed to participate.
11. Method of approach	The participants were selected and approached face-to-face by nursing home staff (e.g. nurses, nursing home physicians) from nine different nursing homes. They did receive written information about the study and had the opportunity to ask clarifying questions before the interview started. Capacity to decide was based on clinical observation and communication with the resident. Nursing home staff who chose residents to participate did know the informants through their daily work. The residents were not formally tested to assess their cognitive function.
12. Sample size	In total, 43 informants participated in the study: 25 nursing home residents from nine nursing homes and 18 relatives from three of the nine nursing homes. Purposive sampling was used. No resident or relative withdrew from the study.
13. Non-participation	Only one resident who was included in the study had to be excluded due to cognitive impairment detected by the researcher G.B.
Setting	
14. Setting of data collection	The data were collected in nine different Norwegian nursing homes. All interviews were conducted in private without participation of staff from the actual nursing home in order to open up for possible negative comments. Data collection was terminated due to data saturation in the collected material.
15. Presence of non-participants	No one else was present beside the participants and the researcher.
16. Description of sample	The sample is described in the 'Methods' section. The participants' characteristics are described in Table 2.
Data collection	
17. Interview guide	Opening questions used in the interviews are shown in Box 2.
18. Repeat interviews	Due to the age and often present multimorbidity of the participants as well as long distances between the researcher and the informants, no repeated interviews were carried out.
19. Audio/visual recordings	All interviews were digitally recorded and stored on a computer according to the rules, regulations, and recommendations of the Regional ethics committee.

Table 1. (Continued)

No item	Description
20. Field notes	The researcher G.B. made field notes during and after the interviews. These included personal impressions and other observations that were not recorded. Field notes were used in the analysis to question and prove the findings.
21. Duration	The duration of the interviews with nursing home residents varied from 10 to 71 min. The shortest interview was of a resident who was excluded due to cognitive impairment which became apparent during the interview.
22. Data saturation	Data saturation was reached for the resident interviews and the focus group discussions. Due to space restriction, this has not been discussed in this article.
23. Transcripts returned	Due to practical reasons (old age of the participants, no possibility to use Internet communication, and long distance between the researcher and the participants), the transcripts were not returned to the participants for comments.
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	All three authors participated in coding of the data.
25. Description of the coding tree	We did not use a coding tree. Themes derived from the data.
26. Derivation of themes	Themes derived from the data and were discussed and agreed on by all the authors.
27. Software	Verbatim transcription of the digital interview recordings was supported by the transcription software f4 from audiotranskription. Analysis and coding of the transcripts were aided by the software QSR NVivo 9.
28. Participant checking	There was no feedback from the participants on the findings (due to practical reasons as explained above). At the end of the interviews, the interviewer gave a short summary of the interview content and asked clarifying questions. This made it possible to enable the informant to check whether the researcher did understand the main content right.
Reporting	
29. Quotations presented	Themes are presented and illustrated by participant quotations that are identified by a participant number. The participant number does not correspond with the number from Table 2 in order to protect the participants and to ensure confidentiality.
30. Data and findings consistent	The presented data and findings are consistent from our point of view.
31. Clarity of major themes	The major themes are presented in the results/findings and illustrated in Figure 1.
32. Clarity of minor themes	Minor themes are described in the result chapter.

Table 2. Participants—nursing home residents.

Nr.	Age (years)	Gender	Main medical diagnoses	Number of nursing home residents in the nursing home
1	66	Male	Multimorbidity Chronic pain Heart disease Depression Stroke	50–100
2	70	Male	Multimorbidity Parkinson's disease Angina pectoris Depression	100–150
3	74	Female	Multimorbidity Rheumatoid disease Diabetes Cold Basalioma Arteriosclerosis	100–150
4	75	Male	Stroke (several times)	100–150

(Continued)

Table 2. (Continued)

Nr.	Age (years)	Gender	Main medical diagnoses	Number of nursing home residents in the nursing home
5	77	Female	Multimorbidity Heart disease Atrial fibrillation Chronic pain Osteomyelitis	100–150
6	79	Male	Multimorbidity Rheumatoid disease Prostate cancer Intestinal diverticulum Ileocolostomy	< 50
7	81	Male	Osteoporosis Rheumatoid arthritis	100–150
8	81	Female	Multimorbidity Diabetes type II Hypertension Depression Renal insufficiency	100–150
9	83	Male	Multimorbidity Parkinson's disease Hypertension Hyperlipoproteinemia Depression	< 50
10	87	Female	Multimorbidity Stroke Cold Atrial fibrillation	< 50
11	88	Female	Rheumatoid disease	50–100
12	89	Female	Multimorbidity Hypertension Depression Biological aortic valve Bypass operation	100–150
13	89	Female	Multimorbidity Heart disease Atrial fibrillation Chronic muscle pain	50–100
14	89	Female	No information provided	150–200
15	91	Female	Multimorbidity Intestinal diverticulum Intestinal cancer Ileocolostomy Coxarthrosis Angina pectoris Intervertebral disc disease	100–150
16	92	Female	Multimorbidity Heart failure Hypertension Osteoporosis Pulmonary embolism Thrombosis	100–150
17	92	Male	Multimorbidity Prostate cancer Macular degeneration Intestinal cancer Paroxysmal tachycardia	100–150

Table 2. (Continued)

Nr.	Age (years)	Gender	Main medical diagnoses	Number of nursing home residents in the nursing home
18	93	Male	Multimorbidity Stroke Hypercholesterolemia Vertebral canal stenosis Cataract Deafness	100–150
19	94	Female	Multimorbidity Stroke Diabetes	50–100
20	94	Female	Multimorbidity Atrial fibrillation Stroke Heart disease Intestinal diverticulum Ileocolostomy	100–150
21	95	Female	Basalioma Arthrosis	100–150
22	96	Female	Multimorbidity Hypertension Depression Stroke	100–150
23	97	Male	Multimorbidity Depression Chronic muscle pain Deafness	50–100
24	99	Female	Multimorbidity Hypertension Stroke Angina pectoris Atrial fibrillation Esophageal reflux	50–100
25	100	Female	Multimorbidity Deafness Aortic stenosis Chronic pain Compression fracture of lumbar vertebrae Glaucoma Esophagitis Coxarthrosis	100–150

In order to protect the residents' privacy and to ensure that they can stay anonymous, the resident numbers in the table do not correspond with the numbers of the citations. One informant was excluded during the interview because of cognitive impairment.

in the data material and the coded text was repeatedly performed. As a measure to validate the findings, repeated reading of the interview transcripts, in order to question the findings in the interview transcripts, and repeated discussions with the co-authors were undertaken.

Results

Participant characteristics

In all, 43 informants from nine Norwegian public and privately owned nursing homes representing different regions and communities of different sizes participated in the study. In total, 25 nursing home residents participated in in-depth interviews. A total of 18 relatives from three different institutions participated in focus groups. After completing three focus group interviews, data saturation was achieved. Source triangulation was used to compare views from residents and relatives. Mean age of the residents and relatives was 87 (66–100) and 68 (41–91) years, respectively. Participants' characteristics are shown in Tables 2 and 3. The residents' relation to the relatives was wife (2), husband (4), mother (9), mother-in-law (1), father (2) and

Table 3. Participants—relatives of nursing home residents.

No.	Age (years)	Gender	Number of nursing home residents in the nursing home
1	41	Female	<50
2	45	Male	100–150
3	53	Female	<50
4	58	Female	<50
5	59	Female	100–150
6	60	Female	100–150
7	66	Female	<50
8	67	Female	100–150
9	67	Female	100–150
10	71	Female	100–150
11	72	Female	100–150
12	73	Female	100–150
13	74	Female	100–150
14	77	Male	100–150
15	77	Female	100–150
16	80	Male	100–150
17	86	Male	100–150
18	91	Male	100–150

In order to protect the relatives' privacy and to ensure that they can stay anonymous, the relative numbers in the table do not correspond with the numbers of the citations. All participating relatives had a relative (e.g. parent or spouse) living in long-term care in a nursing home.

Table 4. Details of the analysis process.

1. G.B., E.G., and J.H.R. read the transcripts and familiarized themselves with the data
2. G.B. and E.G. independently identified preliminary codes and themes
3. G.B., E.G., and J.H.R. compared and discussed the preliminary codes and themes
4. G.B. coded all the material according to the preliminary codes and themes
5. G.B. revised the preliminary codes and themes and compared them to his field notes
6. G.B., E.G., and J.H.R. discussed the revised codes and themes and agreed on the final codes and themes
7. G.B., E.G., and J.H.R. checked the transcripts in order to question the findings
8. G.B., E.G., and J.H.R. discussed the findings and themes and agreed about the interpretation of the data

no information (1). One relative had both parents in the nursing home. The residents' and relatives' views can be summarized in three main themes within a palliative care framework (Figure 1):

ACP: wait and see

One day at a time

A substantial number of the interviewed residents stated that they had no concern about their coming death, and one of the residents expressed what could be representative for most residents:

> I take one day at a time. (Resident 7)

Many residents stated that they had not thought about planning their future at all:

> It may sound easy to say but I haven't thought so much about death. I mean, I live now. (Resident 13)

Some residents talked about their thoughts about accepting death as normal part of life:

> There are two things you know for sure: it is to be born and to die. (Resident 18)

In addition, they also talked about their ambivalent attitude to death and the ambivalence of wanting to live and wanting to die at the same time:

> My wish has been: Let me die. But this can change. One day you think that you want to die but on another day (you want to live) … When you are back in a somehow normal situation where you receive care and food and (pause) you are able to read a bit and such things, then you are there in that moment at least … But it is obvious, that there are times in-between where I think that I would like … that it ended (life) … I am almost wondering, how long shall I sit here? (Resident 15)

No planning for the future means no ACP

Most residents have not been engaged in ACP. When asked whether they have talked about ACP to relatives or the staff, most answered,

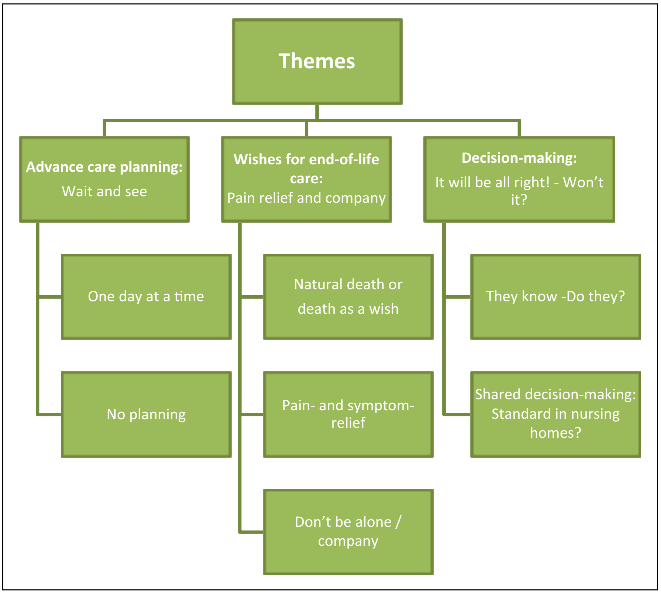

Figure 1. Themes from the interviews of nursing home residents and relatives.

> No, we have not talked about that. (Resident 25)

One reason for the lack of ACP may be the lack of time to talk:

> No, there is little talk about that (ACP) because they (the staff) are so busy. (Resident 18)
>
> It is not possible to talk with them (physicians and staff) about it. (Resident 3)

Or just in part,

> I have talked a bit about it (ACP) with a nurse, and I appreciate to talk about death. I don't have a problem to talk about it (death). Some people put these things aside and do not even want to think about it. (Resident 15)

A few informants talked about ACP, decision-making, and death with their relatives:

> Why shouldn't I talk about it (death and ACP)? …One is afraid … one is afraid of old prejudices, childhood believes … One is afraid to talk about such fundamental things. You don't need to be afraid of talking about it. (Resident 24)

ACP does not seem to be important at all, although many do have concrete wishes for end-of-life care that they had not told anybody:

> I haven't thought so far … but it is pretty obvious … I would, in this case, like "a smooth passage"* between life and death. But I am not hysterical about it. (Resident 5)
>
> *"a smooth passage" was explained to be dying without pain and suffering.

Although many residents mentioned the absence of regular physician visits, some had discussed their wishes for end-of-life care with both their family and a physician:

> Yes, I have talked about it (death and ACP) with my family. And I have told them very early and told the doctor too … that I would say no if they tried to keep me alive! (Resident 24)

Functional status in daily life seems to be more important than choosing between different treatment options. Some residents expressed the view that they want to participate in life and that living without consciousness and the ability to communicate is not worth living:

> I don't want to become a vegetable. (Resident 17)

Many relatives are reluctant to talk about end-of-life care and treatment decisions with the residents. It seems that many fear this topic:

> I do not dare. We are too afraid to take this up (ACP). (Relgr 1/2)
>
> This (ACP and dying) is a subject that you do not talk about. (Relgr 3/4)

Therefore, many relatives do not know the residents' wishes when decisions have to be made. One reason could be that the residents frequently use denial as a coping strategy:

> I wish we had talked about it (ACP) before, but we have not. (Relgr 2/6)

In contrast, it can be experienced as a release if the relatives have talked about wishes and preferences in advance. This can positively lead to certainty about the resident's wishes and preferences:

> It was a difficult process. It really was. But I am very happy that we could talk about it (ACP), he (my husband) and me. (Relgr 2/1)

Wishes for end-of-life care: pain relief and company

Although many informants seemed to feel slightly uncomfortable talking about death and dying in the beginning, most of them were not frightened and talked openly about death as a normal part of life. Many residents had wishes for end-of-life care, but most had not communicated their wishes to the staff or their relatives.

Natural death or death as a wish

Many informants stated that, even when moving in, it was clear to them that they would die in the nursing home:

> It is obvious for most people when they come in here, that this is their last stop. (Resident 15)

Some of them even expressed the wish to die:

> I have said before that I would like to die. I have lived my life. I am done with life … I am not afraid to die. (Resident 20)

Some informants stated that they want to die as natural as possible:

> Yes, I would appreciate a calm and natural death. (Resident 16)

Some stated that a natural death means that physicians should not prolong life without meaning:

> I wish that I do not have to lie there suffering … If the physicians see that it (treatment) will not help any longer, they should not continue. (Resident 7)

In addition, many residents do not want artificial nutrition or life-prolonging medical treatment:

> If it became the norm to withhold life with every technical means possible, it would just postpone that time (death) for many years. And then it is not sure that there will be quality of life … It won't be there, I doubt it … It is just, I want to die with dignity. (Resident 24)

A feeling of control and the certainty of not being kept alive against ones wishes can enhance quality of life:

> If you ask about quality of life, it may sound weird, but to know that you can end your life with dignity has something to do with quality of life. (Resident 24)

The use of life-prolonging treatment is in contrast to the wishes for a natural death of many informants. Resuscitation efforts or life-prolonging treatment, commonly, are not wanted:

> I don't want to receive life-prolonging means. I want to follow the course of nature… No life-prolonging treatment because what would it lead to? A life without living. You are more than just half-dead. Does that make sense? It does not work, it is unreasonable, its' inhuman … to lie there … probably paralyzed and just able to stare at the ceiling … Does it make sense? No there is no sense with it… When life is fading away, you should not extend life with force. This is unnatural and uncomfortable if it will just make you live two days longer. (Resident 24)

Some of the informants seemed to be relaxed and stated that they were waiting to die:

> I do know that I will die soon. That is the only thing I know … I do not know if it will be in 14 days or two years (laughs) … It cannot last much longer, I think. (Resident 14)

Some wished to die because life is troublesome, filled with waiting and suffering, and perhaps, boredom. Waiting was also part of the researcher's own observations. The researcher observed that residents had to wait to get help from the staff on some occasions during the fieldwork:

> Death can be a release, and for me it will be. (Resident 24)

None of the informants expressed the wish for euthanasia or physician-assisted suicide although several residents stated that they waited for death.

Some relatives do know that the residents' wish would be to die and that life-prolonging treatment is definitely not intended:

> I am sure that my mother often wishes to pass away. (Relgr 1/2)

Natural death can also mean to die in the nursing home instead of being sent to a hospital. In Norway, many relatives do have to decide whether the residents shall receive end-of-life care in the nursing home or whether they shall be transferred to a hospital:

> This is a decision we as relatives have to make … Shall they be sent to hospital or not? … I am struggling with that decision. (Relgr 3/4)

Some relatives believe that holistic care is better in nursing homes compared to hospitals because death is more accepted. In hospitals, the intention is to save lives, and as a result, sometimes the needs of dying people are neglected:

> I think it (dying) is calmer in the nursing home than in a hospital. (Relgr 3/3)

Pain- and symptom-relief

Many informants were afraid of pain and expressed their expectations to receive adequate pain relief when needed:

> I have no other wishes than just to be able to die in a peaceful and quiet way without pain or other terrible things. (Resident 22)

Pain medication, as treatment in end-of-life care, is wanted by most informants and does not seem to interfere with the residents' concept of a natural death:

> There is something I am afraid of, which I don't like to think about. That is to experience pain. I don't want to be in pain. I don't like it … And therefore they have told me that they will start to give me morphine injections. So that I won't feel pain. (Resident 20)

Relatives agree with the residents that relief from pain and suffering is most important in end-of-life care:

> If they only are not in pain … Yes, no pain … This is most important. (Relgr 2/5, 6)

> She (the resident) has made it clear that she does not want life-prolonging treatment but that we shall take care that she won't die in pain. (Relgr 2/5)

Don't be alone/company

Not to be alone when facing death is a frequently mentioned wish by many residents:

> You need a hand to hold on to. (Resident 12)

Many would appreciate their relatives to be there:

> Of course I want them (the relatives) to be there when I die. Because this is something unknown … It is not easy for us to be alone then. (Resident 25)

In addition, residents want to be able to contact relatives:

> I would like to be able to talk to my relatives as long as possible. (Resident 5)

Decision-making: it will be all right!—won't it?

Most residents trust their relatives when coming to a decision concerning treatment options, whereas the relatives feel insecure about the resident's wishes.

They know—do they?

Asked whether the relatives knew the residents' preferences about their wishes for end-of-life care and decision-making, most residents stated that their relatives did know their wishes:

> Yes, they know how I feel. I don't think that this will be a problem. (Resident 8)

Many relatives are afraid of making important decisions for the residents and are concerned that they do not know what to choose if being asked to decide:

> I have never talked about that with my husband because he had not accepted that he was ill. So we have not talked about his wishes. And now he is not able to talk anymore … I have not been asked (to decide something for him yet), but I do see … No, this is so complicated … Sometimes I think that this is undignified as he sits there not being able to do anything. I have not accepted the situation myself (sniffles). We (relatives) become so egoistic. We want to retain them. But how can I say what is the best for him? (Relgr 1/5)

Many relatives experience it as a burden to make decisions without knowing the wishes and opinions of the residents:

> I do hope that I will not have to make a decision … I do not want to decide. I cannot decide. (Relgr 1/6)

Shared decision-making: standard in nursing homes?

All residents were asked who should decide if they were incapable to decide themselves. Most of them stated that their relatives should decide:

> My relatives shall decide for me. (Resident 12)

Some believed that shared decision-making is standard and that this means that relatives and physicians talk together in order to make decisions:

> I suppose that the doctor and my children talk together (in order to make decisions). (Resident 14)

Many residents trust in the physicians' ability to make decisions about their medical treatment and feel comfortable when just being informed:

> You know. They (the physicians) decide. I cannot decide anything myself. But they do provide me with information first. (Resident 19)

Many residents think that the withdrawing of life-prolonging treatment is exclusively a medical decision that should be made by the doctor:

> That I do not have to suffer … When the doctors see that it (life-prolonging treatment) does not help anymore, they should not carry on doing it. (Resident 7)

Treatment decisions were often seen as "purely medical decisions" by residents, and although many want their relatives to participate in the decision-making, they want the doctor to decide on issues that the residents regard to be solely medical matters:

> The family cannot decide everything, can they? If it is something that has to do with disease, it shall be decided by the physician. (Resident 8)

Most of the residents trust in the ability of physicians and staff to make decisions for them, but some primarily trust the nurses who know them best:

> I do not think that I can decide such things. I think this has to be done by the staff … I have no contact with the doctors who work here … They are so seldom around that I hardly know them. (Resident 3)

As many residents do not have regular contact with their physician, they prefer shared decision-making by nurses and physicians:

> I just trust in the ones who care for me. What they think is best. (Resident 25)

Many of the relatives seemed to be used to take over decision-making and organization of most things for the residents:

> It is almost as if they hand it (decision-making) over to us. We have already taken over most things … Probably they change when they get old. Maybe they cannot bear to make decisions anymore … Uff? … They just want others to do it. They are tired of it … Maybe she (the nursing home resident) thinks that I know best (laughing). (Relgr 3/2)

Although many relatives do not want to decide alone, they want to participate in decision-making and to be heard. They prefer shared decision-making undertaken together with nurses and doctors:

> But I think that it is important that one of course will be heard and that one can participate in decision-making when the situation turns up … this should be done in cooperation with the nurses and the doctor. (Relgr 1/6)

ACP has been described as an ongoing process with repeated meetings and communication. Some would appreciate regular meetings with the nursing home staff:

> There should be regular meetings between the relatives and the staff at least once a month. (Relgr 1/7)

Discussion

The main findings of the study are that residents trust their relatives, physicians, and nurses to make decisions for them and that most residents believe that the relatives would know their wishes. In contrast, however, many relatives do not know what the resident wants. ACP is lacking in nursing homes.

Relatively, few people have written ACP documents: 8% in England and 10%–20% in the United States, Canada, Australia, Germany, and Japan.[20] There are guidelines on ACP and decision-making in end-of-life care in the United Kingdom[13,20,21] and Norway.[22] Nevertheless, in Norway, limitation of life-prolonging treatment on the family's request might be more frequent than the law permits.[23] Few older adults have expressed their wishes for end-of-life care and many do not talk openly about death.[24] Even if preferences had been discussed, documentation and a systematic approach are lacking.[25,26] Our data show that there is a striking difference between the views of the residents and the relatives concerning the knowledge of the residents wishes for end-of-life care. The absence of ACP seems not to be problematic for the residents but may lead to psychological stress for the relatives. When decisions in end-of-life care have to be made without knowing what the resident would want, problematic situations occur.[27–29] This may cause moral distress for the relatives,[28] nurses, and physicians. Challenges in decision-making, communication, or even conflicts between staff and relatives are described in the literature.[8,14,27,30–32] Many relatives in our study felt that it was problematic to decide for the residents and that they tried to avoid making important health-related and end-of-life care decisions.

A systematic approach to ACP with repeated conversations is needed as many residents and relatives seem to need a third person with knowledge of the residents medical history to initiate a discussion on ACP.[33,34] Both systems to involve residents and relatives in end-of-life care in nursing homes[14,27,35] and training of the staff to enable them to discuss ACP are needed.[36–38] Our findings suggest that residents do not oppose ACP, but that the opportunity is lacking. This is in accordance with findings from other researchers.[39,40] As many residents in nursing homes have cognitive impairment, ACP discussions should be offered much earlier in their disease trajectory.[41,42]

The resident's wishes for end-of-life care in our data were as follows: not to be alone, pain relief, and no life-prolonging treatment. These findings are in accordance with previous findings.[43]

Although some residents talked about death as a wish or relief, none of them mentioned a wish for euthanasia or physician-assisted suicide. One possible reason for a wish to die could be the lack of subjectively felt quality of life perhaps due to lack of activities and contact. Dignity is threatened by illness and the perception of insufficient care.[44] Residents' dignity can be supported and enhanced in many ways including dignity therapy and even by participating in research.[45,46] Interestingly, most informants in our study were grateful to take part in our research and to be able to contribute.

In summary, providing residents with opportunities for ACP and talking about death and preferences for end-of-life care are paramount. Besides planning for end of life, ACP helps the residents to prepare for death[47] and can reduce moral distress for the relatives. ACP has a positive impact on quality of end-of-life care.[48,49]

Strengths and weaknesses of the study

G.B.'s experience as a nursing home physician and consultant in palliative medicine and thus talking regularly about death may be considered both as a strength and as a weakness of this study. It is a strength that the interviewer was comfortable talking openly about death and dying in an empathic manner. Nevertheless, it might be a risk for "going blind" to unknown aspects of the nursing home world. The researcher used metapositions and repeated reflection of his presuppositions during the interviews and analysis. The fact that many participants thanked the interviewer for talking about these matters indicates that there was an open atmosphere that enabled the informants to share their views and concerns. One possible weakness could be the selection of informants by nursing home staff to provide a positive picture of their nursing home. Most informants reported, however, both positive and negative aspects. Nevertheless, it should be noted that they represent only a small part of the nursing home residents. A limitation is the exclusion of residents with cognitive impairment due to ethical considerations.

Implications for clinical practice and future research

ACP should be initiated by healthcare workers (nursing home staff and/or medical doctors) and should be an integral part of nursing home care. It seems that most people do need a third person from outside the family to start conversations about ACP. Future research should focus on methods and communication arenas that can enable residents, relatives, and staff to talk openly about end-of-life care and to solve emerging ethical dilemmas.

Conclusion

Communication about the end of life with the residents and relatives including ACP should be routine in all long-term care facilities. In nursing homes, there is a need to talk about ACP and preferences for end-of-life care in order to enable decision-making.

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Paper III

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EMPIRICAL STUDIES

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Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

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Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

Background: Many ethical problems exist in nursing homes. These include, for example, decision-making in end-of-life care, use of restraints and a lack of resources.
Aims: The aim of the present study was to investigate nursing home staffs' opinions and experiences with ethical challenges and to find out which types of ethical challenges and dilemmas occur and are being discussed in nursing homes.
Methods: The study used a two-tiered approach, using a questionnaire on ethical challenges and systematic ethics work, given to all employees of a Norwegian nursing home including nonmedical personnel, and a registration of systematic ethics discussions from an Austrian model of good clinical practice.
Results: Ninety-one per cent of the nursing home staff described ethical problems as a burden. Ninety per cent experienced ethical problems in their daily work. The top three ethical challenges reported by the nursing home staff were as follows: lack of resources (79%), end-of-life issues (39%) and coercion (33%). To improve systematic ethics work, most employees suggested ethics education (86%) and time for ethics discussion (82%). Of 33 documented ethics meetings from Austria during a 1-year period, 29 were prospective resident ethics meetings where decisions for a resident had to be made. Agreement about a solution was reached in all 29 cases, and this consensus was put into practice in all cases. Residents did not participate in the meetings, while relatives participated in a majority of case discussions. In many cases, the main topic was end-of-life care and life-prolonging treatment.
Conclusions: Lack of resources, end-of-life issues and coercion were ethical challenges most often reported by nursing home staff. The staff would appreciate systematic ethics work to aid decision-making. Resident ethics meetings can help to reach consensus in decision-making for nursing home patients. In the future, residents' participation should be encouraged whenever possible.

Keywords: ethics, ethical problems, nursing home, nursing home staff, residents, relatives, ethical deliberation, ethics consultation, ethics committee.

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Introduction

Many ethical challenges in the care of the elderly and in nursing homes have been reported in the literature. These include, for example, decision-making and other challenges in end-of-life care (1–3), use of restraints (4, 5), lack of resources (1, 5), autonomy and decision-making capacity (1, 6), communication and cooperation between healthcare workers and the patients' next of kin (5, 6) and the resident's privacy and behaviour (7–9). It seems useful to distinguish between ethical challenges and ethical dilemmas in nursing home care. Ethical challenges include all types of ethical issues, whereas an ethical dilemma is a special type of ethical challenge where one has to choose between different options with no discernible good choice.

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A survey of ethical challenges in the provision of end-of-life care in Norwegian nursing homes showed that nursing home staff most often reported a lack of resources and breaches of patients' autonomy (10). The respondents suggested handling of ethical challenges through more ethics education and time for reflection (10). Based on a review of the literature, ethical challenges in nursing homes can be divided in two major groups: 'everyday ethical issues' such as informed consent, use of restraints, autonomy, refusal of medication or food and offensive behaviour, and 'big ethical issues' which mainly are about end-of-life care and decision-making, for example withholding or withdrawing life-sustaining treatments and the question to hospitalise or not (11).

In 2006, the Norwegian government presented a national plan for better care for the elderly, including care in nursing homes (Storting report nr. 25, 2005–2006) (12). Based on this report, cooperation between the Ministry of Health and Care Services and the Norwegian Association of Local and Regional Authorities (KS) was carried out. As a consequence of this cooperation, educational courses on ethics and different tools to enhance ethics reflection in nursing homes and primary care have been established (13). When the first plans were made and the first measures were undertaken, systematic ethics consultation and ethics support were relatively rare in community care and nursing homes in Norway, whereas Norwegian hospitals already had ethics committees. One exception was the Bergen Red Cross Nursing Home, which had both ethics guidelines and an ethics committee (14). A Norwegian pilot study and literature review performed in 2007–2008 showed that a lack of resources and ethical challenges in end-of-life care are frequently mentioned challenges in Norway. It was concluded that ethics support in nursing homes and home health care should be strengthened, and further evaluation of systematic ethics work and its implementation in primary care and nursing homes was needed (5). The term systematic ethics work as used in this study includes the organisations systematic use of different measures, tools and places to enhance ethics discussions and ways to handle ethically difficult situations and choices in nursing homes, for example ethics education, ethical deliberation, different arenas for ethics discussions, ethics consultants and ethics committees.

Aims of the study

1. To explore the opinions and experiences with ethical challenges of the staff of a large Norwegian nursing home including both healthcare personnel and non-medical personnel.
2. To find out which types of ethical challenges and dilemmas occur and are being discussed in nursing home ethics meetings arenas.
3. To investigate whether results from ethics meetings were put into practice. The inclusion of the residents' view by participation of the residents themselves or their next of kin was of special interest.

Ethical considerations and ethical approval

The participants were informed about the study and were given the opportunity to ask clarifying questions before participating. They were informed about the possibility to withdraw from the study at any time. All informants gave their informed consent to participate. Nursing home staff participating in part 1 of the study was asked to fill out a questionnaire once. In order to assure confidentiality, the questionnaire was anonymous. To document ethics meetings in part 2 of the study, all ethics meetings were reported by using a questionnaire with description of the case discussed, but without personal data of the patient, relatives or the other participants. The study protocol was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a.

Methods

The study was based on a mixed-methods approach (15) combining quantitative and qualitative data from surveys with nursing home staff as informants. The reason for using mixed methods in this study was to provide a bigger and richer picture of ethical challenges and ethics consultation in nursing homes. The open qualitative question was also used as additional measure to open up for new themes that probably were not covered by the questionnaire.

Part 1: Questionnaire on ethical challenges in a nursing home

To explore the opinions and experiences of the staff, a 'spotlight approach' (16) was used to get insight from the staff in a typical Norwegian nursing home. A questionnaire, which had been used in a previous pilot study with leaders and ward head nurses as informants (5), was modified and given to all employees of a large Norwegian nursing home including staff from nonmedical professions. The nursing home had 154 beds including beds for rehabilitation and short-term beds. The original questionnaire in Norwegian was shortened and some questions were reframed according to the experiences from the pilot study (5). In addition to the multiple choice questions, the informants were asked to describe a recent ethical challenge or ethical dilemma in their own words. A qualitative question in the questionnaire for nursing home staff was used to emphasise the concerns of the staff members and to open up for descriptions of other challenges or dilemmas that probably were not covered by the questionnaires multiple choice questions. Detailed information on the questionnaire is available on request to the first author.

Informants and recruitment. All staff members were informed by their leaders on staff meetings about the study and were given the possibility to contact the researcher in order to ask questions about the study. They were encouraged to participate and were able to participate within their usual working hours. Table 1 provides an overview of the informants' characteristics.

Data collection. The participants were asked to fill in the anonymous questionnaire that could be sent directly to the researcher. In addition, there was the possibility to fill out the questionnaire within the usual working hours with the researcher present in order to answer questions and to ensure confidentiality by collecting the questionnaires directly.

Data analysis. Analyses of the results from the questionnaire are described by descriptive statistics to summarise the answers and views of the participants from our sample. The results from the survey were compared to those found in a Norwegian pilot study by Bollig, Pedersen and Førde (5). Qualitative analysis of the informants' written communications of a recent ethical dilemma was performed by qualitative description (17–19). The aim of qualitative description according to Neergaard was a 'rich and straight description of an experience or an event', and it is especially useful in mixed-method research (19).

Table 1 Characteristics of participating nursing home staff from Norway (n = 93)

- Gender
  - Female (n = 81)
  - Male (n = 12)
- Age
  - <20 years old (n = 2)
  - 20–29 years old (n = 18)
  - 30–39 years old (n = 22)
  - 40–49 years old (n = 17)
  - 50–59 years old (n = 27)
  - 60–69 years old (n = 7)
- 80 participants worked with health care, 13 in other professions
- Participants' profession
  - Nurse (n = 19)
  - Nurse assistant (n = 34)
  - Physician (n = 2)
  - Other professions (n = 38) as, for example priest, economist, assistant, occupational therapist, technical and cleaning personnel
- Of the participants working in health care, 58 worked on long-term wards, 28 on short-term wards, 3 on palliative wards; some of them worked on more than one ward or part-time in different nursing homes

Part 2: Ethics discussions in nursing homes

In order to give an overview of the types of ethical challenges and dilemmas that occur in nursing homes, a model of good practice for systematic ethics work was sought by the researchers. When the study was planned and started, ethics consultation in nursing homes in Norway was developing; however, it was not possible to find a suitable model of good practice for systematic ethics work in Norway to use in the study. Therefore, a model of good clinical practice with already implemented systematic ethics work from Austria was used instead. Ethics discussions were documented in a cooperation of nursing homes of Caritas Socialis (CS) in Vienna.

Informants and recruitment. The management of the CS was asked to allow a documentation of all types of systematic ethics discussions throughout the organisation. CS had three nursing homes and two special units for people with dementia living in flats within the city of Vienna, altogether a total of 333 residents. The nursing homes have used systematic ethics meetings since 2007. CS in Vienna has established systematic ethics work in four combined arenas for discussing ethical challenges and problems. These arenas include the following: (i) assessment and documentation of the resident's will in everyday work which means that the nursing staff of the Caritas Socialis, Vienna, tries to document relevant wishes or expressed values of the residents. They do that by writing residents statements that could be important in the residents' electronic chart; (ii) a palliative care round table which is a scheduled meeting where challenges in palliative care, in general, ethical challenges and residents cases are discussed; (iii) the resident ethics meeting (REM) which is an ethics consultation at a nursing home ward where a moderator uses Socratic dialogue in order to explore the residents will; and (iv) one ethics committee for all institutions belonging to CS which is responsible to establish ethics guidelines and to coordinate ethics education and whose six to eight members are nurses, physicians, managers and pastoral carers appointed by the management (20). Care throughout CS is based on the Maieutic Model of Nursing Care according to Cora van der Kooij (20). Maieutic means 'assistance at birth' in greek. The term is connected to the Socratic dialogue where the moderator has the role of a midwife in order to give birth to new knowledge and to aid reasoning. Socratic dialogue is the preferred method to discuss ethical problems in the CS. It is a method that is grounded on values and virtues that are accepted as ethically good. Usually, a moderator asks a serious of questions that help the other participants to reach a conclusion. CS received the Teleios Award in 2011, a national Austrian award for innovation and sustainability in elderly care, for their efforts to implement systematic ethics work throughout the organisation (21). The CS model of ethics consultation has been recommended as a model of good practice for respectfulness of human rights and dignity by the European project 'European Partnership for the Wellbeing and Dignity of Older people' in cooperation with the European Commission (22).

Data collection. A questionnaire in German was used to document all ethics discussions on the four different levels that are used by Caritas Socialis in Vienna. The moderators of the ethics discussions were asked to document each meeting. Detailed information on the questionnaire is available on request to the first author.

Data analysis. The analysis of the data from the questionnaire in part 2 was performed in the same way as described under part 1.

Results

Part 1: Questionnaire on ethics from a Norwegian nursing home

The Norwegian nursing home in our study had 140 full-time positions and a total of 238 employees: 115 work directly with health care and nursing. Ninety-three informants answered the questionnaire, representing 66% of the full-time positions or 39% of the total number of employees. Eighty-five of the 93 participants (91%) described ethical challenges as a burden, at least to a minor degree. Eighty-four of the 93 informants (90%) experienced ethical challenges in their daily work. 92.5% of the healthcare workers and 77% of the employees from other professions experienced ethical challenges in their daily work. Figure 1 shows details on the burden of ethical challenges experienced by the informants. The three most common ethical challenges reported by the informants were lack of resources (79%), end-of-life issues (39%) and coercion (33%). Ethical challenges reported by the staff are shown in more detail in Table 2. It highlights that there are differences between the healthcare workers and the other professions. Ethical challenges as end-of-life issues, coercion, lack of professional competence and autonomy issues are more frequently mentioned by healthcare workers, whereas communication issues and other ethical challenges are stated more often by staff members from other professions. Table 3 gives an overview of the nursing home staff's opinions and wishes for the implementation of systematic ethics work. Most of the participants preferred to use informal discussions to handle ethical challenges in everyday work. Ninety per cent of the informants felt that more systematic ethics work was needed in nursing homes. Seventy-three per cent saw a need for more research on the topic. Wishes for the implementation of systematic ethics work were ethics education for the whole staff (86%), time for discussion (82%), meeting places (63%) and the possibility to ask someone with special ethics knowledge (78%). The possibility to consult an ethics committee was expressed by 27% of informants and only 6% wanted to consult a lawyer.

Forty-three participants chose to describe recent ethical challenges in their own words. Recent ethical challenges described by the participants most often included end-of-life issues (e.g. issues about nutrition and treatment), treatment options and medication, especially the practice of covert medication by mixing medication in food without informing the resident, but also coercion, lack of resources and the dilemma of not having enough time to

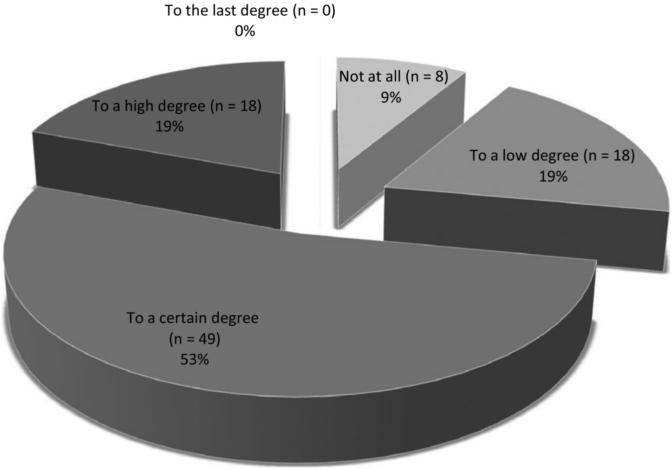

Figure 1 Ethical challenges as burden.

Table 2 Ethical challenges reported by nursing home staff

Type of ethical challenge	*Healthcare personnel (n = 80)*	*Other professions (n = 13)*	*Total (n = 93)*
Resources	(63) 79%	(10) 77%	(73) 79%
End-of-life issues	(34) 43%	(2) 15%	(36) 39%
Coercion	(30) 38%	(1) 8%	(31) 33%
Communication	(24) 30%	(5) 38%	(29) 31%
Lack of professional competence	(26) 33%	(3) 23%	(29) 31%
Autonomy	(24) 30%	(3) 23%	(27) 29%
Others	(1) 1.3%	(1) 8%	(1) 1%

Table 3 Nursing home staffs opinions and wishes for systematic ethics work

	Healthcare personnel (n = 80)	*Other professions (n = 13)*	*Total (n = 93)*
Method currently used for discussion of ethical challenges			
Discussion with colleagues	(70) 88%	(9) 69%	(79) 85%
Discussion with nurse, physician, patient/relatives	(67) 84%	(4) 31%	(71) 76%
Reflection group	(7) 9%	(1) 8%	(8) 9%
Ethics committee	(5) 6%	(1) 8%	(6) 6%
Do not know	(1) 1%	(1) 8%	(2) 2%
More systematic ethics work needed	(72) 90%	(12) 92%	(84) 90%
Research on ethics needed	(56) 70%	(12) 92%	(68) 73%
Preferred method for future systematic ethics work			
Education	(65) 81%	(10) 77%	(75) 81%
Education for resource persons	(40) 50%	(5) 38%	(45) 47%
Education for leaders	(48) 60%	(7) 54%	(55) 59%
Education for the whole staff	(68) 85%	(12) 92%	(80) 86%
Internet-based education	(17) 21%	0	(17) 18%
Reflection tools	(43) 54%	(10) 77%	(56) 60%
Ethics guidelines	(54) 68%	(6) 46%	(60) 65%
Core values	(47) 59%	(12) 92%	(59) 63%
Meeting places	(50) 63%	(9) 69%	(59) 63%
Someone to ask	(61) 76%	(12) 92%	(73) 78%
Staff with ethics knowledge	(51) 64%	(9) 69%	(60) 65%
Ethics committee	(22) 38%	(3) 23%	(25) 27%
Lawyer	(6) 8%	0	(6) 6%
Time to discuss ethics	(65) 81%	(11) 85%	(76) 82%
Community meeting places	(45) 56%	(11) 85%	(56) 60%
University education	(53) 66%	(11) 85%	(64) 69%

provide good care to the patients. Respect and privacy have been described as ethical challenges by some of the informants. Three typical examples from these descriptions are as follows:

Lack of time

> In my opinion lack of time for every patient is a big problem because of lack of resources. Some patients do get too little stimulation. Just to be with them more often and to take the patients to some activities can give them a better quality of life. (Staff member 12)

Covert medication

> To mix medication in the jam (without informing the resident). (Staff member 5)

End-of-life issues

> It is not right that a patient has to die alone. We had a patient where the relatives were not there when he came close to death. When the patient died, he was alone. Afterwards the relatives were in despair and became very sad because of that. (Staff member 21)

Part 2: Ethics meetings (from an Austrian model of good clinical practice)

Thirty-three ethics meetings were documented using a structured questionnaire for each meeting within the 1-year study period. Table 4 shows an overview of all documented ethics meetings including participants and topic. Twenty-nine of these were prospective resident ethics meetings (REMs) where decisions for a resident had to be made. Participants in the REM are staff members and representatives of the resident or the resident himself (20). In all 29 cases, the participants agreed on a conclusion that later was put into practice. Relatives in 26 of 29 REMs represented the residents' views. No resident participated in the meetings; thus, in three cases, neither the resident nor relatives were represented. The number of participating next of kin varied from 0 to 3 (mean 1.5). Ethical challenges discussed in prospective resident ethics meetings were mostly about withholding or withdrawing of life-prolonging treatment, for example artificial nutrition, dialysis and advance care planning, do-not-resuscitate orders, or to hospitalise or not. In one case, measures to enhance the patient's quality of life were the main topic of the meeting. The other four ethics meetings were regularly scheduled meetings of the ethics committee of Caritas Socialis. These were used to discuss common ethical challenges, planning educational efforts and work on own ethical guidelines for use in the organisation. Residents' cases were not discussed in any of these four meetings.

The findings from both parts of the study suggest that there is a difference between the type of ethical problems that the nursing home staff experience in their daily work and those discussed in ethics discussion meetings (REM and ethics committee). In daily work, everyday ethical issues seem to play a major role, whereas big ethical problems are more often discussed in official arenas for ethics discussion. Grounded on the findings from our study and a review of the literature, a model of 'the ethics iceberg' was created. The 'ethics iceberg' shown in Fig. 2 illustrates that ethics work and ethics discussions in nursing homes seem to focus on end-of-life issues. Everyday ethical issues, on the other hand, which occur much more frequent, are often hidden under the surface and thus are not properly addressed and therefore receive less attention, although occurring more frequently.

Discussion

Main findings of part 1 of the present study were that most nursing home staff members experienced ethical challenges in their daily work and that many felt these as a burden. Measures to improve systematic ethics work wanted by most employees were ethics education (86%) and time for ethics discussion (82%). Findings from part 2 showed that 29 of 33 documented ethics discussions were prospective resident ethics meetings where decisions for a resident had to be made. In all 29 cases, consensus was reached and put into practice. Relatives participated in a majority of case discussions, but residents did not participate in any meeting. The main topic of the ethics meetings was end-of-life care and life-prolonging treatment.

In our data, 90% of all employees of a large Norwegian nursing home experienced ethical challenges in their daily work. This included 93% of the healthcare workers vs. 77% of employees from other professions. It is thus obvious that ethical issues are frequent and important for most people working in nursing homes. Compared with studies from other countries, ethical challenges in Norwegian nursing homes in general are not very different from those reported in the literature (1–11). But it is striking that the lack of resources is the most frequently mentioned ethical challenge in a wealthy country such as Norway. Our findings highlight the frequency and importance of everyday ethical issues for the staff and add support to the idea that everyday issues are troubling to many nurses (see Fig. 2). The importance of everyday ethical issues and dignity in nursing homes has also been described different authors (9, 23–26). By respecting the residents' dignity, nursing home staff can probably avoid that nursing homes become 'undignifying institutions' (27–29). For all participants from our study, a lack of resources was the most common concern (79%), followed by end-of-life issues (39% in total; 43% for healthcare personnel and 15% for the other professions) and coercion (33%). Interestingly, there was no difference between healthcare workers and employees from other professions regarding a lack of resources as an ethical challenge (79% vs. 77%). The extent of experiencing ethical challenges seems to vary between professions as shown for end-of-life issues. This difference is illustrated in Table 2. Our findings suggest that closeness to residents seems to increase the percentage of ethical challenges experienced by the informants. Lillemoen and Pedersen have described similar findings for primary healthcare workers (30). Nevertheless, more than three-fourths of other professions from our study experience ethical challenges in their daily work indicating that this is an important and universal topic that should be addressed. Probably ethical sensitivity or ethical awareness can be enhanced by ethics education that helps to recognise especially everyday ethical challenges (31, 32). The first step to deal with ethical challenges and dilemmas is to perceive it (32). We found that more than 90% of the participants experienced ethical challenges as a burden in everyday work and 19% experienced ethical challenges as a high degree burden (Fig. 1). The experience of ethical dilemmas without the possibility to solve them can cause moral distress (33). It is thus important both to discuss ethical challenges and find solutions to relieve the staff's burden. Awareness of ethical

Table 4 Results from documented ethics discussions – Caritas Socialis, Vienna

Nr.	*Part.*	*Type of meeting*	*Profession of participants*[a]	*Number of next of kin*	*Discussion prospective = 1 retrospective = 2 common challenges = 3*	*Reason for the meeting*	*Who asked for the meeting?*	*Ethical problem as stated by the group*	*Comment*
1	9	Resident Ethics Meeting (REM)	N, P, AN, PC,	1	1	Withholding of dialysis as life-prolonging treatment	Relatives and nurses	Withholding of dialysis as life-prolonging treatment: benefit vs. Burden for the patient	
2	6	REM	N, AN, P	0	1	Mobilisation and/or surgical therapy of an decubitus	Nurses	Mobilisation and/or surgical treatment vs. No treatment	
3	7	REM	N, AN, P	2	1	Conflict about nutritional treatment of a diabetic patient between the nurses and the patients wife	Nurses	Benefit or burden of nutrition via PEG	
4	6	REM	N, P	2	1	Patients refuses blood sugar control	Head nurse	Benefit or burden of blood sugar control	
5	6	REM	N, P	2	1	Refusal of nutrition and fluids	Physician	Artificial nutrition or acceptance of the patients wish not to eat and drink	
6	7	REM	N, P, PC	2	1	Refusal of nutrition and fluids	Head nurse	Acceptance of the refusal or artificial nutrition?	
7	6	REM	N, P	2	1	Hospitalisation or not?	Relatives	Benefit and burden of hospitalisation for a patient who is temporarily confused?	
8	4	REM	N, P	0	1	Amputation of a foot because of pain or not?	Head nurse	Benefit and burden of amputation. Has the patient the right to refuse amputation?	

[a] Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
9	4	REM	N, P	1	1	DNR-order? Hospitalisation?	Head nurse	Benefit and burden of resuscitation and hospitalisation.	
10	3	REM	AN, P	1	1	Patient dying? Palliative Care?	Physician	DNR-order? Hospitalisation? Artificial nutrition	
11	6	REM	N, P	3	1	Patient falls often. Hospitalisation in case of every fall?	Physician, head nurse	Frequent hospitalisation after every fall?	
12	4	REM	N, P	1	1	Frail patient who dies not want to live anymore	Physician	Life-prolonging treatment? Hospitalisation?	
13	4	REM	N,P	1	1	Hospitalisation or not?	Physician	Frequent hospitalisation because of anaemia?	
14	6	REM	N, P, PS	3	1	Minimal intake of fluid and food	Head nurse	Benefit and burden of starting artificial nutrition via PEG	
15	4	REM	N, P, PC	2	1	Dying process and treatment options	Nurses, Physician	DNR-order? Hospitalisation?	Patient died on the same day
16	8	REM	N, PS	0	1	To people with dementia are attracted to each other and search for body contact (one of them is married)	Head nurse	The patient's behaviour disturbs the others. Should they have the option to use an own room.	
17	5	REM	N, P	3	1	Frail patient. Hospitalisation? Options?	Head nurse	Benefit and burden of hospitalisation or other treatment options.	
18	8	REM	N, AN, O	2	1	Patient with dementia and minimal intake of food and fluids.	Nurse	Artificial nutrition and PEG in the patient's interest?	Patient died on the same day

[a] Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
19	6	REM	N, P, PC	2	1	Patient with dementia and minimal intake of food and fluids.	Physician, head nurse	Benefit and burden of starting artificial nutrition via PEG. Is the decision the same as 6 months ago?	Same discussion had been done 6 months ago. This meeting should decide if the same decision is still applicable.
20	4	REM	N, P	1	1	Frail patient. DNR-order? Advance Care planning in general. Presumed will?	Head nurse	Care at the end of life. Resuscitation? Plan for food and fluid intake.	
21	6	REM	N, AN, P	2	1	Minimal intake of fluid and food. Refusal of feeding.	Head nurse	Artificial nutrition and PEG in the patient's interest? Hospitalisation?	
22	6	REM	N, AN, P, SW	2	1	Patient's condition is deteriorating. Does he have to move into the nursing home?	Nurse	Benefit and burden of moving to the nursing home.	
23	4	REM	N, A	2	1	Patient does not want to live anymore. How to deal with this statement?	Nurse	DNR-order? Hospitalisation? Artificial nutrition	
24	3	REM	N, A	1	1	Patient with dementia and minimal intake of food and fluids. Advance care planning.	Head nurse	Care at the end of life. Resuscitation? Artificial nutrition/hydration?	
25	6	REM	N, A, PC	2	1	Patient with dementia and minimal intake of food and fluids. Care at the end of life. Dying?	Head nurse	Care at the end of life. Resuscitation? Artificial nutrition/hydration?	Intravenous fluids were withdrawn
26	4	REM	N, A	2	1	Patient with dementia and cancer. Advance Care planning.	Nurse	Care at the end of life. Resuscitation? Hospitalisation? Artificial nutrition/hydration?	

[a] Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	*Part.*	*Type of meeting*	*Profession of participants*[a]	*Number of next of kin*	*Discussion prospective = 1 retrospective = 2 common challenges = 3*	*Reason for the meeting*	*Who asked for the meeting?*	*Ethical problem as stated by the group*	*Comment*
27	5	REM	N, P, PC	1	1	How to enhance quality of life for the patient? What is the patient's will? Pain treatment ineffective.	Nurse	Measures to enhance the patient's quality of life.	
28	4	REM	N, A, SW	1	1	Frail patient. DNR-order? Hospitalisation? Artificial nutrition? Advance Care planning in general.	Nurse	Care at the end of life. Resuscitation? Hospitalisation? Artificial nutrition/hydration?	
29	6	REM	N, AN, PC	1	1	Patient's condition (heart insufficiency) is deteriorating. Advance Care planning in general.	Head nurse, Physician	Advance Care planning. Specialist consultation concerning treatment options. Benefit and burden of mobilisation and extended treatment.	
30	7	EC	N,PC,P	0	3	Fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion
31	6	EC	N,PC,P	0	3	Education planning, participation in research projects, guideline home care	Regular meeting		Discussion of common ethical challenges, no case discussion
32	7	EC	N,PC,P	0	3	Guideline fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion
33	8	EC	N,PC,P	0	3	Guideline fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion

[a] Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

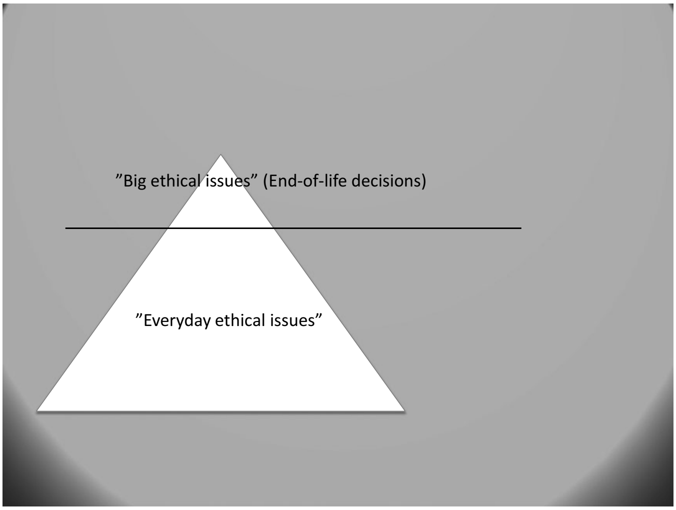

Figure 2 The ethics iceberg.

challenges and time to address these issues therefore seems to have a protective role for the psychological health of the staff. This underlines the necessity of regular ethics discussions in nursing homes.

There is a demand for systematic ethics work in nursing homes. In order to establish a culture of care in nursing homes, the attention for everyday ethical issues and the inclusion of ethics in everyday meetings and discussions have to be more focused in the future. The implementation of special structures or places for systematic ethics work must be based on sensitisation and awareness of ethical aspects in everyday work and communication (32, 34).

Ninety per cent of the healthcare workers and 92% of the employees from other professions expressed that more systematic ethics work is needed. This finding is similar to findings from other studies (5, 10, 30). Most suggested methods to improve ethics work based on our data were ethics education for the whole staff (86%), time for ethical discussions (82%) and to have someone to consult (78%). These findings support previous findings from other studies in Norway where staff management and heads of wards were informants (5, 10). One major benefit for all participants in ethics consultation might be to be heard and to be able to express their concerns. This is important for healthcare personnel, patients and relatives (35). But ethics education alone is not enough. It is also important that managers, policymakers and politicians participate when lack of resources is addressed and discussed. In our findings, 27% of all informants (38% of health personnel vs. 23% of other professions) suggested establishing ethics committees in nursing homes. This confirms the results of Gjerberg et al. (10) where 30% of participants suggested establishing ethics committees. Only 6% of our informants expressed a wish to collaborate with a lawyer compared to 19% in Gjerberg et al. (10) and nine of 19 participants in Bollig et al.’s research (5). In both studies, most of the respondents were managers, head nurses and people with leading positions, whereas the informants from the present study were employees from all professions, many of them working in direct patient care, assuming a closer relationship to the residents. A reason for the difference could be that staff managers and head nurses more often feel that they have to defend their judgements in public and therefore would appreciate consulting a lawyer. Nevertheless, most informants seem to recognise that ethical challenges cannot be solved by consulting a lawyer, but rather through ethics discussions.

Lack of resources and breaches of autonomy were most often reported by Gjerberg et al., (10) whereas end-of-life care issues were often reported when asked to outline a recent ethical challenge. Covert medication has been described by some of our informants as their most recent ethical dilemma. Between 1.5 and 17% of nursing, home residents do receive covert medication, often without documentation and discussion with relevant parties (36, 37). Covert medication in nursing homes thus seems to be a challenge that should be addressed more openly.

Ethics meetings in nursing homes at present seem to focus mostly on big ethical issues such as end-of-life decision-making, whereas many nursing home staff members experience everyday ethical issues such as a lack of resources and coercion more frequently. This finding is shown in Fig. 2: the ethics iceberg. The prominence of end-of-life issues in both ethics discussions and the descriptions of recent ethical dilemmas is truly related to the fact that this theme is connected to the nurses 'advocacy role' and therefore is experienced as more distressing (31).

The results of our study show that systematic ethics discussions including relatives of the residents frequently can lead to consent on acceptable decisions for both staff and relatives, and thus can enhance the decision-making process for frail elderly nursing home residents. In the present study, consent was obtained and action taken according to 100% of the registered cases (Table 4). Dialogue and discussion can thus lead to agreement that is acceptable for all involved parties. Important factors seem to be participation in the discussion, to be heard and an open process of decision-making. Although consensus is reached, it is not sure that this consensus always is a good solution from the residents' point of view. Nevertheless, it enables the staff and relatives to decide and to act when needed. In Vienna, the ethics committee did not have any case discussions but worked on ethics guidelines based on the discussion from minor groups. The ethics project of the Norwegian Association of Local and Regional Authorities (13) was based on participation of employees with limited ethics training as ethics consultants, combined with ethics discussions in peer groups (13). This strategy is in accordance with the findings of our study and of Gjerberg et al. (10).

Resident autonomy and participation seems to be limited at present. For nursing home residents, it is important to experience both choice and control over everyday matters (38). It has been suggested to improve participation in decision-making for nursing home residents, even including persons with dementia (39). So far, the residents' involvement in medical decision-making seems to be limited (40). It is astonishing that no resident participated in any of the 29 prospective resident ethics meetings in our study. It was not possible from our recordings to determine the reasons why no residents were involved; thus, we could only speculate. It might be that the residents were considered to be in too poor condition to participate or that the staff members feared involving residents in difficult ethical decision-making. We suppose that there is a lack of creativity arranging verbal and non-verbal communication to support a person-oriented way of participation. This has to be explored in further studies. In 26 of 29 meetings, the relatives represented the residents' views. One might speculate that a relative may be able to express the resident's true wishes, or decide on behalf of the resident if they have not been appointed to do so on a legal basis. Autonomy to make a decision must be based on both capacity to make decisions and having enough information to be able to decide and to get caring support. In a previous study from the USA, 40% of nursing home residents reported being told nothing about their medical condition at all (40). It seems that informing residents of their medical condition and their right to participate in decision-making has to be improved. Nursing homes should therefore implement strategies to enhance residents' involvement and participation in decision-making (41).

Limitations and strengths of the study

One limitation of the study is the use of a 'spotlight approach' where two nursing homes in two different countries have been chosen to study the topic. The nursing homes were selected on purpose. In Norway, a typical large nursing home with many residents was chosen based on the presupposition that this might uncover a larger variety of ethical challenges. Compared with the results from other studies in Norway, it seems to be similar with other Norwegian nursing homes, indicating that the results may induce future practice. The model of good practice from Austria was chosen because of their long experience with systematic ethics work. A strength of the study was that the results from Austria are built on an established tradition in CS for handling ethical challenges, and therefore, a higher awareness for ethical challenges would be found than in other nursing homes.

Conclusions

In the present study, ethical challenges most often reported were related to lack of resources, end-of-life issues and coercion. Resident ethics meetings may help to discuss ethical challenges and may lead to acceptable decisions for all included parties. Besides the often more prominent and obvious ethical challenges in end-of-life care in nursing homes, everyday ethical challenges such as a lack of resources and coercion have to be dealt with. In the public, as well as in systematic ethics discussions, ethical challenges in end-of-life care are more visible than everyday ethical challenges. Thus, ethics meetings should focus more on everyday ethical challenges. The results of the study support the value of a systematic approach to resolve ethical dilemmas in nursing homes. Systematic ethics work in nursing homes needs to be improved and to be implemented in all nursing homes. Both residents and relatives should be invited to participate in discussions concerning ethical challenges and in ethics meetings. To enable residents to use their autonomy as much as possible, participation of the residents in the resident ethics meetings should be encouraged.

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Author contributions

GB designed the study protocol and the questionnaires used. GS, JH and AH commented on these and suggested modifications. All authors agreed to use Caritas Socialis in Vienna as a model of good practice for systematic ethics work. GB organized data collection, data analysis and drafted the first version of the manuscript. GB and GS collected the data. All authors critically revised the manuscript and took part in the discussion of the results. All authors read and approved the final version of the manuscript.

Ethical approval

The study protocol was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a. The participants were informed about the study and were given the opportunity to ask clarifying questions before participating. They were informed about the possibility to withdraw from the study at any time. All informants gave their informed consent to participate.

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Paper IV

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EMPIRICAL STUDIES

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A European multicenter study on systematic ethics work in nursing homes

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A European multicenter study on systematic ethics work in nursing homes

Background: There are many existing ethical challenges in nursing homes. Although different methods and approaches to discussing the ethical challenges have been established, systematic ethics work is not yet a standard in all nursing homes. The aim of the present study was to explore ethical challenges and approaches to implementing systematic ethics work in nursing homes.
Methods: Data from five institutions in Austria, Germany and Norway were collected, and a mixed-methods two-tiered study approach was chosen. Documentation of ethics discussions was combined with qualitative focus group interviews with staff members regarding the implementation of systematic ethics work in nursing homes.
Results: One hundred and five ethics meetings were documented. The main topics were advance care planning, ethical challenges associated with artificial nutrition, hospitalisation and end-of-life decision-making. Of the meetings, 33% focused mainly on everyday ethical challenges. In 76% of prospective case discussions, agreements about a solution were reached; however, in 29% of these no residents or relatives participated. The advantages of systematic ethics work described by the staff were enhanced openness and dialogue, overall, and a greater ethical awareness. Many voiced a need for structure and support from the administration.
Conclusions: Systematic ethics work is greatly appreciated by the staff and helps to reach a consensus in the majority of case discussions. It should be implemented in all nursing homes. Attention to everyday ethical challenges is important. The participation of relatives and physicians could be improved. The participation of the residents' in ethics discussions should be encouraged to strengthen their autonomy and dignity.

Keywords: ethics, elder care, nursing home care, palliative care, decision-making, autonomy.

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Introduction

In elderly care and the 'nursing home world', many ethical challenges and dilemmas have to be faced. Both 'everyday ethical issues' and 'big ethical issues' have been described in the literature (1–11). The typical ethical challenges in nursing homes are lack of resources (3–5), resident autonomy issues, such as the use of coercion or restraints (4–8), and decision-making surrounding end-of-life care (3, 5, 9–11).

More than 90% of the staff at a Norwegian nursing home experienced ethical problems as a burden (12). A main barrier to the use of ethics discussions and ethics committees in nursing homes seems to be a lack of awareness (9). The Norwegian Association of Local and Regional Authorities started the 'Cooperation for building ethics competence' in order to improve competence in ethics through ethics education and reflection on ethics in nursing homes and primary care in 2007 (13). The project showed that the sustainability of ethics work depends on an assignment from the administration, ethics competence and methods for structuring ethical reflection (14).

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There is a need for systematic ethics work including ethics education and ethics reflection (4, 5, 9), but it is not yet standard in all nursing homes. Systematic ethics work 'includes the organisation's systematic use of different measures, tools and places to enhance ethics discussions and ways to handle ethically difficult situations and choices in nursing homes, for example ethics education, ethical deliberation, different arenas for ethics discussions, ethics consultants and ethics committees' (12). Different approaches to discussing ethics in nursing homes have been established in the USA (9), Germany (15, 16), Austria (16, 17) and Norway (4, 18). At present, theses approaches include, for example, informal discussions, reflection groups, moral case deliberation, ethics consultant, ethics committee, ethics café, ethics rounds or role play (19, 20). Ethics support has become more diverse and adapted to local needs and everyday ethical issues are important topics (1, 19, 20). So far there is no international gold standard or a state of the art for systematic ethics work other than that the need to discuss and handle ethical challenges in nursing homes is widely recognised.

The theoretical background and perspective of this study are the principles of biomedical ethics as proposed by Beauchamp and Childress with autonomy as a central concept in modern bioethics (21, 22), as well as palliative care ethics and hospice philosophy where the patients and their relatives' wishes and needs are paramount (23, 24). Although the principlism that is based on the four moral principles respect for autonomy, nonmaleficence, beneficence and justice (21) is not a classical ethical theory, it is a frequently used ethical framework of moral norms in modern bioethics (22). The four principles approach is widely used in medical ethics to discuss ethical dilemmas in ethics committees and ethics consultations in hospitals. Due to its importance in modern bioethics, the principle of respect for autonomy has even been referred to as being 'first among equals' (25). In order to respect the residents' autonomy in nursing homes, the inclusion of residents and relatives in the discussion about ethical challenges and decision-making is needed (26).

Aims of the study

The main aims of the study were to investigate which types of ethical challenges are discussed and to study approaches to implementing systematic ethics work that have already been incorporated into the daily practices in nursing homes.

The research questions were as follows:

1. Which ethical challenges are discussed in nursing homes?
2. What are the staff's experiences with the implementation of systematic ethics work?
3. Were residents and relatives included in ethics discussions?

Ethical considerations and ethical approval

The documentation of the resident cases from the ethics meetings was confidential. The cases were documented using a questionnaire with a description of the case discussed, but without personal data concerning the resident, relatives or other participants. No resident data other than gender and age were documented. The participants of the focus group interviews were informed about the study and invited to participate by the nursing home management. All participants had the opportunity to ask clarifying questions prior to their participation in the interview and gave informed consent. The Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, approved the study protocol (reference 2009/1339a).

Methods

The study used a mixed-methods approach (27) combining quantitative data from questionnaires on ethics discussions in nursing homes and qualitative data from focus group interviews about systematic ethics work. Mixed methods were used in order to provide a richer picture (27) of systematic ethics work in nursing homes. In part one of the study, a questionnaire about ethics meetings in nursing homes was used to collect data on the types of ethical challenges and ethics discussions. In part two, nursing home staff with experience in the implementation of systematic ethics work and members of nursing home ethics groups or ethics committees were interviewed in focus groups about the implementation and practice of systematic ethics work.

Part 1: Ethics discussions in nursing homes

As there is no existing gold standard for systematic ethics work in nursing homes, we chose to use purposeful sampling (28) and included centres that have introduced programmes to increase the staff's ethical competence as models of good practice.

Informants and recruitment. Five centres from three different countries (Austria, Germany and Norway) participated. Three models of good practice from different countries and two nursing homes were included in the study. These were as follows:

1. The CS Caritas Socialis GmbH (CS) in Vienna, Austria, runs three nursing homes and two special units for people with dementia in Vienna, altogether housing a total of 333 residents. Since 2007, the CS has used four different arenas for ethics discussions throughout the organisation (12, 17). The most frequently used arenas

are the resident ethics meeting (REM) and an institutional ethics committee.

2 The clinical ethics committee in primary care in Oslo, Norway (klinisk etikk-komité i kommunehelsetjenesten, KEKK), serves as a joint ethics committee for 25 nursing homes in Oslo with 2 350 care places (29, 30). It is organised by the administration of the Department of Nursing Home Care, City of Oslo. KEKK's aim is to focus on ethical dilemmas through ethics case discussions, education, counselling and establishing ethics guidelines (29, 30).

3 The network for ethics in elderly care 'Frankfurter Netzwerk Ethik in der Altenpflege' (31, 32) includes two joint ethics committees for nursing homes in Frankfurt and an open ethics discussion arena for staff from elderly care, the so-called Netzwerk NAEHE where ethical challenges can be discussed. In a 'NAEHE' meeting, usually 8–12 participants (mostly nursing home staff) discuss ethical challenges or cases aided by a moderator/ethicist (31, 32).

4 and 5. In addition to these three models, two nursing homes, one from Norway (with 100 long-term care places) and one from Germany (with 88 long-term care places) which were in the starting phase of establishing ethics discussions in their long-term care facilities, were included.

The management at all the facilities were asked to participate in the study by documenting ethics meetings from their ethics discussion arenas.

Data collection. A questionnaire was used to document all ethics discussions from the five participating centres (Table 1). The questionnaire had been used in a previous study from one centre in Austria (12). The moderators of the ethics discussions were asked to document each ethics meeting by filling out the questionnaire within a period of one year. The type of ethics meeting, the total number of cases, the ethical challenges and questions, the conclusions, and the consequences were documented.

Data analysis. For the analysis of the data obtained in the questionnaires, descriptive statistics were used. The results from the questionnaires were compared with data collected from a previous study using CS Vienna as the only location (12) and findings from the literature. Important outcome measures were as follows:

- Was a consensus reached?
- Did residents or relatives participate in ethics discussions?

Part 2: Focus group interviews of nursing home staff

Focus group interviews were used to investigate staff experience with systematic ethics work in nursing homes. Qualitative description was used in order to provide a straight description of the issue in everyday terms (33).

Table 1 Questionnaire about ethics consultation in nursing homes

1. Place and institution:
2. Date:
3. Number of participants:
4. Type of ethics consultation (tick off):
   ☐ Non-formal discussion between colleagues
   ☐ Ethics-reflection group
   ☐ Ethics committee
5. Participants profession (tick off):
   ☐ Nurse
   ☐ Auxiliary nurse
   ☐ Physician
   ☐ Physiotherapist
   ☐ Ergonomist
   ☐ Social worker
   ☐ Priest
   ☐ Others (describe here):___________________________
6. Has the patient attended the meeting himself? (tick off):
   ☐ The patient himself
   ☐ Next of kin, evtl. number
7. Has the patient written advance directives?
8. Was a patient case discussed? (tick off):
   ☐ Actual patient where a decision has to be made
   ☐ Retrospective; after a decision had been made and the patient is not in the nursing home anymore
   ☐ Discussion and general ethical challenges or problems, e.g. use of restraints, withdrawing of life-sustaining treatment, etc.
9. What was the reason for the meeting?
10. Who took the initiative to the meeting?
11. What was the ethical problem/were the ethical problems?
12. Was there consensus about one solution?
   • Has the suggestion been put into practice?

Informants and recruitment. Nursing home staff members or nursing home ethics committee members with experience in the implementation of systematic ethics work or ethics discussions were informed by their leaders at staff meetings about the study and were invited to participate. The five focus group interviews comprised of 43 participants from Austria, Germany and Norway. All participants were engaged in work with the implementation of systematic ethics work in nursing homes and 23 of them were members of nursing home ethics committees. Table 2 provides an overview of the focus group participants' characteristics. The informants received written information and had the opportunity to contact the researcher in order to ask questions about the study. They were able to participate within their usual working hours.

Data collection. The focus group discussions were led by the first author using opening questions (Table 3). An open-ended interview technique with follow-up

Table 2 Focus group participants (n=43)

Focus group nr.	*1*	*2*	*3*	*4*	*5*
Number of participants	11	9	10	4	9
Nursing staff	5		4	3	3
Spiritual care	2			1	2
Management (incl. nursing managers)	2	9	3		
Physician	2				1
Ethicist			3		1
Researcher					2
Ethics committee member	4		10		9

*Some of the participants had more than one profession/function.

Table 3 Opening questions for the focus group interviews

- What are your experiences with systematic ethics discussions in the nursing home?
- What are the advantages or disadvantages of the model of ethics discussion that is used in your institution?
- How do you assure that the residents will is taken into account?
- How can systematic ethics work be improved further within your organisation?
- What are signs of success of the implementation of systematic ethics work in your organisation?

Table 4 Description of the analysis process

1. GB and all co-authors read the transcripts and familiarised themselves with the data
2. GB and EG independently identified preliminary codes and themes
3. GB and all co-authors compared and discussed the preliminary codes and themes
4. GB and EG revised the preliminary codes and themes
5. GB and all co-authors discussed the revised codes and themes and agreed on the final codes and themes
6. GB and EG checked the transcripts in order to question the findings
7. GB and all co-authors discussed the findings and themes and agreed about the interpretation of the data

questions related to the participants' answers and responses was used. The interviews were recorded digitally.

Transcription and data analysis. The first author (GB) and three trained assistants performed a verbatim transcription of the digital interview recordings using the transcription software f4, from Audiotranskription (34). The software QSR NVIVO 9 (35) was used to aid the systematic coding and analysis of the interview transcripts. Data analysis was based on qualitative description and qualitative content analysis with data-derived themes (33, 36–38). During the analysis, the text was coded and similar codes were merged to themes. A description of the analysis process is provided in Table 4. Repeated reading of the interview transcripts and repeated discussions with the co-authors were used as a measure to validate the findings through the whole process of analysis. Repeated comparisons of the researchers' presuppositions with the results, using critical reflection and meta-positions (36) as well as repeated discussions with the co-authors about alternative interpretations of the results, were used to ensure reflexivity.

Results

Part 1: Ethics discussions in nursing homes

A total of 105 ethics meetings were documented. Table 5 provides an overview of all ethics meetings, including the meeting type, the participants and the ethical challenges discussed. Table 6 shows a summary of the most important results. The main topics were advance care planning (ACP), insertion of a percutaneous endoscopic gastrostomy tube (PEG) or ethical challenges associated with PEG use, hospitalisation and end-of-life decision-making. Many meetings focused on decision-making for residents with dementia (Table 5). Of the ethics meetings, 87 were prospective, where decisions for a resident had to be made. Agreement on a solution was reached in 76% of these cases. Relatives participated in most prospective ethics meetings, whereas residents did not participate in any of the meetings. In 29% of these meetings, neither residents nor relatives participated, even though prospective decisions for a resident were to be made. In 97 ethics meetings, the professions of the participants were documented. Nurses participated in 100% of these meetings, physicians in 76%. Meetings that focused mainly on everyday ethical challenges covered a third of all cases. Common ethical challenges presented were about residents' behaviour, coercion, autonomy, sexual abuse, refusal of care or treatment, level of care, the nurses' duty to care, etc. Only two of the documented ethics meetings consisted of informal discussions on ethical challenges.

Part 2: Focus group interviews of nursing home staff

The process of analysis of the interview data (Table 4) led to three main themes and eleven subthemes (Fig. 1), which are presented below.

1. *Ethical challenges – one should listen to the resident's wishes and needs*

This main theme was about ethical challenges with practical consequences for the residents living in the nursing home. These included issues about autonomy, conflicts between residents and relatives, lack of resources, and a change of focus from big end-of-life issues to everyday ethics.

Respecting the residents' dignity and autonomy. Many informants described the need to protect and maintain the

Table 5 Overview over 105 ethics meetings from 5 centres in 3 countries

Nr.	*Type of meeting*	*Profession of participants**	*Discussion type* *prospective = 1* *retrospective = 2* *common challenges = 3*	*Topic for the meeting*
1	EC	N, PC, P	3	Education planning, participation in research projects, palliative medicine and multiple sclerosis, end-of-life care in dementia
2	EC	N, PC, P	3	Guideline pain treatment, education planning, participation in research projects, end-of-life care in dementia
3	REM	N, PC	1	Artificial nutrition and PEG
4	REM	N, PC	1	Hospitalisation vs. palliative care in the nursing home
5	REM	N, PC	1	Artificial nutrition and PEG, Do not resuscitate (DNR)-order, hospitalisation and moving to another nursing home ward
6	REM	N, P, PC, AN	1	Death of the residents wife
7	REM	N, P, PC, AN	1	Resident refuses food, drink and medication
8	REM	N, P	1	ACP, DNR? No communication possible
9	REM	N, PC, P	1	Resident refuses nutrition, ACP
10	REM	N, PC, P	1	ACP, PEG use in the future
11	REM	N, PC, P, PSY	1	Refusal of food and drink
12	REM	N, P, PC, AN	1	Hospitalisation vs Palliative Care in the nursing home
13	REM	N, P	1	ACP, hospitalisation?, assumed will
14	REM	N, P, AN	1	Assumed will, ACP
15	REM	N, P	1	ACP, PEG?
16	REM	N, P, SW	1	Daily care adequate?
17	REM	N, AN, P	1	Resident with dementia, ACP?
18	REM	N, P	1	Artificial nutrition and PEG?
19	REM	N, P	2	Limitation of therapy as documented in another nursing home/residents condition improved
20	REM	N, P	1	ACP, hospitalisation?
21	REM	N, P	1	Overweight in a resident with dementia
22	REM	N, P	1	Nutrition, weight loss
23	REM	N, P	1	Coercion to enable pacemaker control in a patient with dementia?
24	REM	N	1	Place of care, ACP, life-prolonging treatment
25	REM	N, AN, P	1	Hospitalisation, PEG-insertion?
26	REM	N, P	1	PEG-insertion in the hospital against the residents written will. Afterwards removal of the PEG by the resident
27	REM	N, P	1	ACP, Palliative Care planning
2e	REM	N, P	1	Medical diagnostic or treatment
20	REM	N, P	1	Life-prolonging treatment, PEG
30	REM	N, P	1	ACP
31	REM	N, P, PC, AN	1	ACP, PEG, resuscitation
32	REM	N, P	1	Nutrition, weightloss, PEG-insertion?
33	REM	N, P	1	Wish to die, ACP, Palliative Care
34	REM	N, P	1	Resident with dementia and PEG-insertion after hospitalisation
35	REM	N, AN, P	1	Resident with dementia and partial refusion of nutrition, ACP
36	REM	N, P	1	Resident with dementia, ACP?
37	REM	N, P	1	Resident with dementia, ACP?
36	REM	N, AN, P	1	Resident with dementia, ACP?
39	REM	N, AN, P	1	Resident with dementia and refusing of nutrition, ACP
40	REM	N, P	1	Resident with dementia, ACP?
41	REM	N, P	1	Resident with dementia, ACP?
42	REM	N, P	1	Resident with cancer, hospitalisation. Palliative Care
43	REM	N, P	1	Resident with dementia, ACP?
44	REM	N, P	1	Resident with dementia, ACP, hospitalisation, PEG?
45	REM	N, P	1	ACP, PEG, Palliative Care planning

Table 5 (Continued)

Nr.	*Type of meeting*	*Profession of participants**	*Discussion type prospective = 1 retrospective = 2 common challenges = 3*	*Topic for the meeting*
46	REM	N, P	1	ACP, PEG, DNR, Palliative Care planning
47	REM	N, P	1	Resident with dementia, ACP?
48	REM	N, PC, P	1	Resident with dementia, ACP?
49	REM	N, P	1	Resident with dementia, ACP?
50	REM	N, AN, PC, P, PSY	1	Resident refuses food, weight loss
51	REM	N, P	1	Nutrition, depression
52	REM	N, AN, P	1	Nutrition, PEG, ACP
53	REM	N, P	1	ACP, PEG, Palliative Care planning
54	REM	N, P	1	PEG, life-prolonging treatment
55	REM	N, AN, PC, P	1	Resident with dementia, ACP?
56	REM	N, P	1	ACP, PEG, DNR, hospitalisation?
57	REM	N, P	1	ACP, PEG, DNR, Palliative Care planning
58	REM	N, P	1	Nutrition, weight loss, PEG-insertion?, ACP
59	REM	N, P	1	Resident with cancer, hospitalisation, PEG-insertion, Palliative Care
60	REM	N, AN, P	1	Resident with dementia, ACP?
61	REM	N, P	1	Resident with dementia, ACP?
62	REM	N, P	1	Nutrition, weight loss, PEG-insertion?, ACP
63	EC	N, AN, P, O, PC, ET	3	Economical challenges and risk for ethical dilemmas
64	EC	N, AN, P, O, PC, ET	3	Educational efforts, ethical challenges of political reforms
65	EC	N, AN, P, O, PC, ET	3	Alcohol in nursing homes, confidentiality
66	EC	N, AN. P, O, PC, ET	3	Documentation of cases discussed in the ethics committee, documentation of the residents will in the journal in the nursing home
67	EC	N, AN, P, O, PC, ET	3	Celebration of feasts in nursing homes in a multicultural society
68	EC	N, P, PC, ET	1	Future PEG use in a resident with multiple sclerosis
69	EC	N, AN, P, O, PC, ET	1	Resident bad removed a peg several times, PEG-insertion?
70	EC	N, AN, P, O, PC, ET	2	Coercion, withdrawal of life-prolonging therapy
71	EC	N, AN, P, O, PC, ET	2	Young resident with small children who needed a lot of resources for Palliative Care within the holiday period, extra personnel was hired, adequate use of resources?
72	ECS	N	1	Medical condition, lack of cooperation
73	ECS	N	1	Resident with dementia and fear, ACP
74	ECS	N	3	Relatives complain about insufficient care
75	ECS	N, SW	1	Resident with dementia and depression. How to improve quality of life"?
76	INF	N	1	Resident with diabetes mellitus and lack of compliance to medical treatment, autonomy
77	ECS	no info	2	Sexual abuse of a resident by a staff member
78	ECS	no info	1	resident with dementia who believes to be able to move home
79	ECS	no info	1	Resident suicidal?
80	ECS	no info	3	Autonomy, non-compliance of a resident
81	ECS	no info	1	Resident with PEG and written advance directive that states no life-prolonging treatment
82	ECS	no info	1	Resident in a vegetative state, parents and husband have different opinions about the residents will
83	ECS	no info	1	Relative with extreme high expectations of the care of the resident
84	ECS	no info	1	Optimal care for a chronic wound

Table 5 (Continued)

Nr.	*Type of meeting*	*Profession of participants**	*Discussion type prospective = 1 retrospective = 2 common challenges = 3*	*Topic for the meeting*
85	EC	N, P, SW, PC, ET	1	Resident refuses palliative care after being moved from the hospital
86	EC	N, P, SW, PC, ET	1	Aggressive behaviour of a resident
87	EC	N, P, SW, PC, ET	1	Residents will? Inadequate nutrition
88	EC	N, P, SW, PC, ET	1	Resident has financial problems and problems with his insurance company, oxygen equipment
89	EC	N, P, SW, PC, ET	1	Resident shall receive palliative care at the end-of-life, nutrition via PEG?
90	EC	N, P, SW, PC, ET	1	Resident refuses hospitalisation although urgent medical need (bowel obstruction)
91	EC	N, PC	2	Staff sees a decision made but the residents guardian as not appropriate
92	EC	N, PC	1	Residents guardian alcoholic? Residents autonomy and will?
93	EC	N, PC, SW	2	Resident with the need for amputation and shifting will
94	EC	N, PC	2	Death of a resident due to inadequate medical care
95	EC	N, PC	1	Sexual abuse of a resident by a staff member
96	EC	N, PC	1	Problems with advance care planning, recommendation from a judge to write a new ACP
97	EC	N, PC, SW	1	Decision to hospitalise a resident by the guardian
98	EC	N, PC, SW	1	Treatment withdrawal, conflict between physician and nurses
99	EC	N, PC	1	To withhold or withdraw artificial nutrition, resident was not asked about his opinion although he was able to communicate
100	INF	N	2	Placement of a young resident in a closed area
101	EC	N, PC, SW	1	Lacking information of the resident by a physician concerning palliative surgery, informed consent?
102	EC	N, PC, SW	1	Physicians behaviour: the resident was not included in a conversation about the treatment [although this might have been possible), hospitalisation?
103	EC	N, PC, SW, ET	2	Hospitalisation of a resident, the written living will was not send to the hospital with the patient, therefore he received maximal acute therapy in the hospital
104	EC	N, P, SW, PC, ET	1	Insufficient care of a resident by his wife
105	EC	N, PC	1	Residents consent to artificial nutrition?

*Profession of participants N, nurse; AN, assistant nurse; P, physician; PC, pastoral care; SW, social worker; O, occupational therapist; PSY, psychologist; ET, ethicist.

EC, ethics committee; REM, resident ethics meeting; ECD, ethics case discussion; INF, informal discussion.

residents' dignity and autonomy and stated that residents should be treated as autonomous individuals.

> The residents are dependent on our goodwill…to strive for a feeling of equal power so that it becomes almost a balance of powers…and respect for borders. (group 4/2)
>
> …you should not treat all persons the same, but you should treat them with the same (respect and) dignity. (group 4/3)

In order to respect the wishes of the residents, some nursing homes have already implemented regular conversations about the residents' preferences.

> And we do have regular conversations with the residents…About everything from how long they want their egg boiled and their living situation to the end of life…And of course there has to happen something with the demands they utter. (group 5/7)

To enable autonomy in end-of-life care, it is important to listen to the resident's wishes that often may not be stated directly but are embedded in stories that show their attitudes. There is a need to prepare for the end of life over time.

Table 6 Summary of the main results from 105 documented ethics discussions

	Nr. of cases	*Percentage of cases*
Of all ethics meetings	105	
Advance care planning (ACP)	48	46
PEG insertion or ethical challenges associated to PEG use	45	43
Hospitalisation	35	33
Everyday ethical challenges	35	33
End-of-life decision-making	27	26
Of all prospective case discussions	87	
No resident or relative present	25	29
Agreement about a solution reached	66	76

> I think it is important to have a dialogue with the patient and the relatives right from the first day…I think this can prevent many conflicts…if you dare to talk about it. (group 5/9)

The end of life has to be seen in connection with the resident's former life and his views and attitudes. Sometimes a conversation in everyday life can lead to an EOL conversation where the resident describes their wishes regarding care.

> …the theme opera ball has led to the theme dying. On the day of the opera ball a resident told a nurse: she had her dress that she once wore at the opera ball in her wardrobe…and then the resident told the nurse – I want to wear that dress when I am dead. That conversation lead to documentation of the residents wishes in the notes. (group 1/10)

Conflicts between the residents and relatives. There are differing views between residents, relatives and staff members about everyday matters and many ethical challenges are about decision-making in EOL care. Our informants frequently mentioned that the residents and relatives had different opinions.

> A resident says one thing and the relative another. This is often difficult for the staff. (group 5/3)

Often nobody seems to ask the residents or tries to include them in the discussion about what is best for them.

> I think this is the most difficult thing, how many relatives listen to the wishes of their parents, or who tries to…Everybody wants to do the best, but if that is the best, the really good for the resident, I sometimes really doubt it…because often 10 people talk, but nobody asks (the resident). (group 2/3)

Lack of resources. Several informants mentioned there being a lack of resources, which will reduce the amount

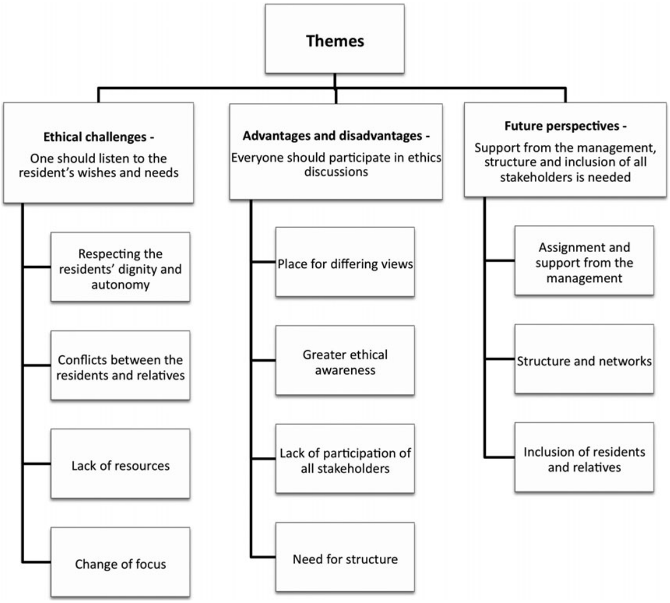

Figure 1 Themes from the focus group interviews of nursing home staff.

of help available to the residents and may thus endanger their feeling of dignity.

> It is also about financial means from the county administration. It is called to enhance effectiveness with nice words. But it is ethics, an ethical dilemma to reduce staff on the wards and to expect optimal care at the same time. (group 4/1)

More resources are needed for palliative care in nursing homes. One informant described the lack of resources for end-of-life care as ageism.

> And I have said: Only because the people in a hospice are younger they do have a total different claim. That topic concerns me very much, if you could balance it…or organise it in another way… (group 2/4)

Change of focus. Many informants perceived a change in the main focus of the discussions from end-of-life care issues to everyday ethical challenges over time. Everyday ethical challenges are frequent and of great importance for the residents, but seem to appear secondary after focussing on ethics in general and big ethical issues such as end-of-life decisions. This is illustrated with the tipping ethics iceberg (Fig. 2).

> …and there is a never ending story about nutrition at the end-of-life and all questions about withholding or withdrawing therapy…but questions about everyday life in the nursing home are increasing…Our ethics committee has discussed intense difficult behaviour….sexuality…privacy and intimacy in the nursing home…we just have begun to excavate the tip…and every day new topics arise. (group 3/2)

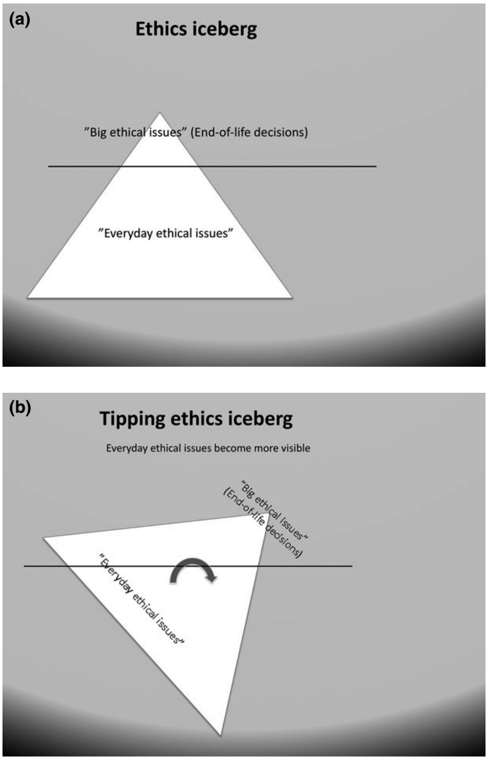

Figure 2 (a) The ethics iceberg. (b) The tipping ethics iceberg.

2. *Advantages and disadvantages – everyone should participate in ethics discussions*

The informants experienced many advantages with systematic ethics work. Different perspectives helped them to view dilemmas from different angles. Discussions became more open and people mentioned having a raised ethical awareness in general. A main disadvantage described was the general lack of participating residents.

Place for differing views. Many informants mentioned that there was respect for others' views.

> …it was a great relief both for the relatives and the staff…that the problem really could be looked at from different angles…and that we came to a conclusion that everyone could accept. (group 3/6)

The whole staff is allowed to participate, even non-medical personnel.

> And I think that it is an advantage that I have experienced that enormous important information came from the cleaning personnel…They know more about (the residents) life-story than others…and they have a different role. To view things from different role perspectives is very interesting. (group 5/3)

A basic precondition for ethics work is an organisational culture that permits questions to be asked.

> What I experience as very positive is that ethics is possible at every level…that asking questions is appreciated. (group 1/10)

More openness was also viewed as sign of the success of the implementation of ethics work.

> That you recognise (people) to be quite frank in the meetings. That they dare to say more… (group 4/2)

Nevertheless sometimes one has to face the fact that there is not always an answer and to share a sort of common uncertainty.

> And there is the conscience which is basic in ethics reflection that there is no answer…That is what we have learnt. (group 5/3)

Greater ethical awareness. Ethics became part of everyday work.

> I think this is a process, and now it (ethical reflection) is part of everyday work. (group 5/3)

Ethical awareness also includes the relatives.

> For me it was a milestone for creating a (ethics) culture in the institution when a relative demanded an ethics consultation for the first time. (group 3/3)

Lack of participation of all stakeholders. The participation of residents in ethics discussions is rare, although many residents are able to express their wishes.

> They (the residents) are pretty certain how they want it…at the end-of-life. But we as relatives and staff do not listen. (group 5/9)

While many informants are used to discussing ethical challenges with a physician, others miss the physician's participation.

> Probably one should pay the physician for attending ethics discussions…Then they would have an incentive to participate in our institution. (group 2/6)

Need for structure. There is a need for structured systematic ethics work.

> I think ethics work has two sides. One side is the ethics work we do everyday during our usual meetings…we do have discussions in everyday work about the difficult cases…But to be able to raise things in structured forms (for ethics consultation)…this is complicated…it is continued that we feel a bit uncomfortable to raise things…That we have an ethics committee where we can raise cases, I think that is a good option…I appreciate it. (group 5/8)

There are different types of arenas needed. In addition to time to reflect on ethics, some informants want an option to discuss ethics in a nursing home ethics committee.

> I think one advantage with our model is that (ethics) reflection is on-going everywhere. And if you raise (a case) it can provide a kind of meta-perspective. (group 5/1)

3. *Future perspectives – support from management, structure and inclusion of all stakeholders is needed*

Many participants have concrete wishes for the future. These included:

Assignment and support from management. Many informants wanted support from management.

> And we do need an assignment from the administration… (so far) we do not have an assignment or order… (group 4/3)

Time needed for ethical reflection should be seen as part of the usual working hours.

> Ethics consultation is work and should belong to the usual tasks of the staff. None of our staff would participate if it (the time for ethics consultation and the NAEHE-meetings) would not count as working time. (group 3/3)

Structure and networks. Many informants appreciated a structured approach to systematic ethics work, including time for reflection, the possibility to talk to an ethics contact person and an ethics committee.

> We need to structure ethics work, everybody is allowed to say something…it is important to be heard…(group 4/4)
>
> Some things can be solved on the wards and some in the institution…And some have to be raised further. (group 3/8)

Some wanted to form a network to discuss ethical challenges in elderly care with others, such as, for example, hospital staff.

> A network with the collaborating hospitals to discuss ethical questions. (group 2/3)

Inclusion of residents and relatives. The participants wanted relatives and residents to participate in ethics discussions and to have the possibility to ask for an ethics meeting.

> I think that cases from relatives should be raised into the ethics committee. (group 5/1)
>
> If the staff and the relative do not agree and stand against each other…probably one should hear what the patient himself wants. (group 4/1)

Discussion

The main findings of the study are as follows: ethics meetings were often about end-of-life care and life-sustaining measures, but a third of the cases dealt mainly with everyday ethical challenges. The advantages of systematic ethics work described by the participants were as follows: a place for differing views, more dialogue and a greater ethical awareness. Many stated that there was a need for structure and support from administration. The lack of participation of residents and too few participating relatives and physicians were mentioned as disadvantages. Suggestions for future ethics work were as follows: support from management, to establish ethics networks with hospitals, and more inclusion of residents, relatives and physicians in ethics discussions. The results and experiences from the three participating countries were similar.

In combination, the results from both parts of the study suggest that systematic ethics work in nursing homes in the beginning focuses mostly on big ethical issues like withholding or withdrawing life-prolonging treatment and end-of-life decision-making. Everyday ethics first arises as an issue when ethical discussions have become common. This change in the focus is illustrated in Fig. 2: the tipping ethics iceberg.

The results are discussed based on the theoretical background of our study consisting of the principle of autonomy and its importance in principlism and palliative care ethics.

Ethical challenges in nursing homes

Compared with other studies (3, 5, 9–12, 15), our results support previous findings that frequently the ethical challenges discussed in nursing homes are about end-of-life care and decision-making. As end-of-life issues are a major concern, the implementation of hospice and palliative care philosophy with patient-centred care models, including ethics discussions, might help people cope with these challenges. In Germany, a new law to enhance palliative care in nursing homes has passed the 'Bundestag' in 2015 (39).

Some of the participants from our study suggested that palliative care and end-of-life care have to be discussed earlier. ACP is paramount in nursing homes and may help to avoid ethical dilemmas in end-of-life care, leading to better quality of end-of-life care, and it may even save costs (40–43). Interestingly, our data indicate that information about wishes for end-of-life care can be drawn from everyday communication and the resident's attitude, in addition to written advance directives.

A change of focus in ethics discussions, from end-of-life themes to everyday ethical challenges, was observed. This is visualised with the tipping ethics iceberg (Fig. 2). The discussion of the more prominent ethical challenges with respect to end-of-life care probably raises awareness of everyday ethics in general. The increasing visibility of everyday ethics, in general, is reflected in an increased number of publications, often dealing with autonomy, dignity, residents behaviour, coercion, but also, for example, with gender and sexuality issues (2, 4–8, 19, 44–54). From the residents' viewpoint, everyday issues, including different 'small' things and, for example, sexuality, are of great importance (2, 55, 56).

Ethical challenges with respect to decision-making and the everyday life of residents with dementia were frequent topics in the documented ethics meetings (Table 5). The ethical challenges connected to dementia in nursing homes concern, for example, patient participation (57), sexual expression as aspect of well-being (51) and the flexible use of time in the care for these persons (58). Older patients who resist help may cause moral distress for healthcare personnel (59). This may be one explanation for the fact that many nursing home staff members perceive ethical challenges as a burden in their everyday work (12).

The principle of autonomy is paramount in medical bioethics and palliative care. Unfortunately, many nursing home residents do have dementia and cannot express their wishes verbally. In such cases, care ethics and relational ethics have to be taken into account. Care ethics as described, for example, by Conradi (60) and Gilligan (61) is based on relation and the reflection of nursing practice (62). The logic of care is quite different from the way of thinking in mainstream ethics. In contrast to prevailing modern ethical theory, care ethics (60–62) does not focus on autonomous rational individuals who subsequently cooperate in the form of contract relations. Care ethics (60–62) reminds us that through many phases of life we are anything but reasonable, autonomous or independent individuals: in childhood, old age, sickness and weakness. In the contrary, from a care ethics perspective, it is indispensable to understand ourselves as fundamentally connected beings.

In summary, the subjects of ethics discussions are not just dilemma situations but meaningful situations in general, which concern the fundamental questions of human life.

Experience with systematic ethics work

Our data show that experiences with ethics consultation were in general very positive, and several participants described developing a greater ethical awareness. Ethics reflection may improve practice (63). Key factors for the implementation of systematic ethics work are as follows: support from administration, ethics education and structures regarding places and times for ethical reflection. Our findings support similar findings from the literature (14, 63, 64). In contrast to previous studies (4, 5), a lack of resources was not as prominent in our data. A main concern described in our data was a lack of participation of residents and, partially, relatives and physicians. As resident wishes may be uncertain, this may hinder the residents from exercising their autonomy and may cause moral distress for the relatives (42).

Data from our study support the idea of using different approaches, such as, for example, ethical reflection and an ethics committee within the same institution. This suggestion is similar to the three-step approach with different levels for ethics consultation in nursing homes as, for example, ethics reflection groups and ethics committees (1, 20).

Systematic ethics work involves reflections around everyday issues on the basis of paradigmatic narratives and connecting with other people by making an effort to understand and to feel with others.

Inclusion of residents and relatives

It is remarkable that the participation of residents is totally absent in the present findings. This is in conflict with the importance of autonomy in principlism. Recent studies have shown that only a few nursing home residents had preparatory conversations about ACP and end-of-life care (42, 65). These findings are in stark contrast to the importance of autonomy in modern bioethics, palliative care and patient-centred care (21–25). Nursing home residents do care about 'small' things and everyday ethical challenges (2, 55) and want to be informed about their medical condition (55, 66). Unfortunately, many residents do not experience that they are autonomous or that their free will is respected (2, 63). Nursing home staff should engage in ACP and active planning for end-of-life care, and offer conversations with residents and relatives about their views and preferences regularly (42, 65, 67, 68). Assessing the residents' preferences leads to more appropriate decisions and may enhance the residents' feeling of dignity (57, 66). Preliminary results from on-going work indicate that resident participation in ethics discussions is feasible and that the staff in general might be too reluctant to encourage residents to participate (69).

Limitations and strengths of the study

One limitation of the study was that only two informal discussions were documented in our data. Therefore, the topics of the more informal discussions might be different from those found in our data. One might speculate that everyday ethical issues are more often discussed in informal meetings and that therefore the percentage with respect to these issues might be even higher than found in our data. Nevertheless, everyday ethical challenges are frequent in our data. As we have chosen to include models of good practice and nursing homes with an interest in systematic ethics work, one might speculate that the ethical awareness of the staff from these locations is higher than average and that the results therefore might not be representative for all nursing homes in the three countries. On the contrary, the ethical challenges might be the same, but they are not observed without an ethical awareness.

Conclusions and implications

Ethical reflection is greatly appreciated by the staff and can help in reaching a consensus in most prospective case discussions. Systematic ethics meetings that include the relatives and residents should be implemented in all nursing homes. Everyday ethical issues should be addressed in addition to end-of-life ethical issues. The regular participation of physicians and relatives could be improved further. The participation of residents in ethics meetings should be strongly encouraged.

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Author contributions

Georg Bollig worked out the study design and the questionnaires used in the study. Gerda Schmidt, Jan Henrik Rosland, Arnd T. May, Eva Gjengedal and Andreas Heller reviewed the study design, commented on it and suggested modifications. All authors agreed on the selection of the participating ethics committees and nursing homes. Georg Bollig organised the data collection, the data analysis and the draft process of the first version of the manuscript. Georg Bollig and Gerda Schmidt collected the data. All authors participated in data analysis and reviewed and revised the manuscript critically and participated in the discussion of the results. All authors read and approved the final version of the manuscript.

Ethical approval

The Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, approved the study protocol (reference 2009/1339a). The documentation of the resident cases from the ethics meetings was confidential. The cases were documented using a questionnaire with a description of the case discussed, but without personal data concerning the resident, relatives or other participants. No resident data other than gender and age were documented. The participants of the focus group interviews were informed about the study and invited to participate by the nursing home management. All participants had the opportunity to ask clarifying questions prior to their participation in the interview and gave informed consent.

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