A good death from the perspective of patients with severe illness and advance care planning (ACP) in patients near **end-of-life**

Lisa Kastbom

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Lisa Kastbom

Department of Health, Medicine and Caring Sciences

Linköping University, Sweden

Linköping 2021

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This too shall pass

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BLACK POSTCARDS

*The calendar is full but the future is blank.
The wires hum the folk-tune of some forgotten land.
Snow-fall on the lead-still sea. Shadows
scrabble on the pier.*

*In the middle of life, death comes
to take your measurements. The visit
is forgotten and life goes on. But the suit
is being sewn on the sly.*
Black Postcards, Tomas Tranströmer
(From "The Deleted World", 1983)

*Almanackan fullskriven, framtid okänd.
Kabeln nynnär folkvisan utan hemland.
Snöfall i det blystillå havet. Skuggor
brottas på kajen.*

*Mitt i livet händer att döden kommer
och tar mått på människan. Det besöket
glöms och livet fortsätter. Men kostymen
sys i det tysta.*
Svarta Vykort, Tomas Tranströmer
(Ur Det vilda torget, 1983)

ABSTRACT

Previous research has indicated that what constitutes a good death is heterogeneous and complex although there are some recurrent themes and similarities regardless individual background factors. Studies on advance care planning (ACP), i.e. making proactive plans regarding content of care and treatment limitations, on nursing home (NH) patients are rare. Positive effects on ACPs are shown, but also that these often are lacking. The overall aim with this thesis was to explore the perceptions of a good death from the perspective of patients with severe illness and to investigate, from different perspectives, experiences of ACP in a NH context.

In **paper I**, patients with cancer in a palliative phase were interviewed on their perceptions of a good death. Death was viewed as a process and previous experiences on the death of others influenced their own perceptions. A good death was associated with living with the prospect of imminent death, preparing oneself and others for one's death and dying comfortably, e.g. without suffering, with independence and with social relations intact. Some were comforted by their belief that death is predetermined, and that after death, there is something else. Others felt uncomfortable when they viewed death as the end of the existence.

In **paper II**, nurses and physicians were interviewed on their experiences of the factors that shape the ACP process in NHs. Exploration of the patient's preferences regarding content of care and treatment limitations was important, as well as integration of the patient's preferences and the views of the family members and staff concerning these questions. ACP documentation had to be clear, updated and available for staff and the implementation and re-evaluation of ACP were also considered important, according to the participants. Significance of clinicians' perceiving beneficence as well as fear of accusations of maleficence were shown to be essential factors to contemplate.

In a retrospective chart review (**paper III**), medical records of 367 deceased NH patients were analysed. A high prevalence of ACP was seen, using two different definitions of ACP (ACP I and ACP II). Moreover, adherence to the ACP content was strong and positive associations were seen between ACP and variables of the three research aims, such as: diagnosis (dementia), physician attendance at NH and end-of-life (EOL) care.

In **paper IV**, family members of deceased NH patients were interviewed on their experiences of ACP in NHs. EOL issues were challenging to talk

about, although the family members appreciated staff raising these questions. The patient's preferences were sometimes explicitly or implicitly communicated. However, in some cases, family members had a feeling of the patient's preferences, although they had not been clearly communicated. Everyday details symbolised staff commitment. The family members viewed the nurse as central. The physician was described as absent and ACP meetings often went unnoticed. Both involvement and lack of involvement could cause the family members feelings of guilt.

In conclusion, we found that what constitutes a good death is highly individual, although recurrent themes are seen. EOL conversations are important and challenging and need staff training and experience. It seems important to support healthcare staff not only to initiate ACP in NH patients, but also to involve the patient and family members in the ACP and planning EOL care. Making proactive plans regarding content of care including treatment limitations could enable patient autonomy, optimise the chances for the patient to experience a good death and enhance for the family members during the dying trajectory and after the patient's death.

SVENSK SAMMANFATTNING

Vad är egentligen viktigt när livet närmar sig sitt slut? Tidigare forskning har visat att vad som karaktäriserar en god död är individuellt även om det finns vissa återkommande teman och likheter oavsett patientens bakgrund. Studier om vårdplaner, dvs. proaktiva planer om vårdinnehåll och eventuella vårbegränsningar (t.ex. att avstå från hjärt-lungräddning eller avstå från sjukhusvård), på patienter på särskilt boende (SÄBO), är sällsynta. Forskning har visat positiva effekter av vårdplaner, men även att dessa sällan upprättas och ofta i ett sent skede. Det övergripande syftet med min avhandling var att utforska vad som karaktäriserar en god död för allvarligt sjuka patienter och att undersöka erfarenheter av vårdplaner på särskilt boende (SÄBO), från flera perspektiv.

I delarbete 1 intervjuades patienter med cancer i livets slutskede kring deras uppfattning om en god död. Patienterna såg döden som en process och tidigare erfarenheter av andras död påverkade deras uppfattning. En god död förknippades med att leva med vetskapen om att döden närmar sig, att förbereda sig själv/andra för döden och att dö en efter omständigheterna behaglig död (t.ex. utan smärta eller annat lidande, med bibehållna sociala relationer). Några kände förtröstan i att döden är förutbestämd, medan andra menade att döden innebär slutet på existensen, vilket skapade obehag.

I det andra delarbetet intervjuades läkare och sjuksköterskor om deras erfarenheter av vårdplansprocessen på SÄBO. Utforskning av patientens egen önskan om vårdens innehåll och eventuella vårbegränsningar, helst i ett tidigt skede, ansågs viktigt, liksom integration av patientens önskan med närståendes och vårdpersonals uppfattning. Man ansåg att dokumentationen behöver vara tydlig, tillgänglig och uppdaterad. Implementering och utvärdering av vårdplansinnehållet var också betydelsefull. Man betonade ambitionen att göra vad man ansåg var det bästa för patienten. Samtidigt uttrycktes oro för att bli anklagad för att i stället göra skada, genom att t.ex. orsaka lidande då man initierar samtal med patient och närstående om frågor som rör livets slut, eller rädsla för att göra medicinska felbedömningar.

I en journalgranskningsstudie (delarbete 3), granskades patientjournaler på avlidna personer som den sista tiden i livet bott på SÄBO. Det visade sig att förekomsten av dokumenterade vårdplaner var hög. Man efterföljde också vårdplansinnehållet i stor utsträckning. Det fanns ett positivt samband mellan dokumenterad vårdplan och förekomst av demensdiagnos,

läkarnärvaro på SÄBO och vård i livets slutskede (förskrivning av vidbehovsinjektioner mot smärta och andra symptom som är vanligt förekommande i slutskedet samt informerande samtal till närstående om patientens försämring och förestående död).

Närstående till patienter som tiden före döden bott på SÄBO intervjuades i delarbete 4 med avseende på deras erfarenheter av vårdplaner på SÄBO. Frågor som rör livets slut uppfattades svåra att tala om. Patienten kunde explicit, eller implicit, ha uttryckt sina preferenser när det gäller livets slut. Närstående menade att ibland kunde man ha en känsla för hur patienten ville ha det, även om det inte var tydligt kommunicerat. De små detaljernas betydelse betonades och kunde, enligt de närstående som intervjuades, utgöra symboler för personalens engagemang och kompetens. Läkaren uppfattades som frånvarande och sjuksköterskans betydelse var central. Närstående ville ofta delta i vårdplansprocessen. Både att delta och att avstå från deltagande kunde orsaka känsla av skuld hos de närstående.

Sammantaget fann vi att hur man uppfattar en god död är högst individuellt, även om det finns vissa återkommande teman. Samtal som rör livets slut och död är viktiga och kräver träning och erfarenhet. Mycket talar för att det är viktigt att inte bara upprätta vårdplaner, utan att också tillse att såväl patient som närstående involveras i processen. Genom att proaktivt planera vårdens innehåll och ta ställning till både vad som ska göras och även vad som bör avstås från i olika situationer, ökas förutsättningarna för att patienten ska få gå en god död tillmötes.

LIST OF PAPERS

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

- I. **Kastbom L**, Milberg A, Karlsson M. A good death from the perspective of palliative cancer patients. *Support Care Cancer* 2017;25(3):933-939.
- II. **Kastbom L**, Milberg A, Karlsson M. 'We have no crystal ball' - advance care planning at nursing homes from the perspective of nurses and physicians. *Scand J Prim Health Care* 2019;37(2):191-199.
- III. **Kastbom L**, Falk M, Karlsson M, Tengblad A, Milberg A. Advance care planning in nursing homes: Does it matter? Submitted manuscript.
- IV. **Kastbom L**, Karlsson M, Falk M, Milberg A. Elephant in the room – Family members' perspectives on advance care planning. *Scand J Prim Health Care* 2020;38(4):421-429.

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PROLOGUE

*Let me not pray to be sheltered from dangers
but to be fearless in facing them.
Let me not beg for the stilling of my pain
but for the heart to conquer it.
Let me not look for allies in life's battlefield
but my own strength.
Let me not crave in anxious fear to be saved
but hope for the patience to win my freedom.
Grant me that I may not be a coward, feeling your mercy in my
success alone; but let me find the grasp
of your hand in my failure.
Rabindranath Tagore*

During my specialist training, I practised at an emergency department (ED) for a few months. I realised that when elderly patients arrived at the ED, frequently alone, not capable of expressing their own preferences and values, they received maximum care. I kept thinking: “Is maximum care always optimal care?” and “What did the individual patient actually want?” This experience started a process in me of thinking about the importance of asking these patients, while they are still capable of expressing their own preferences, what they would prefer in specific situations and if their health deteriorated. I saw the value of thinking proactively and the importance of documenting ACPs in the medical records.

While practising at the department of advanced home care, I was organising my mandatory written scientific work in the specialist medical training programme. I wished to do the scientific work within the field of palliative care. I asked **Marit Karlsson**, MD, PhD and senior consultant in palliative medicine, who suggested that I could conduct a secondary qualitative analysis of interviews with patients in terminal-stage cancer about their perspectives on a good death. This scientific work developed into the first paper of this thesis and caught my interest for further research. Marit was my supervisor and guided me through this work with great enthusiasm together with **Anna Milberg**, MD, PhD, associate professor and consultant in palliative care, who became my main supervisor when I enrolled as a PhD student at Linköping University in June 2017. **Magnus Falk**, MD, PhD, associate professor and general practitioner (GP), also became my supervisor, representing primary healthcare.

A general practitioner (GP) sees patients of all ages, with all sorts of medical dilemmas. I find the encounter with another person who wants to share his or her inner thoughts truly fascinating. For me, it is a privilege to meet an elderly patient, rich with experiences and life events. Such an encounter encourages me to reflect personally on the important aspects of life. Clinical work and research make a satisfying combination, since I believe that research is good for clinical practice and clinical practice enriches research.

ABBREVIATIONS

ACP	Advance care planning
CPR	Cardiopulmonary resuscitation
DNR	Do not resuscitate
EAPC	European Association of Palliative Care
ED	Emergency Department
EOL	End of life
GP	General Practitioner
GP-ST	General Practitioner Specialist Trainee
IAHPC	International Association for Hospice & Palliative Care
MD	Medical Doctor
NH	Nursing home
PhD	Doctor of Philosophy
RCR	Retrospective Chart Review
SRPC	The Swedish Register of Palliative Care
WHO	World Health Organisation

OVERVIEW OF THE THESIS

Table 1.

	Paper I	Paper II	Paper III	Paper IV
Aim	To explore the perception of a good death in dying cancer patients in Sweden.	To investigate clinicians' perspectives on the factors that shape the process of ACP in a nursing home context.	In a Swedish NH setting to explore: <i>i)</i> the prevalence of ACPs (two different ACP definitions), <i>ii)</i> the content of ACPs, <i>iii)</i> adherence to the content of ACPs and <i>iv)</i> possible associations between the presence of ACP and background characteristics (e.g. demographic and diagnosis), physician attendance and EOL care.	To explore family members' experiences of ACP in NHs in Sweden.
Methods	Individual interviews with 66 patients with terminal-stage cancer. Analysis using qualitative content analysis.	Individual interviews with 14 physicians and 11 nurses working at nine selected NHs. Analysis using latent content analysis.	Retrospective chart review (RCR) of 367 deceased patients from 22 NHs in two counties over two years.	18 family members of deceased NH patients were individually interviewed. Analysis using thematic analysis.
Results	Participants viewed death as a process. A good death was associated with <i>living with the prospect of imminent death, preparing for death and dying comfortably</i> . Some were comforted by their belief that <i>death is predetermined</i> . Others felt uneasy because they considered <i>death as the end of existence</i> . Past experiences of the death of others influenced the participants' views of a good death.	<i>Exploring patient wishes</i> regarding EOL issues <i>at an early stage</i> and <i>integration of the patient's wishes and views of family members and staff</i> were considered important. <i>Documentation</i> should be clear and available. The latent theme <i>Establishing beneficence – defending oneself against tacit accusations of maleficence</i> emerged as a deeper meaning of the manifest parts of the ACP process.	<i>High prevalence of ACP</i> was seen (ACP I: 97%, ACP II: 77%). <i>Positive associations</i> were seen between ACP and variables of the three research aims, such as <i>diagnosis (dementia)</i> , <i>physician attendance</i> and <i>EOL care</i> . Analysis indicated <i>adherence to the ACP content</i> .	Five themes were shaped: <i>Elephant in the room</i> , e.g. EOL issues were difficult to talk about; <i>Also silent understanding</i> , e.g. the patient's preferences explicitly communicated or implicitly conveyed. Sometimes, although the patient's wishes were not communicated clearly, the family thought that they knew what they were; <i>Significance of small details</i> , e.g. everyday details symbolised staff commitment; <i>Invisible physician – supporting nurse</i> ; <i>Feeling of guilt</i> , e.g. both involvement and lack of involvement could cause the family feeling of guilt.
Conclusion	Staff caring for palliative patients should consider asking them to describe what they consider to be a good death in order to identify goals for EOL care. Exploring patients' personal experiences of death can help address their fears as death approaches.	Involving patients, family members and staff in the work with ACP in NHs is important. Clear documentation and proficiency in EOL communication related to ACP may be factors that significantly shape ACP in a NH context.	It seems important to support healthcare staff, not only to initiate ACP in NH patients, but also to involve the patient and the family members in the ACP and planning EOL care.	It seems to be important to involve the patient and family members in the ACP process in NHs, thereby adapting the care in line with the patient's wishes, and for the patient to share these preferences with family members. Education in communication seems important to shape ACP.

INTRODUCTION

The focus of this thesis is the concept of a good death from the perspective of patients with severe illness, and advance care planning (ACP) among nursing home (NH) patients who are approaching the end of life. In the introduction, some central terms and aspects of these matters will be briefly explained and discussed, in order to simplify reading. These matters are as follows: ageing in Sweden, death, a good death, palliative care, nursing homes and advance care planning.

Ageing in Sweden

Demography in Sweden

Over time, the structure of the Swedish population has changed. Average life expectancy in Sweden is currently 84.7 years for women and 81.3 years for men, and the trend is towards a decrease in the gender difference (1). Approximately 20% of the population is elderly (>65 years) (2). The number of people in the age group 65–79 years increased by about 40% between 2002 and 2018 (2). The number of people aged >80 years is expected to increase from the current 534 000 to approximately 806 000 by 2030 (1) and by 2050, the number of people aged >85 years is expected to have doubled compared to the number today (2).

Figure 1. The Swedish population pyramid in 2019.
Source: Statistics Sweden, Population statistics. <http://www.scb.se>

Emergency healthcare and hospital admissions among the elderly

Due to developments in medicine and improved living conditions during the 20th century, health status is generally good among the Swedish population. However, with increased longevity, we observe more dementia, cancer and other diseases related to great age. This means that a large number of the population will need healthcare (2). Of all the patients attending emergency departments (EDs), 36% are >70 years (2). According to national registries, heart disease, pneumonia, stroke, chronic obstructive pulmonary disease (COPD) and hip fractures are common diagnoses for people aged 65–79 when admitted to hospital. For people >80 years, urinary-tract infections are added to the common diagnoses among patients attending EDs (2).

Although the proportion of the population >65 years is approximately 20%, this group accounts for half of all hospital admissions and an even greater proportion of the total duration of inpatient care (2). When looking at the causes for people aged >80 being admitted to Swedish hospitals in 2002 and 2018 respectively, there have been some distinct changes. Inpatient care in this age group due to ischemic heart disease had halved by 2018, while inpatient care related to pneumonia or influenza had doubled (2). This shift could indicate that improvements in healthcare have led to a reduced need for inpatient care, and an increased need for primary healthcare efforts, home care and social assistance (2). Although the number of individuals aged 65–79 increased by about 40% between 2002 and 2018, episodes of inpatient care only increased by approximately 20% during the same period, while the total number of inpatient days for this age group decreased, indicating shorter admissions (2). The reasons for this decrease could be a combination of improved health status among this age group, progress in healthcare with better treatment options and a shift towards primary healthcare and home care between 2002 and 2018 (2).

Continuity in primary healthcare is associated with reduced ED attendance and hospital admissions (3). Furthermore, a Swedish study showed that active listing is associated with more consultations in primary healthcare and a reduced mean number of days hospitalised (4).

Death

Figure 2. The Dying Dandy (Swedish: Den döende dandyn).

Nils Dardel, 1918. Source: Moderna Museet. <http://www.modernamuseet.se/stockholm/sv/>

Views on death

When discussing the term “death”, it is important to consider whether we are referring to the view that death is the single moment when life ends; or that death is an event, or rather a period of time during which a person gradually approaches end-of-life (EOL); or death as a transitional process (5). In this thesis, death is seen as a transitional process (6-10) in **papers I, II and IV**, and as an event (11) in **paper III**. Kellehear refers to the *awareness that death is impending*: “*Dying as a self-conscious anticipation of impending death and the social alterations in one’s lifestyle prompted by ourselves and others that are based upon that awareness*” (12).

Death in Sweden

During the 21st century, approximately 90 000 people have died each year in Sweden (1). The number of deaths each year depends largely on the number of individuals in the oldest age groups. Few children were born from the middle of the 1920s until the end of the 1930s. This fact affects the number of deaths today, since these individuals are now among the oldest. Also, the average life expectancy has increased. During the 1940s, the birth-rate

was high. Therefore, the number of deaths each year is expected to increase for the next 20 years (1).

Causes of death

The most common cause of death in Sweden is cardiovascular disease, which caused 32% of all deaths in 2019. The second most common cause of death was tumour diseases, which caused 27% of deaths in Sweden in 2019 (13). Other causes of death were mental illnesses and behavioural disorders (e.g. dementia), diseases of the respiratory tract and neurological diseases (13). During the first six months of 2020, Covid-19 was the third most common cause of death, and in April 2020, Covid-19 was the most common cause of death in Sweden (14).

Where do people die?

Place of death is often used as an indicator of quality of EOL care (15). In 1992, a parliamentary bill was introduced to reform the Swedish healthcare system (Swedish: *Ädelreformen*) (16). As a result of this, there was a shift in responsibility for providing care to the frail and elderly from the previous situation of the regions only to regions and municipalities. The main aim was to provide social and long-term care for frail and elderly people, regardless of whether they lived in ordinary homes or in NHs (16). In a register study between 1987 and 2005 of people aged >64 years, the number of deaths outside hospital increased from 29% to 60%. The greatest change was seen among the oldest (17). This was likely to have been partly an effect of the parliamentary bill. An increase in discharges shortly before death (≤ 2 weeks prior to death) was also observed (17).

The majority of deaths in Sweden in 2012 occurred in institutions (42% in hospitals, 38% in NHs). Among people aged >90, 62% died in NHs (18). Håkanson et al. concluded that the proportion of deaths in NHs was greater than in many other European countries (18). In 2015, approximately one fifth of deaths in the United States and the United Kingdom (UK) occurred in NHs (19). Broad et al. showed in an international comparison of place of death that in people aged >65 years representing 21 populations, 54% of deaths occurred in hospital and 18% died in residential aged care (ranging from 3% in Korea to 38% in New Zealand and Iceland), with percentages doubling with each 10-year increase in age (20). In a systematic review (21), Billingham et al. showed that the presence of a non-malignant diagnosis significantly increased the incongruence between a patient's preferred and actual place of death. Factors associated with increased congruence between preferred and actual place of death include physician- and family support and hospice enrolment, while lack of family caregiver support,

inadequate symptom control and rehospitalisation are associated with less congruence (22).

During the first half of 2020, 46% of the deaths among women and 31% among men in Sweden occurred in a NH (14). Deaths among women with Covid-19 occurred to a greater extent in NHs (55%), than deaths among men, who were more likely to die in hospital (56%). A similar pattern is seen for other causes of death, and this reflects the fact that women in general live longer than men, and that women are more likely to live in NHs (14).

A good death

Historical perspective on the concept of “a good death”

Views of death and the concept of “a good death” have changed over time. Tony Walter and Allan Kellehear, two British sociologists, have studied views on a good death in Western society. Walter describes three cultural and historical responses to death: *traditional death*, *modern death* and *neo-modern death* (23). In what Walter refers to as traditional death, Kellehear separates the *stone age* from the *pastoral age* (12), as described below.

Traditional death – stone age and pastoral death

Before the development of medicine and science, death was present in life for most people. Death occurred within the community, in people’s homes. The church, or religion, was the authority on death during this time. During the *stone age*, the anticipation of death and dying as a human experience emerged. Through this anticipation, people became aware of danger and started to think about what would come after death (12). Death occurred suddenly, giving no time for preparation or contemplation. The experience of dying was seen as an activity that occurred after death, where a good passing was defined by the nature of the journey the deceased would have into the next life, based on the beliefs of the survivors (12).

Unlike dying during the stone age, the dying experience of the *pastoral age* was more predictable, most often caused by infectious diseases (12). These diseases frequently implied a gradual experience of dying, giving people the ability to participate in their own dying. A good death was a death that was prepared for with the cooperation of family and community. Also, life itself was considered a preparation for death (12).

Modern death

During the 19th century, modern medicine developed. Previously, physicians had seen their role as predicting the timing of death. From now on, the physician could help the dying person by relieving pain and suffering, for example by administering opium (12). During this time, the secularisation of society began, and the church was no longer necessarily the authority on death.

At the beginning of the 20th century, deaths that in the pastoral age had occurred in people's homes were transferred to take place in medical institutions. Death in hospital could be viewed as an event that was technical and controlled by healthcare staff (24). Kellehear uses the term "well-managed death" which, according to the author, includes the awareness of dying as well as the participation of healthcare staff in the event of dying (12). The institutionalisation of death was seen by some as a "depersonalization and marginalization of patient and family" (24).

Neo-modern death (1950–present)

In the middle of the 20th century, the sociologists Glaser and Strauss conducted large observational studies in several San Francisco hospitals (23). The investigators examined interactions between patients near EOL and healthcare staff, and variations in the "degree of awareness" concerning the patient's dying were found. There was *open awareness* when there was open communication between the patient, family members and healthcare staff (23). Since this "awareness of the dying theory", there has been a major shift in attitudes towards death and dying, from the belief that hope can be maintained in dying patients if they are kept uninformed of their condition, to the perception that instead patients need to know their situation in order to be able to make decisions concerning the time remaining to them (23). According to Walter (23), postmodern society has adopted ideals of individualisation, independence and autonomy, and Walter further defines a neo-modern death as one in which individualisation and control of the dying is in accordance with the dying individual's own preferences (23).

Parallel to Glaser's and Strauss's studies, the hospice and palliative care movement developed. In 1967, St Christopher's Hospice was opened in London by Cicely Saunders (23). This first hospice opening, which marked the beginning of the hospice movement worldwide, aimed to let the patient define his or her own dying and to let the patient "live fully until he dies as himself" (23). Saunders established the concept of *total pain*, which included not only physical distress, but also the mental, spiritual and social/family dimensions and needs of the dying (25). Furthermore,

Saunders underlined the importance of symptom control and a team approach to EOL care (25).

Kübler-Ross, working with terminally ill patients in America, famously shaped the theory of the five stages of dying, which patients suffering from serious illness commonly experience as they aim to achieve peace. According to Kübler-Ross, these stages are: *denial and isolation, anger, bargaining, depression and acceptance* (26). These five stages have also been used to describe the experience of losing someone else (23).

Colin Murray Parkes and William Worden are two of the most respected authors on bereavement (23). Parkes describes three stages of grief, namely: *numbness, pining and disorganisation & despair*. According to Parkes, these emotions are not constant during any stage, and there are differences from one individual to another both regarding duration and form of each stage (23). Moreover, Parkes means that grief should proceed through pain to resolution. When pain is not shown at early stages, or when resolution is not achieved even after years, grief is considered abnormal, according to Parkes (23).

Worden describes four psychological stages that must be accomplished by the bereaved. These are: accepting the reality of the loss, experiencing the pain of grief, adjusting to an environment without the deceased and emotionally relegating the deceased and moving on with life (23). In contrast to the view of Parkes and Kübler-Ross, Worden describes the bereaved individual as being active, with tasks to complete, rather than a “passive experiencer of emotions” (23).

Today's perspectives on a good death

The American philosopher Daniel Callahan (27) described a *peaceful death* as a process of personal, medical and social factors, such as finding meaning in one's own death; being treated with respect, sympathy and dignity; having the wish that one's own death matters to others; hoping not to be abandoned; not being a burden on others; being conscious and emotional and mentally intact until the very end; and hoping for a quick death without pain or other suffering. According to Callahan, a peaceful death can be understood negatively when *dying is deformed* by deforming the process of dying, such as aggressive medical interventions resulting in prolonged suffering and dying; by deforming the dying self, i.e. fear and anxiety takes control over one's self-worth, resulting in destructive thoughts such as dwelling on losses and failures; and by deforming the community of living, i.e. when fear of death leads to social and political changes created to relieve suffering, such as assisted suicide (27).

When comparing the attributes of a good death in different societies, we can see many similarities between cultures that seem very far apart. For example, people in a rural town in Ghana refer to a *peaceful death*, categorised into the following aspects: a *social* aspect, i.e. being at peace with others; a *psychological/spiritual* aspect, i.e. being at peace with one's own life and soul; a *time* aspect, i.e. "dying in the fulness of time" and a *spatial* aspect, i.e. dying surrounded by relatives, at home (28).

To the best knowledge of this author, the first definition of "a good death" from the discipline of medicine came in 1972, concluded by Dr Weisman (psychiatrist and psychoanalyst) as: "*A form of passage in which everyone involved is aware of and accepts the imminence of death and in which the dying person has resolved socio-emotional and material concerns*" (29).

In a review of a good death in long-term residents (30), Krishnan concluded that the concept of a good death is highly individual and dynamic and what is known about the concept is mainly based on studies conducted from the perspectives of healthcare staff and family members, rather than those of patients. In the review, it was further concluded that the main elements of a good death were: symptom control, making appropriate preparations, the presence of social support and being spiritually at peace, from the perspectives of theology, sociology, care and medicine (30).

Although the concept of a good death is complex and cannot easily be defined in general terms because it could be related to individual preferences and is influenced by cultural, social, religious and historical factors, there are some recurring aspects of what is perceived as a good death from the perspective of severely ill patients, healthcare staff and family members. These aspects will be presented below.

In one review of the literature on a good death from the perspective of patients, family members and healthcare staff, Mak and Clinton listed seven attributes constituting the concept: Comfort or relief from pain and suffering; Openness or being aware of dying; Completion or accepting the timing of one's death; Control or acceptance and autonomy; Optimism or keeping hope alive; Readiness or preparing for departure; and Location or living with one's choice about where to die (7).

According to Emanuel and Emanuel (9), a good death is constituted of seven dimensions, namely: physical symptoms, psychological and cognitive symptoms, economic demands, caregiving needs, social relationships and support, spiritual and existential beliefs and finally hopes and expectations.

The term "quality at EOL" has similarities to "a good death" and the aspects of this term have been studied. Steinhauser et al. identified 26 items that

are rated as important for quality at EOL across all four participating groups (patients, family members, physicians and other care providers). Pain and symptom management, communication with one's physician, preparation for death and the opportunity to achieve a sense of completion were important to most, whereas other factors differed both by individual and by role (31).

In a review of definitions of a good death, Meier et al. (32) found that, among the 11 core themes of a good death, the three most frequent across groups (patients, family members and healthcare staff) were preferences for the dying process, freedom from pain and emotional wellbeing. The authors also observed some differences between groups: family members viewed life completion, quality of life, dignity and the presence of family more frequently (70–80% each) than did the patients regarding these themes (35–55% each) (32).

Although there are recurring themes on the attributes of a good death, as previously described, and these might differ depending on cultural, social, religious and historical context, several studies stress the importance of healthcare staff taking an individualised approach to each patient (5, 6, 9–11, 24, 30, 32–36), rather than focusing on ethnic stereotypes (36). To the best knowledge of this author, studies on a good death from the perspective of patients with terminal illness in Sweden are lacking.

Palliative care

As mentioned previously, the development of the palliative care movement was begun in the 1960s by Cicely Saunders (23). Saunders focused on patients in the terminal stages of cancer. She studied the relationship between physical and mental suffering. Her description of *total pain* included physical, psychological, social, emotional and spiritual components (37). Taking a team approach was seen as essential when working with patients near the end of their lives (25). These are central aspects of palliative care.

Figure 3. Cicely Saunders.

Definition

The World Health Organisation (WHO) first formally defined palliative care in 1989. The revised definition from 2002 is 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”* (38).

In 2018, the International Association for Hospice and Palliative Care (IAHPC) initiated a survey among its members from 88 countries worldwide. This work developed into a new broad, consensus-based definition of palliative care that does not primarily emphasise the diagnosis or the problems associated with life-threatening illnesses, but instead focuses on the patients’ suffering and needs: *“Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers”* (39).

Further development of the palliative care movement

In 1977, the first palliative home-care programme was established in Sweden; the Motala hospital-based home care, as an alternative to hospital care (40).

Hospices and palliative care in the UK expanded significantly during the 1980s. In 1987, palliative medicine was established as a subspeciality. Several countries have followed the same development (41). Since 2015, palliative medicine has also been a supplementary speciality, *“characterized by the management of patients with incurable, progressive, life-threatening disease where the objective is to prevent and alleviate suffering and give the patient the conditions for the best possible quality of life”*, in Sweden (42).

Palliative care organisation in Sweden

Sweden is divided into 290 municipalities and 21 regional councils (43). Healthcare in the country is decentralised, which means that responsibility for healthcare lies with the regional councils, or sometimes with local councils or municipal governments. The Health and Medical Service Act regulates this system (43).

As mentioned previously, approximately 90 000 individuals die in Sweden each year (1). It is estimated that between 70 000 and 75 000 of these require palliative care (44), which is an integrated part of the Swedish

healthcare system, administered through national guidelines for good palliative care at EOL (44) and a national programme for palliative care (45).

Palliative care is divided into general and specialist palliative care. *General palliative care* is provided by municipalities in co-operation with primary care to those patients who are expected to need care by healthcare staff with a basic level of knowledge in such care. *Specialist palliative care* is provided by a specialist palliative organisation to those patients whose situations or symptoms are more complex (45).

Svenska Palliativregistret (The Swedish Register of Palliative Care, SRPC), is a national register of quality set up in 2005 which contributes to the development of palliative care and research in Sweden. The register is based on an EOL questionnaire consisting of thirty questions answered by responsible healthcare staff after the patient's death. It has approximately 60% coverage, i.e. data on 60% of all deaths in Sweden are recorded (46). More than 5300 facilities report data on EOL care to SRPC (46).

Nursing homes

Nursing homes in Sweden

In 2019, 108 500 people in Sweden resided in a NH; two thirds of them were women and one third were men (47). Six percent of all women and 4% of all men >65 years lived in a NH. Among people in Sweden in the oldest age group (>90 years), more than one third of women and one quarter of men lived in a NH in 2019 (47).

Care delivered by a NH is divided between two different authorities: regions and municipalities. Each NH has an attending physician employed at a regional primary healthcare centre, usually a GP or a general practitioner specialist trainee (GP-ST). Nurses and other staff working at NHs are municipal employees. This means that physicians and nurses working with NH patients have different employers, and also use different systems for documentation of patient medical records.

Swedish municipalities planning new housing and residential areas are obliged to ensure that they meet the needs of elderly people and those with disabilities. An increasing number of elderly people in Sweden live in their own homes, sometimes “senior housing”, rather than NHs (48). This has contributed to a situation in which people moving into NHs are usually the oldest and most frail. The proportion of elderly people living in NHs decreased between 2010 and 2019. This could partly be due to improved health and an increase in the average life expectancy of the population, but it might also be an effect of a lack of NH places. Median residency in a NH

is 24 months (2). Approximately 20% of NH patients die within six months of moving into the NH (2).

Palliative care in nursing homes

Since patients in NHs are often old, frail and suffer from several diseases, and thus are near the end of their lives, the majority of deaths in NHs are expected. Therefore, many NH patients will have palliative care needs during their last days.

In palliative care research, studies on patients' perspectives are rare, partly due to ethical challenges, e.g. the vulnerability of this group of patients and difficulties in obtaining informed consent (19). In a study on palliative care implementation activities in 29 European countries, deficiencies in palliative care development and delivery in NHs were identified (49). Pivodic et al. identified a suboptimal quality of EOL care and quality of dying among NH patients in six European countries. Some of the participating countries, such as Belgium, the Netherlands and the UK, are known for having high levels of palliative care development in NHs (50).

Advance care planning

ACP has its origins in the principles of autonomy and self-determination, establishing a patient's views and preferences about future care, and enabling the patient's preferences to be considered, including in the event of diminished capacity (51). From a patient's perspective, however, the primary goal of ACP is more often preparing for impending death (52). ACP is widely accepted as a central aspect of care for patients who are near the end of their lives (52-58).

Definition

Several definitions of ACP are present in the literature. In the various definitions, a decision-making process is often part of the content (52, 59, 60). Seymour et al. (60) concluded that ACP is "*a process of discussion about goals of care and a means of setting on record preferences for care of patients who may lose capacity or communication ability in the future*". Some also highlight the aspect of preparing the patient and family members for the final days of life (52, 59). Martin et al. (52) identified two targets with regard to this aspect. These are: "*to assist patients to make treatment decisions for the event of incapacity*" and "*preparing for death and dying*" through a social process, which is seen as valuable in itself. According to the authors, these two targets overlap, since establishing patients' wishes for future care is presented as a way of assisting the patients to achieve a sense of control and to relieve the burden on the their loved ones,

thus becoming an essential component of “preparing for death and dying” (52).

Aspects frequently present in ACP are proactive planning for future care, patient preferences concerning medical treatment and care, and the involvement of family members. In the EAPC (European Association of Palliative Care)-supported, consensus-based definition, ACP is described as *“the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual’s health condition worsens; and, using trained non-physician facilitators to support the ACP process”* (59).

Effects of ACP

Previous studies have found positive effects of ACPs in NH patients, such as fewer hospital admissions (61-63), medical treatments consistent with patients’ wishes (61, 64), a higher incidence of preferred place of death (63) and reduced healthcare costs (61, 62). In a systematic review of the effects of ACPs in a NH context, Martin et al. (55) showed that ACP decreased hospitalisations by 9-26% and led to a significant increase, of 29-40%, in the number of patients dying in their NH. Medical treatments in accordance with patients’ wishes also increased with ACP. No negative effects of ACP were shown (55).

In a randomised trial in Australia, Detering et al. (65) followed 309 inpatients aged >80 years for six months or until death. Of these participants, 154 were randomised to ACP. Of the patients who had died before the six months had elapsed (n=56), EOL wishes were much more likely to be known and followed for the patients with ACP, compared to the participants lacking ACP. Moreover, among family members of deceased patients with ACP, fewer psychological symptoms were seen. Both patient and family satisfaction was higher in the group with ACP (65).

Brinkmann-Stoppelenburg et al. (53) concluded in a review of the effects of advance care planning on EOL care that ACP is often associated with decreased life-sustaining treatment and a reduction in hospitalisations.

In a multisite, prospective, longitudinal cohort study of patients suffering from advanced cancer, Wright et al. (66) showed that EOL discussions, which are central elements of ACPs, were associated with less aggressive medical care near death, and that aggressive care (e.g. admission to an intensive care unit, ventilation, resuscitation) was associated with reduced patient quality of life and higher risk of psychological symptoms in

bereaved family members. Similar results were found in a review of medical records of inpatients suffering from cancer diseases in the USA (67). Seventy-nine percent of the patients were considered capable of having conversations about EOL when admitted to hospital. However, among these patients, 40% lost this capacity before an EOL discussion could take place. These patients received more aggressive life-sustaining treatments prior to death (67).

Prevalence of ACP

Previous studies have shown that, even though old and frail or severely ill patients often appreciate the opportunity to discuss EOL issues (65, 68-73), which are central elements of ACPs, such communication is often lacking (66, 68, 69, 73-77). Sharp et al. showed in a systematic review of seven papers that only 2–29% of frail older people had discussed some kind of care plan, with their healthcare staff (69). For a large proportion of patients suffering from life-threatening illness, EOL conversations do not occur: Fewer than 40% of patients with cancer disease (66), 15% of patients with COPD (68) and 10% of patients with chronic kidney disease in stage 4 or 5 (77) report having such conversations with their physician.

ACP studies in NHs are rare (52, 78-82) and there are large variations in definitions and content of ACPs, which makes it difficult to compare research results (78). Nair et al. (79) found a very low prevalence of ACPs documented in medical records in residential care institutions, only 0.2% (52).

Treatment limitations in ACP

Cardiopulmonary resuscitation (CPR) was first introduced in the 1960s with the intention that it should be practised on everyone (83). It was later realised that this was not appropriate for all patients, for example terminally ill patients. Different signs or symbols, such as stars or red hearts were written next to patients' names, indicating that CPR should not be practised on these patients (83). These symbols were often misunderstood, which led to the development of the idea to create an order, or code: a do-not-resuscitate order (DNR) (83). CPR can be lifesaving in cases where the cause is reversible. However, outcomes are often poor. The rate of out-of-hospital cardiac arrest survival to hospital discharge is less than 10% (84).

Treatment limitations, such as DNR orders, are often issues to be illuminated and decided upon in ACPs. According to the Swedish National Board of Health and Welfare, the physician who is responsible for patient care is the one to make decisions regarding life-sustaining care and treatment limitations, in consultation with the patient and/or family members (85). The physician should also consult with another registered colleague, such as a

registered physician or nurse, when making such decisions (85). Thus, only physicians have the authority to make decisions regarding life-sustaining care and treatment limitations, preferably based on the patient's preferences and/or family members' views. Nurses are to be consulted and should aid the decision-making and minimise subjectivity. Deficiencies regarding DNR orders include the failure to recognise when resuscitation is not appropriate for a patient and make a timely decision, unclear communication of the decision within the healthcare team as well as to patients and/or family members, and finally deficiencies in documentation and misunderstandings about the decision (86). Previous studies have shown that DNR orders can be misunderstood to mean that treatments other than CPR should also be withheld (87).

Perspectives on ACP

Patients' and family members' perspectives

A systematic review and thematic synthesis of the perspectives of elderly people living in long-term facilities and their family members towards ACP discussions (56) showed that, although most elderly people had never talked about their preferences regarding EOL care with their family members or healthcare staff, some assumed that their preferences were already known (56). However, several studies have shown that family members have a varying amount of knowledge of the patient's preferences in EOL care, ranging from being well informed to having no knowledge at all (73, 88).

Gjerberg et al. highlighted the need for healthcare staff to have a high degree of sensitivity when engaging in EOL conversations and that patients might need time and repeated conversations. According to the authors, these conversations should preferably be seen as a continuous process, and with a receptiveness to changing opinions (73). The ACP process is complex in many ways, from both patients' and family members' perspectives, and requires time, continuity and stability in relationships. Sensitivity to the patient's readiness to discuss EOL issues is essential (56)

A qualitative study based on interviews with patients and family members showed that few had participated in EOL conversations. Most family members wanted such conversations while patients' views varied. The majority of both groups wanted to receive information about the patient's health condition and had a desire to be involved in decisions concerning medical care (73). An association has been observed between patients having been informed about their impending death and better quality of EOL care (89). Lindskog et al. found that, compared to younger patients, elderly patients

suffering from cancer were less likely to be informed by their responsible physician about their impending death, were less likely to be assessed for the presence and severity of pain and other symptoms, and less likely to have injections against palliative symptoms prescribed. Their family members were also less likely to be informed about the patient's impending death or offered bereavement support (90).

Most of the elderly, including those who are relatively healthy, often want EOL discussions at an early stage (56, 58, 69, 73, 91), before the onset of serious health problems or cognitive impairment (56, 58). Some elderly people, however, prefer to postpone EOL conversations until their health deteriorates (56, 58).

In a review by Ke et al. (92), the benefits of ACP, from the perspective of patients, were concluded to be: help for the patients to control their lives, help for significant others to know their wishes through ACP, which could reduce conflicts within families, decreased suffering and increased autonomy, help with planning for the future, which could enhance peace of mind, help for their families to reduce the burden of making healthcare decisions by providing guidance for family members, help for families to cope with their loss and grief after the patient's death and finally to strengthen their relationship with healthcare staff through identifying the goals of care together. Barriers to ACP for old and frail patients could be patient unwillingness to have such discussions, due to not wanting to talk about upsetting or negative topics (58, 69, 93). Other elderly people could be reluctant to talk about EOL care because they are not concerned about the future, hence living life "day by day" (56, 94, 95), or regard such discussions as unnecessary (56, 95).

Family members usually have positive attitudes toward ACP (56, 94, 96). ACP conversations could be seen, from the perspective of family members, as an opportunity for patients to express their preferences, and for the family members to take part of these (56, 95). Family members are often important in the ACP process (69, 73, 97), e.g. to support patients during ACP, to help patients to communicate their preferences for EOL care to the nurse or physician, and to represent patients' thoughts when they can no longer communicate their preferences or make decisions on their own. However, research has shown that family members are often worried about making erroneous decisions when asked about issues concerning the direction of care and treatment limitations (95).

Fosse et al. showed in a review that NH patients and their family members emphasise the importance of physicians being more involved in EOL care and they expected physicians to recognise their preferences, provide guidance in decision-making concerning EOL issues and help with symptom

management (98). Physicians in NHs have been described as absent and, according to family members, there is a lack of communication between NH staff and physicians (98, 99).

Although, as mentioned above, a lot has previously been revealed concerning family members' perspectives on ACP, there is more to explore regarding ACP in NHs from the perspectives of family members, such as their role in the ACP process and their experiences concerning decisions about treatment limitations.

Healthcare staff's perspectives

Seymour et al. found that community nurses viewed ACP as an important part of good nursing care, e.g. engaging with patients to evoke care preferences, facilitating communication within families and enabling a shift in the focus of care towards palliative care (60). The nurses perceived a lack of resources, a lack of knowledge in the general public about the availability of support at EOL, and patients' fears and difficulties in conversations about death (60). Previous studies have shown that, even though nurses believe that they should be involved in treatment decisions, e.g. DNR orders, such decisions are often made by physicians alone (100, 101).

Almack et al. showed in a qualitative study with patients, relatives and healthcare staff across five units delivering palliative care for cancer and non-cancer patients, that most patients assumed that healthcare staff would initiate ACP conversations, while healthcare staff were often hesitant to do so, sometimes due to perceived risks of taking hope away or because of time issues (102).

Research has revealed some of the factors hindering the physicians from initiating ACP and EOL conversations. Such factors include their own discomfort and fear about taking hope away from the patient, a feeling of losing control, prognostic uncertainty, a belief that the patient is unwilling or unable to discuss EOL and death, a lack of time and organisational aspects (103-109).

According to Oberle et al. (110), perspectives on ethical problems in EOL decisions appear to be different among physicians and nurses, since physicians are the ones who have to make the decisions, while nurses have to live with the decisions made by someone else (the physician).

The facts that a high proportion of deaths in Sweden, and in several other countries, take place in NHs (14, 18-20), and that positive effects of ACPs have been shown previously (53, 55, 61-67), make it especially important to study physicians' and nurses' perspectives on the factors that shape the ACP process in a NH context.

ACP in patients with dementia

A large proportion of patients in NHs are suffering from dementia. According to Selbaek et al., approximately 80% of the patients in Norwegian NHs have mild to severe symptoms of dementia (111). Patients suffering from dementia have often lost their ability both to understand and to make their own statements and choices concerning, for example, treatment decisions. Therefore, initiating ACP discussions during an early phase is important (78, 82, 111, 112), and if ACP discussions are initiated when the patient is no longer cognitively intact, it is of great importance to really explore what the family members know about the patient's preferences and values, to ensure that decisions are consistent with what the patient is most likely to have preferred (69). A few studies have found that, when properly approached, patients suffering from cognitive impairment are sometimes able to express their preferences consistently. Therefore, these patients should not be excluded from ACP (56, 113, 114).

According to Swedish law, when a patient lacks the ability to consent, family members have a legal right to receive information about the patient's condition, and to be asked about their knowledge concerning the patient's preferences and values. However, the physician is obliged to make decisions concerning medical care and treatment limitations (85).

ACP during the Covid-19 pandemic

During the work for **paper III** and the writing of this thesis, the Covid-19 pandemic began. As mentioned previously, during the first half of 2020, Covid-19 was the third most common cause of all deaths in Sweden, and in April 2020, it was the most common cause of death, followed by cardiovascular disease and tumour diseases (14). The majority of deaths caused by Covid-19 occurred in hospitals or NHs. More than 50% of people >70 years who died from Covid-19 in Sweden, died in a NH, according to data published in November 2020 (14).

During the Covid-19 pandemic, physicians in primary healthcare in some Swedish counties (e.g. the county council of Östergötland) were encouraged to establish ACP documents concerning serious respiratory-tract infections in frail and elderly patients living in NHs or still in their private homes, receiving municipal home care. The aim of documenting ACPs, with a focus on serious respiratory-tract infections, was to prevent this patient group from being admitted to hospital if it was unnecessary and/or against the patient's wishes, and instead to provide these patients with symptom management and good palliative care in their homes.

AIMS OF THE THESIS

General aim

The overall aim of this thesis was to explore perceptions of a good death from the perspective of patients with severe illness and to investigate, from different perspectives, experiences of ACP in a NH context.

Specific aims

The main aims of the individual papers of the thesis were the following:

- I. To explore the perception of a good death in dying cancer patients in Sweden **(paper I)**.
- II. To investigate clinicians' perspectives on the factors that shape the process of ACP in a nursing home context **(paper II)**.
- III. In a Swedish NH setting to explore: *i*) the prevalence of ACPs (two different ACP definitions), *ii*) the content of ACPs, *iii*) adherence to the content of ACPs and *iv*) possible associations between the presence of ACP and background characteristics (e.g. demographic and diagnosis), physician attendance and EOL care **(paper III)**.
- IV. To explore family members' experiences of ACP in NHs in Sweden **(paper IV)**.

MATERIALS AND METHODS

Table 2.

	Paper I	Paper II	Paper III	Paper IV
Study design	Qualitative explorative interview study	Qualitative explorative interview study	Retrospective chart review (RCR)	Qualitative explorative interview study
Study population				
Setting	66 patients with terminal cancer recruited from five palliative and oncological units in two Swedish counties.	14 physicians and 11 nurses working at NHs in one Swedish county. Participants were recruited from nine NHs (nurses) and four healthcare centres (physicians).	367 deceased patients who had lived in a NH at EOL. Patients included from 22 NHs in two Swedish counties.	18 family members of deceased NH patients. Participants recruited from four NHs in one Swedish county.
Inclusion criteria	Aged ≥ 18 years, suffering from cancer in a palliative phase and having been informed of this, being Swedish speaking, having no obvious disorientation, not currently suffering from a psychological crisis, agreeing for the interview to be recorded.	Being a nurse or a physician working at a NH, being Swedish speaking, agreeing for the interview to be recorded.	Deceased NH patients having lived in any of the selected NHs during the last days of life (death could have occurred in the NH, but also somewhere else) during the inclusion interval.	Being a family member of a patient who lived in a NH at the EOL, being over 18 years, not suffering from cognitive impairment, agreeing for the interview to be recorded.
Background characteristics	Participants aged 30–90 years, 44% men, 42% died within three months from time of interview.	Participants aged 26–64 years, 24% men, having worked 3–37 years since degree, having worked at a NH for 0.5–27 years.	Patients aged 53–103 years at death, 36% men, 86% died in the NH, 14% died in hospital, 0–140 months recidency at NH, 75% with cardiovascular disease, 20% with diabetes, 61% with dementia.	Participants aged 39–75 years, 39% men, 67% being son/daughter of deceased patient. Deceased patient aged 69–99 years at death, having lived <1–98 months in NH, 44% with dementia/MCI diagnosis.
Data collection period	1997 (n=54), 2007 (n=12)	2016	June 2018 - May 2020	2018–2019
Analysis	Qualitative content analysis, manifest approach.	Qualitative content analysis, latent approach.	Pearson's chi-square test was used when comparing distribution between groups. Fischer's exact test was used when expected number was less than five in any cell. Mann Whitney U-test was used for group comparisons of continuous variables.	Thematic analysis, latent approach.

How it all started

Paper I

The first paper of the thesis was initiated in 1997 by a fellow researcher and physician as a study aiming to explore the whole situation of dying. Perspectives regarding life and death, communication, support, cancer care and euthanasia were explored. Unfortunately, the researcher fell ill and subsequently passed away. Prior to her death, the study material was given to Professor Strang. A few years later, the study was restarted by Marit Karlsson (MK), who at the time was a PhD student supervised by Professor Strang. Additional interviews were conducted in 2007. Results addressing the topic of euthanasia were presented in two papers (115, 116).

In 2014, a secondary analysis of the previously conducted interviews was undertaken, as a mandatory written scientific work for LK (at the time in specialist training) under the supervision of Marit Karlsson, MD, PhD. The scientific work evolved into **paper I** of this thesis.

Settings

Paper I

Data for this study were collected from five units; palliative care wards, palliative home-care organisations and an oncological outpatient clinic in two Swedish counties. Data were collected twice, in 1997 (n=54) and in 2007 (n=12).

Paper II

The setting for this study was nine NHs in one Swedish county. Data were collected in 2016.

Paper III

Data were collected between June 2018 and May 2020 from 22 NHs in two Swedish counties.

Paper IV

In this study, participants were recruited from four NHs in one Swedish county. Data were collected in 2018–2019.

Participants and data collection

Paper I

Inclusion criteria for this study were as follows: being an adult (aged over 18 years), suffering from cancer in a palliative phase and having been informed of this, being Swedish speaking, having no obvious disorientation, not currently suffering from a psychological crisis and agreeing to the interview being recorded. Participants were recruited by healthcare staff in five different oncological and palliative care units. To reach broad variation, the participants were selected through maximum variation sampling (117) regarding gender, age, social status, diagnosis and time since diagnosis (aged 30–90 years; 44% men; 42% died ≤ 3 months after the interview), see Table 3.

Table 3. Demographics and characteristics of study population, n=66.

Age mean (range)		64.7 years (30–90)
Gender men/women (n)		44% (29) / 56% (37)
Social status cohabitant/living alone (n)		52% (34) / 48% (32)
Having children yes/no (n)		83% (55) / 17% (11)
Having religious faith (n)		21% (14)
Diagnosis: Malignancy of the (n)	Digestive organs	30% (20)
	Female genital organs	17% (11)
	Lymphoid and blood system	14% (9)
	Respiratory tract	12% (8)
	Breast	12% (8)
	Urinary tract	5% (3)
	Various	10% (7)
Time from cancer diagnosis to interview	<3 months	9% (6)
	4–12 months	33% (22)
	>1 year	58% (38)
Time from interview to death	<1 month	12% (8)
	1–3 months	30% (20)
	4–12 months	27% (18)
	>1 year	30% (20)
Type of care when interviewed	Oncological outpatient clinic	35% (23)
	Palliative care ward (hospice)	35% (23)
	Palliative home care	30% (20)
Ongoing palliative oncological treatment		12% (8)

The participants were interviewed once (n=54 in 1997–1998; n=12 in 2007) by one of two researchers who were senior physicians (in 1997–1998 a specialist in oncology; in 2007 a specialist in geriatrics and palliative medicine), not involved in the medical care of the participants. The interviews, which took place either (most often) in the home of the participant, or on a ward, consisted of open questions regarding life and death,

communication, support, cancer care and euthanasia. They were digitally recorded and transcribed verbatim.

Paper II

Inclusion criteria for this study were the following: being a nurse or physician working at a nursing home, being Swedish speaking and agreeing to the interview being recorded. Physicians were recruited from four of the health centres in charge of the greatest number of NHs in the central area of the district chosen and nurses were recruited from nine of the NHs with the most care recipients in the same district, with the purpose to reach broad variation (117) in terms of characteristics such as: age, gender and time since medical/nursing degree.

Table 4. Background characteristics of the participants, n=25.

Nurse/physician (% (n))	44% (11) / 56% (14)
Age mean (range)	43 years (26–64)
Age mean; nurses (range)	44 years (26–59)
Age mean; physicians (range)	45 years (35–64)
Gender men/women (% (n))	24% (6) / 76% (19)
Gender nurses men /women (% (n))	18% (2) / 82 % (9)
Gender physicians men/women (% (n))	29% (4) / 71% (10)
Number of nursing homes participating (n)	9
Nursing homes, rural location (n)	2
Nursing homes, urban location (n)	7
Number of health centres participating (n)	4
Health centres, rural location (n)	1
Health centres, urban location (n)	3
Years worked since degree mean (range)	14 years (3–37)
Years worked since degree mean (range), nurses	13 years (3–36)
Years worked since degree mean (range), physicians	15 years (6–37)
Years worked at nursing home mean (range)	8 years (0.5–27)
Years worked at nursing home mean (range), nurses	5 years (0.5–13)
Years worked at nursing home mean (range), physicians	10 years (2.5–27)

Recruitment of participants was carried out after approval by the head of unit/chief and after approval by the Regional Board of Ethics. An e-mail was sent to each potential participant. Information about the study was given and the physician or nurse was asked to reply by e-mail or post if willing to participate. Only one reminder was sent to the potential participants. Eleven nurses and 14 physicians decided to participate. Consent forms were collected at the time of the interviews. Participant recruitment continued until redundancy appeared (117).

An interview guide, which served as a checklist during the interviews, to ensure coverage of the relevant topics (117), was developed by the research group. The interview guide was tested on two participants, and these were included in the study because the content of these two interviews was considered to be of good quality. The interviews consisted of open questions

regarding ACP, such as “When should ACP be initiated?”, “Who should be involved in ACP?” and “What are facilitators and obstacles to good ACP?” Clarifying questions (117) were asked to reduce any uncertainty regarding the statements made by participants.

In total, 11 nurses and 14 physicians were interviewed. None of the participants dropped out at any phase from inclusion in the study. All the individual interviews were conducted by LK (the author of this thesis), who has experience of working at a primary healthcare centre as a GP. The researcher did not share a workplace with any of the participants in this study. The interviews were conducted in 2016 at primary healthcare centres, in nursing homes or by telephone, according to each participant’s preference. The interviews were digitally recorded and transcribed verbatim.

Paper III

The study was performed as a retrospective chart review (RCR), in which patients were included from selected NHs over a period of two years (June 2018–May 2020). Inclusion criteria were: deceased NH patients having lived in any of the selected NHs during their last days of life (death could have occurred in the NH, but also somewhere else) during the inclusion interval. The NHs included in the present study were long-term care homes including dementia care. Attending physicians were employed at ten different primary healthcare centres.

Participants were identified through different means in the two counties. In County A, a data search was performed in a municipality healthcare administrative systems database (Treserva, CGI) to identify deceased patients who had lived in any of the 14 NHs in the municipality (private NHs being excluded). In County B, a data search was performed in the county’s electronic medical record system (Cambio Cosmic), identifying deceased patients who had lived in any of the eight NHs with connections to the two selected primary healthcare centres during the inclusion interval.

The broad definition of ACP (ACP I) utilised in this study was “*a proactive plan to handle a future serious deterioration of the patient*”, based on the existing accepted definitions of ACP in the literature. Inspired by the consensus-based definition of ACP supported by the European Association of Palliative Care (EAPC) (59), a narrower definition was also developed (ACP II). *ACP II included the definition of ACP I, and also i) the presence of the patient’s preferences concerning medical treatment and care (only patients who were capable of expressing their own preferences, i.e. patients without cognitive impairment, were included regarding this aspect of the ACP II definition), and ii) involvement of family members in the ACP.*

In Sweden, a decision to shift the focus from any level of prolonging or life-sustaining care to strictly palliative care is a widely used strategy, referred to as “breakpoint decision” (118), and internationally termed a “palliative care plan”. In this study, such a decision documented in a medical record was considered to be an ACP document.

LK performed the RCR in 2020. In total, 367 medical records were analysed. In the medical record review, data on the prevalence of ACP was collected, as well as variables regarding background characteristics (e.g. gender, age, diagnoses), physician attendance (number of physician consultations at NH during the final six months of the patient’s life) and EOL care (information given to family members about the patient’s deterioration and impending death, ED visits and periods of inpatient care during the patient’s final six months of life, prescription of palliative injections, a “benefit for care of closely related person” certificate (i.e. an employee’s right to take time off work in order to attend a closely related person who is seriously ill and receive financial compensation through Swedish social insurance (119))). Adherence to the content of ACP was explored by studying the associations between a documented instruction to limit hospital care and the actual frequency of ED visits or inpatient care. Hospital care limitations in ACP was defined in this study as written instructions in the patient’s medical record to limit hospital care, in favour of care at the NH, such as patient should never receive hospital care, or hospital care only in case of fracture, acute chest pain, etc.

Initially, a pilot study was performed, during which the data-collecting protocol and the coding were evaluated. One of the co-authors (MK) recoded a subsample of the medical records, and if there was disagreement about the coding, it was discussed to reach consensus in the interpretation and understanding of the data extraction.

Paper IV

In this study, a “family member” was defined as a person who was specified, in the patient’s medical record, as someone who had been chosen (often by the patient him- or herself) to be contacted in the first instance concerning patient issues. This person did not necessarily need to be a relative, but could also be someone else close to the patient, e.g. a close friend, a son-/daughter-in-law, etc.

Inclusion criteria were as follows: being a family member of a patient who lived in a NH at the end of life, being over 18 years of age and agreeing for the interview to be recorded. Exclusion criteria were: inability to understand and/or speak Swedish sufficiently, or cognitive impairment (according to the nurse who helped with the recruitment of possible participants).

Participants were recruited through purposeful sampling (117). Initially, six NHs gave consent to participate. However, due to circumstances such as staffing issues, two NHs dropped out, i.e. four NHs were finally included in the study. Possible participants who met the inclusion criteria of the study were informed briefly about the study and were asked by a nurse working at the NH if they would agree to be contacted by the research team to receive more information. Usually, this first contact by the nurse was made about four to eight weeks after the death of the NH patient at the time of a so-called “bereavement follow-up” with the family member. Of the family members who were asked to participate after receiving information from the research team about the study, all except one agreed to participate.

When the potential participant had agreed to be contacted by the research team, the nurse at the NH contacted LK by mail stating that there was a potential participant. LK then contacted the nurse by phone to receive information about the family member, such as age, gender and type of relationship to the deceased NH patient, and patient factors, such as age, gender, diseases, presence/absence of cognitive impairment and time between moving to the NH and death. For background data about the participants and deceased patients, see Tables 5 and 6. Participant recruitment continued until redundancy appeared (117).

Table 5. Background characteristics of the participants, n=18.

Age mean (range)	62 years (39–75)
Gender	
Men (% (n))	39% (7)
Women (% (n))	61% (11)
Relationship to deceased patient	
Son/daughter (% (n))	67% (12)
Husband/wife (% (n))	11% (2)
Brother/sister (% (n))	5.5% (1)
Grandson/granddaughter (% (n))	5.5% (1)
Niece/nephew (% (n))	11% (2)
Employment	
Working person (% (n))	39% (7)
Pensioner (% (n))	61% (11)
Location of interview	
Health centre (% (n))	61% (11)
Home/office of participant (% (n))	11% (2)
By telephone (% (n))	28% (5)
Time from death to interview mean (range)	93 days (82–131)

Table 6. Background characteristics of the deceased NH patients.

Age at death mean (range)	88 years (69–99)
Gender	
Men (% (n))	28% (5)
Women (% (n))	72% (13)
Place of death	
Nursing home (% (n))	89% (16)
Hospital (% (n))	11% (2)
Time between moving to NH and death, mean (range)	32 months (<1–98)
Presence of dementia/MCI diagnosis (y/n)	44% (8) / 56% (10)
Number of nursing homes participating (n)	4
Nursing homes, rural location (n)	1
Nursing homes, urban location (n)	3

Participants were recruited after approval by the Regional Board of Ethics and after approval from each head of unit at the NHs. The researcher who performed the interviews (LK) contacted each potential participant by phone. Information about the study was given and of the potential participants, all except one decided to participate.

An interview guide was constructed consisting of open questions concerning the deceased patient's communication with the family member about patient preferences near the end of his/her life, the shape of EOL care including ACP and treatment limitations, and the participant's experiences of the patient's dying process. Clarifying questions (117) were asked to minimise the risk of obscurities in any of the statements made by the participant.

Each participant was individually interviewed once about three months after the death of the NH patient. This interval since death was considered to be sufficient to be past the initial phase of crisis due to grief related to the loss of a loved one, but also recent enough for the participant to manage to remember. Consent forms were collected at the time of the interviews. The interviews were carried out in the participant's home or work office, at health centres or by phone, according to the participant's preference. LK conducted the 18 interviews in 2018–2019. They were digitally recorded and transcribed verbatim.

Qualitative research methods

As the goal in **papers I, II and IV** was to gain deeper knowledge based on human experiences, a qualitative methodology was considered suitable (117).

Qualitative content analysis

According to Krippendorff (120), content analysis is an empirically grounded method that focuses on communication and the content of a text; it is “*a research technique for making replicable and valid inferences from text (or other meaningful matter) to the contexts of their use*”.

The term *content analysis* first appeared in English in 1941. However, the systematic analysis of texts dates back to theological studies in the 17th century. Initially, content analysis was used by researchers as either a quantitative or a qualitative method. In the 1950s, Berelson described content analysis as an empirical scientific method in his studies of propaganda in mass communication and journalistic practices (121). He referred to content analysis as a research technique “*for the objective, systematic and quantitative description of clear content of communication*” (121). Content analysis has changed from textual analysis to a quantitative method to, finally, a qualitative method (120).

More recently, the qualitative approach of content analysis has been recognised and the method has become increasingly popular in healthcare research. Hsieh and Shannon define qualitative content analysis as “*a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns*”, in its summative approach, which involves counting and comparisons of content, followed by the interpretation of the underlying context (122).

When analysing a text, different depths of interpretation and levels of abstraction can be used. According to Graneheim and Lundman, who have further developed qualitative content analysis into their own approach, *manifest content analysis* describes the visible, obvious components of a text, using little interpretation, while *latent content analysis* involves a deeper analysis of the underlying meaning of a text (123). The term *category* is used in manifest content analysis and the term *theme* is used in latent content analysis (123). Graneheim and Lundman have been criticised over the years, mainly based on the opinion that their article from 2004 (123) should not be seen as a core source. Furthermore, their construction of latent content analysis has been criticised for being seen as a mixture of several qualitative methods, because the original description of content analysis is descriptive (manifest), not latent (117). In a more recent

article from 2017, Graneheim et al. discuss the meaning of interpretation, and claim that manifest as well as latent content analysis requires interpretation, but that the interpretation may vary in depth and level of abstraction. Moreover, according to these authors, a high level of abstraction must not be confused with a high degree of interpretation (124).

In **paper I**, qualitative content analysis with a manifest approach was the method chosen (120, 123). In **paper II**, the analysis was conducted using latent qualitative content analysis (123).

Thematic analysis

Thematic analysis is a qualitative method used to identify, analyse and report patterns (themes) within data. It has become widely used, perhaps partly because one of the values of the method is its flexibility.

Thematic analysis can be an essentialist or realist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society. It can also be a “contextualist” method, sitting between the two poles of essentialism and constructionism. (125).

Themes/patterns in the data can be identified in one of two different ways in thematic analysis: in an *inductive* way; coding without pre-existing patterns, or in a *deductive/theoretical* way, which is more analyst driven. A *semantic* or *latent* approach is used to describe the level of interpretation in thematic analysis. Under the semantic approach, the data are organised to show patterns in a descriptive manner. When using a latent approach, the analysis goes beyond the semantic content of the data, seeking the underlying meanings and ideas (125).

In **paper IV**, an inductive, latent approach to thematic analysis was considered suitable because the motive of this study was to search for themes/patterns in family members' perspectives on the topic (advance care planning).

Analysis

Paper I

The interviews were analysed using qualitative content analysis with no predetermined categories (117, 123). The analysis was performed using the following seven steps: (1) The transcribed interview was read through to obtain an overall impression and to gain a broad understanding (naive reading). (2) Segments of the texts dealing with the topic of *a good death* were identified and meaning units were constructed. (3) The meaning units were condensed and abstracted into codes. (4) These codes were compared and sorted into categories. (5) Categories were compared to the entire interview, to make sure that the interpretation was consistent and coherent with the text as a whole. (6) The categories were compared to avoid overlaps and content descriptions were developed. (7) Quotations were used to exemplify the categories.

Paper II

The interviews conducted by LK were transcribed verbatim by a medical secretary linked to the study. As LK did not transfer the interviews to text herself, the texts were carefully read through to identify any possible misunderstandings or errors.

The interviews were then analysed using qualitative content analysis, taking a latent approach (123) using the following steps: (1) The transcribed interview was read through to obtain an overall impression and gain a broad understanding. (2) Segments of the texts dealing with the topic *Advance care planning* were identified and meaning units were constructed. (3) These meaning units were condensed and abstracted into codes. (4) The codes were compared and sorted into categories. (5) Categories were compared to the entire interview, to make sure that the interpretation was consistent and coherent with the text as a whole. (6) The categories were compared to avoid overlaps and content descriptions were developed. (7) A latent theme was then constructed to link the manifest categories together and to interpret the underlying (deeper) meaning of the text. (8) Quotations were used to exemplify the categories and theme (123, 124).

Paper IV

Analysis was begun after the data collection had finished. A latent approach to thematic analysis was chosen in order to be able to understand the underlying meanings and ideas in the data (125). The interviews conducted by LK were transcribed verbatim by a medical secretary linked to the study. In the process of coding, all the transcripts were given equal attention. The initial coding was mainly undertaken by the researcher who performed the interviews (LK) and main supervisor (AM).

The interviews were qualitatively analysed using the following steps: (1) Familiarising with the data, (2) Generating initial codes, (3) Searching for themes, (4) Reviewing themes, (5) Defining and naming themes and (6) Producing the report (125). The six steps are described below:

Step 1: In the first step, each interview was read through in an active way at least twice to achieve a broad understanding of the content and to search for patterns and meanings.

Step 2: Interesting parts of the interviews on the topic under study were identified. Initial codes were produced and organised into meaningful groups.

Step 3: The codes were sorted into themes using tables, and a thematic map was shaped illustrating codes grouped into the initial themes.

Step 4: The themes were reviewed, i.e. some of the themes shaped in step 3 were considered to overlap with another theme and two or more themes were then grouped into a new theme.

Step 5: The reviewed themes were defined and given suitable names.

Step 6: In this final step, a report was produced. To exemplify the findings of the study, citations from the interviews were used.

Trustworthiness

The scientific quality of qualitative research must be available for assessment according to accepted criteria(126). Malterud refers to qualitative research methods as systematic and reflective processes, in which the researcher must use strategies for: *i)* questioning findings and understandings, rather than taking them for granted, *ii)* assessing the internal and external validity, rather than judging them as obvious or universal, *iii)* reflecting on the effect of context and bias, and *iv)* showing and discussing the process of analysis (126). According to Lincoln and Guba (127), *trustworthiness* in a qualitative research study is essential for it to have value. Trustworthiness involves the following four key concepts: *dependability*, *credibility*, *confirmability* and *transferability*. These different concepts of trustworthiness of the qualitative papers in the thesis (**papers I, II and IV**) are discussed below:

Dependability

This term refers to stability and shows that the findings are consistent and could be repeated, i.e. it is parallel to reliability in quantitative studies. In all of the papers, we tried, within the limited space allowed in the journals

(due to restricted maximum word count), to give a rich description in each step in the research process from the start of the project to the reporting of the findings, i.e. an audit trail could easily be followed through the whole process. Therefore, dependability was strengthened, according to the researchers.

Credibility

Credibility (parallel to internal validity) reflects confidence in the truth of the findings of a study and refers to the process by which the data are collected and the analysis procedures carried out. According to Lincoln and Guba (127), prolonged engagement, i.e. sufficient time at the research site, and persistent observation, i.e. detailed focusing on the elements that are considered most relevant to the study, are relevant in attending to credibility. In all the studies of this thesis, several researchers were involved in the analysis of the data, thus providing an opportunity to validate the findings, which can be seen to have strengthened the results through investigator triangulation (117). Data in all papers were collected from several settings, thereby using a variety of data sources. This *investigator triangulation* and *data triangulation* partly ensured credibility, providing assurances of a close link between the participants' views and the reconstruction of the findings (117).

Confirmability

Confirmability (parallel to objectivity) refers to the neutrality or objectivity of the data; the extent to which the findings of a study are shaped by the participants and not the researcher. *Audit trail*, *triangulation* and *reflexivity* are techniques to establish confirmability.

As described above (see under "dependability") the authors provided an *audit trail* for the reader in all the papers, since a rich description of each step of the research process from the start of the project to the reporting of the findings was given. *Data triangulation* as well as *investigator triangulation*, as described above under "credibility", were carried out in all the studies. Malterud describes *reflexivity* as "*an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process*" (126).

In **paper I**, researchers participating in study design and data collection were senior consultants in palliative care. When conducting the secondary analysis in 2014 (which developed into **paper I** in this thesis) the researchers participating in the analysis process were a general practitioner (LK) and senior consultants in palliative care and geriatrics (MK and AM). In **papers II** and **IV**, GPs (in **paper II**: LK, in **paper IV**: LK and MF) and senior consultants in palliative care and geriatrics participated in the

design, data collection and analysis. Having these backgrounds, meant that all the researchers had experience of meeting elderly people near the end of their lives, and the GPs had experience of working with NH patients.

In **papers I, II and IV**, several researchers, all physicians, participated in the data analysis, supplementing and contesting each other's readings and preunderstandings (126). Coding and the development of preliminary categories were mainly carried out by the first author (LK) and one of the authors with extensive experience in qualitative methodology (MK or AM), who discussed and revised the preliminary categories. Then, the whole research group (LK, MK and AM; in **paper IV**, MF also participated in this process) discussed the categories to find alternative possible interpretations, through a reflexive dialogue, until agreement was reached, not necessarily with the goal of achieving consensus.

The interviews in **papers II and IV** were all conducted by LK, who has experience of working as a GP, where dealing with NH patients is an essential part of daily practice. This fact could perhaps have influenced the answers given by the participants during the interviews. However, the interviewer was aware of this risk and related to it neutrally during the interviews as well as during the process of analysis, in her striving to be a *neutral investigator*. Through taking the pre-understandings concerning the topic into consideration, any bias due to her own influence was minimised (117).

Transferability

Transferability means showing that the findings of a research study have applicability to other contexts. Through giving rich descriptions, a type of external validation can be achieved, according to Lincoln and Guba (127). According to the researchers/authors of all the papers in this thesis, sufficiently rich descriptions of each step throughout the whole research process were given, thereby strengthening transferability. As **papers I, II and IV** are qualitative studies and therefore the purpose is not statistical generalisation from samples to a larger population, the term "transferability" rather than "generalisability" is preferred.

Other criteria used to measure quality of analysis

In **paper I** and **paper II**, trustworthiness, with its three components according to Graneheim and Lundman, i.e. credibility, dependability and transferability (123), was valued, as a complement to trustworthiness according to Lincoln and Guba presented previously (127). To value the quality of thematic analysis, Braun and Clark (125) refer to a 15-point checklist of criteria for good thematic analysis. This checklist was used in **paper IV** to evaluate the quality of the whole process regarding transcription, coding, analysis, overall expression and the written report. However, this was a

complement to evaluate the quality alongside the quality criteria according to Lincoln and Guba (127).

Statistical analyses

In **paper III**, data were analysed using IBM SPSS Statistics 27 (IBM Corporation, New York, USA) and Excel. Categorical variables were presented as numbers (n) and proportions (percentages), and continuous variables as medians and means. Pearson's chi-square test was used when comparing distribution of proportions between groups, and Fischer's exact test was used when the expected number was less than five in any cell. For group comparisons of continuous variables, the non-parametric Mann Whitney U-test was used, because the data was considered not to be normally distributed between the groups. For all analyses, a *p* value of <0.05 was considered statistically significant. A statistician was consulted about the results presented in **paper III**.

Validity, reliability and generalisability

The quality aspects of quantitative research are *validity*, *reliability* and *generalisability*. In **paper III**, using two different ACP definitions, of which one is EAPC-supported and consensus-based (59), strengthened the content *validity*. The RCR was mainly performed by one reviewer (LK), which could be seen as a methodological circumstance that may raise questions about *reliability* and subjectivity. However, a limited proportion of the medical records were also independently reviewed by one of the co-authors (MK), and the results were compared to ensure consensus in the interpretation and understanding of the findings. The fairly large study population consisting of individuals from 22 different NHs with broad variation (the NHs included in the study were long-term care homes including dementia care) from two counties supports the *generalisability* of the findings.

Ethical considerations

All the papers in the thesis were approved by regional boards of ethics (**paper I**: Dnr 97-042, 167-06, **paper II**: Dnr 2015/385-31, **paper III**: Dnr 2019-04699, **paper IV**: Dnr 2018/173-31).

Voluntariness

Participation was voluntary in **papers I, II and IV**. This was made clear when information about the studies were given. The participants were

informed of their right to discontinue participation during any phase of the studies, with no motivation needed. In **paper I**, neither of the physicians who performed the interviews were involved in the medical care of the participants. In **paper II**, the physician conducting the interviews did not share a workplace with any of the participating physicians or nurses. In **paper IV**, none of the researchers worked at any of the NHs from which the participants were recruited. In **paper III**, the participants being studied were deceased.

Confidentiality

Study participation was treated confidentially (117) in all papers. In **papers I, II and IV**, names and personal data of the participants were not digitally recorded. Where names, places or other identifiable data were mentioned in the interviews, this kind of data was anonymised and not given in quotations when reporting the results. The results of the studies were presented at a group level only. In **paper III**, the names and personal data of participants were treated confidentially and when searching the medical records of the deceased patients, only very few people were involved (two different administrators in the two counties and LK who made all the examinations of the deceased NH patients' medical records. A limited proportion of the medical records were also reviewed by one of the co-authors (MK)).

Sensitivity

Participants in **papers I, II and IV** were given information about the focus and aim of the study before starting the interviews, and during the interviews the researcher aimed to be very receptive to any discomfort exhibited by the participants. If the researcher had perceived such discomfort during an interview, a break would have been offered. The benefits of speaking about questions regarding the topics of the studies were believed to outweigh the risks of causing harm. No discomfort was observed during the interviews and none of the interviews had to be discontinued. In the interviews in **paper IV**, many of the participating family members being interviewed expressed a great need to speak about questions regarding EOL care and several participants expressed their gratitude.

RESULTS

Paper I: A good death from the perspective of palliative cancer patients

The qualitative analysis revealed that the participants viewed death as a process, not an event. Past experiences of the deaths of others had influenced the participants' views on what constitutes a good death. Four main categories were shaped during the analysis of the 66 interviews. These categories describing a good death were: *living with the prospect of imminent death*, *preparing for death*, *dying comfortably* and *on being dead*. Figure 4 illustrates these four categories.

Figure 4. Categories describing a good death.

Living with the prospect of imminent death

Participants said that their *view of life* was affected when facing death. Some experienced a *change of perspective* on life after having been diagnosed with cancer. Moreover, they expressed the importance of leading a meaningful life as death approached.

Preparing for death

Preparations for death included *preparing oneself* for death, such as sorting out unfinished affairs, saying good-bye to loved ones, making funeral

arrangements, putting things in order and writing down specific requests, as well as *preparing others* for their impending death, thereby minimising the suffering and burden for loved ones. *Acceptance* of one's own death was often described as important in the preparation for death. However, some participants had never accepted that death was impending.

Dying comfortably

This category included the moment and timing of death, as well as the presence of others and decisions regarding treatment and care. Participants often hoped for death to occur *quickly*, rather than experiencing a prolonged dying, which was associated with suffering for the patient him- or herself and their loved ones. Physical, social and psychological aspects of *independence* were valued. Some expressed fear of "being a package", and thus losing their autonomy and control as they became dependent on others. A good death was often associated with *minimised suffering*, e.g. freedom from pain and anxiety. Many trusted healthcare staff's competence, while others had experiences of suffering at the EOL from attending the deaths of others. Keeping *social relations intact*, e.g. the presence of family and loved ones through the dying process, was important for many of the participants.

On being dead

Some participants were comforted by their belief that *death is predetermined*, and that after death, there is something else. Others felt uncomfortable due to having the view that death is the *end of existence*.

Paper II: 'We have no crystal ball' - advance care planning at nursing homes from the perspective of nurses and physicians

Analysis of the 25 interviews using latent content analysis according to Graneheim and Lundman's approach (123), resulted in four manifest categories: *Exploration of preferences and views*, *Integration of preferences and views*, *Decision and documentation of the ACP* and *Implementation and re-evaluation of the ACP*. The latent theme *Establishing beneficence – defending oneself against tacit accusations of maleficence*, gave a deeper meaning to all four (manifest) parts of the ACP process (see Figure 5).

Figure 5. Overview of clinicians' perspectives on the different parts of the ACP process. All four manifest categories related to the latent theme *Establishing beneficence – defending oneself against tacit accusations of maleficence*.

Exploration of preferences and views

Exploration of the patient's preferences regarding the content of care and treatment limitations, as well as the views of family members and healthcare staff concerning these issues, was seen as important. Such exploration included EOL issues and, according to the participants, it was essential not only to focus on treatment limitations, but also to underline what to offer in specific potential situations, such as an acute deterioration of the patient's condition. Not knowing the patient was seen as a barrier to initiating ACP, while continuity enhanced the exploration. Participants highlighted the importance of undertaking ACP at an early stage, when the patient is still capable of articulating his/her own statements and preferences.

Integration of preferences and views

Integration of the patient's preferences and the views of family members and healthcare staff was important. The nurse was seen as a facilitator in this process, by preparing the patient and family members before an appointment with the physician, and through raising questions concerning preferences and views about EOL issues.

Decision and documentation of the ACP

Although the physician is responsible for decisions regarding the content of the ACP, including direction of care and treatment limitations, the views of nurses were taken into consideration concerning these matters, according to the physicians. To enable adherence to the content of the ACP, the documentation had to be available to staff and clearly written in order to avoid misunderstanding or subjective interpretations. According to the

participants, ACP content should be revised when the patient's condition deteriorates. Some believed that ACP documents should be revised on a regular basis, such as during an annual physician consultation.

Implementation and re-evaluation of the ACP

Besides the implementation of the ACP, re-evaluation was considered important, i.e. nurses following up with the patient and family members after an ACP appointment to confirm the content of the documented ACP, including direction of care and treatment limitations. According to the participants, when ACPs are not complied with, this could be due to the ACP document not being easily accessible to staff, different systems for documenting in patients' medical records, and staff becoming stressed and insecure in acute situations, causing non-adherence to ACP content.

Establishing beneficence – defending oneself against tacit accusations of maleficence

All the manifest categories presented above derived from the latent theme, *Establishing beneficence – defending oneself against tacit accusations of maleficence*, which gave a deeper meaning to the content. An important factor in establishing beneficence, i.e. doing what is perceived as best for the patient, is that the patient's preferences are taken into consideration. This deeper meaning also involved the nurses or physicians feeling uncomfortable and being afraid of causing harm to the patient, e.g. by raising EOL questions or making incorrect assessments of the patient's condition and prognosis. Adherence to the content of the ACP was seen as important for avoiding accusations of maleficence.

Paper III: Advance care planning in nursing homes: Does it matter?

Of the total study population (n=367), 86% died in their NH, while 14% died in hospital. Median residency in the NH was 26 months (range 0–140 months). Table 7 illustrates the content of the ACPs in the deceased patients' medical records.

Table 7. Overview of the content of the ACPs in the deceased patients' medical records. ACPs according to the broader definition (ACP I) used in this study were identified in 355 of the total study population of 367 cases. ^a Patient's preferences concerning direction of care and treatment limitations. ^b Family members participating in ACP, either physically or by phone. ^c A written instruction in the ACP to limit hospital care, such as: patient should never receive hospital care, or hospital care only in case of fracture, acute chest pain etc.

Variable	Number (%)	Median (range)	Mean (SD)
Number of ACPs per patient		2 (0-7)	2.2 (1.1)
Time from move into NH to first ACP (months)		8 (0-120)	18.5 (23.7)
Time from last ACP to death (months)		0 (0-37)	1.3 (4.5)
Patient's preferences ^a documented			
Patient's preferences present	117 (33%)		
Patient's preferences missing, no cognitive impairment	34 (10%)		
Patient's preferences missing, cognitive impairment	204 (57%)		
Family members involved in ACP			
Family members participating ^b in ACP	239 (67%)		
Family members informed of ACP content	305 (86%)		
Do-not-resuscitate order (DNR)	297 (81%)		
Hospital care limitation ^c	265 (72%)		

The vast majority of the study population (n=355; 97%) had at least one ACP for which the broader definition (ACP I) was fulfilled. ACP II, i.e. the narrower definition of ACP, was present for 77% (n=282) of the individuals. ACPs concerning serious respiratory-tract infections (Covid-19) during the 2020 pandemic were present in 74% and 17% of cases, respectively, in the two counties represented in this study. ACPs concerning palliative care, i.e. palliative care plans (in Swedish: "breakpoint decisions"), were documented in 86% of the study population. In 15 of the 52 patients (29%) without a palliative care plan, death occurred suddenly or without obvious deterioration prior to death, according to the medical records of these patients.

Table 8 shows that, among patients with hospital care limitations (written instructions in the ACP to limit hospital care, such as patients should never receive hospital care, or hospital care only in case of fracture, acute chest pain etc.) in ACP I or ACP II, both ED visits and inpatient care occasions were significantly less frequent than among those without such limitations. The most common reasons for ED visits among the 66 individuals in the study population despite hospital care limitations in the ACP were: infections (n=23), hip fractures (n=10), dyspnea (n=8), trauma from falls (n=4), suspected stroke (n=4), abdominal pain (n=3) and cardiac failure (n=2).

Table 8. Adherence to hospital care limitations^a in ACP (two different definitions: ACP I and ACP II) were evaluated by using frequency of ED visits and inpatient care during the final six months of the patient's life. Pearson's chi-square test was used for group comparisons of categorical data. *p* values <0.05 were considered significant. ^a Written instructions in the ACP to limit hospital care, such as: patient should never receive hospital care, or hospital care only in case of fracture, acute chest pain etc.

Variable	ACP I and hospital care limita- tions (n=265)	ACP I and no hospi- tal care limitations (n=90)	<i>p</i> value	ACP II and hospital care limita- tions (n=218)	ACP II and no hospi- tal care limitations (n=64)	<i>p</i> value
≥ One ED visit(s) dur- ing the pa- tient's final six months of life (n, %)	66 (25%)	50 (55%)	<0.001	53 (24%)	35 (55%)	<0.001
≥ One period of inpatient care during the patient's final six months of life (n, %)	52 (20%)	48 (53%)	<0.001	40 (18%)	35 (55%)	<0.001

There were associations between the presence of ACP and the variables in all three research aims of the study, namely background characteristics, physician attendance and EOL care (see Table 9). ACP II was positively associated with dementia, but negatively associated with cardiovascular disease and kidney failure. Physician consultations at NH during the final six months of the patient's life were significantly more common in individuals with ACP I than without ACP. Both ACP I and ACP II were positively associated with information being given to family members about the patient's deterioration and impending death, as well as prescriptions of palliative injections, which were twice as common in patients with ACP compared to patients lacking ACP.

Table 9. Overview of associations between ACP and background characteristics, physician attendance and EOL care. Pearson's chi-square test was used for group comparisons of categorical data. Fischer's Exact Test was used when the expected number was less than five in any cell. *p* values <0.05 were considered significant. Mann Whitney U-test was used for group comparisons of continuous variables because the data was not considered to be normally distributed. Two different definitions of ACP were used: ^aACP I included a proactive plan to handle deterioration in the patient. ^bACP II included the definition of ACP I, the patient's preferences concerning medical treatment and care (when cognitive impairment was not a limitation), and the involvement of family members. ^cAn employee's right to be off work in order to attend a closely related person who is seriously ill and receive financial compensation through Swedish social insurance. (In Swedish: *Närståendepenning*).

	No ACP I ^a n=12	ACP I n=355	<i>p</i> value	No ACP II ^b n=85	ACP II n=282	<i>p</i> value
Background characteristics						
Age at death (years; median, mean)	89, 84	89, 88		89, 88	89, 87	
Gender (n, %):			0.763			0.280
Female	7 (58%)	227 (64%)		50 (59%)	184 (65%)	
Male	5 (42%)	128 (36%)		35 (41%)	98 (35%)	
Death in NH	9 (75%)	306 (86%)	0.39	68 (80%)	247 (88%)	0.079
Diagnosis (n, %):						
Cardiovascular disease	9 (75%)	265 (75%)	1.00	74 (87%)	200 (71%)	0.003
Diabetes	0 (0%)	72 (20%)	0.13	20 (24%)	52 (18%)	0.300
Dementia	7 (58%)	218 (61%)	1.00	34 (40%)	191 (68%)	<0.001
Pulmonary disease	0 (0%)	51 (14%)	0.39	11 (13%)	40 (14%)	0.771
Cancer disease	3 (25%)	44 (12%)	0.19	11 (13%)	36 (13%)	0.966
Stroke	1 (8%)	81 (23%)	0.31	22 (26%)	60 (21%)	0.372
Psychiatric disease	5 (42%)	127 (36%)	0.76	24 (28%)	108 (38%)	0.090
Kidney failure	2 (17%)	61 (17%)	1.00	23 (27%)	40 (14%)	0.006
Physician attendance						
Number of physician consultations at NH during the patient's final six months of life (median (range), mean (SD))	1 (0–3), 1 (1.0)	2 (0–10), 2.2 (1.9)	0.003	1 (0–10), 2 (1.9)	2 (0–10), 2.2 (1.9)	0.708
EOL care						
Family members informed of the patient's deterioration	0 (0%)	296 (83%)	<0.001	41 (48%)	252 (89%)	<0.001
Family members informed of the patient's impending death	0 (0%)	282 (79%)	<0.001	40 (47%)	241 (85%)	<0.001
ED visits during the patient's final six months of life (median (range), mean (SD))	0 (0–1), 0.3 (0.5)	0 (0–4), 0.4 (0.7)	0.675	0 (0–2), 0.5 (0.6)	0 (0–4), 0.4 (0.7)	0.452
Inpatient care occasions during the patient's final six months of life (median (range), mean (SD))	0 (0–1), 0.3 (0.5)	0 (0–3), 0.4 (0.6)	0.606	0 (0–2), 0.4 (0.6)	0 (0–3), 0.3 (0.6)	0.317
Prescription of palliative injections	5 (42%)	331 (93%)	<0.001	66 (78%)	270 (96%)	<0.001
"Benefit for care of closely related person" certificate ^c	0 (0%)	64 (18%)	0.137	10 (12%)	54 (19%)	0.116

Paper IV: Elephant in the room – Family members’ perspectives on advance care planning

Thematic analysis of the 18 individual interviews generated five themes describing family members’ experiences of ACP in NHs. These themes were: *Elephant in the room*, *Also silent understanding*, *Significance of small details*, *Invisible physician – supporting nurse* and *Feeling of guilt*. The themes are shown in Figure 6.

Figure 6. Final thematic map illustrating the themes describing the ACP process in a NH context from the perspective of family members.

Elephant in the room

EOL issues were difficult to talk about. Some assumed that the patient was afraid of talking about such questions due to the risk of causing harm and sadness to family members. Sometimes, according to the family members, reluctance was also seen among healthcare staff to talk about EOL questions, perhaps due to a desire to avoid causing worry and sadness to the patient and family members. The participants emphasised the importance of healthcare staff raising these questions with the patient and family members, and preferably at an early stage, while the patient is still capable of making their own statements and expressing preferences. However, the

staff's attunement to the patient's and family members' readiness to discuss EOL issues was essential, according to the participants.

Also silent understanding

The patient's preferences might be explicitly communicated, but they could also be implicitly conveyed. In some cases, family members had a sense of the patient's wishes, even though their preferences had not been openly communicated. Silent understanding was based on knowledge of the patient's life, experiences and values, and the family members applying this in the current situation.

Significance of small details

Family members perceived everyday details as symbols of staff engagement, competence and commitment, and of how the patient was treated overall. Moreover, these details, such as staff undertaking more than just ordinary routine tasks, reflected trust that staff would follow the ACP and respect the patient's preferences and autonomy. Continuity was associated with staff being more personal, engaged and committed, according to the participants.

Invisible physician – supporting nurse

The nurse was seen as a gatekeeper, providing a first line of assessment, and reporting to, or consulting with, the physician when considered necessary. The role of the nurse in ACP was viewed as central, whereas involvement by the physician was often perceived as lacking. Consultations that had taken place with the physician preceding an ACP document frequently passed unnoticed.

Feeling of guilt

Family members expressed the desire to be involved in ACP, including decisions regarding the direction of care and treatment limitations. However, both involvement and lack of involvement could cause feelings of guilt among family members. They highlighted the importance of respecting the autonomy of the patient, and family members needed guidance on questions regarding decisions about the direction of care and treatment limitations. To limit family members' feelings of guilt, communicating EOL issues was seen as important in order to align ACP with the preferences of the patient.

DISCUSSION

One important reason to have EOL conversations and to establish ACPs is to proactively establish the four ethical principles set out by Beauchamps and Childress (128), namely: the principles of autonomy, beneficence, non-maleficence and justice. To comply with these principles, healthcare staff should provide care and treatments that are beneficial and avoid causing harm through investigations and treatments that are not beneficial. Moreover, the patient should be invited to participate in discussions concerning decisions regarding the content of care. In today's society, "the self" is central, both during life and also during the dying trajectory. According to Walter (23), postmodern society has adopted ideals of individualisation, independence and autonomy, and Walter further defines neo-modern death as one where individualisation and control of the dying is in accordance with the dying individual's own preferences (23). As concluded in **paper I**, in order to create conditions enabling the patient to experience a good death, in accordance with his or her own perceptions, staff caring for the patient need to investigate what constitutes a good death for each specific individual for whom they are caring. Moreover, in **paper I**, several categories describing a good death involved activities undertaken by the patient (e.g. preparing for death, independence, involvement in decision-making). These findings support the idea that healthcare staff caring for dying patients should inform them about their impending death, to enable further activity and to create conditions for the patient to live life until the end. In **paper II**, we concluded that exploration of the patient's preferences is essential in the ACP process, to enable all the aspects of individualisation, independence and autonomy. Moreover, in order to respect the patient's autonomy, the importance of undertaking such an exploration at an early stage, preferably while the patient is still capable of communicating his/her preferences concerning the direction of care and treatment limitations, was shown.

The results of **paper II** indicate that EOL issues and conversations about a patient's impending death can be challenging from the perspective of nurses and physicians. These findings are consistent with previous research findings (74, 76, 129-131). The perceived challenges might derive from difficulties in dealing with strong emotions (131) or fear of destroying hope or causing harm (74, 129, 130). However, Lundqvist et al. (89) showed that giving information to patients with terminal cancer about their impending death did not increase either their anxiety or their symptom burden. Instead, improved EOL care and conditions for experiencing a good death were shown. Informing the patient about deterioration and a poor

prognosis does not only include providing information about their impending death, but also involves how healthcare staff can support the patient in coping with that information (132). Maintaining hope has been identified as important to terminally ill patients and their family members (133-135). Furthermore, balancing hope with honesty seems to be an essential skill for healthcare staff. Clayton et al. (133) showed in a review that patients can sustain hope while also being aware of the terminal nature of their disease. These authors concluded further that healthcare staff should help patients to cope with their severe illness and encourage the development of realistic forms of hope. Hope could relate to the finding of a cure, prolonging life, preserving quality of life and/or achieving a good death (136).

Previous research has indicated that old and frail or severely ill patients, as well as their family members, often wish to be involved in EOL conversations and ACP (56, 65, 68-73, 94, 96). In line with this, we observed in **paper IV** that family members wanted to participate in the ACP process, although many said that these conversations were difficult and emotionally challenging. From the family members' point of view, it was considered best to have these discussions at an early stage. However, participants underlined the importance of healthcare staff being attuned to the patient's and family members' readiness to discuss EOL issues. The importance of navigating the patient's and family members' readiness when discussing these issues has been shown previously (74, 132, 136). Assessing optimal timing for these conversations can be difficult for healthcare staff. Abdul-Razzak et al. suggest asking the patient about readiness (136). Moreover, both patients and their family members might need time and repeated conversations when talking about patients' preferences at the end of their lives. Gjerberg et al. (73) highlighted that EOL conversations should be seen as a continuous process and that healthcare staff also need to be receptive to patients changing their preferences. This is consistent with the findings of **paper II** and **paper IV**, where the participants took the view that ACP is a process based on several conversations involving the patient, family members, the physician, nurse and other staff caring for the patient. Postponing EOL conversations, such as ACP, until later, or waiting for patients or their family members to initiate such conversations, could result in withholding patients' right to be involved in their EOL care.

We conclude, from the findings in **paper IV**, that EOL conversations can be challenging, not only for the patient and healthcare staff, but also for family members. Although it is understandable that people are reluctant to talk about death and dying, people who have experienced the crisis of impending death might find that communication is most difficult the first time and becomes easier with increased experience (137). When the patient and family members communicate in more meaningful and deeper senses,

they “may find a closeness and understanding that only suffering can bring” (137). Based on this view, inviting the patient and family members to have EOL conversations could be helpful, not only in the moment, but also for enabling further conversations between the patient and his or her family members to occur. According to our findings, good communication with patients and family members, as well as between healthcare staff seems to be fundamental to creating conditions in which patients near the end of their lives can experience autonomy, participation and a good quality of life as death approaches, and for family members to feel confident and involved in the care of their loved ones. Lack of time resources, as well as aspects of leadership and organisation, have previously been shown to be barriers to EOL conversations and ACP (69, 74, 75, 108, 109). NH staff find it challenging to make time for non-scheduled tasks, such as conversations with dying patients, given the limitations in resources (138). The importance of education for staff in EOL communication, awareness of the need for ACP and how the ACP process should be performed has been shown previously (74, 94, 139-141). In a randomised controlled trial, Aasmul et al. showed that implementation of an ACP intervention based on an education programme targeting physicians and nurses at NHs improved communication and family and staff satisfaction, as well as reducing staff distress (139). During follow-up, however, these positive effects did not persist, indicating that staff members need ongoing support and training regarding ACP, according to the authors (139). “Normalising” EOL conversations has been suggested to help encourage staff to engage in such conversations [140]. In a combined training/education intervention of internal medical residents with changes in clinic work, where all patients aged >65 years were asked about ACPs and preferences about discussing them before an appointment, Allen et al. (142) showed that the intervention resulted in increased confidence about discussing ACPs. Moreover, patients were interested in talking to their physician about their preferences (142).

Kübler-Ross (137) states that the patient can help his or her family members to meet his or her impending death in different ways. One such way is to share some of his or her thoughts and feelings with family members in order to help them to do the same. Moreover, according to Kübler-Ross, if the patient is able to work through his or her own grief and show family members how one can die with equanimity, the family members will remember his or her strength, and their own sorrow might be less heavy to bear (137). In the dual-process model of coping with bereavement developed by Stroebe and Schut (143), the dynamic, back-and-forth process, called oscillation, is central, and refers to the alternation between loss- and restoration-oriented coping strategies of grief (143). For the family member to go through the different stages of grief according to Kübler-Ross, and Parkes and Worden, described previously (23, 26), confrontation with the

reality of loss is essential (143). Family members' participation in EOL conversations with the patient, i.e. preparing themselves for the death of a loved one, could be one way of confronting the reality of loss, which is essential to the grieving process (143).

Previous research has reported that ACPs among NH patients are rare (52, 78-82). However, in **paper III**, we found a high prevalence of ACPs, since ACP was performed in the vast majority (97%) of the study population. When using the narrower definition (ACP II), which also required the patient's preferences (if the patient was capable of expressing them) and the involvement of family members, a high prevalence (77%) was still shown. It seems to me, working as a GP with elderly, frail patients at NHs in everyday practice, that ACPs for these individuals is a prioritised task for GPs in primary care. At the beginning of the Covid-19 pandemic, physicians working in some Swedish counties were encouraged to perform ACPs concerning serious respiratory-tract infections (Covid-19) in elderly, frail patients who were living in NHs or in those receiving home care. This was the case in Östergötland County Council, where I work. The intention with this work was to create proactive care plans for these frail patients in case of rapid deterioration with serious respiratory-tract infections and to decide upon treatment limitations, to avoid care or treatments that were not considered to benefit the patients. A few written instructions, which could be used as examples of formulations for the physician in the development of such ACP documents, were offered by a working group to facilitate this work. However, individual assessments and the involvement of both patient (if considered capable) and family members were repeatedly emphasised. Therefore, the work of developing ACPs concerning serious respiratory-tract infections should not be seen as a routine task on a to-do-list, but as an important proactive task aiming to offer the patient care and treatment that is considered to be of benefit and not harm. If not taking an individual approach, but instead having the view that this work should be done quickly in a check-list manner on a to-do-list without reflection or genuine accuracy, the important principles of autonomy, beneficence, non-maleficence and justice (128) would have been jeopardised in the performance of proactive plans during the Covid-19 pandemic.

The findings in **paper IV** demonstrate, from the perspective of family members, a perceived lack of physician presence at the NH, and little awareness of ACP appointments with physicians. Family members viewed the nurse as a central person, and nurses were often described as engaged, competent and committed. Modin et al. (144) showed that GPs were active in the care of patients receiving home nursing, although they seldom visited these patients. The fact that the patients were regularly assessed by nurses might have diminished the need for physician consultations, according to

the authors of that study (144). The central role of nurses at NHs is supported by Bollig et al. (95), who showed that trust-based relationships between nurses and NH patients, and between NH staff and family members, were essential. When planning care for NH patients, however, physician competence should be seen as central, not replaceable, since physician competence is needed when balancing risks, benefits and prognostic factors. It is also essential throughout the entire process of ACP, including exploring patient preferences and values, thus respecting the patient's autonomy, as well as informing and anchoring the ACP with the patient and family members.

According to our findings in **paper III**, adherence to the ACP content is strong, since ED visits and periods of inpatient care were significantly less frequent among patients with hospital care limitations included in their ACPs, compared to where such limitations were missing. However, even among patients with hospital care limitations of some kind, the frequencies of ED visits and periods of inpatient care during the final six months of the patient's life were surprisingly high, approximately 25% and 20% respectively. To the knowledge of the authors of **paper III**, studies on adherence to ACP content are missing; thus, comparisons with other studies regarding this question are not possible. Reasons for non-adherence to ACP content and treatment limitations when an acute deterioration of the patient's condition occurs could include uncertainty of prognosis and how to handle situations, as well as fear of being accused of maleficence, as shown in **paper II**. An increased focus in the ACP document on what staff could do in case of patient deterioration, instead of only focusing on what not to do (e.g. treatment limitations), might contribute to NH staff feeling safer and more secure about how to handle acute situations, thus creating conditions for stronger adherence to ACP content. Moreover, as shown in **paper II**, in order to achieve adherence to ACP content, the ACP documentation should be clearly written, with no room for subjective interpretation or misunderstandings. However, it is not possible for the physician to make plans covering every single reason for deterioration that could affect the patient. To quote one of the participants from **paper II**: "We have no crystal ball", i.e. we cannot predict either what will cause patient deterioration, or when the deterioration will occur. However, through the creation of ACPs, patients and family members are given the opportunity to talk about their values, preferences and views concerning EOL issues. Through giving them this opportunity, healthcare staff can help the patient to receive care in line with his or her wishes, thereby respecting autonomy even as death approaches. Moreover, family members might experience better conditions for handling grief in the process of losing a loved one.

Strengths and limitations

The strengths and limitations of **papers I, II and IV** are discussed in detail under “Trustworthiness” and those of **paper III** under “Validity, reliability and generalisability”. Here, a few additional aspects are discussed.

Generalisability is limited in **papers I, II and IV** because a non-probability strategic sampling was applied with the aim of reaching maximum variation (117). However, the results are transferable to similar settings (117).

Neither the sociocultural nor socioeconomic backgrounds of the participants in the studies of this thesis are known. One inclusion criterion for **papers I, II and IV** was being Swedish-speaking, and the vast majority of the study populations are presumed to be Swedish natives, which affects the transferability of the studies.

Data collection was conducted on two occasions for **paper I**, giving an opportunity to study whether the perceptions of a good death had changed over times. This gives strength to the results of the study. However, when qualitatively comparing the contents of the interviews conducted on the two different occasions, no such change was observed.

In **paper II**, all of the participating nurses and physicians worked in NHs. This could be seen as a limitation because interviews with clinicians working at EDs and nursing wards would have contributed to additional aspects and views on experiences of ACPs in NH patients.

In **paper IV**, the interviews with the family members of deceased NH patients were performed approximately three months after the death of each patient. The fact that some time had passed between the death of the patient and the time of the interview could have led to family members’ recall bias.

Including a researcher who was a non-physician in **papers I, II and IV** might have enriched the analysis. However, in all of these studies, the physicians constituting the research team had different clinical backgrounds, giving strength to the qualitative analysis of the data.

Clinical implications and future research

The results of this thesis have implications for healthcare staff caring for elderly, frail individuals, particularly in NHs, and individuals suffering from severe illness. To establish the principles of beneficence and non-maleficence, and to comply with the WHO definition (38) and the IAHP-supported consensus-based definition (39) of palliative care, healthcare needs to adopt an individualised view of dying patients. The results of this thesis,

and the findings of previous studies (74, 94, 139-141), indicate that EOL conversations require experience and communication training and that sensitivity and attunement to patient readiness for these conversations is essential (73, 74, 132, 136). Moreover, staff should consider thinking about their own values and preferences in relation to a good death. What I, as a physician, consider a good death might not be in accordance with my patient's views. As the perception of a good death is heterogeneous and great diversity has been shown, each patient who is near EOL should have the opportunity to describe what a good death means for him or her.

ACP documents in the patient's medical record facilitate physician decision-making concerning the direction of care when the condition of a patient deteriorates, such as shifting focus, when appropriate, from saving life to palliative care. Proactive planning through performing ACPs in this group of patients benefits not only the patient and family members, but also healthcare staff, such as physicians in charge who are not familiar with the patient, and the nurse and other staff working at the NH, as well as the entire healthcare system.

Some knowledge gaps were identified in this thesis and these raise ideas for further studies in this field. Since 1997 and 2007, when the interviews for **paper I** were performed, palliative care in Sweden has been transformed. General palliative care today is provided by municipalities in cooperation with primary healthcare. Only patients whose situations or symptoms are more complex will receive specialist palliative care provided by a specialist palliative organisation (45). Since a majority of the participants in **paper I** received specialised palliative care, transferability to settings where the majority of current patients with terminal cancer receive care might be limited. Therefore, further studies on patients with terminal-phase cancer who receive general palliative care may be able to add knowledge to this field.

The study designs of **papers I, II and IV** are qualitative explorative interview studies, while **paper III** is a quantitative retrospective chart review. Since all the participants in the qualitative studies of this thesis were Swedish-speaking, and the vast majority of the study populations would be native Swedes, studies on non-Swedish-speaking, foreign-born individuals' perspectives and experiences of ACP would add further aspects. A prospective study design involving interviews with patients and family members following the performance of ACP would increase the possibilities for patients' preferences to be considered and to minimise family members' recall bias. Observational studies filming meetings concerning ACP, or observational studies of clinicians and patients at NHs focusing on ACP, would also contribute to more knowledge within this field. Finally, interventional studies preparing patients and family members with a question prompt list,

i.e a list of questions targeting ACP, before an ACP meeting may help to overcome communication barriers and add useful knowledge regarding EOL communication and ACP.

With the global increase in the number of elderly in the population, more research about ACP in NH patients is needed. To facilitate comparisons between different study results, adaptation to well-established definitions, such as the EAPC-supported consensus-based definition of ACP (59) is essential.

As mentioned previously, a high prevalence of ACPs was found in **paper III**. The findings of this quantitative study raise many qualitative questions, which could be used in further qualitative research. What is really the incentive for the performance of ACPs to such a great extent? Is there an incentive to increase patient autonomy? Or is clinicians' fear of being accused of maleficence an underlying incentive? Is there a juridification going on within the field of medicine, which causes physician to perform ACPs in order to do what one is expected to do, without reflecting on the content of the ACP or the individual whom the ACP concerns, with the intention of protecting oneself against being accused of maleficence? Or is there an ethical incentive to the performance of ACPs, in order to make plans to benefit the patient? If so, why is it that patient involvement was not always present (even where the patient was considered capable of expressing his/her preferences) in **paper III**? Was there a lack of time? Or was the physician's fear of doing harm by raising EOL questions a reason for this? Were there perceived difficulties in talking about EOL issues according to the physician? Or was the patient in fact involved in the ACP, but such information was missing from the ACP document?

CONCLUSIONS

General conclusions

Based on the findings of the papers included in this thesis, we can conclude that the concept of a good death is complex and highly individual, although some recurring themes did emerge. EOL conversations are important and require training as well as experience and competence among the staff engaging in them. It seems important not only to perform ACPs, but also to involve the patient and family members in the process. Making proactive plans about the content of care, including treatment limitations, could enable patient autonomy, optimise the chances for the patient to experience a good death and enhance the experience of family members during the dying trajectory and after the patient's death.

Specific conclusions

Paper I: Patients' perceptions of a good death are highly individual and, although there is great diversity, some recurring themes do emerge, such as preparation for death, maintaining autonomy throughout the dying process and freedom from suffering. It seems important that staff caring for patients with severe illness should consider asking them to describe what they perceive as a good death, in order to identify goals for EOL care.

Paper II: Exploring patients' preferences regarding EOL issues and treatment limitations at an early stage seems important, as well as involving family members and staff in the ACP process in NHs. The significance of clinicians' perceiving beneficence as well as their fear of accusations of maleficence are essential factors to contemplate.

Paper III: A high prevalence of ACPs and adherence to the ACP content were shown in a Swedish NH context. There were positive associations between the presence of ACPs and dementia, physician attendance at NHs and EOL care (such as prescriptions of palliative injections and information given to family members about patients' deterioration and impending death). It seems important to perform ACPs and also to involve the patient and family members in the ACP process in a NH context.

Paper IV: EOL issues seem to be difficult to talk about. Sometimes, family members have a feeling for what the patient wants, even when their preferences have not been communicated, either explicitly or implicitly. Small details of the patient's everyday life in the NH symbolise staff competence.

To limit family members' feelings of guilt, EOL communication is important in order to perform ACP in accordance with the patient's preferences.

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*Somewhere over the rainbow, way up high,
there's a land that I heard of, once in a lullaby.
Somewhere over the rainbow, skies are blue.
And the dreams that you dare to dream really do come
true.*

H Arlen, Y Harburg

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Division of Prevention, Rehabilitation and Community Medicine

Linköping University
SE-581 83 Linköping, Sweden

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