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

Name of the PhD-candidate: Georg Bollig

Department: Department of Clinical Medicine, University of Bergen, Norway
Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital, Bergen, Norway
Department of Anaesthesiology, Intensive Care, Palliative Medicine and Pain Therapy, HELIOS Klinikum Schleswig, Germany

Main supervisor: Jan Henrik Rosland
Co-supervisors: Eva Gjengedal and Andreas Heller
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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<td>ACP</td>
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<td>ADLs</td>
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<td>EOL</td>
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<td>KS</td>
<td>Kommunesektorens organisasjon (The Norwegian Association of Local and Regional Authorities)</td>
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<td>NHS</td>
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<td>PEG</td>
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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.

The Norwegian Extra Foundation for Health and Rehabilitation was the main funding source for the research project through EXTRA funds (grant nr. 2008/2/0208). The Norwegian Red Cross supported the project.
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).

Many thanks as well to the Norwegian Committee on Research in General Practice, the Norwegian Medical Association and Olaf og Gullborg Johannessens legat for financial support of the project and the grants that helped to start and run the PhD project.

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

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

Paper III

Paper IV
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 an 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; Dùwell 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 for 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:

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.
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](image)

*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, 2010b). 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)
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 (Kommunesektores 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 (Kommunesektores

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 (Kommunesektores 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 combine 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).

![Ethics iceberg](image)

**Figure 6: Ethics iceberg**

![Tipping ethics iceberg](image)

**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](image)

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 resident 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 $\frac{3}{4}$ 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 focusing 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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