

End-of-life care: Patients' preferences and relatives' experiences

with focus on communication and advance care planning

NINA ELISABETH HJORTH

Thesis for the degree of Philosophiae Doctor (PhD)
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The work in this thesis was conducted during the years 2014-2021.

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Collaborators:

The Norwegian network group for research and development of ACP, led by the Centre for Medical Ethics at the University of Oslo.

The international ERANet-LAC CODE (Care of the Dying Evaluation) project group.

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Introduction

As long as I can remember, different ways of communication have been of great importance to me. Communication at home, at school, with friends and with the elderly, verbally, or non-verbally like body language – and in the world of music. Music has been very important for me, and I have experienced how it can be an alternative language in times when other languages cannot express feelings and thoughts. Through lived experience, certainly, but also through my short period as student in psychology, I have seen how crucial it is, and how difficult it can be to communicate clearly, gently and respectfully at all times.

When I started to study medicine (1990), I thought I would learn how to manage clinical communication in a decent way, but had to realize the education was rather fragmented. I had to find my own role models after the criterion “what kind of doctor would I like to be”. So, I picked up something here, something there; I have stumbled, and I have failed. Sometimes, I have also stumbled into situations with good clinical communication, and felt thrilled by these experiences.

After ten years of practice as a physician (2008), mostly in hospitals, I discovered “SPIKE – A six-step protocol for delivering bad news: application to the patient with cancer”, which was encouraging as I realized I was not alone in demanding a better structure for clinical communication. The knowledge about structures for clinical conversations, and about psychological aspects of communication, may all be of help for the clinician in difficult clinical conversations. These clinical conversations are professional conversations, and in order to take good care of our patients during – and after – the conversations, we as healthcare professionals should know what we do, and what we ought to do, regardless of whether we, ourselves, have a good or a bad day.

At the same time that I discovered SPIKE, I experienced how difficult communication about prognosis and end-of-life (EoL) care can be. I was working at the Department of Thoracic Medicine, Haukeland University Hospital, at that time, and in 2012, I went to Dagny Faksvåg Haugen at the Regional Centre of Excellence for Palliative Care to search expert advice in order to help both me and my patients. Together with Katrin

Sigurdardottir, she introduced me to Advance Care Planning (ACP) – a certain kind of EoL goals-of-care conversations. With the knowledge I had at the time about the communicative needs of patients with advanced pulmonary diseases, I jumped to the conclusion that ACP would be the answer to my questions. Since then, I have learned so much more, and I have understood that conclusions need to be well-founded in research. I will be forever thankful for the kind guidance Dagny has given me into the academic universe of research! I have learned so much more than I thought I could. And I have understood how little I know about the academic art of research, and about communication: I am still not an expert in communication, as I am sure my family, friends and colleagues will confirm.

Now that this thesis has been completed, I hope this work may be of help for both clinicians, patients and relatives. Because of its potential contributions to better practice in clinical communication, I hope that ACP will be implemented at Haukeland University Hospital, and even in the rest of the Norwegian healthcare system. However, regardless of my hopes, this thesis will never be useless: I will be forever thankful for all I have learned from the patients, relatives and colleagues that have contributed to increase my knowledge about clinical communication, and for all I have learned from Dagny, Katrin and Margrethe about clinical and palliative care research.

Abstract

Background and aim: Advance care planning (ACP) is a communication process for mapping patients' priorities for end-of-life care. Preparing for an introduction of ACP in Norwegian hospitals, we wanted to explore patients' views on ACP and which topics they wanted to discuss, and how patients, relatives and clinicians experienced ACP conversations. Finally, we wanted to explore whether an invitation to ACP would influence perceptions about care and support among bereaved relatives.

Methods: Focus group interviews (2014-15) were conducted with patients having advanced pulmonary diseases. Based on the results, a semi structured ACP conversation guide was developed. Individual ACP conversations were held with hospital inpatients in an ACP implementation pilot (2014–2017). Clinicians' views on ACP were explored in focus group interviews. Responses to the post-bereavement survey of the ERANet-LAC International Care of the Dying Evaluation (CODE) project (2017-2020) in Argentina and Norway were studied to examine any associations between being offered an ACP conversation and perceptions about care and support. Transcribed focus group interviews and ACP documents were analysed by systematic text condensation, the survey results by descriptive statistics and mixed-effects ordinal regression models.

Results: Focus group patients (13) called for support, information and transparency, and they preferred an invitation to an ACP conversation at certain "turning points" in the disease trajectory. Both the invitation and the conversation itself should be patient-centred and individually tailored. In the pilot, 51 patients with advanced lung disease took part in ACP conversations; relatives participated in 18 of them. All participants appreciated the conversations. Four themes emerged: (i) disturbing symptoms, (ii) existential topics, (iii) care planning, and (iv) important relationships. Clinicians acted as gatekeepers for participation, but the documentation of the conversations revealed information previously unknown to clinicians. Many of them saw ACP as pertinent, and called for implementation resources. The post-bereavement survey had 276 participants (Argentina: 98). Fifty-six percent had been invited to ACP conversations, and their perceptions about care and support were significantly more positive than

those of the not-invited; in the latter group a majority (68%) would have wanted an invitation to an ACP conversation.

Conclusion: ACP should be offered, with a patient-centred approach, at turning points in the disease trajectory. An attention towards present and future symptom control may be useful. ACP may support patients and relatives by responding to their needs, whether emotional or practical, and providing tailored information. Important aspects for implementing ACP are management support, education, training, feasible routines and allocated time to perform the conversations, as well as safe and easily retrievable documentation and sharing of this between healthcare levels.

Norsk sammendrag

Bakgrunn: Forhåndssamtaler er en kommunikasjonsprosess for å kartlegge pasienters prioriteringer for behandling, omsorg og pleie i livets slutfase. Før introduksjon av forhåndssamtaler i norske sykehus, ønsket vi å utforske pasienters synspunkter på forhåndssamtaler, hvilke tema de ønsket å ta opp, og hvordan samtalene ble opplevd av pasienter, pårørende og helsepersonell. I tillegg ønsket vi å undersøke om forhåndssamtaler påvirket etterlattes oppfatninger om behandling og støtte i pasientens siste levedøgn.

Metode: Fokusgruppeintervjuer (Studie I: 2014-15) ble gjennomført med pasienter med langtkommet, livstruende lungesykdom. Basert på resultatene utviklet vi en semi-strukturert samtaleveileder som ble benyttet i 51 forhåndssamtaler med pasienter innlagt i sykehus (Studie II: Pilotstudie 2014-17). Helsepersonells erfaringer med prosjektet ble undersøkt i fokusgruppeintervjuer. Svar fra en spørreundersøkelse blant etterlatte i Argentina og Norge som ledd i prosjektet ERANet-LAC International Care of the Dying Evaluation (CODE) (Studie III: 2017-2020) ble undersøkt med tanke på effekter av forhåndssamtaler. Transkriberte fokusgruppeintervju og dokumentasjon av forhåndssamtaler ble analysert med systematisk tekstkondensering, resultater fra spørreundersøkelsen med deskriptiv statistikk og ordinale regresjonsmodeller for blandete effekter.

Resultat: Fokusgruppedeltakerne ba om støtte, informasjon og åpenhet, og ønsket tilbud om forhåndssamtale ved ulike vendepunkt i sykdomsforløpet. Både invitasjonen og selve samtalen måtte være pasientsentrert og individuelt tilpasset. Femtien forhåndssamtaler ble gjennomført med pasienter, hvorav 18 med også pårørende til stede. Alle deltakerne satte pris på samtalene. Fire tema ble avdekket: (i) Plagsomme symptomer, (ii) eksistensielle tema, (iii) planlegging av behandling, pleie og omsorg og (iv) viktige relasjoner. Helsepersonell opptredte som portvoktere for deltakelse, men verdsatte samtalereferatene hvor de fant nye opplysninger. Mange vurderte forhåndssamtaler som nyttige og etterspurte ressurser for implementering. Etterlatteundersøkelsen hadde 276 deltakere (Argentina 98). Femtiseks prosent hadde blitt invitert til forhåndssamtale, og deres inntrykk av behandling, pleie og støtte var signifikant mer positive enn hos de som ikke hadde blitt invitert; i den siste gruppen

hadde flesteparten (68%) ønsket å bli tilbudt en forhåndssamtale.

Konklusjon: Forhåndssamtaler bør ha en pasientsentrert tilnærming og tilbys ved vendepunkt i sykdomsforløpet. Oppmerksomhet mot lindring av nåværende og fremtidige symptomer kan være en nyttig innfallsvinkel. Ved å respondere på pasientenes behov, emosjonelle eller praktiske, og gi individuelt tilpasset informasjon, kan forhåndssamtaler bidra til å støtte pasienter og pårørende. Viktige punkter for implementering av forhåndssamtaler er ledelsesforankring, undervisning og opplæring, gjennomførbare rutiner og tid til å gjennomføre samtaler, samt oversiktlig og trygg dokumentasjon og deling av informasjon på tvers av nivåer i helsetjenesten.

List of publications

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Abbreviations

ACP	-	Advance Care Planning
AD	-	Advance Directive
i-CODE	-	International Care Of the Dying Evaluation
COPD	-	Chronic obstructive pulmonary disease
CPR	-	Cardiac Pulmonary Resuscitation
DFH	-	Dagny Faksvåg Haugen
DNR	-	Do Not Resuscitate
EAPC	-	European Association for Palliative Care
EoL	-	End of life
ESAS-r	-	Edmonton Symptom Assessment System revised
ICT	-	Information and Communication Technology
KRS	-	Katrin Rut Sigurdardottir
MAS	-	Margrethe Aase Schaufel
NEH	-	Nina Elisabeth Hjorth
NGO	-	Non-Governmental Organization
NHS	-	National Health Service (British)
OR	-	Odds ratio
PF	-	Pulmonary fibrosis
POLST	-	Physician Orders for Life Sustaining Treatment
PSDA	-	Patient Self-Determination Act
Q	-	Question
QoL	-	Quality of life
SDM	-	Shared decision making
STC	-	Systematic text condensation
WHO	-	World Health Organization

1. INTRODUCTION

“Cure sometimes, treat often, comfort always.”

(Hippocrates)

1.1 Medicine – and the palliative care perspective

Medicine reflects life itself, diverse and shifting, thus leading to many different medical branches and domains. Like a tree, the trunk, the Human Being, consisting of body, soul and spirit, connects them all. (In Greek: Soma, Psyche and Pneuma.) Most medical specialties have a focus on how diseases affect different parts of the body – the branches of the tree – such as cardiology, pulmonary medicine and gastroenterology, while other specialties are more rooted in the nature of the disease itself, like oncology and psychiatry. In a few medical specialties, the centre of attention is the patient as a whole, considering what impact diseases have on the human being – the trunk – by including psychosocial and existential aspects as well as physical elements. The specialties of family medicine and of physical medicine and rehabilitation often take this perspective, and for palliative care, it is fundamental.

Palliative care is treatment, care and support for patients suffering from life-threatening incurable diseases, and their relatives, with the aim of maintaining the best possible quality of life (QoL) (1). In order to give the patients the best possible care throughout the disease trajectory, healthcare professionals need knowledge about the patients’ understanding and interpretation of their situation, including their main goals of care, as well as medical knowledge about the disease itself and possible treatments and outcomes (2). This holistic, but also individual perspective demands exquisite

clinical communication, as well as interdisciplinary cooperation and teamwork across diverse medical specialties and care pathways (3). Palliative care is expedient when creating seamless and individual care pathways across a diversity of specialty-related borders (4). Starting out as a counterpart and a supplement to traditional Western medicine, palliative care slowly evolved into an integrated part of oncology, and has also during the last decades become increasingly important for patients within other medical fields (5-7). The growth of palliative care reflects a fading perception of the Human Being as a mechanistic organism, an increasing perception of the Human Being as an autonomous individual, and a decreasing belief in death as a failure of the medical profession (8).

*“The care of the dying demands all that we can do to
enable patients to live until they die.”*

(Cicely Saunders)

1.2 Palliative care – from England to the world

1.2.1 The need for and effect of a definition

The modern history of Palliative Care began with Dame Cicely Saunders (1918-2005) and the Hospice movement in England during the 1960s (9, 10). Explaining the holistic approach of palliative care, Cicely Saunders introduced the term “Total pain” – to illustrate the complexity of the Human Being with the *physical*, the *emotional*, the *social* and the *spiritual* components of pain. In England, though closely related to oncology, palliative care matured into an independent medical subject during the 1970s. The global need for this care approach cleared the way for a worldwide spread and development of palliative care, and the need for a definition (11). Among several definitions of palliative care, those elaborated by the World Health Organization (WHO) and the European Association for Palliative Care (EAPC) are now the most frequently employed (Text box 1). Promoting joint forces and a common path, the

definitions have been important for the development of the subject palliative care. This development has produced changes, which again have generated a need for new revisions of the definitions (2, 10, 12).

Text box 1 Two definitions of palliative care

The World Health Organization (WHO 2002) (13)

Palliative care

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

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- enhances quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

European Association for Palliative Care (EAPC 2009) (1)

Palliative care

is the active, total care of patients whose disease is not responsive to curative treatment. Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms. Palliative care is interdisciplinary in its approach, and encompasses the care of the patient and their family and should be available in any location including hospital, hospice and community. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death.

1.2.2 Palliative care in Norway – from a movement to a medical specialty

In Norway, palliative care has developed as a subject, mainly within oncology, with gradual growth and increasing systematization of the discipline since the beginning of the 1990s (6, 14, 15). In later years, palliative care has attracted attention from other medical specialties such as paediatrics, nephrology, neurology, cardiology, and lung diseases, adopting a palliative care approach for patients with non-cancer diagnoses (3, 5, 6, 16-18).

Even though palliative medicine has been recognized as a medical specialty in many countries, this is still not the case in Norway (11, 19, 20). However, strong signals from the professional community, as well as political authorities, have started the process of giving this discipline the necessary formal approval. A formal approval will probably give a more robust structure for teaching, research and development, leading to strengthened clinical palliative care services (21).

1.3 Palliative care – from fundamental principles to Advance Care Planning

1.3.1 If quality of life is the aim, patient-centred care is the base

Palliative care is about preserving the best possible QoL, as defined by the individual, thus making patient-centred care and patient autonomy fundamental terms in palliative care (1). A patient-centred focus is an approach to explore the patient's needs, conferring with the patient within the physical, psychosocial and spiritual domains, with the intention to provide tailored treatment and care (22, 23). In Norwegian healthcare services, like in most of the Western world, an increasing demand for patient autonomy has emerged, enforcing the need for patient-centred care (24, 25). The Cambridge Dictionary defines Autonomy as “the ability to make your own decisions without being controlled by anyone else”. However, the palliative care patient mostly experiences a narrower reality, framed by limitations of juridical, medical, familial, economic, organizational or social genre. These limitations are already well known in palliative care (8, 26). Palliative care professionals strive to

support the patients in preserving their autonomy and the best possible QoL by the use of proficient and skilled patient-centred clinical assessment and communication (27). Lamentably, the complexity of life itself, along with changes caused by the disease, often reduce the autonomy to a relational autonomy (28-30). This term, from feministic theories and medical ethics, may be explained by sayings such as “no man is an island”, meaning that even though autonomy is the norm, relations affect and may even diminish it (31).

1.3.2 Patient-centred care requests well performed clinical communication

Clinical communication is a professional form of communication in which qualified healthcare professionals lead conversations with patients, and often, their relatives (32, 33). The interaction between the participants may span from challenging to delightful (34-36). Themes in clinical communication are mainly diagnosis and treatment alternatives, prognostic factors and symptom management, but sometimes also disease-induced social changes in life (36). More seldom, there is a transparency and a room for psychologic and existential themes. Such themes are fundamental when exploring the patient’s basic values and attitudes, important for the individual’s QoL and thus also indicative for choices of treatment and care (8, 37). The art of clinical communication may be at its finest in the process of Shared Decision Making (SDM) (38, 39). In SDM, patients are given sufficient information to empower them to select their preferences about treatment and care, independently, though not alone - supported by their physician (40).

1.3.3 Prioritization in a prosperous society – demanding for both patients and physicians

During the last decades, an increasing trend of overtreatment has been seen in the affluent part of the Western world, reflecting the challenges caused by technological developments and complex treatment choices (41, 42). A combination of possibilities and fears intensifies the focus on treatment to such an extent that it may lead to overtreatment: Almost endless treatment options, many with marginal effect, but not without unpleasant or even dangerous side effects, challenge the physician and the patient to choose wisely. In addition, the fear of failing to do all that is possible, may

lead to overtreatment (6, 43). Predominantly, the problem of overtreatment within oncology is connected to futile use of new lines of chemotherapy and immune-modulating therapies during the last months of the patient's life (44, 45). Within cardiology and pulmonary medicine, the problem of overtreatment is similar, also connected to new therapies and technological possibilities (46-48).

1.3.4 Patient-centred clinical communication as a means against overtreatment and unnecessary expenditures

Risking overtreatment, prioritizing medical treatment and care evokes several ethical dilemmas concerning not only the patients' and their families' QoL, but also socioeconomic effects of expensive and possibly futile treatments (49).

The continuous work to elaborate wise and up-to-date guidelines for diagnosis and treatment within each specialty is highly important for the reduction of overtreatment. Elaborating national guidelines for the prioritization of health welfares is equally imperative, but *communication* may also be a part of the cure: At macro-level, there is a need for more information around the risks for and dilemmas of overtreatment near the end of life (EoL), both in the public domain and within the medical society. Within the medical society, a promising campaign with the intention of reducing overtreatment, "Choosing wisely", has spread since 2012, also branching off in Norway recently (50, 51). At micro-level, a focus on patients' relational autonomy and patient-centred care through systems promoting clinician-patient communication may be a central ingredient of the solution (52-55). Partly built on the principle of SDM, Advance Care Planning (ACP) has emerged as a useful system in palliative care for clinical communication about preferences and choices for EoL treatment and care (56, 57). In addition to promoting better communication between patients, relatives and healthcare professionals, ACP may contribute to a reduction of overtreatment (56, 58).

1.4 Advance Care Planning

– clinical communication about end-of-life care

ACP is clinical communication about a possible future situation when a life-threatening disease, or an acute illness/accident, reduces QoL and may even affect the patient's ability to speak up for him-/herself (59). Healthcare professionals invite patients and their relatives to ACP conversations with information exchange between all involved. Thus, on the one hand, ACP may increase patients' understanding about their diagnosis and prognosis and about relevant choices for treatment and care, and, on the other hand, provide relatives and healthcare professionals with information about the patients' wishes, preferences and priorities for the last phase of life. Another feasible outcome of ACP conversations is the possibility of choosing a proxy who can be the patient's representative in case of future cognitive incapacity (56). The precursor to ACP was Advance Directives (ADs), consisting of two main elements: a living will and a durable power of attorney (proxy). The idea of ADs developed over time and in many different countries (60, 61).

1.4.1 The international development from Advance Directives to Advance Care Planning

USA

The history of ACP began in the USA. Creating ADs was recommended from the mid-1970s, and a personal living will was legally binding at different levels from the late 1980s (61). However, a growing need appeared for committing healthcare professionals and relatives more firmly to the patient's preferences for EoL care. Experiences with comatose and severely brain-damaged patients who were artificially kept alive for years, led to a need for changes in the health legislation. Several cases, such as the Cruzan case, were only solved in court (62, 63). These litigations led up to The Patient Self-Determination Act (PSDA, USA 1991) imposing healthcare professionals to be responsible for giving written information about ADs, advising patients on their right to refuse or accept medical treatment, and to document completed ADs in the medical record (64). Due to different state or provincial legislations, AD documents have been respected to different extents. In addition, even

though legislation in favour of respecting ADs exists in many states, relatives and medical staff often have problems accepting ADs due to low validity of the content (65).

In 1997, the US Institute of Medicine (Committee on Care at the End of Life) launched ACP to compensate for the many inadequacies of ADs (66). The need to improve clinical EoL communication was prioritized above the need to complete documents and forms, although the change also contributed to an improvement of the content and reliability of the forms. Being more complete than ADs, but also more complex, the process of ACP conversations has ingredients such as SDM, documentation and sharing of central information from the conversations, recurring conversations, and if necessary, repeated revisions of the documentation, which may also include ADs.

Now, after thirty years with the PSDA in the USA, recent research has revealed that about 70 percent of elderly US citizens have completed ADs before they die (67). No other country can display similar results as USA; an incorporation of ADs into national legislation with a link to quality indicators seems to be essential for the high number of completed ADs (68, 69). The American Society of Clinical Oncology (ASCO) endorsed ADs as an indicator for quality of care by rewarding documentation obtained by the third visit with the oncologist, and for new cancer patients, ACP is required during one of the first three visits, according to the Oncology Care Model (70-72).

In Oregon during the 1990s, a system for clinical EoL communication was developed to compensate for the weaknesses of ADs: Physician Orders for Life Sustaining Treatment (POLST). POLST combines ADs with patients' wishes and a Do not resuscitate (DNR) order (56). SDM is used to assure the patient's wishes and preferences are included in the POLST documentation. The POLST form follows the patient, and it is now facilitated by electronic solutions increasing its availability.

Germany

From the 1970s, ADs developed in Germany from a "patient letter", via a "patient will" to a "patient advance directive". The start was slow during the first two decades

with a small percentage of completed ADs in the population (2.5% in 1998). After the turn of the millennium, an increasing interest arose, but without an equivalent increase in completed AD documents. After a long process with both discussions and litigations, a legislative foundation for ADs was elaborated and decided in 2009, but still only about twenty percent of the population complete their ADs (56).

Canada

In Canada, ACP developed in parallel with the USA and with the same diversity, partly connected to diverse legislation in different provinces. In contrast to the USA, Canada has a publicly funded healthcare system giving most Canadians access to healthcare, and this has been important for the implementation of ACP. The organization “ACP in Canada” which is rooted in the Canadian Hospice and Palliative Care Association, has been important for both research and implementation of ACP, and all the major relevant national professional associations and NGOs (Non-Governmental Organizations) are engaged in the endorsement of the implementation. The creation of a national framework for ACP (with four basic building blocks: 1. Engagement, 2. Education, 3. System Infrastructure and 4. Continuous Quality Improvement) has also been a major contribution to the implementation of ACP in Canada. From an early focus on EoL care in Canada, ACP is now increasingly associated with public health (56).

Australia and New Zealand

In both Australia and New Zealand, an early interest in ADs and then soon the successor, ACP, appeared. While Australia looked to Wisconsin, USA, and the Respecting Choices program in La Cross County, New Zealand adopted the Canadian ACP implementation model, “Four basic building blocks”, finding this suitable for a whole system approach putting the individual at the centre (56, 73). Both countries have a concept with “train the trainer” education, and national health authorities together with a national ACP platform (The National ACP Cooperative in New Zealand, and Advance Care Planning Australia, ACPA) have been promoters for a successful implementation of ACP. The use of comprehensible internet sites to spread information, encouraging both healthcare professionals and the public to start the

process of ACP, and to present ACP courses, templates, reports and research papers seem to be part of the foundation for a successful implementation of ACP in Australia and New Zealand. In Australia, the prevalence of completed ACP documents among older people (≥ 65 years) is about 30 % and the prevalence in New Zealand is believed to be about the same, though exact numbers are difficult to find due to a lack of published studies (74, 75). In both countries, there is a continuous engagement in order to increase the prevalence.

Great Britain

By giving individuals legal rights to appoint a proxy in case of incapacity, the UK Mental Capacity Act (2005) gave the British their fundament for ADs and ACP (76). The British have, however, had a focus on *conversations* about EoL care goals more than the *document* (AD) itself (77). The British National Health Service (NHS) creates general guidelines warranting for a fair nationwide healthcare system, but opening up for local variations. After a central NHS initiative in 2008 (the End of Life Care Strategy, Department of Health), different plans and strategies for EoL care were formed, such as: “Living and Dying Well” (Scottish Government, 2008), and “Living Matters: Dying Matters” (Department of Health, Social Services and Public Safety, Northern Ireland 2010). Accordingly, different ACP documents have also been made (“The Preferred Priorities for Care” and “Thinking Ahead”) (77). The documents are not legal documents, but aim to facilitate conversations between patients, relatives and healthcare professionals. Indirectly, the documents are included in the legislation: According to the British health legislation, patients should have the opportunity to talk about EoL care in advance, and before making care decisions on behalf of their patients, clinicians should esteem any care preferences available (Department of Health 2008). Unfortunately, the prevalence of ACP documents is persistently low; in 2016, only 4% of patients dying in hospitals had such a document (78).

1.4.2 Advance Care Planning – a pertinent alternative to Advance Directives

ACP thus evolved as a pertinent answer to the need for patient-centred care, for reduction of overtreatment and for taking care of both patients and their families near

the EoL, at the time of death and into the period of bereavement (56, 58, 59, 61). Thus gradually, a shift of paradigm has developed from a "legal transactional approach" (AD) to a "communication approach" (ACP) (61).

1.5 Facilitation of Advance Care Planning

Corresponding with the need for a definition of palliative care, the diversity of ACP programs generated a need for an international consensus about ACP practice (79). After a Delphi process, dr. R. Sudore and colleagues presented a definition in January 2017, and after an even larger Delphi process, the EAPC presented another definition nine months later (Text box 2) (79, 80). The two definitions are rather similar, and differ mostly in the wording, though there are some disagreements about where to focus. The major differences between the two definitions are:

- (1) The claim for decisional capacity (EAPC).
- (2) The emphasis on the *process of communication before documentation* (EAPC).
- (3) The *goal* of ACP: To what degree there should be a consistency between received medical care and patients' values, goals and preferences (Sudore et al.).
- (4) The emphasis on relatives as participants in ACP conversations (EAPC).
- (5) The emphasis on the appointment of a personal representative (EAPC).

More details about the definitions are given in Text box 2.

1.5.1 How to perform Advance Care Planning

Both Delphi processes came up with a set of recommendations for the facilitation of ACP conversations, and WHO supports these recommendations. However, the EAPC Delphi process led by Judith Rietjens was far more thorough and resulted in a more complete set of recommendations for ACP, fulfilling the requirements for an EAPC “white paper” on the topic (2017). The EAPC white paper on ACP, consisting of “timing”, “roles and tasks”, “the elements of ACP”, “policy and regulations”, and “the evaluation of ACP”, gives a robust foundation for the facilitation of ACP (80).

Text box 2 Two definitions of Advance Care Planning

Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care (Rietjens et al. 2017) (80)

Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers.

ACP addresses individuals’ concerns across the physical, psychological, social, and spiritual domains.

It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they at some point be unable to make their own decisions.

Consensus Definition of Advance Care Planning for Adults (Sudore et al. 2017) (79)

Definition statement:

(1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

(2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

(3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.

Invitation to Advance Care Planning

Timing: As stated in the EAPC recommendations, ACP engagement may be possible in all phases of life, but its content can be more targeted when the individual is approaching the EoL, either because of serious life-threatening illness or because of age. However, as personal values and preferences might change over time, ACP needs to be a process of several conversations with a resulting updating of the ACP documentation after each conversation (80). While the Delphi process lead by Sudore put the emphasis on how adults could be optimally supported in an ACP process, Rietjens et al. stressed the need for professional knowledge about triggers for ACP, the times and situations during a disease trajectory when patients may have a certain need to talk about their current and coming challenges.

Inviting: Both Delphi groups drew attention to how patients and their relatives should be invited to ACP conversations, and recommended matching the invitation to their readiness to engage in ACP. Rietjens et al. also claimed that the individual's readiness to engage in ACP should be respected when *performing* the conversations. In addition, the EAPC Delphi group recommended "exploring the individual's understanding of ACP, and explaining the aims, elements, benefits, limitations, and legal status of ACP". Healthcare professionals should encourage the patient to talk to their next-of-kin and include them in the ACP conversations (56, 59). Educating the population about ACP is also regarded as an important part of a thorough ACP program (80).

The Advance Care Planning conversations

Conversation guides: In order to facilitate ACP, many conversation guides have been created, some for certain patient groups (e.g., geriatric), and some for more general use (56, 81-83). In qualitative research, semi-structured guides have proven to be useful as they promote a natural flow of the dialogue (56, 84, 85). By giving help to ease as well as to structure the dialogue, semi-structured guides are also helpful for initiating and leading ACP conversations.

Roles and tasks: However, even with good guides for ACP conversations, experiences harvested through more than twenty years of ACP practice suggest to educate designated ACP facilitators to improve participation among both patients and

healthcare professionals (80, 86). The EAPC white paper states that any healthcare professional can perform ACP, provided they have the necessary skills to facilitate such conversations. These skills include “an openness to talk about diagnosis, prognosis, death, and dying with individuals and their families” as well as skills in empathic and person-centred clinical communication (80). Also, laypersons may be able to support the individual in ACP, provided they have acquired the necessary competence (80). The Royal College of Physicians recommends specific training for facilitators, regardless of profession, because they consider the conversations as possibly challenging (87). Even though ACP facilitators do not have to be clinicians, knowledgeable healthcare professionals are needed when diagnosis, prognosis and treatment options are on the agenda. Sometimes, a need will arise to explore whether the patient’s goals and preferences are realistic, thus demanding a facilitator who possesses appropriate professional competence in medical treatment and care (80). Because such conversations are normally personal and sensitive, they should preferably build upon a trusted clinician-patient relationship (56, 59, 80).

Elements of ACP: According to Rietjens et al., a person-centred approach is important when performing ACP, underlining that the conversations need tailoring to the individual’s health literacy, their style of communication and their personal values (80). Exploration is an important part of the process, and healthcare professionals, or lay facilitators, may explore the patient’s goals for future treatment and care by inviting to a conversation about different scenarios from the past, the present or an anticipated future. The exploration of the individual’s understanding of ACP, and needs for information about diagnosis, disease course, prognosis and advantages and disadvantages of possible treatment options and care options are all of equal importance (80). When appropriate for the patient and the situation, there may be a need to give information about the disease, treatment and care in the present and in the future. ACP might include clarification of goals and preferences for future medical treatment and care, and sharing thoughts and preferences with family and friends may be an important part of the process.

The possibility of writing an AD document and its legal status may be part of the conversation, and ACP might include the completion of an AD. The individual should be encouraged to share its content with family and healthcare professionals (80). During the conversations, the willingness to appoint a personal representative and what importance this may have for the individual may be explored, and the consequences, juridical and personal, of appointing a proxy may be discussed (80). With this abundance of possible themes for ACP conversations, it should be obvious that one conversation will seldom be sufficient, and that ACP should be a *process of conversations*.

1.5.2 Documentation – and regulations

Balancing patient autonomy and transparency: The patient record in transformation

The patient record has always been an important tool for the documentation of patients' medical histories, and for the exchange of vital information between healthcare professionals, thus contributing to structuring the information and increasing safety in patient care. During the last decades, two changes have influenced the patient record simultaneously: (1) The process of increased patient autonomy and patient participation has given the patients legal access to their own medical record. (2) The technological development has given new Information and Communication Technology (ICT) solutions for the electronic medical record and thereby eased the sharing of its content. Following this development while still ensuring both patient autonomy and confidentiality, there will be a need for patient involvement in the documentation of ACP.

For the documentation and sharing of contents from ACP conversations, ACP facilitators have to be healthcare providers with the appropriate professional competence and access (80). As recommended by Rietjens et al., ACP documentation needs to be formed in two parts: 1) In case of emergency, one part needs to have a structured, easy-to-read format for identification of specific goals and preferences, and 2) An open-text format for the description of the individual's values, goals, and preferences (80). However, the problem of retrieval and sharing across different health

organizations and between specialist and generalist services is still not completely solved (68). As outlined by the EAPC, healthcare organizations need to develop reliable and secure systems for storage of ACP documentation, as well as for retrieval, sharing and updating of the documentation (80).

1.5.3 Policy and regulations

The EAPC recommendations for ACP state that either healthcare organizations, governments or health insurers should be responsible for developing potential triggers for the initiation of ACP, as well as securing appropriate funding and organizational support for ACP. Rietjens et al. also state that laws should be designed with the purpose of respecting the results of an ACP process (such as a surrogate decision-maker and ADs) as a legally binding guidance for medical decision-making.

1.5.4 Effects of Advance Care Planning – and how to measure them

Effects of Advance Care Planning

An observed consequence of ACP is an EoL care that holds better quality and is more closely aligned with the patient's preferences (88). Also, the relatives seem to benefit from ACP as it may contribute to a reduction of stress and anxiety, both before and after the death of the patient (89). Performed ACP seems to lead to a reduction of purposeless life-sustaining treatment and unwanted hospital admissions, and to an increase of hospice care and palliative care (90). However, some studies have failed to verify these positive effects of ACP (91, 92). Reasons for the diverging results may be related to study settings with diverse starting points for dissimilar ACP interventions, the use of different outcomes, and diverse methods for the measurement of possible effects (58, 93).

How to evaluate the effects of Advance Care Planning

Both Delphi process groups pointed at the importance of finding the best approach for the evaluation of ACP, and the EAPC group listed fourteen topics for evaluation. In order to promote consistency in evaluations, EAPC encourages the application of these topics (Text box 3). Knowledge about ACP and readiness to engage in the process are among the first topics. Next, the content of the conversations is targeted: If goals and

preferences are communicated with family members, and with healthcare professionals, if a personal representative is appointed, and if important issues from the conversations are documented. The guidelines advise to ask the participants (patients, family, healthcare professionals) to rate the conversation (according to meaningfulness, quality, and satisfaction), and finally, to assess the “use of healthcare” during and after a process of ACP, and the consistency between the care received and the expressed goals and preferences (Text box 3) (80).

Text box 3 Evaluation of ACP according to the EAPC white paper on ACP (80) (Recommendations number 27 and 28)

27	Depending on the study or project aims, we recommend the following constructs be assessed:
A	Knowledge of ACP (rated by individuals, family, and healthcare professionals)
B	Self-efficacy to engage in ACP (rated by individuals, family, and healthcare professionals)
C	Readiness to engage in ACP (rated by individuals, family, and healthcare professionals)
D	Identification of goals and preferences
E	Communication about goals and preferences with family
F	Communication about goals and preferences with healthcare professionals
G	Identification of a personal representative
H	Documentation of goals and preferences
I	Revision of ACP discussions and documents over time
J	Extent to which ACP was considered meaningful and helpful (rated by individuals, family, and healthcare professionals)
K	Quality of ACP conversations (rated by individuals, family, and facilitators or healthcare professionals, or both)
L	Satisfaction with the ACP process (rated by individuals, family, and healthcare professionals)
M	Use of healthcare
N	Whether care received was consistent with the individual’s expressed goals and preferences

28

We recommend identifying or developing outcome measures based on these constructs so that results can be pooled and compared across studies or projects; these outcome measures should have sound psychometric properties, be sufficiently brief, and validated within relevant populations

1.5.5 Barriers for initiating Advance Care Planning

Even though international research has shown positive effects of ACP, barriers for the initiation of the ACP process are numerous and frequent. Some barriers are clinician-related, some patient-related and some more related to organizational factors.

Healthcare professionals

Healthcare professionals may lack medical knowledge about expected disease trajectories, or lack knowledge about palliative care. Even though on retreat, paternalism among clinicians may lead to withholding of information in order to protect the patient from despair and anxiety (94, 95). Lack of skills in clinical communication and ACP may negatively influence the uptake of ACP (94, 95). Even if they recognize the need for ACP, professionals may still question the right timing and setting for starting the process, and in addition, the delay of a palliative diagnosis may postpone the initiation of ACP (94).

Patients

Patients may have poor medical literacy and lack insights into their own disease, expecting that clinicians will initiate ACP when appropriate (95, 96). Positive thinking is often a disguise for a dread of talking about EoL themes, leading to refusals of ACP offers out of a hidden fear of abandonment or death (94, 97). Some patients blame themselves for being ill and carry a burden of a detaching shame, making them refrain from ACP conversations (96). Others may experience an insidious deterioration from a deadly disease as a normal part of the ageing process, without understanding the seriousness of the situation (96). Patients and relatives often protect each other from emotionally tough situations and thus refuse offers of ACP conversations (36).

Organizational factors

The presence of a clinical culture focusing on treatment at all costs may be a barrier for palliative care and ACP, and lack of continuity of care dissolves the responsibility of initiating and following up the ACP process (95). Lack of support from the management and lack of formal training on communicating EoL care options may also be barriers (95).

In hospitals, time limitations often prevent clinicians from offering ACP, thus reflecting the hectic schedules of both patients and clinicians. Jabbarian et al. found time barriers to be partly a system error and partly an individual (health worker) prioritization of the time available (95).

1.6. Advance Care Planning in Norway

1.6.1 Limitation of life-prolonging treatment in the postmodernist society

Norway has had its own EoL conflicts between relatives and healthcare professionals. The tragic “Kristina case” from 2005 is maybe the best-known case in which healthcare professionals and relatives disagreed about treatment intensity and when to consider the treatment as futile (98). This case underlined the importance of communication between all relevant parties, including the public, and contributed to a change in procedures for termination of futile intensive medical care (99). In 2009, the guideline “Decision-making processes for limitation of life-prolonging treatment” was first published (revised in 2013) as a support for healthcare professionals dealing with ethically challenging cases near the EoL (100).

1.6.2 Patient involvement – and the right to refuse

According to Norwegian health legislation, patients have the right to receive relevant and necessary information in order to be able to understand their own health condition and the treatment offered (101). Physicians have a duty to provide patients and relatives with relevant information. However, patients have a right to refuse both information and treatment, showing the importance of asking patients about their individual needs and preferences for information (101).

1.6.3 Lack of continuity in healthcare

Relating to different carers at different levels of the healthcare system, many patients experience fragmented care. Especially in the hospital sector, there is a lack of continuity in care through the disease trajectories, and non-communicating electronic medical records do not ameliorate the communication between hospital and primary care services (19, 102, 103). This fragmentation weakens the patient-doctor relationship and dissolves the responsibility, thus threatening the treatment safety (104). The value of planning for palliative care, EoL care, and for other serious illness scenarios, is less recognized than the importance of making plans for cancer treatment (95, 105). A systematic introduction of ACP in Norway may contribute to a reduction of these communicative problems, and in the creation of care pathways (19, 106, 107).

1.6.4 Pulmonary medicine – a compound group of disorders with a common palliative denominator

Pulmonary medicine is one of the branches of the tree of medical specialties. The major medical focus is on how diseases affect the body, in particular the lungs. Due to this organizing style, the same healthcare professionals treat such basically different diseases as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis (PF) and different malignancies of the lung. Embossed by sudden exacerbations, the disease trajectory for COPD is often winding, while the trajectories for PF and lung cancer have a more consistently falling slope towards the end. Among the public, COPD, as opposite to cancer, tends not to be recognized as a mortal illness, and PF is a rather unknown and insidious disease (108). Nevertheless, a common mutual denominator towards the EoL is the increasing burden of symptoms, such as dyspnoea, fatigue, cachexia, anxiety and depression, and even pain, thus necessitating exquisite clinical communication and palliative assessment and care. Unfortunately, among neither patients nor professionals these needs are well-pronounced (95, 109-111). Especially patients with COPD seem to have barriers toward EoL communication, even though research has pointed at their need for ACP as well as special concerns to consider when introducing the conversations (94, 112-114).

1.6.5 Increasing focus on clinical communication in a prosperous society

In Norway - a prosperous society - dilemmas about prioritization and overtreatment are well known, and like in many other Western countries, an increasing focus on clinical communication has accompanied the increasing claim for patient involvement and autonomy (115-117). At the same time, palliative medicine has become a new branch shot to the tree of medical specialties. Even though palliative medicine is not entirely integrated into the Norwegian medical community, its pertinent contributions to patient-centred care and to clinical communication are increasingly known. Correspondingly, the need for ACP is increasingly acknowledged by healthcare professionals as well as by the health authorities (19, 106, 107).

1.6.6 Clearing the path before implementation of Advance Care Planning in Norwegian hospitals

During the last decades, a growing interest for clinical communication, SDM and ACP has emerged, and some research projects on ACP have been carried out (118-122). In nursing homes, variants of translated ACP guides have been in use for some time. As ACP is not in general use in Norway, most patients have not had such a conversation before admittance to a nursing home. At the time of admittance, a substantial number of patients suffer from moderate to advanced dementia, affecting their decision-making capacity to some or a significant extent (123, 124). During recent years, research on ACP in Norwegian nursing homes has displayed the important role of the relatives as the patients' spokespersons by virtue of a profound knowledge about the patient's attitudes and values during life (96, 121, 125-127).

ACP is not used systematically in any Norwegian hospital, but some pilot projects have been carried out, and the use of SDM in oncology is increasing (128-131). Implementation of and research on both SDM and ACP are implored by the health authorities (3, 14, 19, 24, 132).

International research has revealed many barriers to ACP, but also that ACP is in the midst of person-centred care. Believing that ACP will be an important contribution for patients and the healthcare system in Norway, we wanted to explore the usefulness and

feasibility of introducing ACP in a hospital setting, and we performed a project in three parts. Experienced in the field of Pulmonary Medicine and Specialist Palliative Care, it was expedient to focus on patients having advanced pulmonary diseases, with the already explained challenges concerning communication (1.6.4). The patients' views on ACP and their pronounced needs for EoL communication should be essential when creating a Norwegian ACP guide for this special group of patients. As healthcare professionals may find ACP conversations challenging to initiate as well as to perform, we saw the need for piloting our Norwegian ACP guide on a Thoracic Medicine ward. Finally, an international research project gave the opportunity to explore – in both Argentina and Norway – whether an invitation, or the lack of an invitation, to an ACP conversation had any influence on bereaved relatives' perceptions about EoL care.

2. AIMS

2.1 The overall aim

The overall aim of this PhD project was to illuminate conditions for successful implementation of ACP in Norwegian hospitals.

2.2 Specific aims

2.2.1 Study I

To explore the needs and preferences for ACP in patients with advanced incurable pulmonary diseases.

2.2.2 Study II

To pilot a simple ACP guide in conversations with inpatients with advanced pulmonary disease on a Thoracic Medicine ward.

- To explore which topics patients brought up during the conversations.
- To assess how patients, relatives and staff experienced and evaluated the contents and the feasibility of performing ACP.

2.2.3 Study III

To use data from an international post-bereavement survey in which questions about being offered an ACP conversation were included for participants from Argentina and Norway, to answer the following questions:

- What proportion of the bereaved relatives were offered an ACP conversation?
- What proportion of the relatives that were not offered an ACP conversation would have wanted it?
- Were there differences in outcomes between the relatives offered an ACP conversation and those not, with special reference to communication issues and emotional and spiritual support?
- Do the answers to the above questions differ between participants from Argentina and Norway?

3. METHODS

This thesis is based on a research project in three parts (Table 1): In the two first studies, mainly qualitative methods were used, while quantitative methods were used in the third study:

- Study I: A focus group study with patients.
- Study II: A pilot study of ACP conversations, involving patients, relatives and healthcare personnel.
- Study III: A post-bereavement survey involving relatives.

Table 1 Synopsis of the three studies

STUDY	DESIGN	SETTING	MATERIAL	POPULATION
I	Qualitative interview study	Hospital department	Four focus group interviews	A purposive sample of in- or outpatients (13) with advanced pulmonary disease
II	Qualitative text analysis and interview study	Hospital department	51 summaries of ACP conversations Two focus group interviews	Inpatients with advanced pulmonary disease Ward staff
III	Survey	Hospital departments in Argentina and Norway	276 survey questionnaires, filled in through self-completion or via interview	Bereaved relatives after cancer deaths in hospitals

3.1 Study I: The focus group study

In Study I, we intended to explore the thoughts, attitudes, wishes and needs patients with advanced pulmonary disease had towards ACP. With this intention, a qualitative

study design would be the method of choice (133-135). We decided upon a focus group study, as this method integrates the interview within the process of a group conversation (85, 136). A focus group interview allows the participants to interact with each other while discussing the topic of interest, thus stimulating each other's cognitive processes, with minimal interference by the moderator (137). This group process may produce a richer – and less controlled – result than individual interviews, opening up for new information about the subject studied (136, 137). All the researchers in cooperation made the interview guide for the focus groups during an interactive process.

3.1.1 Study setting

The focus group interviews took place at the outpatient clinic of the Department of Thoracic Medicine at Haukeland University Hospital in Bergen, Norway.

3.1.2 Population

Patients receiving treatment for advanced lung cancer, COPD or PF were eligible for inclusion. To be included in a focus group, participants should be over 18 years old, diagnosed with non-curable pulmonary disease, able to communicate orally in Norwegian, able and willing to provide written informed consent and an in- or outpatient at the Dept. of Thoracic Medicine. Exclusion criteria for focus group participants were cognitive impairment or other circumstances (e.g., anxiety, impaired hearing, reduced functional ability) representing a severe challenge to group participation and dynamics.

3.1.3 Recruitment

Striving for a purposive sample with a diversity in age, sex, diagnosis and education, the recruitment phase lasted from January 2014 to February 2015 (138). In addition to a dedicated study nurse, both physicians and nurses working at the Dept. of Thoracic Medicine contributed to recruiting patients to the focus groups. Most participants were recruited from the outpatient clinic, while some were recruited from the inpatient wards. Several of the recruited patients had advanced disease, and fearing attrition due

to worsening of their condition, an interview was carried out as soon as a small group was recruited.

3.1.4 Participants

Among the 42 patients approached, 17 (40%) agreed to participate, but only 13 managed to contribute, due to a deteriorating condition of the remainders. The 13 participants were divided between four focus groups. The participants had a mean age of 65 (range 52-80), one was Danish, twelve were Norwegian, seven were females. The participants had worked as shop assistants (4), healthcare workers (2), sailors (2) or office (3) or factory workers (2). Three lived alone while the rest lived with their spouses. Seven had lung cancer, four had COPD stage IV and two had PF. One had WHO performance status III, three had performance status II and the rest (9) I. Overall, their symptoms were fairly well controlled, with tiredness and dyspnoea as the worst complaints (mean score 5 on Edmonton Symptom Assessment Scale revised (ESAS-r); NRS 0-10).

3.1.5 Data collection

The interviews were moderated by N.E. Hjorth (NEH) while co-supervisor M.A. Schaufel (MAS) served as secretary. Since the concept of ACP conversations was not known among the participants, the moderator started all four interviews with a brief introduction about this concept. After that, the focus group interview guide was used, supplemented with additional questions when the conversation tended to halt or when some participants were too eager at the expense of others (Table 2).

Table 2 Interview guide for the focus group interviews in Study I

OVERALL QUESTION:	DO YOU THINK THERE IS A NEED FOR ACP CONVERSATIONS?
THREE MAIN QUESTIONS	<ol style="list-style-type: none"> 1. <u>With whom</u> would you like to have a conversation about preferences and wishes for the last phase of life? 2. <u>Which themes</u> would be relevant in such a conversation? 3. <u>When</u> will be the right timing for a conversation about planning the last phase of life?

SUPPLEMENT QUESTIONS	<ol style="list-style-type: none"> 1. <u>Where</u> would be the right place for such a conversation? (At home? In the hospital, on the ward or at the outpatient clinic?) 2. <u>Which parts</u> of such a conversation would be acceptable and appropriate to <u>document</u> in the medical record? 3. Relevant follow-up questions to avoid misunderstandings, <u>without privately invading questions</u>.
AFTER THE INTERVIEW	<p>Check out whether the participants have questions or reactions related to the interview. If so, offer to discuss them in the group, or privately with the moderator and secretary, or offer a conversation with a nurse* at the Department of Thoracic Medicine.</p> <p>(*An appointed nurse who was not part of the research group.)</p>

Before the interview, the participants were given oral and written information about ACP and the project, about the research method, including the need for an internal confidentiality within the group, as well as the questions set up in this interview guide. The interviews lasted 49–66 minutes. The audio files were transcribed word-for-word by a secretary. According to the concept of information power, data collection was closed when the collected data were assessed adequate for illuminating the research topic by the research group, i.e., data saturation was obtained (138, 139). To characterize the study population, demographic and medical information was collected from the medical record.

3.1.6 Analysis

To support the analytical work, we took reflexion notes as well as documented the different choices we made in a decision trail (140). Systematic Text Condensation (STC) was used to analyse the transcripts. This is a cross-case thematic analysis, pragmatic and suitable for analysis of semi-structured interviews (individual or focus group), written texts and observational studies (85). Kirsti Malterud has developed this descriptive and explorative method (137, 139). Clear and concise, the method is well explained by Malterud in four steps (Table 3), making it easy to use also for new and inexperienced researchers as was the case here (first author). Because we had rather concise research questions and did not strive for new theories or new hypotheses, STC stood out as the best alternative compared to other methods for qualitative analysis,

such as used in phenomenological or narrative traditions or in Grounded theory. Table 3 presents an overview of the four steps of analysis in STC, also explained more in detail in the following paragraphs.

Table 3 The Systematic Text Condensation (STC) method by Kirsti Malterud

The FOUR STEPS of STC	DESCRIPTION of the ANALYTIC PROCESS
Step 1: Obtaining an <u>overall impression</u>	Read the material to obtain an overall impression. Associate with previous preconceptions, and make preliminary themes.
Step 2: Identifying <u>units of meaning</u>	Identify units of meaning, and make coded groups and subgroups. These represent different aspects of the informants' views on and experiences in the field explored.
Step 3: <u>Abstracting</u> the meaning	Abstract the meaning within each of the coded groups and subgroups to make condensates, and illustrate each with a citation.
Step 4: <u>The generalized descriptions:</u> Reflecting the most important issues that are reported by the informants	To reflect the most important needs and perspectives regarding the research topic as reported by the informants, summarize the contents of each coded group and make them into generalized descriptions and concepts.

The stepwise analysis of Systematic Text Condensation in Study I

Having no predefined categories for study I, the four transcribed focus group interviews were the basis for this analysis. In order to ensure a thorough and broad analytic process while enhancing intersubjectivity and reflexivity, MAS and NEH cooperated on this analysis, negotiating units of meaning and looking for descriptions that would shed light on what ACP meant for patients with advanced pulmonary diseases. The stepwise analysis was data-driven and done successively alongside with new interviews that supplemented the results until the reach of saturation when no new information appeared (138, 139). Below (items 1 to 4), the method STC is further described, followed by a short résumé of the actual step in the analysis of Study I:

Step 1 Total impression – from chaos to themes

First, the analysts read all the transcribed text in order to get an overview of the data and discover preliminary themes. Striving for an open mind and lending a respectful ear to the voice of the participants, the research questions may influence this step, but preconceptions should not dominate in the search for preliminary themes. This aspect underlines the need for knowing the analysts' preconceptions.

The analytic process started with interviews 1 and 2, and proceeded through steps 1 to 3 before the analysis was supplied with interviews 3, and then 4, successively. MAS and NEH found 4 and 5 preliminary themes, respectively, which were rather similar, and after negotiation the list of preliminary themes consisted of: 1) Team player; 2) Give me what I need; 3) The dramatic turning point; and 4) The difficult, but important transparency. The preliminary themes appeared to be expedient; supplementary interviews 3 and 4 fitted into the same pattern.

Step 2 Identifying and sorting meaning units – from themes to codes

At this stage, the researchers carefully read the text over again, searching for elements of meaning related to the issue studied, thus systematizing the text according to the research questions, creating new codes. The coding process consists of identifying, classifying and sorting these units of meaning under the negotiated themes. Step two requires time and flexibility because the researchers will need to go back and forth in the text and the decision trail to consider, and to reconsider, as new codes emerge, and sometimes replace the first ones. This reorganizing of the units of meaning creates new pairings of text fragments and is called "decontextualization".

MAS and NEH did step two manually, by literally cutting the units of meaning out of the transcribed text, followed by sorting the units into envelopes marked with the preliminary themes. Next, we critically discussed and negotiated the codes. We ended up with categories that corresponded well with the preliminary themes from step one.

Step 3 Condensation – from code to meaning

Abstraction of the content is achieved by condensation: The text, consisting of systematized meaning units, is transformed into artificial quotations. The detachment

and mixture of the meaning units in this part of the analysis promote the anonymization of the participants. Specific original quotations that illustrate well the different codes – and sub codes – are saved for use in the Results section.

Condensing all the text from the units of meaning equally to avoid any bias due to preconceptions, we tried to maintain the participants' original terminology as far as possible. Again, interviews 1 and 2 were first analysed, then successively 3 and 4. This led to some regrouping and re-systematization within each code group, but still without any significant change from the former grouping of themes and codes.

Step 4 Synthesizing – from condensation to descriptions and concepts

At step four, the condensates from step three are re-conceptualized by systematically synthesizing and contracting the artificial quotes into new, coherent stories. The researcher acts as a re-narrator telling the stories in third person in a generalizing style, but with one eye on the original context to ensure validity, and the other eye on the research questions to evaluate whether the story, grounded in the empirical data, really answers the questions. Checking the results against the researchers' preconceptions and against what already is known about the research theme is also an important part of the analysis at this step. A refined step four condensate may be used directly as the result part in an article.

Reconceptualization of the condensates gave cross-case knowledge about what patients suffering from life-threatening pulmonary disease needed concerning communication about EoL issues. The headings we found suitable at this stage matched quite well the former preliminary themes and codes, and were formed as imperatives giving the participants in the focus groups a clear voice: 1) "Provide good team players"; 2) "Offer conversations with basic information"; 3) "Seize the turning point" and 4) "Balance transparency". The thematic groups were coherent internally, and we did not find a need to divide them any further by using sub-headings. Finally, an overarching theme dependent on the four underlying themes emerged: "The comforting safety".

3.1.7 Ethics and approval

Study I was approved by the Regional Committee for Medical and Health Research Ethics West, Norway (2013/1479 REK vest). In addition to written informed consent, we requested confidentiality within each focus group. Audio files and demographic information were stored on a protected research server, and pseudonym participant names were used in the transcription and analysis.

3.2 Study II: The pilot and feasibility study

In Study II we wanted to explore which topics patients brought up during ACP conversations, and to assess how patients, relatives and staff experienced and evaluated the contents and the feasibility of performing ACP. The study was accomplished in three phases, and lasted from February 2014 to August 2017:

- First, an ACP conversation guide was developed.
- Second, using the conversation guide as support, ACP conversations were conducted with patients and relatives.
- Finally, focus group interviews were arranged with ward staff.

3.2.1 Study setting

Initially, partly based on the results from study I and partly based on results from international research, a simple, semi-structured guide for ACP conversations was created (Text box 4) (56, 141).

Subsequently, using the guide as a support, ACP conversations were conducted with patients on the inpatient wards and their relatives. All participants were asked about how they experienced the ACP conversation. The patient's room, or a separate room on the ward, was used for the conversation. A summary of the conversation was documented in each patient's medical record.

After the last ACP conversation, ward staff were invited to participate in focus group interviews about how they experienced the research project, whether they had

participated in it, and if they had suggestions for improvements. They were also asked whether they had wanted an earlier termination of the study or whether they had wanted it to be continued longer than the project period. For further information, see Table 4 “Interview guide for focus group interviews with staff”.

Text box 4 Semi-structured guide for ACP conversations in the pilot study (This guide was piloted in Study II, and published with this study) (142)

<p>Part one: PLANNING THE CONVERSATION</p>
<p>(1) Does the patient wish an ACP conversation? (Includes information about ACP and about the project)</p> <p>(2) Which themes are (currently) relevant?</p> <p>(3) Who is going to attend?</p> <p>(4) Time and place for the conversation?</p> <p>(5) Is there a need for an interpreter?</p>
<p>Part two: POSSIBLE THEMES FOR THE ACP CONVERSATION (A list to choose from)</p>
<p>(1) Information about the disease – past, current and future. Does the patient have special needs or reservations concerning information?</p> <p>(2) The patient’s expectations for the future – based on past and present experiences.</p> <p>(3) What gives the patient strength and resilience? Key words: Coping strategies, existential and/or spiritual attitudes, values and beliefs.</p> <p>Does the patient wish...</p> <p>(4) ..to appoint a proxy?</p> <p>(5) ..help with legal or economic challenges?</p> <p>(6) ..to document specific wishes concerning the last phase of life (e.g., DNR/CPR/Respirator) in their medical record?</p> <p>-----</p> <p style="text-align: center;">Evaluation of the ACP conversation:</p> <p>(1) What does the patient – and relative(s), if applicable – think about participating in this conversation?</p>

3.2.2 Population

Participants eligible for inclusion in study II were inpatients at the Department of Thoracic Medicine who had advanced non-curable lung diseases. More details about inclusion and exclusion criteria are presented in Table 5, including inclusion criteria for participants in the focus group interviews with ward staff.

Table 4 Study II Interview guide for focus group interviews with staff

Item	Main questions	Supplementary questions
1	How have you experienced the ACP project that has been ongoing on the ward for approximately 2.5 years?	- Did you know the inclusion criteria? - What can be the purpose of this project? - Who may benefit from ACP conversations?
2	Did you participate in the project? - If so: In what way?	- Could you please describe experiences of difficulties in the recruitment of participants, if you had any? - Who should lead these conversations?
3	Could you please describe suggestions for improvements of this project, if you have any?	- What do you think about the documentation?
4	Could you please describe your thoughts about whether this project should have been stopped earlier – or whether it should be continued now?	- If it should be continued, what do you request to be able to offer ACP conversations to those who need it?

3.2.3 Recruitment

Initially, NEH gave written and oral information about ACP and the project to the ward staff. In order to encourage an interest in the recruitment and the intervention in the ward, two staff members were connected to the study team. However, due to barriers related to gate-keeping and time, but also poor availability of the two designated staff members, the first phase of recruitment was not so fruitful. To facilitate recruitment to the ACP conversations, an external study nurse was employed part-time on the ward. His presence became crucial during the project period as he identified and invited potential participants, carried out most of the conversations and wrote the summaries. In addition, he was continuously approaching the ward staff,

inviting them to be involved in the project. Whenever possible, the researchers NEH and MAS also participated in the project on the ward to facilitate recruitment.

Some leaders in the department contributed to recruitment of participants to the focus group interviews together with the researchers. We strived for a purposive sample of staff working on the ward during the project period. Unfortunately, but not surprisingly, physicians were difficult to recruit, probably mostly due to logistic factors. In order to facilitate responses, we invited physicians to respond to the main questions in the interview guide per secured hospital e-mail, and got four answers which we incorporated into the data material from the regular focus group interviews. However, when submitting the manuscript, these supplementary data were regrettably not accepted by the reviewers, resulting in withdrawal of these data from the analysis and results to be published (article 2).

Table 5 Inclusion and exclusion criteria for participation in study II

Part of study	Inclusion criteria	Exclusion criteria
ACP conversations with patients	<ul style="list-style-type: none"> - Inpatient (Department of Thoracic Medicine) - Advanced, non-curable pulmonary disease (e.g., inoperable lung cancer, COPD or PF) - Age > 18 years - Ability to communicate orally in Norwegian - Written informed consent 	<ul style="list-style-type: none"> - Severe cognitive impairment - Other circumstances that challenge reasoning and/or communication (e.g., anxiety, impaired hearing and reduced functional ability)
Focus group interview with ward staff	<ul style="list-style-type: none"> - Nurses or physicians - Working at the department of Thoracic Medicine during the study period - Age > 18 years - Written informed consent 	

3.2.4 Participants

We approached 118 patients and included 53 patients (2 drop outs) in this pilot study. Their mean age was 69 (41-86), and 11 of the included patients were females. Relatives participated in only 18 conversations (35%) due to reasons spanning from disinterest to logistic challenges.

The patients' symptoms were assessed using the ESAS-r, showing the highest mean scores for the whole group for tiredness and dyspnoea (5), then came drowsiness and loss of appetite at 4.8 and 4.5, respectively. In many medical records, WHO performance status was not reported, unfortunately, and could therefore not be used when describing the population. Demographic data taken from the medical records showed that 28 participants had completed education at secondary level, 12 at tertiary level, while in 11 cases we did not find information about educational level. Forty-one participating patients had lung cancer, nine had COPD and one had PF. Many had additional diagnoses; among the most frequent were heart disease and COPD/emphysema.

Approximately 45% of the invited patients participated, but up to 70% of the invited were positive to a conversation either now or later. Thirty-six patients (55% of non-participating patients, 31% of all) declined to participate for reasons such as “too demanding” (15 patients), or “have already had a similar conversation in private” (10 patients; 15 %). Four patients were positive at first, but then declined after discussing with a relative. Seven patients gave no cause for abstaining from the pilot.

A total of eight clinicians participated in two focus groups. Their age spanned from 25 to 58 years (mean 39). Their working experience at the department was from 1.5 to 29 years (mean 9.4; median 4.5). One was a male physician; seven were female nurses; two of them were specialist nurses and two were nurse leaders.

3.2.5 Data collection

Demographic data and medical information were taken from the patients' medical records and were organized according to the EAPC basic dataset and “List of Educational Levels” from Statistics Norway (143, 144).

Participating patients took part in the planning of the conversation as sketched out in the guide (Text box 4). The conversations were conducted in a patient-centred manner, supporting patients to communicate matters of individual importance for their present and future life. Wanting the ACP conversations to be similar to other clinical conversations, we did not record the conversations in any way. As normally done in the clinic, documentation was performed as the facilitator recalled the conversation. After an introductory training, the study nurse facilitated most of the conversations and documented them thereafter. Relatives could participate in the conversations and their comments were included in the summaries. At the end of an ACP conversation, participants were asked about their experiences with the conversation. During the project, we also began to ask the patients whether they put any restrictions on the summaries or if important sequences of the summaries could be shared with cooperating physicians and nurses in primary care.

Two focus group interviews, lasting 35 and 40 min respectively, were arranged with ward staff. NEH acted as facilitator and MAS served as secretary during the interviews. The recorded interviews were transcribed verbatim by a secretary.

3.2.6 Analysis: Mixed methods

Quantitative data were taken from the medical records and registered in Microsoft Excel spreadsheets. This facilitated the use of descriptive statistics with results presented as counts and percentages (i.e., recruitment, population, activities, ESAS-r).

The summaries from the ACP conversations were also collected from the medical records. Together with the focus group transcripts, the summaries were anonymized and stored on a protected research server at Haukeland University Hospital. All authors participated in the qualitative text analysis of both the summaries of the ACP conversations and the transcripts of the focus group interviews. NEH documented the analytic process in a decision trail (140).

Summaries and transcripts were analysed by STC (see previously). In the current section, only specific details on the analysis of Study II are described sequentially, first

the analysis of summaries of the ACP conversations, then the analysis of the transcripts from the two focus group interviews with ward staff.

The four steps of Systematic Text Condensation in Study II

ACP conversations with patients and relatives:

Step 1. Total impression – from chaos to themes

The analysis of the summaries from the conversations started by reading the summaries from the five first conversations to get an overview and search for preliminary themes. When a pattern of themes had emerged, all summaries were included and systematized according to the preliminary themes. The preliminary themes were: 1) “Alleviation of symptoms” – or “Symptoms”; 2) “The loss” – or “The existential”; 3) “Issues to plan” – or “To plan for the last phase”; and 4) “Team players’ needs and the patients’ need for them” – “Allies/Helpers and the problems they may have”. The researchers were rather co-ordinated in their choice of preliminary themes. After negotiations, they ended up with the following themes: 1) “The symptoms”; 2) “The existential”; 3) “To plan”; and 4) “The team players”.

Step 2. Identifying and sorting meaning units – from themes to codes

Step two was executed in a Word document on the computer, coding the text with colours before cutting out and sorting the meaning units under the different code groups. Most of the text was possible to sort into the four groups, strengthening the analytic choices that had been made at step 1.

Step 3. Condensation – from code to meaning

As the material was rich containing many meaning units, the process of condensing required both time and space. At this point, there was a need to refine the condensation in several steps, reducing the text for each step. The codes from steps 1 and 2 became categories supplied by subcategories: 1) “The symptoms” with subcategories (a-d): a. *Dyspnoea*, b. *Pain*, c. *Psychological symptoms* (anxiety, sleeping problems) and d. *Other bothering symptoms*. 2) “The existential” with subcategories (a-e): a. *Experiences concerning illness and disease*, b. *The grief over present and anticipated losses*, c. *The death*, d. *The most important in life*, e. *What makes me strong*. 3) “To plan” with subcategories (a-f): a. *Motivations for planning*, b. *Information*, c.

Treatment and Care, d. Advance Directives, e. The housing situation, f. The death and the funeral. 4) “The team players” with subcategories (a-c): a. *The family*, b. *Solitude and loneliness*, c. *Professional and non-professional helpers (outside family)*.

Step 4. Synthesizing – from condensation to descriptions and concepts

The condensates went through a significant reduction during the process of reconceptualization, and were organized in approximately the same categories as the codes in step 2: 1) “*Troublesome symptoms and alleviation of these*”; 2) “*Existential themes*”; 3) “*Planning for the last phase of life*”; and 4) “*Good relationships*”. Due to the need to reduce the text to an optimum length to fit the form of a medical journal article, the sub-categories were not presented in separate paragraphs, but incorporated into the text.

Focus group interviews with healthcare personnel:

Step 1. Total impression – from chaos to themes

After the first reading of the material, some preliminary themes appeared: 1) “How the healthcare personnel experienced the pilot.” 2) “The positive effects of ACP for patients and relatives.” 3) “The value of documentation.” 4) “The benefits that ACP could add to healthcare personnel’s work, even in the everyday bustle at a busy medical ward.”

Step 2. Identifying and sorting meaning units – from themes to codes

The preliminary themes followed closely to the original questions used for the focus group interviews, and during step two a different code pattern appeared: 1) “Benefits of ACP.” 2) “To find time for ACP.” 3) “Timing of ACP.” 4) “Challenges concerning the ACP project.” Some of the meaning units could be sorted under more than one code group thus leading the analysts to take another critical review of the codes.

Step 3. Condensation – from code to meaning

The uncertainty about the coding, mentioned under steps 1 and 2, led to another regrouping and systematization of codes and meaning units during the condensation of the material. This process refined and clarified the presentation of the healthcare

personnel's views on ACP in general, and illuminated important obstacles for the feasibility of introducing ACP, especially on a busy clinical ward.

Step 4. Synthesizing – from condensation to descriptions and concepts

In order to fit the form of a medical journal article, we chose to present the final results from this analytic process in the form of a table instead of in plain text. We systematized the findings hierarchically with two overarching categories: 1) "Benefits of ACP – as perceived by clinicians", and 2) "Challenges concerning feasibility". The latter category was divided into the main categories "Barriers" and "Organization". "Barriers" consisted of two subcategories, "Time" and "Knowledge". When sorting "Knowledge" under "Barriers", we prioritized the challenges in acquiring the adequate knowledge and not the advantages of having it. "Time" was divided again into the subcategories "To find time on a busy medicine ward" and "To find the right timing for an ACP conversation".

3.2.7 Ethics and approval

The study was approved by the Regional Committee for Medical and Health Research Ethics West (2014/1054 REK vest). Written informed consent was obtained from all participants. For participation in focus groups, we requested also an internal confidentiality. Anonymized summaries, focus group transcripts and demographic and medical data were stored on a secure research server belonging to Haukeland University Hospital.

3.3 Study III: The international post-bereavement survey

In Study III we wanted to explore what proportion of bereaved relatives were offered an ACP conversation, and how many of those not offered such a conversation that would have wanted it. Additionally, we investigated whether having been offered an ACP conversation was related to the participants' perceptions about the EoL care given. We also wanted to examine differences between Argentina and Norway for the above-mentioned questions.

This study was a sub-study of an international post-bereavement survey: CODE International Survey conducted as part of the ERANet-LAC CODE project 2017–2020: “International Care Of the Dying Evaluation” (CODE): Quality of care for dying cancer patients as perceived by bereaved relatives” (145). Focusing on the two last days of life and the immediate period of bereavement, relatives answered questions about the topics listed in Table 6 (146, 147).

In Argentina and Norway, two questions about ACP conversations were added to the F-section of the i-CODE questionnaire, questions 32a and b (Table 7, and Appendix).

Table 6 The sections of the international version of the validated CODE™ questionnaire, i-CODE

THE SECTIONS OF i-CODE

A	The care received from the nurses & doctors
B	The control of pain & other symptoms
C	Communication with the healthcare team
D	The emotional & spiritual support provided by the healthcare team
E	The circumstances surrounding his/her death
F	Overall impressions
G	Information about you and your relative or friend

3.3.1 Study setting

From 15th August 2017 to 15th September 2018, participants were recruited to this post-bereavement survey from hospitals in Argentina and Norway: Seven public hospitals of which three were university hospitals (Norway), and three university hospitals of which one private (Argentina). Participants were recruited from medical, surgical, and oncology wards (both countries), palliative care inpatient units (Norway) and intensive care units (Argentina).

3.3.2 Population

Possible participants were adult relatives of adult, deceased cancer patients in one of the partaking hospitals. Next-of-kin should have been documented in the patient's medical record. Patients had to have been hospitalised for at least three calendar days, with the relative present at least some of the time during the last two days. Exclusion criteria were a sudden or unexpected death of the patient, and language difficulties or impaired cognitive functioning in the relative, influencing the ability to answer the questionnaire. The participants were mostly close relatives; 46% (Argentina) and 62% (Norway) were spouse/partner, 36% (Argentina) and 28% (Norway) were son/daughter. Most of them were between 50 and 79 years old; 66% (Argentina) and 70% (Norway) were female.

3.3.3 Recruitment

Recruitment procedure: Some of the ward staff that served as local project coordinators (Norway), or a separate local study team (Argentina) identified eligible persons by screening the patients' medical records (Norway) or lists of deceased patients through the last month (Argentina). In Norway, information (verbal and written) was given to the relative after the patient's death, but before the relative left the hospital. If this procedure failed, a letter with an information flyer was sent by mail. In Argentina, relatives fulfilling the inclusion criteria were contacted by telephone, or sometimes invited by the specialist palliative care team prior to leaving the hospital.

3.3.4 Data collection

Six to eight weeks after bereavement, the survey tool (i-CODE questionnaire) was presented to the participants. Data collection was either by telephone or face-to-face interview or by e-mail (Argentina, respectively 50%, 37%, 13 %), or by post (Norway, 100%), with one reminder after four weeks to the non-responding (Norway). Medical and demographic data were collected from the deceased patients' medical records by ward staff.

3.3.5 Analysis

Primary outcomes

The analyses were based on the two primary outcomes of CODE International Survey: The participants' perception of how much of the time the patient was treated with respect and dignity in the last two days of life by doctors and by nurses (Table 7, Q30 (question 30), two questions), and whether the participant was adequately supported during the same time period (Table 7, Q31).

These outcomes were analysed against the two questions about ACP (Table 7, Q32a and Q32b) which functioned as explanatory variables.

Data analysis

Demographic data were presented as counts and percentages.

To examine differences in outcomes between the participants offered an ACP conversation and those not, we fitted separate mixed-effects ordinal regression models with i-CODE questions Q16, Q17, Q20–Q24, Q31 and the two Q30 questions as response variables (Table 7). The same type of model was used to compare, for those not offered such a conversation, the outcomes between those who would have *wanted* to be offered a conversation and those not.

Table 7 Questionnaire items and corresponding response options

<i>ITEM</i>	<i>QUESTION / STATEMENT TEXT</i>	<i>RESPONSE OPTIONS</i>
<i>Response variables</i>		
<i>Q16</i>	During the last two days, how involved were you with the decisions about his/her care and treatment?	Very involved; Fairly involved; Not involved
<i>Q17</i>	Did any of the healthcare team discuss with you whether giving fluids through a “drip” would be appropriate in the last two days of life?	Yes; No; Don’t know
<i>Q20</i>	How would you assess the overall level of emotional support given to you by the healthcare team?	Excellent; Good; Fair; Poor
<i>Q21</i>	Overall, his/her religious or spiritual needs were met by the healthcare team.	Strongly agree; Agree; Neither agree nor disagree; Disagree; Strongly disagree
<i>Q22</i>	Overall, my religious or spiritual needs were met by the healthcare team.	Strongly agree; Agree; Neither agree nor disagree; Disagree; Strongly disagree
<i>Q23</i>	Before s/he died, were you told that s/he was likely to die soon?	Yes; No
<i>Q24</i>	Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g., symptoms that may arise)?	Yes; No
<i>Q30</i>	How much of the time was s/he treated with respect and dignity in the last two days of life? [Doctors / Nurses]	Always; Most of the time; Some of the time; Never; Don’t know
<i>Q31</i>	Overall, in your opinion, were you adequately supported during his/her last 2 days of life?	Yes; No
<i>Explanatory variables</i>		
<i>Q32a</i>	When it became clear that s/he was seriously ill and had limited time left to live, did the healthcare team (nurse or doctor) invite you and him/her to a conversation about your wishes for his/her remaining life time?	Yes; No; Don’t know
<i>Q32b</i>	Would you have wanted this type of conversation?	Yes; No; Not applicable, we had this type of conversation

To examine country differences, extended versions of the above models were created by adding country and the interaction between country and each explanatory variable.

The response variables had different response options, either ordinal or binary. For binary variables, the ordinal model is reduced to a logistic model. To take into account any general differences in outcomes between hospitals, hospital was included as a random intercept. The output from each model is an odds ratio (OR). A common OR is estimated over all possible cut-offs of the response variable, which was coded such that an $OR > 1$ indicates that a “yes” response to Q32a/Q32b was associated with a more positive response.

Before analysis, the data were recoded to remove any internal inconsistencies (e.g., people responding “yes” to Q32a, but not “not applicable” to Q32b). When a participant had missing data on a question – either a lack of response or a “don’t know” response – they were excluded from the analyses that used that question (but included in other analyses). Consequently, we also reported how many responses each analysis was based on.

Microsoft Excel spreadsheet files were used for storing of data, and statistical analyses were done using R version 4.0.2. (148). The R package “ordinal” version 2019.12-10 was used to fit the regression models (149).

3.3.6 Ethics and approval

Patients and user representatives were involved in the development of the CODE™ questionnaire (147, 150). In Argentina and Norway, the translated versions were piloted with bereaved relatives as well as other volunteers ahead of the study onset (146).

Written informed consent was mandatory for participation, and all person-related data were anonymized. Approval was given by the Regional Committee for Medical and Health Research Ethics West, Norway (2017/640/REK vest), and Guía de Buenas Prácticas de Investigación Clínica en Seres Humanos, Ministerio de Salud de la Nación Argentina (Resolución 1480/2011).

4. RESULTS

4.1 Study I

In the focus group interviews, patients suffering from advanced life-threatening pulmonary diseases (COPD, PF and lung cancer) described a principal need for security during the disease trajectory and near the EoL. An overriding concept protruded: “The comforting safety.” This safety was important both within their family and in the healthcare settings. There were four underlying elements of this comforting safety: (1) Provide good team players: Knowledgeable and supporting persons, preferably somebody they already had a good relation to, were wanted in the healthcare settings as well as in the domestic sphere. Chief skills for these important persons were the abilities to relate to and communicate empathically with the patient. (2) Offer conversations with basic and tailored information: Stressing individual differences in the need for prognostic information, the participants requested information according to each patient’s specific needs. (3) Seize the turning point: At important moments during the disease trajectory, patients have a special need for conversations about their situation and future, and they should be offered ACP conversations at these turning points. (4) Balance transparency: Patients have different wishes and limits for transparency, challenging the communication both when inviting to and performing ACP conversations.

The informants considered ACP conversations as delicate, but important patient-centred conversations facilitating an exchange of information between healthcare personnel, patients and their relatives, thus enabling patients to make decisions in line with their values. They preferred a proactive approach from the healthcare system, but they also emphasized the difficult balance of transparency. The patient and their relatives should receive the invitation to ACP conversations in time to allow preparing for the conversation, but also in such a way that they could easily refuse the invitation. ACP should be offered while the patient still was cognitively clear, and sufficiently relieved from distressing symptoms during the conversation.

4.2 Study II

Piloting the guide: At a Norwegian University Hospital, 51 ACP conversations were performed with inpatients having advanced pulmonary diseases. Only eighteen of the conversations included a close relative, mostly due to logistic challenges. In the ACP conversations, the guide appeared relevant, and four main topics appeared: (1) Troublesome symptoms and alleviation of these: Fear of insufficient symptom relief here and now and in the last phase often exceeded their fear of death itself. The participants' perceptions about their treatment were often related to their interpretation of troublesome symptoms. (2) Existential themes such as coping, resilience and death: Acknowledging the approaching death, many chose to focus on life at present. Religion was an existential theme for some of the patients. For most patients, their family and places for family gatherings were sources of strength. (3) Planning of future treatment and care: Information was essential for making plans, but also the way it was delivered influenced the patients' feelings of safety. Other themes mentioned were the funeral, making a will, reorganizing their private economy, and specific wishes for end-of-life care. Quite a few talked about "dying with dignity", meaning being safe and certain to get help when needing it. (4) Important relations: Only seven patients named specific proxies, all from close family. The important support from someone who knew and understood their situation was frequently found within family. Several patients also mentioned a supportive staff member on the ward contributing to their safety.

Evaluation of ACP conversations by patients and relatives: All participants appreciated the conversation, and many recommended it to be offered routinely.

Feasibility – as perceived by ward staff: Two focus group interviews were performed with ward staff; one physician and seven nurses. The resulting themes were: (1) Benefits of ACP for patients and clinicians. They considered ACP to ease challenging communication about issues of delicate and ethical character, and found valuable information in the conversation summaries. (2) Challenges concerning feasibility, divided into two subgroups: (i) *Barriers against implementation of ACP*, and (ii) *organizational aspects*. Concerning the barriers, they experienced several

problems with time, timing and knowledge about ACP. Implementation was regarded challenging in many ways, and they requested an overarching plan for the implementation as well as for the documentation of ACP conversations.

4.3 Study III

Setting and participants: A post-bereavement survey in Norway and Argentina with 299 participants (Argentina 105: median age 50-59, 68% women; Norway 194: median age 60-69, 70% women). Those who responded to a question about whether they had been invited to an ACP conversation, were included in this study (276); 56% responded positively to this question (Argentina 58%, Norway 54%).

How an invitation affected perceptions about care and support: The participants who had been invited to an ACP conversation perceived that the dying patient had been treated with respect and dignity more of the time. They also perceived that the patient had received better spiritual support. The participants themselves felt better supported in the patient's last days, and they perceived that they were more involved in care decisions, received better emotional and spiritual support and were better informed about what to expect in the dying phase.

Sixty-eight percent in the group of not invited would have wanted this type of conversation, and these participants perceived that the dying patient had been treated with respect and dignity less of the time. Those who would have wanted a conversation, without being offered one, rated the communication and emotional and spiritual support less favourably than the ones who had not wanted such a conversation. There was, however, no difference in their perception of their degree of involvement in care decisions.

Differences between countries: In Argentina, 39% of those not invited to an ACP conversation had also not been informed about the patient's impending death; among the invited, the proportion was 7%. In Norway, the corresponding proportions were 11% for both groups. Further differences between the two countries were only related to nursing care, and understood as related to the scarcity of qualified nurses in Argentina.

5. DISCUSSION

5.1 Methodological Considerations

5.1.1 Design, Recruitment and Participation

The aims in Studies I and II were to explore ideas, opinions, needs and perceptions about ACP, and which topics the participants raised in ACP conversations. Qualitative methods such as interviews are known to be suitable to explore such issues, and we chose focus group interviews in order to benefit from the group process (85, 151). The participants in a focus group may influence each other positively in a group process through associations forwarding the conversation in a more productive way than usually possible in individual interviews (136, 137).

The process of recruitment was demanding in both Studies (I and II). In Study I, some patients reacted negatively to the wording in the written study information to the point that we had to change from the expression “EoL” to “the last phase of life” (however, without any obvious improvement in recruitment). Unfortunately, we did not register reasons for accepting or declining participation. Moreover, among the recruited patients, several experienced disease exacerbations preventing their participation. Under such conditions, individual interviews would have been more efficient because they allow for a direct succession of interview after recruitment.

When conducting ACP conversations in Study II, this benefit of successive recruitment was obvious: Due to logistic challenges and disease exacerbations, hesitations would have caused lost opportunities for participation in an ACP conversation. Thus, the conversations were conducted as soon as possible after recruitment of a patient.

In Study III, the aim was to find out whether an invitation to an ACP conversation could influence the perceptions about communicational issues, and about emotional and spiritual support in the care for dying patients and their relatives. Linking our study to an international post-bereavement survey employing a validated questionnaire, gave the possibility of coupling well-proven questions and outcomes

with two specific questions about ACP. Recruitment of participants and data collection were conveniently handled through the main study. Asking questions about an invitation to a conversation, but without knowing whether the conversation actually took place, and whether the conversations were performed in a patient-centred manner, implies that we can only present associations. To look for a more causal relationship, we could have used a design with randomized participation in ACP, and control groups, but a questionnaire for all participants regardless of participation in ACP. Although this design would still have challenges, it would have given better control over the variables, but this approach was not possible as part of the CODE project.

5.1.2 Analysis

STC, thoroughly explained under Methods, is a well-established method for thematic cross-case analysis when the aim is to analyse the content of a text and maybe find new depictions and terms, but without the aim of creating new theories. When searching for the participants' *views* on and *thoughts* about ACP, STC stood out as the most suitable method to apply on the material in Studies I and II. Built on well-defined steps that are not too difficult to understand and use, even for beginners, STC helps in structuring the material while at the same time respecting the voices of the participants (139). At the time of planning this project, we did not find any theory suitable for our research questions. Retrospectively, a coupling to the theories about coping, resilience and self-efficacy by Albert Bandura, or to concepts within medical ethics such as relational autonomy, for instance, could have made the results even more interesting and further strengthened the analytical focus of our research (136).

In Study III, the use of a well-prepared and piloted survey with numbered items lent itself to the use of quantitative statistical methods. However, the statistical calculations were challenging, as they required the two explanatory variables of our sub-study to be combined with several variables defined by the outcomes of the main study. In addition, when estimating the individual effect while at the same time trying to generalize the results for the two countries, any systematic differences between the hospitals were necessary to take into account. These analyses required the use of rather complicated statistical models (explained under Methods), and the professional work

by biostatistician Karl Ove Hufthammer was essential. OR was used as a measure for the perceived quality of the care given by nurses and doctors. Mixed-effects ordinal regression models were used to discover differences in outcomes related to whether the participants had received an invitation to ACP, or whether they had not received such an invitation, but would have wanted it.

5.1.3 Reflexivity and preconceptions

Based on the idea that ACP would be helpful for both patients, relatives and healthcare professionals, NEH started up the project together with DFH, Head of the Regional Centre of Excellence for Palliative Care, Western Norway. This centre had already discussed the implementation of ACP as part of its future strategy. MAS and KRS were both researchers linked with this centre at the time. The researchers MAS and NEH were either working (MAS), or had been working (NEH), at the Department of Thoracic Medicine. Having years of experience in oncology, pulmonary medicine and in palliative care, all researchers had a proficiency in the care for patients with advanced pulmonary diseases, and they were skilled in clinical communication at the verge of life. This competence in the field of clinical communication gave strength to the accomplishment of both the interviews and the ACP conversations, but this experience also led to considerable preconceptions.

Working at the Department of Thoracic Medicine (2007-13), I (NEH) had experienced rather difficult conversations with patients and relatives. Some patients, or relatives, expressed surprise or even anger when told that the therapy against cancer or COPD had reached a concluding and terminal stage. Some of them seemed not to be aware of themselves or the patient having a life-limiting disease, and I saw their suffering through their anger and frustration. I asked myself how I could perform these difficult clinical conversations in a better way. In addition, I wondered whether the information given at an earlier stage had been too vague, or if the patients had not been able to grasp the meaning of the information given. Especially patients suffering from lung cancer, but also some patients with COPD or PF, seemed to be in need of a more thorough form for clinical communication than we offered at the time. Working with a focus on patient-centred care and palliative care, these experiences made me think that

ACP could contribute to better clinical communication with patients and relatives, and ultimately better palliative care for patients with advanced pulmonary diseases. These preconceptions influenced me both when telling the participants about ACP in the beginning of each focus group interview (Study I), and when leading the interviews. The analysis could also be affected by these preconceptions, thus requiring an attention towards them throughout the process of analysis.

Accordingly, an important challenge of the researchers was to identify their own preconceptions, and to let the patients' voices be much stronger than their own thoughts during the whole process. Reflection notes may help researchers to be aware of their preconceptions (140). The use of a semi-structured interview guide with open questions, and letting the participants talk as freely as possible without too many interruptions from the moderator, the secretary, or the other group participants, may also contribute to letting the patients' voices be clearly audible. During the focus group interviews, there was a need to interfere sometimes and moderate the discussion, e.g., when participants' associations brought the conversation far outside the focus area, or when the conversation halted (137). Leading the conversation in focus groups may mean to balance between curiosity, eagerness, objectivity, encouragement, quietness and the duty of confidentiality. Sometimes patients may pose medical questions during the group conversations, tempting the physician researchers to forget their rather neutral role in the interview situation. In addition, questions may be interpreted differently according to which profession the questioner belongs to. In Studies I and II, we saw examples of these situations, but several of the participants had a pronounced wish of contributing to better patient care at the department, giving the impression that they answered our questions without withholding their opinions on the subject.

Opting at a free and open analytic process in Studies I and II, we focused on the transcripts of the interviews and the ACP summaries (137). These summaries had already been through a form for interpreting process with the person who had documented the conversations (most often accomplished by the study nurse), and we do not know whether the patients and relatives who participated in these 51 conversations would agree with the documented content. This was a choice we made

in order to perform ACP conversations and the documentation of these by using the same method that normally is used when documenting clinical conversations. We experienced that keeping a log about the choices that were made during both the interview phase and the analytic phase, was useful. Taking reflective notes and negotiating themes within the research group were also measures that helped to neutralize preconceptions during the analytic process (137, 140).

5.1.4 Validity

Internal validity

Some of the transcribed texts and summaries were distressing to read, exposing the troubles and tensions patients with advanced disease may have. This underlines the need to let the patients' voices be heard clearly and systematized individually before coupling the themes with the research questions in the final condensation process. Bearing the research questions in mind, while at the same time preventing the researchers' preconceptions to dominate, was challenging during the analytic process. The researchers' preconceptions could contribute to a more positive interpretation of the participants' answers than the participants originally had meant, but we found a consistency of the results, and thus a strengthened internal validity (85). Our participants imparted vulnerable experiences and both negative and positive views on the subject, making it likely that they answered in honest terms and felt comfortable to reveal their opinions.

MAS and NEH were, or had been, working as physicians at Department of Thoracic Medicine, consequently they had doctor-patient relations with some of the participants in Studies I and II, and they had collegial relations with healthcare professionals on the wards. These relations may have influenced both the recruitment and the interviews/conversations, and we do not know exactly how (134, 152). There is a possibility that some participants felt an asymmetry in relational power that may have contributed to participation in the studies, and may as well have influenced their answers. In addition, there will always be a possibility that participants misunderstand questions given in an interview, thus emphasizing the importance of the modulation both in interviews and in clinical conversations (137).

Without a formal registration of reasons for patients' consent or refusal to participate in Study I, we do not know how the doctor-patient relationship influenced the recruitment or the interviews. On the other hand, in Study I, we gave the participants a possibility of debrief with a nurse after the interviews, and as far as we are aware, only one participant made use of this offer. Several of the participants gave the impression that they enjoyed the conversations (Studies I and II). In Study II, healthcare professionals – former or actual colleagues of the researchers – participated in focus group interviews. To use colleagues as research objects may be challenging, and although the participation was optional, we cannot be sure that they did not withhold opinions in order to not disturb the collegial relation they had with MAS or NEH (152, 153). Consequently, we cannot know how the relationships between the participants and the researchers have influenced the internal validity of Studies I and II.

In Study III, we do not have knowledge about any relational factors affecting the process of recruitment, and the participants were relatives of the patients, thus not dependent, apparently, on the healthcare professionals performing the recruitment. In the Argentinian part of the study, many of the participants were interviewed by phone or face-to-face, thus bringing in the same considerations about relational asymmetry as in the two qualitative studies. In Norway, the participants answered the questionnaire by themselves, and mistakes and misunderstanding of content could happen, thus reducing the internal validity of the questionnaire data. However, the use of an already piloted survey increased the validity of this study.

External validity

The principles of sample size in qualitative research is quite different from quantitative research (134). While in quantitative research it is mostly a question of statistical variables such as confidence interval, standard deviation and of population size, the research questions and the method for analysis are of the highest importance when deciding on the requested number of participants in qualitative research. If the sample consists of many participants, the resulting data material may be too big and the researcher will have difficulties in preserving control during the analytic process. Also, when performing a study using exploring interviews related to a specific theory (e.g.,

psychologic or philosophic), not so many participants should be necessary at all (85, 138).

In Study I, the number of participants was determined by the principle of information power. In a qualitative study setting, this principle states that the necessary number of participants needed is determined by the information obtained as related to the research questions. Five elements influence the information: (1) the study aim, (2) the sample specificity, (3) the use of established theory, (4) the quality of the dialogue, and (5) the analysis strategy (138). Following this principle of information power, we strived for a purposive sample showing a distribution in diagnoses, and differences in gender, age and in social status of the participants. Due partly to the difficult process of recruitment, partly to the normal distribution of pulmonary diseases, we ended up with a convenience sample in which most participants belonged to the lower socio-economic middle class and were women older than 50 years with lung cancer, though COPD and PF were also well represented (130). The analyses were done before and in parallel with recruitment of the last focus groups in order to find the optimal sample size, thus optimizing the external validity (138).

In Study II, recruitment to the focus groups with healthcare professionals was challenging related to the arduous schedule of nurses and especially the physicians. Thus, we tried to expand the sample by sending the focus group questions per e-mail to some of the absent physicians, but as this was a rather poor replacement, we accepted the reviewers' refusal of using these interviews. In retrospect, inviting physicians to individual interviews would have strengthened the external validity of Study II (133).

Only patients who appreciated to talk about their situation volunteered to participate in Studies I and II, apparently, but some exceptions were revealed in the conversations, strengthening the external validity of the studies.

Both Studies I and II were performed at a Norwegian hospital department with patients having advanced pulmonary diseases, and the results are related to this setting. The

semi-structured conversation guide was piloted with this group of patients, and we do not know whether it is usable in other settings.

However, quite a few of the results were related to existential issues triggered by having a life-limiting diagnosis, thus they seem to be more universal, connected to aspects of being human. In Study III, we found very similar results in both Argentina and Norway, strengthening the transferability of the results across national and cultural borders.

The models used for the statistical analysis in Study III are well documented and reliable. Even though we did not find many similar studies, we did find corresponding results in the literature, which also strengthens our findings (154, 155).

5.1.5 Ethical considerations

During the recruitment to Study I, an unknown number of patients refused to participate in the focus groups because they found the topic too tough, while others declined participation without giving a reason to the study nurse working with the recruitment. The participants were informed about the study orally and in writing before they decided to participate. Even though patients with advanced disease and in the palliative care phase may be particularly vulnerable, studies show that many of them want to contribute in research projects (156). In this project, several participants agreed to contribute in order to have a say, and with the hope of contributing to a positive change of routines for patient care. Some of them also benefitted personally from the interviews: they shared experiences and consequently bonded with other participants after the interviews, which reduced their feeling of loneliness.

The affiliation of both MAS and NEH to the Department of Thoracic Medicine as physicians may have affected the participation of some of the participants. Accounting this possibility, a study nurse dealt with the recruitment formalities, and if issues of concern manifested after the interviews, another nurse, who was not part of the research team, could be contacted by the participants. Reasons for not participating, but not for participating, were registered in Study II. However, we know from their

answers that the participants drew personal benefits from the conversations, also known from other settings (157).

Interviewing colleagues, as we did in Study II, may be challenging both ethically and methodologically, and although none of the researchers were the superior to any of the participants, and participation was optional, we cannot know how the participants really felt about the interview situation (152, 153). However, the contributions in the interviews witnessed about a wish and a will to improve patient care.

5.2 Discussion of results

5.2.1 Special needs in special times

Patients and relatives

Quavered by the diagnosis of a serious, non-curable disease and facing a forthcoming death, patients and their relatives need special attention from the healthcare system (Studies I-III). Their needs reflect all dimensions of human life, relating to body, soul and spirit. Patients need to discuss important issues with healthcare personnel, especially troublesome symptoms at present and in the future, existential themes related to their identity and inner values, planning of care and place of death, and central issues concerning their main relations (Studies I and II) (58, 105, 158).

Relatives, in the same way as patients, have needs for competent care and support as shown in Study III: When there were indications that a need for an invitation to ACP was neglected, perceptions about care and support were rated less positively than when relatives had been invited to ACP conversations, or would not have wanted such an invitation. Continuous support, respecting individual transparency and tailored information given at certain turning points during the disease trajectory contribute to a comforting safety (Study I). However, one size does not fit all, and these three studies, among others, also point to the fact that not everybody wants ACP (159, 160).

Realizing that life is approaching the end, humans tend to narrow their circles, concentrating more on their nearest and dearest, and on making the everyday as normal as possible (8, 161). For some patients, spending their precious time on ACP

conversations with healthcare personnel may not seem the right thing to do. The need for conversations may also be covered within their family, or the themes in ACP conversations may seem too arduous to expose either themselves or their relatives to (36). Many patients prefer to take one day at a time without talking about their future, but this is also a well-known barrier to ACP participation (95, 141).

Patients with advanced pulmonary diseases often suffer from an increasing weakness, partly because of dyspnoea and hypoxia which steal their time and reduce their QoL (162). The diseases lead to profound changes in life, and many patients are bothered by anxiety triggered by dyspnoea and other disturbing symptoms (163, 164). Having an advanced and life-threatening disease makes the patients vulnerable in many ways, as also often seen among other patient groups in palliative care (17, 165). ACP may be a tool to bring up difficult topics, and even a bridge to better palliative care (158). Early integration of palliative care for patients with lung cancer has led to improved QoL and better emotional functioning, and less aggressive care at the EoL, in spite of longer survival (166, 167).

Studies I-III have shown that patients with advanced pulmonary diseases have special needs for patient-centred care, and that well-performed ACP may contribute to supporting both patients and relatives in their search for resilience throughout the trajectories (168). These findings also correspond with results from other studies (105, 141, 159, 169, 170). Viridun et al. (2015), found that patients ranged “effective communication and shared decision making” as the most important element of inpatient EoL care, while relatives ranged this as a number two after “expert care” (169). Well-performed, patient-centred conversations, in which the patient is respected, seen and heard, increase transparency and may contribute to improved health literacy and increased patient autonomy (6, 36, 54, 171). On the contrary, lack of a patient-centred perspective may decrease patients’ possibilities to acquire the necessary information about their disease and situation, and hence, decrease their possibilities to be involved in making plans for treatment and care (6, 95, 172). ACP meets these requirements by giving room not only for information exchange between patient, relatives and healthcare providers about the patient’s disease and concrete

physical needs, but also linking the patient's preferences and wishes to their more profound values and attitudes through topics within the social, psychological and spiritual domains (56, 61, 173).

Healthcare personnel

Healthcare personnel experience challenges when their patients have increasing palliative care needs. They are often confronted with difficult considerations about treatment intensity and communication (174). Representing a hope for cure or, at least, a hope for prolongation of life, starting another line of chemotherapy when the last one had no effect may seem the best alternative for the physician as well as the patient (175). In addition, for all involved, a new line of therapy will maintain the re-assuring routine of regular consultations at the hospital, and postpone the need for focusing on the inevitable EoL. However, due to side effects, a consequence of this choice may be a deteriorated QoL near the EoL, or even a shortening of the patient's lifetime (176-178). In addition, understood in a socio-economic perspective, the most expensive treatment is the one that does not work.

Healthcare personnel face an increasing claim for autonomy from patients and their relatives, daily. This mirrors the overarching changes in our postmodernist society with increased access to knowledge (by the internet) and increased individualism and self-governance alongside a continuous technological development (179). In addition, an increasing pluralism regarding values, cultures and belief systems is manifesting itself, concomitantly with a declining power among physicians and other authorities (99, 179). In order to solve dilemmas about prioritization and overtreatment, an increased focus has been set by both the healthcare authorities and clinicians on competence development through guidelines and clinical communication (117). Healthcare professionals' roles are changing, and the responsibility of promoting patients' autonomy claims a larger part now than before (31). Based on patient-centred care and with QoL as the aim, palliative care and communication tools such as SDM and ACP might be some of the answer to the challenges of autonomy in postmodernist healthcare. In Study II, healthcare personnel saw ACP as pertinent for patients and for clinicians, and they recognized the relieving effect a systematic approach to ACP

could bring to their clinical work. They also saw chief hindrances for the implementation of ACP. So, even though they discussed who should have the responsibility for initiating and conducting ACP, they requested management support and measures such as time and expertise to conduct such conversations themselves (180).

5.2.2 Special tools for special times

Special times and the concept of relational autonomy

International research has shown that ACP leads to an increase in EoL care conversations between patients and healthcare professionals, and an increase in completed ADs (181). Several studies have shown positive results of ACP in the psychological domain, and improved QoL (56). These outcomes are apparently related to the increase in communication: Both patients and relatives have reported an improved feeling of security and a reduction of fear (partly found in Studies I-III), and ACP has positively influenced the process of grief among relatives (partly found in Study III) (56, 89). Wishing for a team of supporters both privately and in the healthcare sector, and for tailored information, patients in Study I assumed that ACP conversations could be helpful in their search for a comforting safety. In Study II, both patients and relatives welcomed the ACP conversation and described it to be “relieving”. In Study III, we found a positive association between an invitation to an ACP conversation and perceptions about support and care, however, without knowing whether the conversation really took place, or whether the actual intervention was a conversation or a ward culture with communication and care as central elements.

Correspondingly, in a qualitative interview study, Johnson et al. found that more than autonomy, patients value veracity, trust and comfort at the EoL (182). Being increasingly dependent on healthcare providers and relatives during the disease trajectory, the autonomy of patients in palliative care is frequently reduced to a “relational autonomy” (183). This is a concept from medical ethics that attempts to explain how social relationships may influence individuals' autonomy both positively and negatively. “Relational autonomy” may help to interpret tensions between the patient, the relatives and the healthcare professionals in general, and particularly in the

manifestation of serious disease (30). This implicates that when facilitating for patients' autonomy, clinicians need to consider the patients' social relations (28). According to Entwistle et al., a relational approach to autonomy requires a redefinition of the relationship between clinicians and patients, and that clinicians should contribute to strengthening the patients' autonomy (184).

“Relational autonomy” underlines the importance of including relatives in the process of ACP, in order to relate its contents to the past, present and future, and by doing so, increase the probability that the patient's wishes for EoL care will be respected (125, 185-187). Relatives are very important for the ACP process, especially when patients have reduced or deficient decisional capacity. Even though the intention is to arrange ACP conversations before the persons lose their decisional capacity, such conversations are rarely performed before admittance to nursing homes. At the time of admittance, a substantial number of patients suffer from moderate to advanced dementia. Apparently, this seems to give the relatives a bigger role in the first ACP conversation than intended in the EAPC guidelines. Further research will be necessary to find out how to best integrate those who have diminished decisional capacity in ACP (125, 188).

Instructions for use

Palliative care tools such as ESAS make patients' subjective matters more comprehensible for healthcare providers. In clinical goals-of-care communication, ACP is such a tool. Often used near the EoL, ACP is expedient for the planning of this phase, but it is also suitable to use whenever discussing potential serious illness scenarios, and even for decision-making concerning an imaginable organ donation (189).

Due to continuity, ACP seems to be most suitable for use in primary care, but because adverse incidents, exacerbations or other (dramatic) changes of the disease trajectory often lead to hospital admittance, and treatment changes often occur in specialist care, hospitals have a significant responsibility for initiating ACP conversations (Studies I-III). Planning for hospital discharge for patients in need of palliative care is often challenging, and as recognized by clinicians in Study II, ACP may be a pertinent

communication tool for discharge planning, increasing the safety for all parts involved (Studies I-III). ACP can contribute to an exchange of important, summarizing information, distribution of responsibilities, and the possibility of writing concrete plans for the homecoming and the future (56). However, in order to have time to optimize patient care while hospitalized, the assessment of care needs must be performed at an early stage during the hospital stay.

There is a need to offer ACP systematically, but as shown in Studies I and II, the right timing for ACP is individual. A minority (estimated to 10-30%) does not want ACP conversations when invited, but may be positive at another stage of the disease trajectory (190-192). Consequently, if ACP is to be offered systematically upon discharge, it is important to offer another form of discharge conversation to those who reject ACP.

The guide

ACP conversations include all dimensions of human life: the physical, the psychological, the social, and the spiritual dimensions (80). The conversations often contain themes such as health-related experiences, worries, attitudes and values. To facilitate open exchange of thoughts, emotions and information, the climate of the conversations needs to be empathetic, mild and caring, always respecting the patient's limits for transparency and privacy (193). SDM tools promote patient-centred conversations. Used in ACP conversations, they stimulate a fruitful communication among patients, their relatives and healthcare providers, thus contributing to increased knowledge for all involved (39).

As recommended by the EAPC, we used a semi-structured guide to facilitate ACP conversations. Piloting the guide, it promoted information exchange about matters of importance for the patient at present and for planning EoL care. When conducted in a patient-centred manner, both patients and relatives were comfortable with the conversations, often describing them as "relieving". The guide is most likely usable for other patient groups than patients with advanced pulmonary disease. However, it is uncertain whether there is a need for different conversation guides for different

situations and patient groups, or if a common guide can cover all. Thus, more research about this matter is needed.

Documentation

A frequent problem with ADs is that they often do not cover clinically relevant situations or lack information about what the patient really meant and/or understood at the point in time when the document was written (56). As opposed to ADs, an ACP document may be closely linked with the patient's inner values and closest relations, thereby providing useful and valuable information in clinical situations that were not postulated in advance. The EAPC White Paper on ACP recommends the use of a semi-structured ACP document, with a structured format for easy retrieval of specific goals and preferences in case of emergencies, and an open-text format for documentation of values, preferences and goals (80). However, it is important to bear in mind that an ACP document cannot be valuable without the consent from a conscious and cognitively clear patient, or if the patient has lost his/her consent ability, his/her closest relatives or appointed proxy. Patients' wishes may evolve and change during the disease trajectory, giving the need for a process of EoL goals of care conversations (105, 194). If this ripening process is not taken into account, and ACP documentation is used rigorously without checking its validity by asking the patient or a proxy, there will be a risk of not treating the patient according to his or her present wishes for real-time EoL care. The voice of a decision-competent patient can never be overridden by a document.

Due to the postmodernist development and the increased claim for patient autonomy, patients' access to the medical record and patient participation when documenting in the medical record have become increasingly relevant. This new transparency may strengthen patient safety and contribute to increased patient autonomy. However, having access to their own medical record, patients may experience the content as incomprehensible or harsh to read. On the other hand, realizing patient access may lead to healthcare personnel restricting their documentation and thus devaluing the medical record as a tool for information exchange (68). In Study II, both patients and clinicians pointed at the importance of patient participation in documentation, and of a

safe system for documentation and sharing of the content, to strengthen confidentiality and to ensure that only necessary information is passed on.

It is a known problem that ADs often are inaccessible, either because the document is missing, or because the existence of the document itself is unknown to relatives and clinicians (195, 196). The need for reliable and safe systems for storage, retrieval and sharing of medical information is also stated in the EAPC recommendations, giving national healthcare organizations and governmental authorities this responsibility while claiming for good organization and funding (80). Thus, safe documentation is a matter of systematization and ICT innovations, which may contribute to a smoother implementation of ACP.

Evaluation

The evaluation of ACP is a matter of dispute, and different starting points in diverse contexts give variation in the results. For example, while some studies have proven ACP to be therapeutic in reducing anxiety and distress among both patients and relatives, other studies have not managed to show this (56, 58, 91, 92, 197). Evaluating the possible economic benefits and costs of ACP may be challenging, partly because there are limited data available, and partly because the economic focus itself may affect the communication process in a way that diminishes individual autonomy (198). Hence, as long as ACP leads to a reduction of overtreatment near the EoL, it may give possible economic benefits, but vice versa; it would be ethically problematic to use ACP intentionally for the reduction of expenditures (199).

Dr. R. Sean Morrison, among others, has argued that years of research on ACP have not given clear facts about its effectiveness (200). Dr. Morrison's arguments are partly based on the opinion that formulation of ADs is the foremost goal of ACP, and that the main outcome is "goal-concordant care". When using "goal-concordant care" as the main outcome for the evaluation of ACP, and comparing patients' written wishes for EoL care and for place of death with the actual EoL care received, one often experiences disappointments and concludes that ACP does not work (201-204). In an answer to Dr. Morrison's criticism, Tishelman et al. wrote about "a need to identify outcomes of ACP that are more closely related to its process and not only its product

(ACP document), and to involve people themselves and their carers in articulating such outcomes” (205).

Thus, opponents to Dr. Morrison and other critics argue for an adjustment of the goals for ACP and a need for consensus about more realistic outcomes for the evaluation of ACP. They also request an improvement of the healthcare system towards more systematic and frequent ACP conversations, systematic reviewing of ACP documents, and better infrastructure for information-exchange between different levels of patient care (206). In response to this, Dr. Morrison explains thoroughly his view based on results from ACP research, concluding that there is a need for a change towards SDM communication about actual severe disease situations in real life, instead of unrealistic planning of an unknown future (201). Apparently, EoL care can be as difficult to plan as it is to plan a birth in advance, and especially if patients have non-realistic wishes and preferences for EoL care, or if the plans that are made are non-compatible with the given socioeconomic frames for healthcare (201). Underlining the complexity of ACP interventions and in finding the right outcomes for such interventions, Gilissen et al. highlighted several organizational factors that could facilitate the implementation and sustainability of ACP in nursing homes, such as the availability of physicians (207, 208).

As mentioned by critics, ACP is a resource-craving intervention, making the evaluation of the intervention both important and challenging. Humans tend to change their minds over time, and one ACP conversation is not enough, even if it should result in an ACP document (209). Regarding ACP as a patient-centred communication process, the search for the patient’s values and attitudes towards life and death and the resulting priorities for care should be central. This approach may be more useful and also more reliable than aiming at hard endpoints such as DNR orders that may not suit future EoL care situations. Thus, to avoid comparing apples with pears, evaluation of ACP needs a consensus about both goals and outcomes, and a consistency in how to measure them. Until now, the two Delphi processes led by Sudore and Rietjens have given the best collection of advice for the evaluation of ACP (80, 93). In addition, we

believe that post-bereavement surveys, as shown in Study III, may be a pertinent tool in the evaluation.

5.2.3 Implementation of ACP

ACP is a complex intervention, which makes the implementation process challenging, and it may even include new arrangements to some extent. Consequently, ACP demands a systematic implementation that is well supported by national health authorities and local health management (3, 19). In Norway, national health authorities have recently started the process of implementation, and the first national recommendations are now under preparation (192).

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Implementation of ACP will have to be compatible with the national medical legislation (210). While the intention of ACP is to strengthen the patient's voice, Norwegian medical legislation gives the physician, and the clinical team, the last word in medical decisions (101). Although having the right to refuse assessment and treatment, Norwegian patients cannot demand non-adequate treatment. In addition, it is a patient's right to refuse information (100). As patients described in Study I, taking the intentions and needs for ACP into consideration for all involved, transparency may be difficult to balance. Prognostic information, which is essential for EoL planning, is not always requested by the patient, and sometimes only by the relatives or clinicians (211). Although this makes ACP more difficult, and in some cases even impossible to perform, Studies I-III have reminded us about the importance of being seen, invited and given the possibility to talk about what each individual finds important when facing dramatic changes in life.

Barriers

All parts involved in ACP may have barriers (Ch. 1: 1.5.4), as shown in several studies, including Studies I and II (94, 95, 212). However, a postponement of planning for the last phase of life may result in missed opportunities for making autonomous plans, and thus a resulting reduction of patient autonomy (213, 214). Patient- and relative-related barriers need to be known and recognized in order to find the best approach when introducing and inviting to ACP conversations, so patients may get

what they need (215). Conducting ACP conversations in a patient-centred manner may help to overcome most patient- and relative-related barriers as shown in Studies I and II (216).

Healthcare professionals experience several barriers themselves, often related to time and knowledge, as outlined in Study II (95, 212, 217). Implementing ACP through a whole-ward approach may help to manage clinician-related barriers by increasing their knowledge about ACP, including the right timing for ACP, and reducing gate-keeping and misunderstood overprotection of patients (121). Such an approach will need full support from the management, including helping the clinicians structure their time to make space for these important conversations (217).

Implementation of ACP

Aiming at seamless and individual palliative care pathways, communication is essential (3, 6). ACP is a clinical communication system combining patient-centred care, SDM and documentation that is patient-safe and retrievable. Due to the continuous process and the person-centred approach, ACP promotes patient autonomy, relational autonomy and patient-centred communication and care.

As stated by Lund et al., to educate a specialist cadre of ACP facilitators would not be sustainable, and structured tools are not enough (217). However, ward culture seems to be important (Study III) (218). Thus, when initiating and facilitating ACP, a whole-ward approach is recommended (121, 219). Healthcare professionals will need education in how to perform ACP, including timing of the conversations, the best ways of inviting/introducing, and how to document the conversations (80, 188, 217). When conducting Study II, the need for a facilitator appeared. In addition to leading the conversations, he facilitated the selection of participants and coordinated appointments. However, patients prefer to have the conversations with someone they relate to in the healthcare system (Study I) (157). Thus, a facilitator should preferably have the supervising role of a coordinator and an instructor during the process of implementation. Since working closely with patients and their relatives, nurses may have a special position to conduct ACP (113, 220, 221). The EAPC white paper on

ACP suggests that any clinician can facilitate ACP, but physicians need to be involved for the discussion of medical topics (80).

Implementation of ACP in Norway will require organizing factors such as good leadership during the process and safe and communicating ICT systems for sharing and retrieval of medical information (180). Linking the performance of ACP to reimbursement may lead to an increase of initiated ACP processes, but does not guarantee for the quality of the processes (199). The process will require resources for education of healthcare personnel, but also of patients and the general public through national campaigns, as well as allocation of time for the conversations. Evaluation of the effects of ACP also needs attention after implementation, and the EAPC recommendations for the evaluation of ACP (Text box 3) should be used (80).

6. CONCLUSIONS

Patients with advanced pulmonary diseases and their relatives need special attention from healthcare personnel, and they ask for well-performed clinical communication and care. ACP is a pertinent tool to meet these needs and may empower patients and relatives by providing tailored information. Transparency may be difficult to balance, but introducing ACP at turning points in the disease trajectory, having a patient-centred focus, and an attention towards present and future symptom control may be rewarding. ACP is a complex intervention to implement, with important aspects such as management support, feasible routines and allocated time, education, training and safe systems for documentation and sharing of information.

7. FUTURE PERSPECTIVES

Our postmodernist society holds an increasing claim for autonomy, and this also influences the healthcare system. Additional research on autonomy, and relational autonomy, in healthcare settings should be fruitful for the approach towards better clinical communication and more patient-centred care.

When preparing for a future exacerbation or progression of a chronic disease, ACP is a pertinent system for clinical communication with patients and their relatives. However, ACP may also be useful for communication with healthy persons when talking about a possible future critical illness scenario, and there is a gap of knowledge towards the best approach (222).

In addition, when informing the general public, ACP may contribute to an increased awareness and understanding of death and dying, as requested by the Norwegian government (19). When discussing implementation of ACP in Norway, this broad perspective should be considered.

Although there is a large amount of research on ACP internationally, further research will be necessary in the Nordic countries in order to find the best ways of executing ACP in the Nordic context, and within different patient groups. To create national ACP guidelines and to agree upon a consensus about goals and evaluation of ACP, preferably by following the recommendations outlined by the EAPC white paper, will provide for the most reliable consistency in further research on this topic.

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9. THE THREE PAPERS

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Advance care planning in life-threatening pulmonary disease: a focus group study

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ABSTRACT Advance care planning (ACP) is a communication process for mapping a patient's wishes and priorities for end-of-life care. In preparation for the introduction of ACP in Norway, we wanted to explore the views of Norwegian pulmonary patients on ACP.

We conducted four focus group interviews in a Norwegian teaching hospital, with a sample of 13 patients suffering from chronic obstructive pulmonary disease, lung cancer or lung fibrosis. Analysis was by systematic text condensation.

Participants' primary need facing end-of-life communication was "the comforting safety", implying support, information and transparency, with four underlying themes: 1) provide good team players; 2) offer conversations with basic information; 3) seize the turning point; and 4) balance transparency. Good team players were skilled communicators knowledgeable about treatment and the last phase of life. Patients preferred dialogues at the time of diagnosis and at different "turning points" in the disease trajectory and being asked carefully about their needs for communication and planning. Transparency was important, but difficult to balance.

ACP for patients with life-threatening pulmonary disease should rest upon an established patient–doctor/nurse relationship and awareness of turning points in the patient's disease progression. Individually requested and tailored information can support and empower patients and their relatives.



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Advance care planning may increase patients' feeling of "a comforting safety", meeting their need for support, information and transparency <http://ow.ly/DMQJ30jdIPt>

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Introduction

Advance care planning (ACP) is a structured communication process enabling 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 [1]. During one or more conversations, physical, social, psychological and spiritual aspects of life are discussed [2]. Studies have shown that using a list of questions as a guide is better than using a paper-based scheme and tick boxes [2]. Important details can be outlined in a document, often as part of the medical record, and may be reconsidered and altered if the patient changes his/her mind [2].

ACP is in common use in several English-speaking countries, and effects on improved care and quality of life for both patients and their relatives have been demonstrated [2, 3]. So far, ACP has not been introduced in any Norwegian hospital, but Norwegian health authorities have encouraged research on ACP and pointed to the need for implementation of guidelines and advisory material [4, 5]. In the general population, the concept of ACP is mostly unknown.

Patients with advanced incurable lung diseases are a diverse group, comprising patients who may have been living with chronic obstructive pulmonary disease (COPD) for years [6, 7], patients with an insidious progression of pulmonary fibrosis [8] and patients with lung cancer who may have galloping trajectories with only months between the time of diagnosis and death [9]. All these patients often have burdensome symptoms such as dyspnoea and pain, and they often share a feeling of their life being threatened, hence, planning for the best possible care at the end of life (EoL) is important [10–12]. Believing ACP to be a feasible tool for Norwegian healthcare professionals and their patients, and working particularly with patients with advanced lung diseases (authors NEH and MAS), we designed a study to explore pulmonary patients' needs and preferences regarding ACP in order to prepare for the introduction of ACP in Norwegian hospitals.

Material and methods

We conducted a focus group study interviewing patients with advanced pulmonary disease [13, 14].

Participants and study setting

The focus group interviews took place at the outpatient clinic of the Department of Thoracic Medicine at Haukeland University Hospital in Bergen, Norway. This department has ~17000 outpatient consultations and ~3000 in-patient admissions per year. All participants were recruited from this department.

The recruitment period lasted from January 2014 to February 2015. Patients receiving treatment for advanced lung cancer, COPD or lung fibrosis were invited to participate by a dedicated research nurse, other nurses on the ward or at the outpatient clinic, or attending physicians. 42 patients were asked to participate. 17 (40%) agreed, but only 13 participated, due to the worsening condition of the others. As soon as a group was established through successive recruitment, an interview took place. We strived for a purposive sample, aiming for diversity in age, sex, diagnosis and education. Our final sample consisted of six males and seven females, distributed between four focus groups. 12 patients were Norwegian and one was Danish. Inclusion and exclusion criteria are listed in table 1.

Ethical statement

The study was approved by the regional committee for medical and health research ethics of Western Norway (REK number 2013/1479). Written informed consent was obtained from all participants. To

TABLE 1 Inclusion and exclusion criteria for focus group participants

Inclusion criteria	Aged >18 years In- or outpatient at the department of thoracic medicine (Haukeland University Hospital, Bergen, Norway) Diagnosed with advanced (noncurable) pulmonary disease, e.g. inoperable lung cancer, COPD or pulmonary fibrosis Able to communicate orally in Norwegian Able and willing to provide written informed consent
Exclusion criteria	Cognitive impairment Other circumstances (e.g. anxiety, impaired hearing or reduced functional ability) representing a severe challenge to group participation and dynamics

COPD: chronic obstructive pulmonary disease.

secure confidentiality, pseudonym participant names were used in the transcription and analysis, and patients were asked specifically not to share information about other co-informants elsewhere. Audio files from the interviews were stored safely on a research server belonging to the University of Bergen.

Data collection

NEH served as facilitator in all interviews and MAS acted as secretary taking field notes. No relatives attended the groups. The facilitator invited participants to talk about EoL issues and communication preferences regarding these. To balance eager participants against the more modest, we guided the discussions using questions, both to the whole group and directly to some of the participants. The interviews lasted 49–66 min and were transcribed verbatim by a secretary. Data collection was closed after four focus group interviews, as we assessed the data as sufficient to illuminate the research topic according to the concept of information power [15].

In addition to the data collected in the focus group interviews, demographic and medical information was taken from the medical record and registered in a non-identifiable form to characterise the study population.

Analysis

Data analysis was performed in collaboration between the authors NEH and MAS, using systematic text condensation, a cross-case thematic analysis suitable for both focus group data and individual semi-structured interviews [16]. The analysis proceeded through the following stages: 1) reading all the material to obtain an overall impression, bracketing previous preconceptions; 2) identifying units of meaning, representing different aspects of the patients' views on and experiences of ACP; 3) condensing and abstracting the meaning within each of the coded groups; and 4) summarising the contents of each code group to generalised descriptions and concepts reflecting the most important needs and perspectives regarding ACP as reported by the informants. Analysis was done stepwise with new interviews supplementing the sample, and a decision trail documented the choices during the analytical process [17].

Results

Having an advanced life-threatening pulmonary disease gave the patients a need for security concerning treatment and human relationships, in hospital as well as in private life. The participants' primary need facing EoL communication was "the comforting safety", implying support, information and transparency, with four underlying themes: 1) provide good team players; 2) offer conversations with basic information; 3) seize the turning point; and 4) balance transparency. Good team players were skilled communicators knowledgeable about treatment and the last phase of life. Patients preferred dialogues at the time of diagnosis and at different "turning points" in the disease trajectory, and being asked carefully about their needs for communication and planning. Transparency was important, but difficult to balance.

Demographic and disease-related information for the focus group participants is presented in table 2 and figure 1. All citations from participants are presented with pseudonyms.

Provide good team players

"The comforting safety" could be established by providing the patient with good team players. The participants talked about the importance of having a network of people who were knowledgeable, supportive and caring. These team players were found both in their own family, among friends and among healthcare professionals. At the hospital, the participants wanted to be offered ACP conversations, as expressed by a woman in her fifties:

I wish there was an option when you received the message that you have limited time left to live; that a doctor could talk with me about the situation and what worries me. (...) It is difficult to talk about this, but I think it can help me to talk with someone knowledgeable. (Suzanna, lung cancer)

Additionally, knowing they had good relationships with professionals in the hospital and a reliable way to get in contact with them, now and in the future, was important. Everybody in the focus groups would prefer the Department of Thoracic Medicine to offer conversations about the last phase of life. However, they pointed to the need for delicacy and respect when extending an invitation to such conversations, giving the invited patient the possibility of accepting or rejecting participation. They would prefer to have EoL conversations with people they already knew in the department, regardless of profession; it could be a nurse, a doctor or a psychologist. According to the participants, a professional having knowledge about both the patient and his/her disease was considered to be the right person in the healthcare system to talk to, including when it came to conversations about the last phase of life. Some argued the age difference should not be too big between patient and healthcare professional; indicating that they preferred a person either about their own age or older. The quality of the relationship and rapport were the most important

TABLE 2 Demographic and disease-related information for focus group participants

Age years	65 [52–80]
Sex	
Female	7
Male	6
Occupation	
Shop assistant/office worker/factory worker	9
Academic	1
Seaman	2
Self-employed	1
Living situation	
Alone	3
With spouse/partner	10
Disease	
Small cell lung cancer disseminated disease	2
Nonsmall cell lung cancer stage III–IV	5
COPD GOLD criteria stage IV	4
Idiopathic pulmonary fibrosis	2
Treatment	
Inhalation therapy	5
Chemotherapy	7
Immune-modulating therapy	3
Radiation therapy	1
Comorbidities	
Asthma, COPD, emphysema, bronchiectases, OSAS	9
Chronic pain, osteoporosis and/or arthrosis	7
Coronary heart disease	6
Diabetes mellitus	2
Dermatological diseases	3
Other malignancies	2
Renal failure	2
Medication	
Nonopioid analgesics	6
Opioid analgesics	7
Corticosteroids	6
Benzodiazepines	3
Antiemetics	3
Laxatives	4
Antidiabetics	2
Inhalation aerosol	5
Antihypertensives, statins, diuretics or nitrates	4
WHO performance status	
I	9
II	3
III	1

Data are presented as mean [range] or n. COPD: chronic obstructive pulmonary disease; GOLD: Global Initiative for Chronic Obstructive Lung Disease; OSAS: obstructive sleep apnoea syndrome; WHO: World Health Organization.

aspects when choosing a team player; the sex of the individual followed. The most important qualification when offering EoL conversations was being competent in supportive teamwork and clinical communication, making the patient feel safe and understood while at the same time imparting important information:

I don't think it is painful to talk about dying as long as I have a person teaming up with me, and who really knows what it is all about. (Nancy, lung cancer)

Most participants emphasised that it might be painful and difficult to talk about EoL issues. Several mentioned they were not capable of talking about everything on their mind with their nearest and dearest, or abstained from doing so in order not to hurt them. Several stories referred in particular to situations at times of disease worsening, when patients wanted a conversation with relatives, facilitated by healthcare professionals:

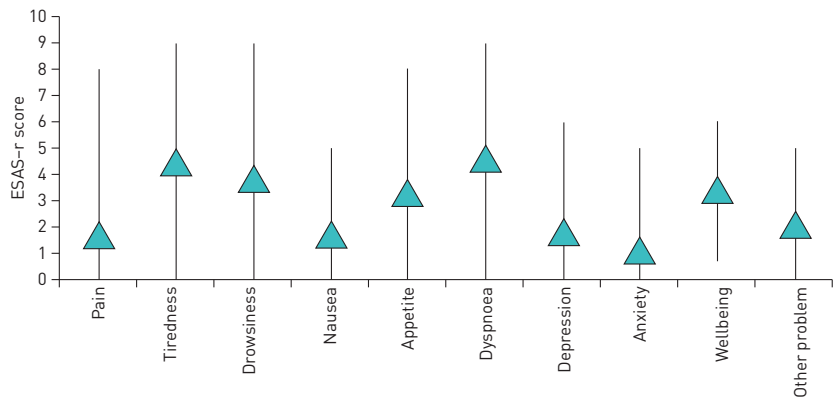


FIGURE 1 Symptom scores for the study participants using the Edmonton Symptom Assessment System, revised (ESAS-r), a numerical rating scale. 0: no symptom; 10: worst possible symptom. Data are presented as mean [range].

I am rather open minded, we are open minded at home, but I don't manage to talk about death. I think it may be easier to talk about death with someone who's on the outside. (Gary, COPD)

Offer conversations with basic information

Many participants stressed the importance of receiving the information they needed. Information about present and future symptom management was important for most of the participants. Several mentioned anxiety-provoking dyspnoea as well as fearing future pain and other distressing symptoms. They wanted information about topics such as practical aids, medications, legal rights and social benefits, finance and who to contact when they needed help. Talking about challenges and services available for the last phase of life was mentioned as a prerequisite for good quality of life:

Because I have limited time left to live, I want to know everything that may happen to me. I want healthcare professionals in the hospital to inform me of my rights and benefits, the expected disease trajectory and the last phase of life in order to fulfil my wish for dignity at the end of life. (Nancy, lung cancer)

Others expressed a wish for thorough information in the future, underlining that they did not feel ready for it yet. Some emphasised how important it was that doctors did not give wrong information, but ensured adequate knowledge about treatment and side-effects, enabling patients to make decisions in line with their own preferences. The participants did not talk much about future planning. Yet, when thinking about a possible future situation when they no longer could make decisions for themselves, some of them mentioned a wish for a proxy:

My children shall be my attorneys if I should become so ill I am no longer in control over my own thoughts; so that I will not receive more treatment than I would have wanted. (Paul, lung cancer)

Participants described how information about the disease as well as social benefits supported relatives in a difficult situation. Some expressed difficulties knowing what to ask for when they had an appointment with the doctor, but at the same time wished to know what was happening to them. In addition, they described the immense challenge of being severely ill, including reduced capacity to remember all eventualities and needs. Thus, they wished for a proactive approach from the healthcare system, with the option to refuse an offer of conversation rather than having to ask for it themselves when they already were so heavily burdened, outlined like this:

I have so many thoughts on my mind now that I'm ill, so it is difficult to remember what I should ask about; it is better that they offer information about what they think I need to know. (Evangeline, lung cancer)

Seize the turning point

Most participants wanted a tailored EoL dialogue at the time of diagnosis. However, the COPD patients suggested that their entering the most serious disease stage (stage IV) would be a suitable time for an ACP conversation, even if they might have several years left to live. All participants underlined that an individual approach was mandatory, respecting each patient's particular needs:

I think there is a need for more than one conversation, and that we could be offered one in the beginning, then one or two later on when the condition is getting worse. It must be an individual approach. (Peter, pulmonary fibrosis)

It was also important that they received a “warning shot” in advance, to be able to prepare for the conversation mentally and practically, and especially to invite persons they wanted to be present. They regarded it as important that ACP conversations were held while the patient was cognitively sound, and that distressing symptoms such as dyspnoea and pain were well treated beforehand. Some participants wished for an early informative and prognostic dialogue, before they became so ill that it was difficult to make a prospective care plan. One patient described how she had been struggling alone without help from healthcare professionals after having received her diagnosis, searching to find resilience and unable to talk with her close ones. After some years, she had finally found a sort of balance:

I wanted a conversation about diagnosis and prognosis much earlier in the trajectory than what I have been offered. Now, after four years, it is too late. (Evangeline, lung cancer)

Even when patients themselves received adequate and successive disease-related information, this was not necessarily enough to establish a common ground and understanding of EoL issues in their families. Several participants expressed the need for more help informing their closest ones about their diagnosis and prognosis. The participants named key turning points that often were consistent with major medical changes. Examples of such turning points were an infection triggering change, a new metastasis, increasing pain, increasing dyspnoea, loss of a function, decline in their general condition and stopping chemotherapy. At the time of treatment changes, several had wished for thorough information in order to reduce anxiety:

It is something about change; that every change can increase anxiety. (Nathan, COPD)

Balance transparency

Some participants wanted open and honest conversations about their disease, yet acknowledging it could be difficult to find a proper balance. It was upsetting if friends, neighbours and other acquaintances avoided meeting them because they felt it was difficult to talk with them. Transparency through honest conversations about their state of health and feelings was regarded very important:

Being open about everything concerning me and my family makes me feel secure. I feel safe and I feel that I make those around me safe, too, by being open. (Nancy, lung cancer)

Some needed transparency about their prognosis to be able to spend their remaining time with their family in the best way. Receiving news about limited time left to live could yield possibilities for preparing themselves as well as family members practically and psychologically for the inevitable course of the disease. Many wanted full openness and information about their disease in order to correctly inform children and grandchildren, even though this could be difficult to do by themselves:

In the nights, I cried in bed alone without telling everything to my family, but now I no longer try to hide it. (Evangeline, lung cancer)

There was broad agreement that healthcare professionals should ask the individual patients in a careful and respecting manner about their need for information and for ACP, as this could be very different from one patient to another. Documenting all given information in the patient’s medical record, including any restrictions on what the patient wished to know, was regarded mandatory to avoid information errors:

The information I’ve received must be documented in my medical record, as well as what I don’t want to know about my disease. I would find it horrible if I was given more information than I wanted. So I think medical records should clearly state the patient’s preferred details and content of information. (Miranda, lung cancer)

Discussion

Facing incurable pulmonary disease, our informants described the need for a safe foundation and comforting understanding provided by EoL discussions with knowledgeable healthcare professionals at important turning points during the disease trajectory. Here, we discuss the impact of our findings and the strengths and limitations of this study.

Discussion of the results

Our results are in line with previous research demonstrating that most patients offered ACP conversations want them [9, 18]. The challenges in finding the desired balance in transparency, both for healthcare

professionals and patients, has been mentioned by SIOUTA *et al.* [19]. The concept of the “comforting safety” created by tailored ACP conversations and how it may improve quality of life among Norwegian patients with advanced pulmonary disease have not been demonstrated before.

This study expands our knowledge about ACP for pulmonary patients by showing that good relationships between patients and their healthcare providers are important for the basic trust needed to address sensitive themes in an ACP conversation. Patients need a tailored approach, both when it comes to the invitation to ACP conversations as well as the choice of themes. As the participants pointed out, turning points of the disease trajectory: at the time of diagnosis, a serious infection, progression of the disease, loss of a function or change in therapy, can bring uncertainty and anxiety. Awareness of these turning points is important in order to comprehend patients’ special needs and vulnerability, and to seize the opportunity to introduce ACP conversations. This finding coincides with the recommendations in the Norwegian Action Programme for Palliative Care [5].

Cultural differences are important factors to consider when starting an ACP programme [20]. Since ACP has never been used in a Norwegian hospital before, the Norwegian context needed to be explored. This study demonstrates important attitudes and viewpoints on ACP conversations in Norway before any ACP programme has been started.

Whether or when it is appropriate to communicate about the last phase of life is not always obvious. LOVELL and YATES [21] found that factors influencing ACP are complex and multifaceted. Both patients’ and doctors’ attitudes towards the diagnosis and their understanding of the prognosis determine whether to start an ACP conversation or not. SIOUTA *et al.* [19] found that patients with chronic heart failure and COPD are quite unlikely to participate in discussions concerning EoL issues, partly because it is more complicated to initiate such conversations for patients with a less certain prognosis [22–24]. VERMYLEN *et al.* [25] found that doctors avoid conversations about ACP with patients suffering from COPD due to unique communication barriers, *e.g.* lack of prognostic factors and difficulty of predicting which patients are at the highest risk of premature death. Although patients may not initially be interested in discussing advance directives with their doctors, many patients still have unexpressed wishes that may not be respected if the conversation is not broached delicately. In addition, the public understanding of these diseases is not directly linked to dying, so including EoL issues in conversations can elicit negative reactions from patients [26, 27]. Our patients pointed to the need to give the invitation to ACP conversations in a gentle manner. They expressed the need for a tailored approach, both concerning the invitation to discuss ACP, and the choice of themes.

As JABBARIAN *et al.* [28] have pointed out in a recent review, ACP is surprisingly uncommon in chronic respiratory disease. SIOUTA *et al.* [19] have remarked on the implications of not having ACP conversations: the scarcity of patient–doctor discussions concerning treatment options and preferences, and the frequent total absence of discussions on EoL issues result in less informed patients. Many patients search for relevant information on the web, which may make them challenge or question medical decision making [29]. With the increasing claim for patient autonomy and shared decision-making, ACP can be a tool to facilitate conversations that may cover this claim.

Some recent trials of clinical EoL communication have taken place in Norway, with promising results [18]. Even so, there is a need for better mapping of similarities and differences among the various groups of patients with advanced disease in Norway, and we will still have to look to experiences from other countries where ACP is incorporated into the general healthcare system [30]. Our informants wanted to be offered ACP conversations, but found it difficult to know what to ask for. Thus, the question is more about form and content than about having such conversations or not.

TABLE 3 What is known about advance care planning [ACP]? What does this study add?

What is known?	ACP is used in many countries, and most patients offered conversations want to discuss it Using a list of questions as a guide is better than using a paper-based scheme and tick-boxes only Patients’ and relatives’ satisfaction with end-of-life care increases with the use of ACP Transparency is difficult to balance
What does this study add?	ACP for Norwegian patients with life-threatening pulmonary disease should rest upon an established patient–doctor/nurse relationship ACP is perceived to increase the patient’s feeling of “a comforting safety”, meeting their need for support, information and transparency ACP conversations involving both patient and relatives may support the relatives in their role as good team players Turning points of the disease trajectory are times when patients may be especially in need of ACP conversations

Strengths and limitations

A strength of our study is that the interviewer had extensive experience in EoL conversations, both as a pulmonologist and palliative care specialist. This experience guided the follow-up questions and influenced the analytical process. Additionally, we believe that the interviewer's clinical experience created an openness towards contrasts and nuances in the participants' stories. Some of the participants had been in contact with the hospital's palliative care team, but they had not met the interviewer as a palliative care physician.

Exposing vulnerability in a group, compared to individual interviews, may limit data collection, but might at the same time expand the process, as one participant's reflections may contribute to an open atmosphere giving co-participants the courage to talk. The latter was observed in all groups. Hence, we believe that, facilitated by group reflection, the participants' experiences were presented without excessive concern about making a favourable impression.

The process of recruitment was challenging and had a span of ~1 year. Many patients refused to participate, for various reasons. In addition, 23% of possible participants did not manage to come to the focus groups, mainly because of a worsening of their conditions. Many other patients were never asked to join the study, as both doctors and nurses found it difficult to raise the topic of the study. Consequently, we might have been able to recruit patients more open to, and more interested in, talking about sensitive themes, which is a possible limitation of our study. Even so, the sample recruited was representative of the clinic, and the participants represented variations in age, sex and diagnosis and family, working and living conditions; adding external validity to the findings to other hospitals treating patients with incurable lung disease in the same cultural context. Table 3 summarises current knowledge about ACP.

Conclusion

As far as possible, ACP for patients with life-threatening pulmonary disease should rest upon an established patient–doctor/nurse relationship and awareness of turning points in the patient's disease progression. Healthcare professionals can support and empower patients and their relatives by providing individually requested and tailored information. ACP may strengthen patients' resilience during the disease trajectory.

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Feasibility and acceptability of introducing advance care planning on a thoracic medicine inpatient ward: an exploratory mixed method study

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ABSTRACT

Background and aims Advance care planning (ACP) is communication about wishes and preferences for end-of-life care. ACP is not routinely used in any Norwegian hospitals. We performed a pilot study (2014–2017) introducing ACP on a thoracic medicine ward in Norway. The aims of this study were to explore which topics patients discussed during ACP conversations and to assess how patients, relatives and clinicians experienced the acceptability and feasibility of performing ACP.

Methods Conversations were led by a study nurse or physician using a semistructured guide, encouraging patients to talk freely. Each conversation was summarised in a report in the patient's medical record. At the end of the pilot period, clinicians discussed their experiences in focus group interviews. Reports and transcribed interviews were analysed using systematic text condensation.

Results Fifty-one patients participated in ACP conversations (41–86 years; 9 COPD, 41 lung cancer, 1 lung fibrosis; 11 women); 18 were accompanied by a relative. Four themes emerged: (1) disturbing symptoms, (2) existential topics, (3) care planning and (4) important relationships. All participants appreciated the conversations. Clinicians (1 physician and 7 nurses) participated in two focus group interviews. Reports from ACP conversations revealed patient values previously unknown to clinicians; important information was passed on to primary care. Fearing they would deprive patients of hope, clinicians acted as gatekeepers for recruitment. Although they reported barriers during recruitment, many clinicians saw ACP as pertinent and called for time and skills to integrate it into their daily clinical practice.

Conclusions Patients, relatives and clinicians showed a positive attitude towards ACP. Focusing on present and future symptom control may be an acceptable way to introduce ACP. Important aspects for implementing ACP in this patient group are management support, education, training, feasible routines and allocated time to perform the conversations.

INTRODUCTION

Advance care planning (ACP) is a process of conversations enabling individuals to define goals and preferences for future medical

Key messages

- ▶ To explore feasibility and acceptability of introducing advance care planning (ACP) in a Norwegian hospital.
- ▶ Patients and clinicians perceived ACP conversations as pertinent, though a future implementation is not without challenges.
- ▶ In the conversations, patients revealed four main topics important for their future situation.

treatment and care; to discuss these goals and preferences with family and healthcare providers across the physical, psychological, social and spiritual domains; and to record these preferences if appropriate.¹ ACP encourages individuals to identify a personal representative and to regularly review any preferences, so that their wishes can be taken into account should they, at some point, be unable to make their own decision.²

Patients with advanced pulmonary disease (chronic obstructive pulmonary disease (COPD), lung cancer and lung fibrosis) often suffer from a high symptom burden and severe prognosis.^{3–5} Studies show that this patient group may benefit from ACP, but also that it is often not offered.^{6–8} Good decision-making processes are increasingly warranted in clinical medicine with the heightened focus on patient autonomy, but the need for and openness toward ACP might vary between cultures and different diagnostic groups.^{3, 6, 9, 10}

In Norway, ACP is still in its infancy and not used routinely, and there is a lack of research addressing how ACP can support patients with advanced pulmonary disease.^{3, 11–15}

The aim of the present research was to improve our understanding of how ACP could ideally be approached in Norway, with particular attention to the needs of patients with advanced pulmonary disease. The objectives

Box 1 Semistructured guide for advance care planning (ACP) conversations in the pilot study

Part 1: planning the conversation

1. Does the patient wish an ACP conversation? (includes information about ACP and about the project)
2. Which themes are (currently) relevant?
3. Who is going to attend?
4. Time and place for the conversation.
5. Is there a need for an interpreter?

Part 2: possible themes for the ACP conversation (a list to choose from)

1. Information about the disease: past, current and future. Does the patient have special needs or reservations concerning information?
2. The patient's expectations for the future based on past and present experiences.
3. What gives the patient strength and resilience? Key words: coping strategies, existential and/or spiritual attitudes, values and beliefs.

Does the patient wish...

4. ...to appoint a proxy?
5. ...help with legal or economic challenges?
6. ...to document specific wishes concerning the last phase of life (eg, do not attempt resuscitation/respirator) in his or her medical record?

Evaluation of the ACP conversation:

1. What does the patient—and relative(s), if applicable—think about participating in this conversation?

The availability of the study nurse, usually limited to 1 or 2 days a week, regulated both the inclusion of new participants and conversations completed. Patients agreeing to participate took part in the planning of the conversation as outlined in [box 1](#). An appointment was scheduled on the same day or one of the next days.

The conversations took place in the patient's room or in a separate room on the ward. After having received some practical training initially from the first author, the study nurse led most of the conversations (42); only 9 conversations were facilitated by the first author (8) or the attending physician (1). The participating patients were encouraged to talk freely about matters of importance for their present and future situations ([box 1](#)). If relatives attended, they participated actively in the ACP conversations and their comments were included in the reports. Before closing, participants were asked how they had experienced the conversation. A summary of the conversation was documented as a report in the patient's medical record and was also anonymised and stored on a secure research server.

After the last ACP conversation had been held, phase III started. Clinicians working on the ward during the pilot period had been informed about the study orally and in writing and had been invited to participate in phase II. In phase III, they were invited to participate in focus group interviews exploring their ideas about and experiences with the ACP pilot study.^{21 22} Two of the authors (NEH as facilitator and MAS as secretary) facilitated the focus groups. Most of the participants knew the facilitators as present or former colleagues on the ward, NEH being a consultant in the palliative care team and MAS being a consultant at the department. Two focus group interviews took place, lasting 35 and 40 min, respectively. The interviews were recorded and transcribed verbatim by a secretary.

Data analysis

Data analysis was by mixed methods: quantitative data, such as recruitment and activities, were analysed using descriptive statistics, while qualitative methods, in terms of systematic text condensation, were used when analysing reports of ACP conversations and the transcribed focus group interviews. Qualitative analysis was performed in collaboration between the authors, with the analysis proceeding through the following stages: (1) reading all the material to obtain an overall impression, bracketing preconceptions; (2) identifying units of meaning representing different elements and coding for these; (3) condensing and abstracting the meaning within each of the coded groups; and (4) summarising and generalising description and concept categories.²³

Patient and public involvement

Before making the ACP guide, patients in the target group participated in focus group interviews, giving their opinion on ACP: if this should be offered, with whom and when they would want such conversations, and what topics they found relevant.¹⁹

RESULTS
Participants in ACP conversations

One hundred and eighteen patients were invited to participate in the ACP conversations; 51 finally participated. Sixty-five patients declined participation for reasons spanning from disinterest to bad timing. Twenty-nine of the non-participating patients (45%, 25% of all approached patients) gave reasons indicating that they were positive but that the timing was bad for practical reasons or that their time was already occupied, or that they were too ill. Thirty-six patients (55% of non-participating patients, 31% of all) declined for reasons such as 'too demanding'

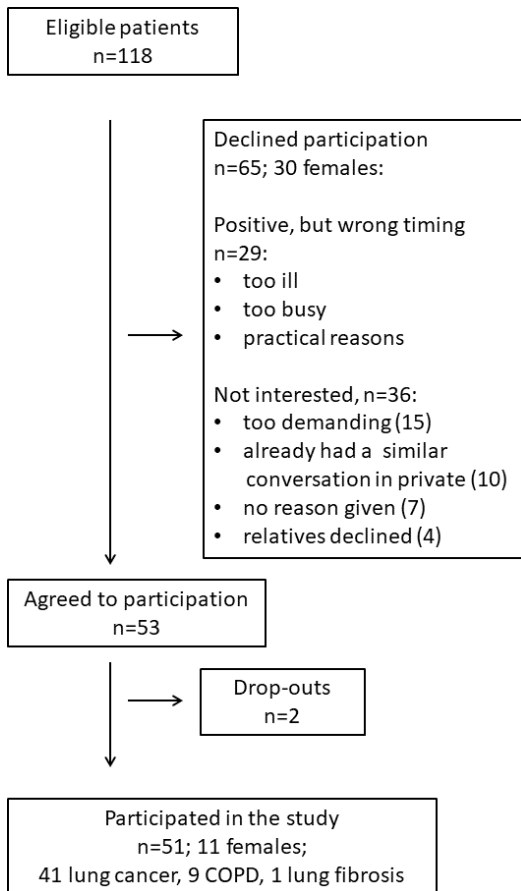


Figure 1 Overview of the recruitment process for advance care planning conversations. COPD, chronic obstructive pulmonary disease.

(15 patients) or ‘had already had a similar conversation in private’ (10 patients, 15%). Seven patients gave no reason for refraining from participation. Four patients were initially positive but declined after consulting a relative. [Figure 1](#) gives an overview of recruitment. Eighteen conversations included a close relative. Reasons for not bringing a relative spanned from lack of closeness to wanting to protect them from a tough conversation, but most often, it was a matter of logistics. The conversations lasted 30–60 min, sometimes longer. Characteristics of the participating patients are presented in [table 1](#) and in [figure 2](#).

Participants in focus groups

One male physician and seven nurses (all women), with a mean age of 39 years (range 25–58), participated in focus group interviews. They had been working at the department from 1.5 to 29 years (mean 9.4, median 4.5). Two

were specialist nurses and two were leaders. For logistic reasons, the participants were divided into two groups.

Contents

The themes from the guide appeared relevant, as displayed in [table 2](#).

Topics of the ACP conversations

From the qualitative analysis of the conversation summaries, four main categories emerged: (1) troublesome symptoms and alleviation of these; (2) existential themes such as coping, resilience and death; (3) planning of future treatment and care; and (4) important relations.

Troublesome symptoms and alleviation of these

Most patients were troubled by several symptoms related to exhaustion and loss of functions, with dyspnoea and tiredness as the most frequent ([figure 2](#)). Many of the participants feared insufficient symptom relief in the last phase of life, and this fear could exceed their fear of death itself. Many requested better alleviation.

Anxiety was triggered by changes, as by other symptoms, especially dyspnoea, and by the way information, examinations and treatments were introduced and given. How symptoms were perceived was often related to the interpretation of their importance, illustrated by a patient questioning his cancer treatment because he had overwhelming pain. Some patients experienced pain as an invading scourge reducing their quality of life, taking away their feeling of control and stealing their courage. Even though patients were grateful for the help they received, several problematised the dependence on others to obtain pain relief, stressing the importance of being believed and respected, and getting medication at the right moment. Relatives also voiced how difficult it could be to support a patient in agony.

Existential themes

Most patients described their own family as the basis for their existence. Thus, places for family gatherings—their house, cabin, garden, or holiday trips—became important existential factors and sources of strength. Through their stories about the past, they described sorrow over lost functions, lost dignity, lost relations and lost future. Life would be shorter than expected, and although this was a sensitive theme, several raised it. Earlier experiences with illness and disease, either as a relative or as a patient, mostly increased their present resilience.

While some participants were open about their religious beliefs, others expressed that this area was too private to share. Many presented indifference to religious questions while at the same time admitting a belief in something superior, such as a Christian childhood faith. Some expressed a negative attitude towards religiousness. Acknowledging the approaching death, many chose

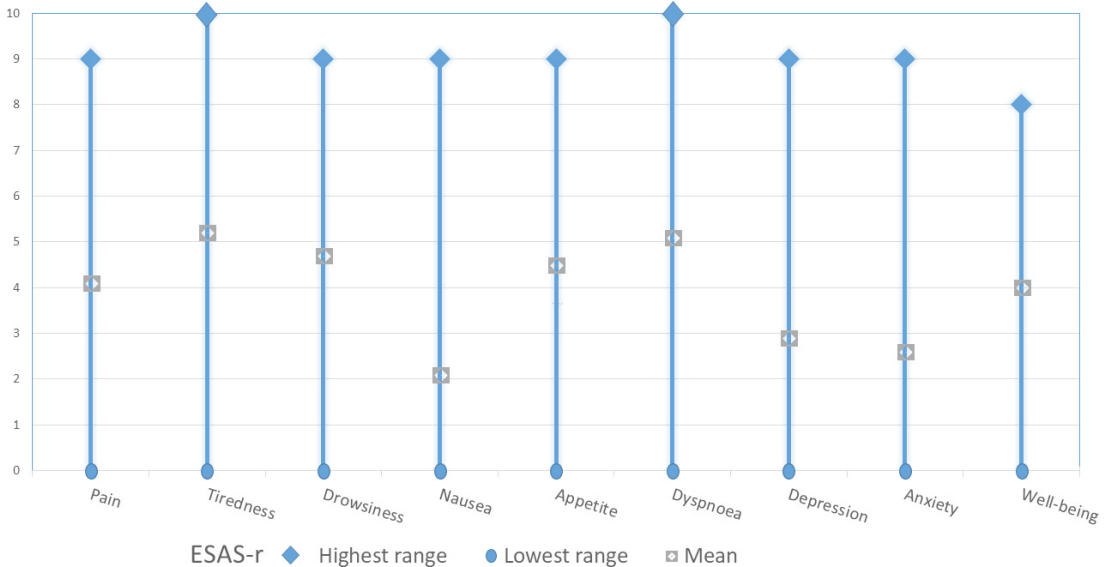


Figure 2 ESAS-r: participating patients' expression of symptoms rated by Numerical Rating Scale. ESAS-r, Edmonton Symptom Assessment System Revised.

to focus on life at present, taking one day at a time, often called 'positive thinking'.

Planning for the last phase of life

While many preferred positive thinking and postponed planning for the future, others talked about reorganising their private economy and transferring their responsibilities. Some had written a will, and some had even planned their funeral. Some participants described specific wishes concerning end-of-life care, and some had discussed this with their next of kin. While several mentioned an unwillingness to be treated purposelessly, a few demanded that clinicians should respect their choices for treatment dictated by themselves or their proxy.

Quite a few talked about 'dying with dignity', meaning being safe and certain to get help when needing it. Important for the patients' feeling of a comforting safety were the community personnel, at home or in a nursing

home, necessary equipment and financial aid, the ambulatory specialist palliative care team and having open access to the local hospital.

It was important to all patients that information be given with empathy, respecting their needs, as well as limits, for receiving medical information. Several patients told about difficulties remembering information and the resulting difficulties making plans. Some patients asked for more thorough information on diagnosis, prognosis and treatment in order to make their plans.

Good relationships

Patients talked about how important it was to be supported by someone who knew and understood their situation. Many of them got this support from close family members, others through their jobs or as members of clubs or associations. It was highly valued to bring their spouse or child to consultations, and seven patients named specific proxies, all from close family. Some had a clear wish for home death and found safety in a declaration of support from their relatives.

Approaching death, patients found that disharmony in relations was especially painful. Some talked about remoteness, either as related to their personality, their family history or to the situation of having advanced disease. A few expressed grief because of loneliness and told about lacking support from their next of kin. Several patients told about a supportive staff on the ward contributing to a feeling of safety.

Table 2 Number of participants who talked about each item under possible themes for the advance care planning conversation

Themes for conversations (from the guide)	Patients who talked about each theme (n)
Information about the disease	35
Expectations for the future	49
Sources of strength and resilience	40
Appointment of proxy	7
Legal or economic challenges	8
Documentation of specific wishes	12



Evaluation of ACP conversations by patients and relatives

Several patients expressed relief after talking about end-of-life issues, while others said that the conversation had started an important process of thinking ahead. A few wanted a follow-up conversation with a psychologist or a chaplain.

All patients and relatives expressed that they appreciated the conversation, and many recommended it to be offered routinely at the department.

Feasibility

Findings from focus group interviews with clinicians

The following main themes came up during the focus groups with clinicians: (1) benefits of ACP and (2) challenges concerning feasibility, divided into two subgroups: (1) barriers against implementation of ACP and (2) organisational aspects. Clinicians reading the ACP reports found new and valuable information that sometimes was passed on to the primary care services. Some suggested ACP as an optional part of discharge planning. Many experienced barriers against ACP, and implementation was regarded challenging in several ways: appropriate patient selection and timing of the conversation were regarded as crucial factors for an acceptable practice. To avoid deprivation of hope, clinicians regarded respect for the patient's boundaries concerning transparency and communication as highly important. They called for time, applicable routines and skills to integrate ACP into their daily practice. The findings are presented in table 3.

DISCUSSION

Patients talked about principal topics when planning for their last phase of life. In addition to symptoms, future alleviation of these and care planning, they discussed identity, beliefs and important relations. Although questioning the organisation of ACP and having barriers for its uptake, clinicians saw the need for ACP conversations and called for management support, requesting education, time and a feasible arrangement for ACP. We discuss these findings further, including the strengths and limitations of this study.

Content: ACP conversations

This was the first time systematic ACP conversations were performed on a thoracic medicine ward in Norway. Only 15% of the eligible non-participating patients had previously participated in such conversations. This underlines the need for a better organisation of ACP in Norway.

Hospitals may not seem the obvious place for ACP, but an admission may trigger the need for it.^{20 24} We know that breaking points during the disease trajectory, such as a change in therapy, are triggers for ACP conversations.^{19 20 25} In this study, a rather large number of the participating patients with cancer (27/41) did not receive anticancer therapy when joining the study. Worsening

of the disease might have triggered a need for an ACP conversation. Early integration of palliative care for patients with lung cancer has been proven to be beneficial.²⁶ ACP may be an important aspect of this approach. If clinicians avoid these conversations, an opportunity to improve the care for patients with advanced pulmonary disease will be missed.^{4 26}

We practised a person-centred ACP using the guide only as a support while focusing on the patient's wishes, needs and preferences, respecting individual limits for transparency, as recommended by Waldrop and Meeker, among others.^{20 27 28} A consequence of a person-centred focus may be that sensitive topics are avoided, with uncertainty about reasons for avoidance. However, we experienced that many patients raised rather challenging topics, indicating that the person-centred focus was both sensitive and reliable (table 2). As the reports of the conversations gave new and varied information, we conclude that our guide (box 1) may be useful in person-centred ACP conversations.

Almost all participating patients talked about troublesome symptoms, and many expressed distress related to fear for insufficient alleviation in the future. Patients needed to understand what the symptoms represented during the disease trajectory. From this observation, we derive that focusing on bothering symptoms and loss of functions, at present and in the future, may facilitate an ACP conversation. We have not found this approach described previously as a systematically used conversation technique.

While many patients found resilience when focusing on the present, some preferred to talk about their past. This gave clues about the patients' values and coping strategies, important information for future decision-making. This correlates to findings of Thoresen and Lillemoen when studying ACP conversations in nursing homes.¹⁴

The process of ACP is a multifactorial task in which knowledge about prognosis, expected care and support are important topics. In a review describing the five most important elements in end-of-life care, as judged by hospital inpatients and their relatives, effective clinical communication and shared decision-making were ranked as number one.^{29–31} This pilot study confirms this finding in that the described perceived lack of information, with the resulting difficulty in making plans, emphasises the need for more effective clinical communication.³² Supporting relations—in the healthcare system and especially within the family—were decisive when determining the level of care on discharge, contributing to patients' feeling of safety.

Feasibility of ACP conversations

In this study, feasibility of ACP conversations was challenging mainly because of barriers, divided into time and knowledge, and organisational aspects. According to Jabbarian *et al*, time barriers are partly a system error,

Table 3 Results from focus group interviews with clinicians

Challenges concerning feasibility			
Benefits of ACP	Barriers	Timing of the ACP conversation	Knowledge
<p>Clinicians perceived that ACP conversations may</p> <ul style="list-style-type: none"> Help patients prepare for the last phase of life. Help patients to be more conscious about the choices they might have. Contribute to the feeling of control in a difficult and new situation. Contribute to clarification of treatment intensity. Create a basis for communication about ethically challenging decisions. Clinicians found new valuable information about patients in the summaries, which they sometimes chose to pass on to the primary healthcare services. 	<p>Time</p> <p>To find time on a busy medicine ward</p> <ul style="list-style-type: none"> It was difficult to find time for structured conversations during short admissions. Clinicians found it hard to find time for ACP conversations in their busy daily schedule. Clinicians felt they knew the patients and called for time to carry out ACP conversations themselves. 	<ul style="list-style-type: none"> Clinicians were afraid of violating patients and depriving them of hope. They preferred to defuse the subject of ACP by introducing it during the physician's round. They questioned if a hospital stay was the optimal timing for an ACP conversation, compared with the outpatient clinic in a more stable phase of the disease. 	<p>Organisation</p> <ul style="list-style-type: none"> Some clinicians highlighted that many of the patients at the department of thoracic medicine are diagnosed with incurable disease, which makes an early focus on ACP and mapping of palliative care needs important. It was not clear who should be responsible for ACP conversations; physicians wanted to have this communication with their patients, but nurses more often asked for it. Introducing an unknown person (the study nurse) for ACP conversations near the end of life was debatable. The participants called for education, training and allocated time to be able to have these conversations themselves. Some questioned whether ACP was a task for clinicians in hospitals or community services, and pointed at the key position of general practitioner. The fact that hospitals and community services have different electronic patient record systems that do not communicate with each other was mentioned as a problem. The new, electronic national Summary Care Record was regarded as the optimal place for both ICP and ACP documentations. The participants called for an overarching policy and plan for ACP at the hospital, as a means to integrate ACP conversations as an obvious part of the discharge planning, optimally as part of an ICP that assigns tasks and responsibilities.
			<p>Knowledge</p> <ul style="list-style-type: none"> Clinicians acted as gatekeepers during the process of recruitment. Clinicians were concerned about the purpose of ACP, whether it was solely for the patient or if the intention also was to equip relatives and staff with important information. There was a dissent: whether only a minority of the patients needed ACP conversations or if these conversations were relevant for many patients at an early stage of their disease.

ACP, advance care planning; ICP, individualised care plan.



while the barrier of timing for ACP, though known universally, is more individual.^{6,8}

Patient-related barriers for the uptake of ACP are known as diverse and are described in several studies.^{6,8,20,33} We observed that both patients and relatives wished to protect one another from tough conversations.^{34,35} When patients decline participation because of 'bad timing', it may reflect the load of sickness and logistics or, on the other hand, patient hesitation for discussing treatment preferences.^{33,36} Patients' focus on positive thinking is a known patient-related barrier for the uptake of ACP.^{33,37,38} Additionally, we observed that patients need to be primed to conduct ACP, that time limitations often prevent clinicians from conducting ACP and that logistics of hospitalisations are also barriers (table 3).^{8,39}

The literature shows that patients with COPD are especially difficult to introduce to ACP, partly because they have an unpredictable disease trajectory and partly because the importance of early introduction of ACP is poorly recognised.^{6,8,34} In the present study, the number of participating patients with COPD as their principal diagnosis was only nine, which does not reflect the proportion of admissions of patients with COPD during the study period. This finding supports the low uptake of ACP in this diagnostic group and underlines the need for extra attention when inviting patients with COPD to ACP conversations.^{6,25,35}

In the focus groups, a debate about organising and standardising ACP conversations and documentation of these came up as a consequence of the positive impact of the project. So, despite having barriers against ACP, clinicians perceived ACP as important, as also shown by others.^{8,9,20,40-43} Starting up the pilot study with help from ward staff, we soon discovered problems for recruitment related to time and knowledge (table 3), and we introduced a study nurse. In line with the study by Friis and Førde, our study did not show a necessity of having a long-term relation with the patient before introducing ACP.^{13,44} Clinicians were uncertain about which profession should facilitate ACP conversations. International guidelines state that any member of the clinical team can do ACP as long as they have relevant communication skills and are empowered to do so.^{2,24,45,46}

Lacking knowledge about how ACP may strengthen patients' hope by talking about their future, clinicians acted as gatekeepers in order to protect patients against possibly tough conversations.^{34,45} This illustrates the importance of providing sufficient documentation and information, as well as installing engagement, to accomplish successful implementation of ACP.^{8,43}

We chose to use a free text summary in the hospital's electronic medical record for documentation and not a rigid template. The EAPC white paper on ACP recommends the use of both forms of documentation: the first for documenting attitudes and values, and the latter for an easy retrieval of concrete wishes and preferences.² Clinicians in our study suggested the documentation to be placed in a new, electronic national Summary Care

Record, possibly as part of an individual palliative care plan.⁴⁷ However, this national record does not have the form or space to contain a complete ACP document. It is important to find a common Norwegian approach to these challenges concerning documentation.

Strengths and limitations

Strengths

Arranging focus group interviews with patients in the target group before constructing the guide and conducting this ACP pilot study allowed patients' voices to be heard and respected. The patient-centred focus contributed to increased patient autonomy. Recruited patients suffered from advanced disease; thus, our study develops knowledge about important patient-selected topics at this sensitive point in their illness trajectory. Our study sample showed variations regarding comorbidity, education, age and functional status, suggesting that our findings are transferable to other hospital settings with similar patient populations. Seventy per cent of the invited patients were positive to ACP, demonstrating that our model for integrating ACP on a thoracic medicine ward was acceptable to the majority, even though a proportion for different reasons were prevented from study participation.

Limitations

To be included in the study, patients should either be able to read the patient information sheet or understand the meaning when being informed about it and give written informed consent. This criterion might have given a risk of excluding the sickest. Using a study nurse, a stranger to the patients, could be a limitation during the recruitment process. Patients did not have the possibility to review the summaries; consequently, we do not know if they had wanted amendments. The number of participating women (11) was comparably lower than the number admitted during the study period. In retrospect, considering a rather high staff turnover causing lack of continuity on the ward, we realise that the research team did not give clinicians sufficient information during the study period. This discontinuity was also a limitation for evaluation of the project. Only one physician participated in the focus groups due to logistic reasons; thus, our findings regarding ACP evaluation may not be transferable to the medical profession. The research team knew the department and several participants well, which may have prevented negative feedback. However, the informants' critical outline of challenges regarding ACP, as well as descriptions of benefits, makes it likely their comments were delivered in honest terms.

CONCLUSIONS

Patients with advanced pulmonary disease, their relatives and clinicians found patient-centred ACP pertinent, yet a sustainable implementation seemed challenging to establish. When introducing ACP, a focus on present and

future symptom control may facilitate the conversations. Important aspects for implementing ACP for this patient group are management support, education, training, feasible routines and allocated time.

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Patient consent for publication Not required.

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Data availability statement Deidentified participant data are available upon reasonable request from the corresponding author.

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Hospital care for the dying patient with cancer: does an advance care planning invitation influence bereaved relatives' experiences?

A two country survey

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ABSTRACT

Objectives Advance care planning (ACP) is not systematically performed in Argentina or Norway. We used the post-bereavement survey of the ERANet-LAC International Care Of the Dying Evaluation (CODE) project (2017–2020) to examine the proportion of relatives who were offered an ACP conversation, the proportion of those not offered it who would have wanted it and whether the outcomes differed between those offered a conversation and those not.

Methods Relatives after cancer deaths in hospitals answered the CODE questionnaire 6–8 weeks post bereavement, by post (Norway) or interview (Argentina). Two additional questions asked if the relative and patient had been invited to a conversation about wishes for the patient's remaining lifetime, and, if not invited, whether they would have wanted such a conversation. The data were analysed using mixed-effects ordinal regression models.

Results 276 participants (Argentina 98 and Norway 178) responded (56% spouses, 31% children, 68% women, age 18–80+). Fifty-six per cent had been invited, and they had significantly more positive perceptions about care and support than those not invited. Sixty-eight per cent of the participants not invited would have wanted an invitation, and they had less favourable perceptions about the care, especially concerning emotional and spiritual support.

Conclusions Relatives who had been invited to a conversation about wishes for the patient's remaining lifetime had more positive perceptions about patient care and support for the relatives in the patient's final days of life. A majority of the relatives who had not been invited to an ACP conversation would have wanted it.

Key messages

What was already known?

- Systematic implementation of advance care planning (ACP) programmes increases in-advance end-of-life discussions.
- Questions about ACP are not routinely included in post-bereavement surveys.

What are the new findings?

- Relatives who had been invited to an ACP conversation had more positive perceptions about support and patient care in the patient's final days.
- Relatives who had not been invited to an ACP conversation, but would have wanted it, had the least favourable perceptions about support and care.

What is their significance?

- Clinical
 - Offering ACP and goals-of-care discussions may positively influence relatives' experiences of end-of-life care.
- Research
 - Post-bereavement surveys may be used to evaluate the effect of ACP.

INTRODUCTION

Good care for the patient with cancer requires knowledge about the expected disease trajectory, the broad spectrum of treatments and the patient's perspectives on treatment and care.^{1 2} The patient's perspective is obtained through shared decision-making, with health-care personnel and the patient working together to make achievable plans for future treatment and care.^{3–5} This

approach is crucial when planning end-of-life (EoL) care, commonly described as advance care planning (ACP). ACP is defined as a process of conversations which ‘enables 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’.⁶ ACP addresses individuals’ concerns across the physical, psychological, social and spiritual domains.⁶ Although ACP is used worldwide, the timing and degree of offering such conversations vary, which probably influences patient autonomy and the quality of EoL care.^{7 8}

Argentina and Norway are two countries still without national ACP programmes informing and offering the population to plan ahead in case of serious illness scenarios. A systematic ACP approach for patients diagnosed with serious or advanced disease is also non-existing. Thus, ACP as a concept is not generally known in the population nor among healthcare personnel, even though Argentina has a law that allows people to formulate advance directives. Standardised and easily retrievable ACP documentation about patients’ wishes and values is not in use in hospital care. Consequently, ACP conversations are not offered on a regular basis, although there is a growing interest in shared decision-making as part of goals-of-care discussions due to an increasing claim for patient autonomy. This situation allows us to study how different approaches to communication about EoL issues influence the quality of care for dying patients.

Norway had 11 000 cancer deaths in 2018; 34% took place in hospitals.⁹ In Argentina, 61 000 individuals died from cancer in 2018. Figures on the proportion that died in hospitals are not available, but almost 70% of all deaths in this country take place in ‘health-care institutions’.¹⁰ The hospital setting thus lends itself to research aiming at improving the quality of care for dying patients with cancer.

Data presented in this paper were collected as part of an international post-bereavement survey after cancer deaths in hospitals in seven European and South-American countries.¹¹ The survey used the international version of the CODE (Care Of the Dying Evaluation) questionnaire.^{12 13} In Argentina and Norway, two additional questions about being offered an ACP conversation in advanced disease were included in the survey, with the aim to answer the following research questions:

1. What proportion of the bereaved relatives were offered an ACP conversation?
2. What proportion of the relatives that were not offered an ACP conversation would have wanted it?
3. Were there differences in outcomes between the relatives offered an ACP conversation and those not, with special reference to communication issues and emotional and spiritual support?

4. Do the answers to the above questions differ between participants from Argentina and Norway?

METHODS

Study design

This substudy was part of CODE International Survey, conducted as part of the ERANet-LAC CODE project 2017–2020: ‘International Care Of the Dying Evaluation (CODE): Quality of care for dying cancer patients as perceived by bereaved relatives’.^{11 14} The survey employed the international version of the validated CODE questionnaire, i-CODE.^{12 13} This questionnaire focuses on the two final days of life and the immediate bereavement period. It has the following seven sections: (A) The care received from the nurses and doctors, (B) the control of pain and other symptoms, (C) communication with the healthcare team, (D) the emotional and spiritual support provided by the healthcare team, (E) the circumstances surrounding his/her death, (F) overall impressions and (G) information about you and your relative or friend.¹³ In Norway and Argentina, two questions were added to section (F) (Q32a) ‘When it became clear that she/he was seriously ill and had limited time left to live, did the healthcare team (nurse or doctor) invite you and him/her to a conversation about your wishes for his/her remaining life time?’ (response options: Yes/No/Don’t know); (Q32b) ‘Would you have wanted this type of conversation?’ (response options: Yes/No/Not applicable, we had this type of conversation). In the following, we use the term *ACP conversation* for the conversations addressed in these two questions.

Study setting

Participants were recruited to this post-bereavement survey from 22 hospitals in seven countries in Europe and South America from 15 August 2017 to 15 September 2018. In Norway, participants were recruited from medical, surgical and oncology wards and palliative care inpatient units at three university hospitals and four acute care hospitals (all public). In Argentina, participants were recruited from medical, surgical and oncology wards and intensive care units at three university hospitals (two public and one private).

Participants

Adult relatives of adult patients with cancer dying an expected death in one of the selected hospitals in Norway and Argentina were eligible for inclusion. Their relation with the patient had to be documented in the patient’s hospital record. Written informed consent was mandatory for participation. Patients had to have been hospitalised for at least three calendar days, with the relative present at least some of the time during the last 2 days. A *patient with cancer* was defined as any patient with a solid cancer or haematological malignancy, but not necessarily dying from the malignant disease. The attending physician was

consulted in case of doubt about whether the death was expected or not. If the physician was not available, any death of a patient with cancer without resuscitation being attempted was accepted. Participants were excluded if the patient had a sudden and unexpected death or if the relative was unable to complete the questionnaire due to impaired cognitive functioning or lack of language abilities.

Procedure

Recruitment

Upon the death of a patient, local project coordinators among the ward staff (Norway) or local study teams (Argentina) identified potential participants by screening the case notes (Norway) or lists of deceased patients during the last month (Argentina). In Norway, information was given in verbal and written form prior to the relative leaving the hospital. If missed, a leaflet was sent by surface mail. In Argentina, eligible relatives were approached by telephone; in some cases, relatives were approached by the specialist palliative care team before leaving the hospital.

Data collection

The questionnaire was presented to the participants 6–8 weeks after bereavement. In Argentina, participants were either interviewed by telephone (50%) or face-to-face (37%) by social workers or physicians with relevant research experience, or responded by email (13%). In Norway, data collection was only by postal survey, with one postal reminder to non-respondents after 4 weeks.

In addition to the questionnaire data, the following information was collected from the patients' medical records by ward staff: primary site of the cancer, length of hospital stay, type of ward (place of death), contact with a specialist palliative care team and use of an individualised care plan for care of the dying. The data were stored on a protected research server.

Primary outcomes

The two primary outcomes of CODE International Survey were the participants' perception of how much of the time the patient was treated with respect and dignity in the last 2 days of life by doctors and by nurses (Q30, two questions), and whether the participant was adequately supported during the same period (Q31).

Patient and public involvement

The validated CODE questionnaire was developed according to acknowledged questionnaire development methodology, with input from lay persons and representatives from the target group at every step.¹² The translated versions in Norway and Argentina were piloted and pretested with volunteers and bereaved relatives before being used in the survey.¹³

Data analysis

We present demographic data as counts and percentages. To examine differences in outcomes (eg, quality

of communication, or emotional or spiritual support) between the relatives offered an ACP conversation and those not, we fitted separate mixed-effects ordinal regression models with questions Q16, Q17, Q20–Q24, Q31 and the two Q30 questions as response variables (table 1). The same type of model was used to compare, for those not offered such a conversation, the outcomes between those who would have *wanted* to be offered a conversation and those not.

The response variables had different response options, either ordinal (eg, for the level of emotional support given (Q20), 'poor', 'fair', 'good' or 'excellent') or binary ('no' or 'yes'). For binary variables, the ordinal model is reduced to a logistic model. The explanatory variables were Q32a and Q32b (separate models). To take into account any general differences in outcomes between hospitals, hospital was included as a random intercept. The output from each model is an OR. A common OR is estimated over all possible cut-offs of the response variable, which was coded such that an OR >1 indicates that a 'yes' response to Q32a/Q32b was associated with a more *positive* response (eg, better communication, or better spiritual support).

To examine country differences, we created extended versions of the above models by adding country and the interaction between country and each explanatory variable. The original and extended models were compared using likelihood ratio tests. Results stratified by country are presented in the supplemental material published online only.

Before analysis, the data were recoded to remove any internal inconsistencies (eg, people responding 'yes' to Q32a but *not* 'not applicable' to Q32b). When a patient had missing data on a question—either a lack of response or a 'don't know' response—they were excluded from the analyses that used that question (but included in other analyses). We also report the number of responses each analysis is based on.

The data were stored in Microsoft Excel 2016 spreadsheet files, and all recoding and statistical analyses were done using R V4.0.2.¹⁵ The regression models were fitted using the R package 'ordinal' V2019.12–10.¹⁶

RESULTS

Participants and patients

The survey included 194 participants in Norway and 105 in Argentina (response rate 58% in both countries). The majority of participants were women (Argentina 68% and Norway 70%), with 50–59 (Argentina) and 60–69 (Norway) years as the median age groups. In the following, we analyse only the 276 participants (see flowchart, figure 1) who responded 'yes' or 'no' to the question (Q32a) about whether they were invited to an ACP conversation. Table 2 gives an overview of characteristics of both participants and patients.

Original research

Table 1 Questionnaire items and corresponding response options

Item	Question/statement text	Response options
Response variables		
Q16	During the last 2 days, how involved were you with the decisions about his/her care and treatment?	Very involved; Fairly involved; Not involved
Q17	Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last 2 days of life?	Yes; No; Don't know
Q20	How would you assess the overall level of emotional support given to you by the healthcare team?	Excellent; Good; Fair; Poor
Q21	Overall, his/her religious or spiritual needs were met by the healthcare team.	Strongly agree; Agree; Neither agree nor disagree; Disagree; Strongly disagree
Q22	Overall, my religious or spiritual needs were met by the healthcare team.	Strongly agree; Agree; Neither agree nor disagree; Disagree; Strongly disagree
Q23	Before she/he died, were you told she/he was likely to die soon?	Yes; No
Q24	Did a member of the healthcare team talk to you about what to expect when she/he was dying (eg, symptoms that may arise)?	Yes; No
Q30	How much of the time was she/he treated with respect and dignity in the last 2 days of life? (doctors/nurses)	Always; Most of the time; Some of the time; Never; Don't know
Q31	Overall, in your opinion, were you adequately supported during his/her last 2 days of life?	Yes; No
Explanatory variables		
Q32a	When it became clear that she/he was seriously ill and had limited time left to live, did the healthcare team (nurse or doctor) invite you and him/her to a conversation about your wishes for his/her remaining life time?	Yes; No; Don't know
Q32b	Would you have wanted this type of conversation?	Yes; No; Not applicable, we had this type of conversation

ACP conversations

As shown in [figure 1](#), 56% of the patients and participants had been invited to an ACP conversation (Argentina 58% and Norway 54%). In the group not invited, 68% would have wanted this type of conversation, the same proportion in both countries.

Perceptions about care and support

We wanted to explore whether having been offered an ACP conversation was related to the participants' perceptions about the care given. The main outcomes are shown in [figures 2 and 3](#). The participants who *had been invited* to an ACP conversation perceived that the dying patient had been treated with respect and dignity *more of the time*, by both doctors and nurses ([figure 2](#)). In the group that had *not* been offered an ACP conversation, the participants who *would have wanted* to be offered one, perceived that the dying patient had been treated with respect and dignity *less of the time*, by both doctors and nurses ([figure 3](#)).

Results of the ordinal regression models examining differences in main outcomes, communication and support between the participants offered an ACP conversation and those not, are presented in [table 3](#), left panel. Here, an OR >1 indicates that the participants who had been invited to an ACP conversation gave more positive responses. The participants perceived that they were more involved in care decisions, received better emotional and spiritual support, and were better informed about what to expect in the dying phase. Overall, they felt better supported

in the patient's last days. They also perceived that the *patient* received better spiritual support and was more often treated with dignity and respect by the doctors.

Differences between countries were only found for Q23 and Q30 for *nurses*, for which the p values for country differences (including an interaction effect) were 0.002 and 0.004, respectively. All other p values were >0.10. Detailed results are shown stratified by country in online supplemental table A1, available in the supplemental material published online only. In Argentina, 39% of those *not invited* to an ACP conversation had also *not* been informed about the patient's impending death. Of those who *had* been invited, the corresponding proportion was 7%. In Norway, the corresponding proportions were 11% for both groups. The OR for the Q30 item for nurses was similar in the two countries, but the item was answered less favourably in Argentina than in Norway. This was anticipated, as there is a huge lack of qualified nurses in Argentina.¹⁷

The results for participants who had not been offered an ACP conversation are presented in [table 3](#), right panel. The OR values <1 indicate that the participants who would have wanted a conversation rated the communication and emotional and spiritual support less favourably than the ones who had not wanted such a conversation. There was, however, no difference in their perception of their degree of involvement in care decisions. Again, the only country differences were

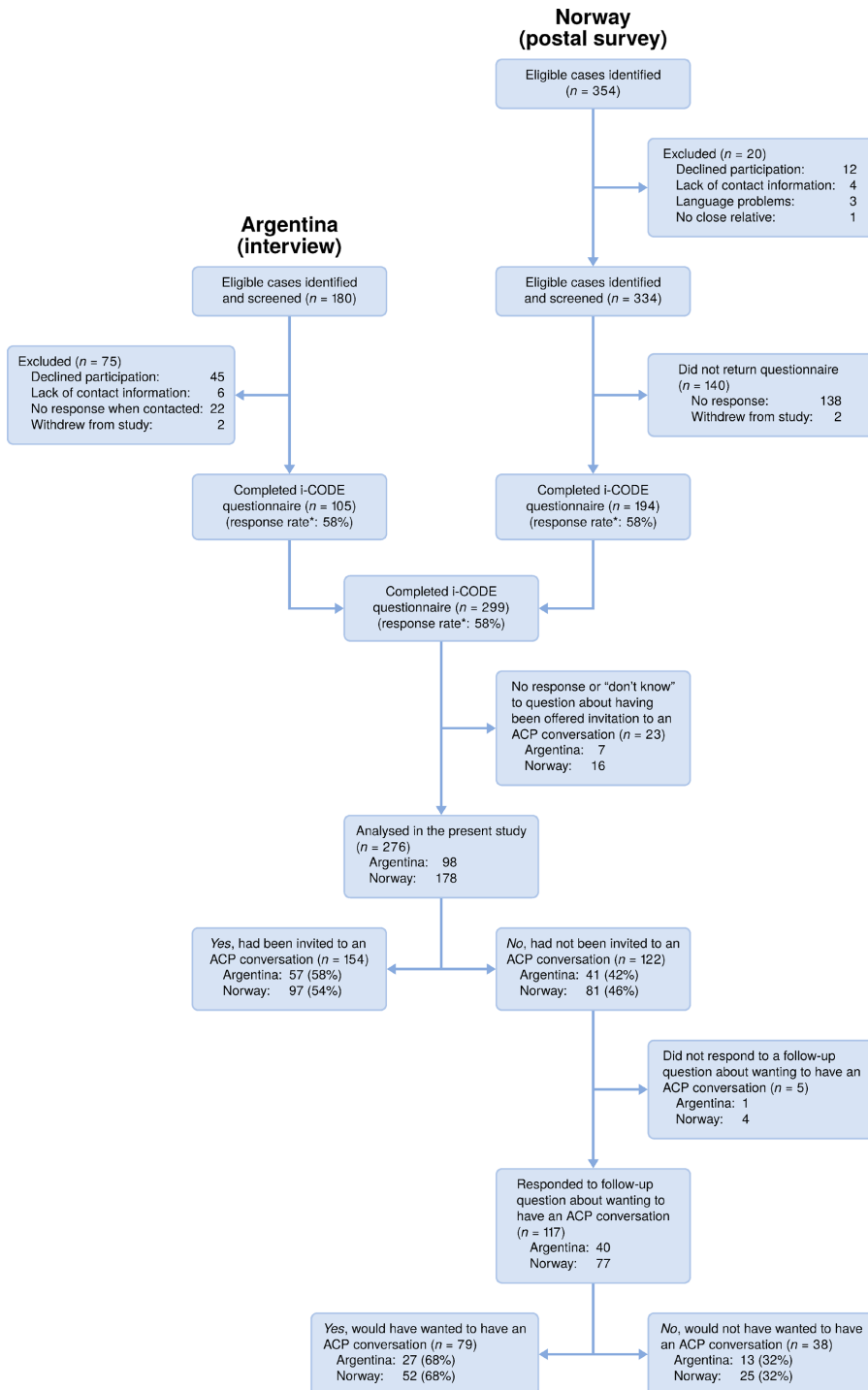


Figure 1 Flowchart showing participants and responses. *Based on the number of eligible cases *identified and screened*. ACP, advance care planning; i-CODE, international version of the validated Care Of the Dying Evaluation questionnaire.

Original research

Table 2 Characteristics of the deceased patients and study participants

	Deceased patients				Participants (relatives)			
	Argentina		Norway		Argentina		Norway	
	No.	Prop.	No.	Prop.	No.	Prop.	No.	Prop.
Gender								
Male	55	56%	114	64%	32	33%	51	29%
Female	43	44%	64	36%	65	66%	124	70%
(Missing)	0	0%	0	0%	1	1%	3	2%
Age								
18–29	0	0%	1	1%			1	1%
30–39	4	4%	4	2%	16	16%	7	4%
40–49	7	7%	10	6%	17	17%	19	11%
50–59	9	9%	27	15%	20	20%	39	22%
60–69	34	35%	49	28%	18	18%	40	22%
70–79	23	23%	56	31%	14	14%	24	13%
80–89	18	18%	27	15%	4	4%	6	3%
90+	3	3%	4	2%	9	9%	42	24%
Religious affiliation								
None	13	13%	38	21%	15	15%	33	19%
Christian (all denominations)	83	85%	124	70%	76	78%	132	74%
Any other religion	2	2%	11	7%	7	7%	10	6%
(Missing)	0	0%	5	3%	0%	0%	3	2%
Participant was the patient's								
Spouse/partner	–	–	–	–	45	46%	111	62%
Son/daughter	–	–	–	–	35	36%	50	28%
Brother/sister	–	–	–	–	10	10%	8	4%
Son-in-law/daughter-in-law	–	–	–	–	1	1%	1	1%
Parent	–	–	–	–	2	2%	4	2%
Friend	–	–	–	–	2	2%	2	1%
Other	–	–	–	–	3	3%	1	1%
(Missing)	–	–	–	–	0	0%	1	1%
Cancer diagnosis (possible with more than one)								
Gastrointestinal, incl. pancreatic	55	56%	63	35%	–	–	–	–
Respiratory organs	14	14%	40	22%	–	–	–	–
Urological, incl. prostate	8	8%	23	13%	–	–	–	–
Leukaemia/lymphoma	8	8%	14	8%	–	–	–	–
Breast	2	2%	9	5%	–	–	–	–
Brain	3	3%	4	2%	–	–	–	–
Gynaecological	1	1%	2	1%	–	–	–	–
Other	8	8%	30	17%	–	–	–	–
Type of ward where the patient died								
Medical or surgical ward	73	74%	65	37%	–	–	–	–
Palliative care unit	0	0%	78	44%	–	–	–	–
Oncology ward	23	23%	33	19%	–	–	–	–
Intensive care unit	1	1%	0	0%	–	–	–	–
Emergency ward	1	1%	0	0%	–	–	–	–
(Missing)	0	0%	2	1%	–	–	–	–
Specialist palliative care team involved in the patient's care before death								
Yes	80	82%	117	66%	–	–	–	–
No	18	18%	59	33%	–	–	–	–
(Missing)	0	0%	2	1%	–	–	–	–
Care of the patient supported by an individualised care plan								
Yes	60	61%	63	35%	–	–	–	–
No	38	39%	115	65%	–	–	–	–

incl., including; No, number; Prop, proportion.

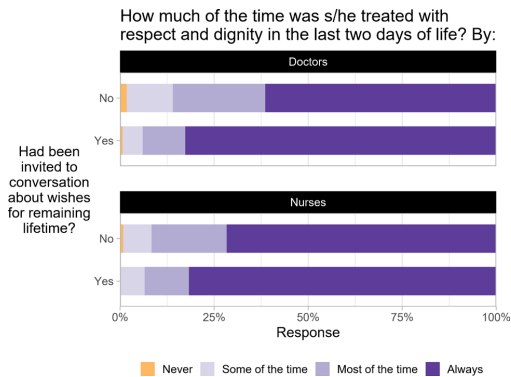


Figure 2 Association between having been invited to an advance care planning conversation and the participants' perception of how much of the time the patient was treated with respect and dignity (n=274).

found for Q23 and Q30 for nurses (p values 0.005 and 0.02, respectively).

DISCUSSION

In this post-bereavement survey, 56% of the participants had been invited to an ACP conversation. The majority (68%) of those who were not invited would have wanted such a conversation. Having been invited to an ACP conversation was associated with more favourable perceptions of the support and care given to both the patients and the participants themselves in the patient's final days.

In cancer care, the growing demand for shared decision-making has led to an increasing focus on goals-of-care discussions.¹⁸ During the last decade, ACP programmes have been implemented and studied as a means for these discussions, exploring patients' wishes and preferences for EoL care.^{7 19} In the present

study, we asked about an invitation to a conversation about wishes for the patient's remaining lifetime, but, based on the participants' responses about support and participation in EoL care discussions, we assume that the invitation normally led to a conversation.

The reported prevalence of ACP documentation in the USA varies between 18% and 70%, presumably because of variations in the implementation of ACP programmes.²⁰ As shown in Australia, the prevalence of ACP documentation is higher in regions where ACP is thoroughly implemented.²¹ In 2019, ACP documentation in Australia was 41% across all sectors, and about 50% among people aged 65 or older.^{21 22} However, counting documents does not give the full picture, as several conversations may be necessary before any documentation is produced. In a setting without an ACP programme, Fakhri *et al* discovered that only about 30% of patients with life-limiting diseases experienced EoL care discussions with their physician.²³ Acknowledging the fact that neither Argentina nor Norway has any formal ACP programme in hospitals, it is encouraging that as many as 56% of the participants in the present study had been offered a conversation about wishes for the patient's remaining lifetime. However, a high proportion of the patients had been in contact with a specialist palliative care service, especially in Argentina (table 2). As goals-of-care discussions are often provided by specialist palliative care services, this may be part of the explanation why a surprisingly high percentage of ACP conversations were reported despite the lack of a systematic ACP approach.

Even though more than half of the participants in this study were invited to an ACP conversation, 44% were *not* offered a conversation, which indicates an unmet need. This interpretation is supported by the fact that these participants perceived care and support less favourably than those offered a conversation. ACP conversations may contribute to a better understanding and acceptance of prognosis, and thus to a higher degree of consensus about treatment and care.^{7 24 25} Disagreement on values and preferences for life-sustaining treatment between seriously ill and hospitalised patients and their relatives may be considerable, and ignorance of this disparity may result in conflicts between family members and health-care personnel.²⁶ Johnson *et al* found that relatives of patients with cancer considered ACP as useful for themselves as for the patients, since the discussion contributed to reduced conflict and stress within the family.²⁷ The process of ACP in itself can be therapeutic, and studies have shown that ACP leads to a reduction of stress, anxiety and depression among the bereaved.^{7 19 28}

Thirty-two per cent of the relatives not offered an ACP conversation, expressed that they would not have wanted such a conversation. Their information needs may have been met in other ways. However, protective buffering or belief in positive thinking have been

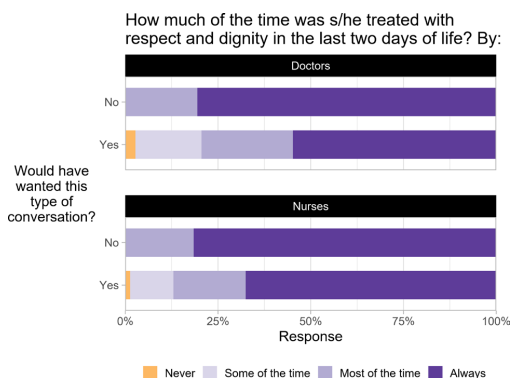


Figure 3 Association between having wanted to have an advance care planning conversation (but not offered one) and the participants' perception of how much of the time the patient was treated with respect and dignity (n=115).

Table 3 Relationship between the two ACP questions and the primary outcomes and outcomes related to communication and support in the CODE International Survey (n=276)

Outcome/response variable*	Q32a: Invited to conversation about wishes for remaining lifetime? (n=276)				Q32b: Would have wanted this type of conversation? (n=117)			
	No.	OR	95% CI	P value	No.	OR	95% CI	P value
Q16: Participant involved in decisions about care	273	2.5	1.6 to 4.0	<0.001	114	0.8	0.4 to 1.7	0.58
Q17: Participant involved in discussions about hydration	250	3.7	2.1 to 6.4	<0.001	107	0.9	0.4 to 2.3	0.89
Q20: Level of emotional support received	272	2.8	1.8 to 4.5	<0.001	116	0.3	0.1 to 0.6	0.001
Q21: Patient's spiritual needs met	263	2.6	1.7 to 4.2	<0.001	112	0.5	0.2 to 1.0	0.05
Q22: Participant's spiritual needs met	264	2.7	1.7 to 4.3	<0.001	113	0.4	0.2 to 0.8	0.01
Q23: Informed about impending death	272	2.6	1.3 to 5.3	0.008	115	0.4	0.1 to 1.3	0.12
Q24: Informed about what to expect in the dying phase	272	3.4	2.1 to 5.7	<0.001	115	0.5	0.2 to 1.1	0.08
Q30: Patient treated with dignity and respect by doctors	264	2.8	1.6 to 5.0	<0.001	109	0.2	0.1 to 0.6	0.003
Q30: Patient treated with dignity and respect by nurses	273	1.8	1.0 to 3.2	0.06	115	0.4	0.1 to 1.0	0.04
Q31: Participant adequately supported	270	6.2	2.4 to 16.1	<0.001	113	0.2	0.1 to 0.8	0.03

The table shows ORs from ordinal mixed-effects regression models. Each row shows the results for the corresponding outcome variable. For item Q32a, an OR >1 indicates that the participants who *were invited* to an ACP conversation gave more *positive* responses on the outcome items in the questionnaire. For item Q32b, an OR <1 indicates that of the participants who *were not invited*, those who *would have wanted* such a conversation gave more *negative* responses on the outcome items; that is, they had unmet needs.

*See table 1 for complete description.

ACP, advance care planning; CODE, Care Of the Dying Evaluation; No, number of participants.

discovered as the most frequently reported barriers against ACP among relatives.²⁹ Because of differences in preferences and needs among patients and relatives, mapping of individual needs and attitudes towards such conversations is essential for ACP recruitment.^{30 31}

The invitation to ACP conversations was positively associated with the relatives' perceptions about support and dignity and respect shown by doctors and nurses. We do not know whether this relates to the conversation per se or whether the offer of an ACP conversation is an indicator of a ward culture acknowledging the importance of communication and involvement. In Argentina, being informed about the patient's impending death was closely associated with having been offered an ACP conversation, as opposed to Norway, where the proportion of relatives being informed about impending death was the same for those offered an ACP conversation and those not. This was the only major difference detected between the countries. As Norway has a much longer tradition for palliative care than Argentina has, this finding strengthens the interpretation that ACP in this study may be seen as an indicator of a patient-centred and family-centred ward culture.

We believe that our results underline how important communication is for emotional and spiritual support and perceptions about care. Discordance between the patient and the oncologist about goals of care may negatively influence caregivers' satisfaction in EoL care.³² Similarly, proxies who never attend medical visits report significantly worse medical care and care coordination than proxies who always attend such visits.³³ In a longitudinal communication approach for patients with advanced lung cancer, patients and relatives described times of shock and coping deficits

often related to insufficient communication and poor continuity of care.³⁴ The feeling of safety, often highly valued by patients, may be increased by performing patient-centred ACP conversations in which patients and their relatives are seen, met and heard during the process of making achievable plans.^{18 27}

This study used a post-bereavement questionnaire to ask about ACP conversations. We have identified one similar survey. Mori *et al* asked bereaved relatives to patients with advanced cancer about EoL care and support, with the aim of evaluating the effects of in-advance EoL discussions on the quality of inpatient EoL care.³⁵ Primary caregivers had higher ratings of overall EoL care and support and lower problem scores if an EoL discussion had taken place. In a longitudinal study, Garrido and Prigerson investigated modifiable predictors of caregivers' bereavement adjustment and found that encouraging ACP for patients with advanced cancer had a positive influence on the adjustment.³⁶

Strengths and limitations

Although our study was limited to two countries, the countries differ in both culture and geography, and the study included a mix of hospitals in each country. We also had a moderately high response rate.

The CODE questionnaire focuses on the last 2 days of the patient's life and the immediate bereavement period, while the two additional ACP questions are not limited to the terminal phase. We cannot rule out that this distinction may have been overlooked by the respondents. On the other hand, piloting the questions did not reveal any comprehensibility problems. This also concerns the wording of the first ACP question, in which the expression 'your wishes' in English may be

understood as singular or plural, while the expression in Norwegian and Spanish is exclusively plural.

Respondents who answered 'don't know' to the first question (Q32a) were excluded from the analysis. There is a risk that relatives who either had forgotten a conversation or who did not have a conversation have been excluded.

We do not have information about how and to which extent the ACP conversations were carried out. Another important limitation is that a high proportion of the patients were supported by a specialist palliative care team (both countries) or died in a palliative care unit (Norway). While specialist palliative care teams are available in almost all hospitals in Norway, this holds true only for a minority of Argentinian institutions, limiting the generalisability of the findings.^{37 38}

The study focused on expected deaths, so attempted resuscitation was an exclusion criterion. This may have excluded some patients who did not have ACP.

Implications for practice

Our findings show a positive association between the relatives being offered ACP and their perceptions of the care and support given. We do not know, however, whether this association is a direct effect or rather an indicator of a clinical culture and approach. Our findings nevertheless underline the importance of effective communication and involvement of patients and relatives in the planning of treatment and care.

There is an ongoing debate about which outcomes should be used to evaluate the effects of an ACP programme.³⁹ In this study, there was an association between ACP being offered and outcomes such as *respect and dignity*, and *emotional and spiritual support*, which suggests that these outcomes may be considered for evaluation of ACP programmes.

CONCLUSION

Participants who had been invited to a conversation about wishes for the patient's remaining lifetime had more positive perceptions about care and support in the patient's final days of life, for the patient as well as for themselves. Most of the participants who were not offered an ACP conversation would have wanted it. This was true for both Argentina and Norway. Our findings suggest that a systematic approach to ACP and goals-of-care discussions may improve EoL care for patients with advanced cancer and support for their relatives.

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APPENDIX

The i-CODE questionnaire:

Norwegian version

**English translation of the Norwegian
version**

Du har fått tilsendt dette spørreskjemaet fordi du er registrert som nærmeste pårørende til en pasient som døde på vårt sykehus. Spørreskjemaet spør om behandling, pleie og omsorg i de siste timene og dagene av din pårørendes liv og dine opplevelser og erfaringer i det tidsrommet. Selv om vi kjenner pasientens navn, bruker vi han/henne eller hans/hennes i spørreskjemaet for å sikre konfidensialitet.

Vi er klar over at dette spørreskjemaet kan fremkalle sterke minner og følelser og at det kan være vanskelig å lese det første gangen. Det kan være du ønsker å vente og finne et rolig sted for å lese spørreskjemaet. Hvis du på noen måte føler deg urolig eller tynget, trenger du ikke fortsette med å fylle ut skjemaet. Du kan avslutte når som helst.

Veiledning for utfylling

Når du svarer på spørsmålene, ønsker vi at du skal fokusere på de siste **to dagene** i hans/hennes liv. Vennligst fyll ut så mye av spørreskjemaet som du kan.

Når du går gjennom spørreskjemaet, så vennligst følg veiledningen og svar på spørsmålene ved å krysse av i den rubrikken som passer best, på denne måten:

Her er et eksempel på et spørsmål:

Vennligst se på følgende utsagn og kryss av i svar-rubrikken som passer best med din mening.

1. Det var nok hjelp tilgjengelig til å møte hans/hennes behov for personlig stell og pleie, slik som å vaske seg, personlig hygiene og toalettbesøk.

Svært enig	<input type="checkbox"/>
Enig	<input checked="" type="checkbox"/>
Verken enig eller uenig	<input type="checkbox"/>
Uenig	<input type="checkbox"/>
Sterkt uenig	<input type="checkbox"/>

Hvis, utfra din mening, du var enig i at det var nok hjelp til å møte hans/hennes behov for personlig stell og pleie, ville du krysse av i rubrikken «Enig» slik som i eksempelet. Hvis du helst ikke vil svare eller ikke kan svare på et av spørsmålene, så vennligst gå til det neste.

**Svarene dine vil bli behandlet strengt konfidensielt.
Enkelt personer vil ikke kunne gjenkjennes i de rapportene vi skriver.**

Del A: Behandling og pleie gitt av sykepleiere og leger

Disse spørsmålene angår den generelle behandlingen og pleien din pårørende ble gitt av leger og sykepleiere, og for noen av spørsmålene også omgivelsene der behandlingen og pleien ble gitt. Spørsmålene omhandler de siste **to dagene** i hans/hennes liv og angår de legene og sykepleierne (inkludert hjelpepleiere, helsefagarbeidere og/eller assistenter) som var mest involvert i hans/hennes behandling og pleie i denne tiden.

Vennligst se på følgende utsagn og kryss av i svar-rubrikken som passer best med din mening.

1. Det var nok hjelp tilgjengelig til å møte hans/hennes behov for personlig stell og pleie, slik som å vaske seg, personlig hygiene og toalettbesøk.

Svært enig
Enig
Verken enig eller uenig
Uenig
Sterkt uenig

2. Det var nok hjelp med stell og pleie, slik som å gi medisiner og hjelpe ham/henne til et godt leie i sengen.

Svært enig
Enig
Verken enig eller uenig
Uenig
Sterkt uenig

3. Sengeområdet og tilgrensende omgivelser var komfortable for ham/henne.

Svært enig
Enig
Verken enig eller uenig
Uenig
Sterkt uenig

4. Sengeområdet og tilgrensende omgivelser ga ham/henne nok privatliv.

Svært enig
Enig
Verken enig eller uenig
Uenig
Sterkt uenig

5. Etter din mening, hvor ren var den delen av avdelingen som han/hun var i?

Svært ren
Ganske ren
Ikke ren i det hele tatt

6. Hadde du tiltro og tillit til sykepleierne som tok seg av ham/henne?

Ja, til alle sammen
Ja, til noen av dem
Nei, ikke til noen av sykepleierne

7. Hadde du tiltro og tillit til legene som tok seg av ham/henne?

Ja, til alle sammen
Ja, til noen av dem
Nei, ikke til noen av legene

8. Sykepleierne hadde tid til å lytte og drøfte hans/hennes tilstand med meg.

- Svært enig
- Enig
- Verken enig eller uenig
- Uenig
- Sterkt uenig

9. Legene hadde tid til å lytte og drøfte hans/hennes tilstand med meg.

- Svært enig
- Enig
- Verken enig eller uenig
- Uenig
- Sterkt uenig

Del B: Lindring av smerter og andre symptomer

Disse spørsmålene angår symptomene han/hun hadde og behandlingen og pleien han/hun mottok de siste **to dagene** av sitt liv.

10. Etter din oppfatning, virket det som om han/hun hadde smerter de siste to dagene?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, det virket som om han/hun ikke hadde smerter

11. Slik du ser det, gjorde legene og sykepleierne nok for å hjelpe til å lindre smertene?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, ikke i det hele tatt
- Ikke aktuelt, han/hun hadde ikke smerter

12. Etter din oppfatning, virket han/hun urolig eller rastløs de siste to dagene?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, han/hun virket ikke urolig eller rastløs

13. Slik du ser det, gjorde legene og sykepleierne nok for å hjelpe til å lindre uroen eller rastløsheten?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, ikke i det hele tatt
- Ikke aktuelt, han/hun var ikke urolig eller rastløs

14. Etter din oppfatning, virket det som om han/hun i de siste to dagene hadde en støyende, «raslende» lyd når han/hun pustet?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, han/hun hadde ikke noen støyende, «raslende» lyd ved pusting

15. Slik du ser det, gjorde legene og sykepleierne nok for å hjelpe til å lindre den støyende, «raslende» lyden når han/hun pustet?

- Ja, hele tiden
- Ja, noe av tiden
- Nei, ikke i det hele tatt
- Ikke aktuelt, det var ingen støyende, «raslende» lyd når han/hun pustet

Del C: Kommunikasjon med behandlingsteamet

De følgende spørsmålene handler om kommunikasjonen som du, dine familiemedlemmer og venner hadde med behandlingsteamet som var mest involvert i hans/hennes behandling og pleie de siste **to dagene** i hans/hennes liv. Med «behandlingsteamet» mener vi legene, sykepleierne og eventuelle andre ansatte som tok del i behandlingen eller pleien av ham/henne, f eks sosionom eller sykehusprest.

16. I de siste to dagene, hvor involvert var du i beslutningene om hans/hennes behandling og pleie?

Svært involvert
Ganske involvert
Ikke involvert

17. Drøftet noen fra behandlingsteamet med deg om det ville være hensiktsmessig å gi væske gjennom et «drypp» de siste to dagene?

Ja
Nei
Vet ikke

18. Ville en drøfting rundt hensiktsmessigheten av å gi væske gjennom et «drypp» de siste to dagene vært til hjelp for deg?

Ja
Nei
Ikke aktuelt, vi hadde slike drøftinger

19. Forklarte behandlingsteamet hans/hennes tilstand og/eller behandling på en måte som du syntes var lett eller vanskelig å forstå?

Svært lett
Ganske lett
Ganske vanskelig
Svært vanskelig
De forklarte ikke hans/hennes tilstand eller behandling for meg

Del D: Den følelsesmessige og åndelige støtten gitt av behandlingsteamet

De følgende spørsmålene handler om den følelsesmessige og åndelige støtten som ble gitt av behandlingsteamet til deg og din pårørende i de siste **to dagene** i hans/hennes liv. Med «**åndelig støtte**» mener vi støtte i forhold til viktige personlige overbevisninger. Disse overbevisningene kan være knyttet til en spesifikk tro/religion eller et spesifikt livssyn, men kan også være personlige overbevisninger om meningen med livet, hva som ga håp til deg eller din pårørende og hjalp dere med å mestre situasjonen.

20. Alt i alt, hvordan vil du vurdere den følelsesmessige støtten behandlingsteamet ga deg?

- Utmerket
- God
- Nokså god
- Dårlig

21. Alt i alt ble hans/hennes religiøse eller åndelige behov møtt av behandlingsteamet.

- Svært enig
- Enig
- Verken enig eller uenig
- Uenig
- Sterkt uenig

22. Alt i alt ble mine religiøse eller åndelige behov møtt av behandlingsteamet.

- Svært enig
- Enig
- Verken enig eller uenig
- Uenig
- Sterkt uenig

Del E: Omstendighetene rundt hans/hennes død

De følgende spørsmålene handler om omstendighetene rundt hans/hennes død og dine følelser om hvordan behandlingsteamet behandlet deg og din pårørende i denne tiden. Med «**behandlingsteamet**» mener vi legene, sykepleierne og eventuelle andre ansatte som tok del i behandlingen eller pleien av ham/henne, f.eks sosionom eller sykehusprest.

23. Før han/hun døde, ble du fortalt at han/hun sannsynligvis kom til å dø snart?

- Ja
- Nei

24. Snakket noen fra behandlingsteamet med deg om hva du kunne forvente deg da han/hun var døende (f.eks. symptomer som kunne komme til å oppstå)?

- Ja
- Nei

25. Ville det ha vært en hjelp å drøfte hva man kunne forvente når han/hun var døende?

Ja

Nei

Ikke aktuelt, vi drøftet dette

26. Hvor døde han/hun?

Hjemme

På sykehus

På hospice eller på en lindrende enhet

I sykehjem

Annet sted, vennligst beskriv:

27. Etter din oppfatning, døde han/hun på rett sted?

Ja, det var rett sted

Nei, det var ikke rett sted

Ikke sikker

Vet ikke

28. Jeg ble gitt nok hjelp og støtte fra behandlingsteamet på det tidspunktet han/hun døde.

Svært enig

Enig

Verken enig eller uenig

Uenig

Sterkt uenig

29. Etter han/hun var død, var personer fra behandlingsteamet hensynsfulle i den videre kontakten med deg?

Ja

Nei

Ikke aktuelt, jeg hadde ikke kontakt med behandlingsteamet etterpå

Del F: Generelle inntrykk

De følgende spørsmålene handler om dine generelle inntrykk av behandlingen og pleien han/hun fikk i de siste **to dagene** av livet og dine opplevelser og erfaringer i det tidsrommet.

30. Hvor mye av tiden ble han/hun behandlet med respekt og verdighet i de to siste dagene av livet?

Vennligst svar for både leger og sykepleiere

Hele tiden

Leger

Sykepleiere

Det meste av tiden

Noe av tiden

Aldri

Vet ikke

31. Alt i alt, etter din oppfatning, ble du støttet på en tilfredsstillende måte i hans/hennes to siste levedager?

- Ja
Nei

32. Hvor sannsynlig er det at du vil anbefale dette sykehuset til venner og familie?

- Svært sannsynlig
Sannsynlig
Verken sannsynlig eller usannsynlig
Usannsynlig
Svært usannsynlig
Vet ikke

32a. Da det ble klart at din pårørende var alvorlig syk og hadde begrenset tid igjen å leve, inviterte helsepersonellet (sykepleier eller lege) deg og ham/henne til en samtale om hva dere ønsket for hans/hennes siste levetid?

- Ja
Nei
Vet ikke

32b. Ville dere ha ønsket en slik samtale som beskrevet i spørsmålet over?

- Ja
Nei
Ikke aktuelt, vi hadde en slik samtale

Selv om fokuset i dette spørreskjemaet har vært svært mye på hans/hennes siste levedager, er vi klar over at det kan være andre forhold ved behandling, pleie eller støtte før denne perioden, som du kan ønske å gi tilbakemelding om. Hvis du ønsker det, føl deg fri til å kommentere på hvilket som helst forhold ved behandlingen, pleien og støtten dere fikk; både tidligere i forløpet og i de siste to dagene. Legg gjerne ved et ekstra ark, om du ønsker det.

Del G: Informasjon om deg og din pårørende

Vi vil gjerne få vite litt mer om deg og din pårørende. Dette vil hjelpe oss til å gjøre oss ytterligere nytte av informasjonen du gir oss, og vil bli behandlet strengt konfidensielt.

33. Hva var din relasjon til ham/henne?

Var du hans/hennes:

- Ektefelle/partner
- Sønn/datter
- Bror/søster
- Svigersønn/svigerdatter
- Mor/far
- Venn
- Nabo
- Ansatt i sykehjem eller omsorgsbolig
- Verge/formynder
- Annet

34. Hva er din alder?

- 18 – 19
- 20 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 – 79
- 80 – 89
- 90+

35. Hva er din nasjonalitet?

Har du innvandrerbakgrunn?

- Ja
- Nei

Hvis ja, fra hvilke(t) land?

36. Er du:

- Mann
- Kvinne

37. Hva er din tros- eller livssynsmessige tilhørighet?

- Ingen
- Kristen (alle kirkesamfunn)
- Humanetiker
- Hindu
- Buddhist
- Jøde
- Muslim
- Sikh
- Annen tro / annet livssyn

38. Dette spørsmålet handler om sykdommene han/hun hadde i de siste dagene og timene av livet. Her er en liste over sykdommer som er vanlige hos mennesker mot slutten av livet. Vennligst sett kryss ved alle de sykdommene han/hun hadde i de siste dagene av livet.

- Kreft (inkludert leukemi og lymfom)
- Hjertesvikt
- KOLS (kronisk obstruktiv lungesykdom)
- Sluttstadiet av nyresykdom/nyresvikt
- Demens
- Motonevronsykdom (for eksempel ALS)
- Slag (hjerneblødning)
- Vet ikke
- Noe annet

39. Hva var hans/hennes alder da han/hun døde?

- 18 – 19
- 20 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 – 79
- 80 – 89
- 90+

40. Hva var hans/hennes nasjonalitet?

.....

Hadde han/hun innvandrerbakgrunn?

- Ja
- Nei

Hvis ja, fra hvilke(t) land?

.....

41. Var han/hun:

- Mann
- Kvinne

42. Hva var hans/hennes tros- eller livssynsmessige tilhørighet?

- Ingen
- Kristen (alle kirkesamfunn)
- Humanetiker
- Hindu
- Buddhist
- Jøde
- Muslim
- Sikh
- Annen tro / annet livssyn
- Vet ikke

Tusen takk for at du tok deg tid til å fylle ut dette spørreskjemaet!

Vi ber deg sende det til oss i vedlagte svarkonvolutt.

You have been sent this questionnaire as you are registered as the next of kin to a patient who died in our organisation. This questionnaire is asking about care provided in the last hours and days of their life and your experience of that time. Although we know the patient's name, to ensure confidentiality we have used the phrase 's/he' in the questionnaire.

We realise this questionnaire may bring back strong memories and emotions and that reading it for the first time may be difficult. You may wish to wait and find someplace quiet to read the questionnaire. If you feel upset or distressed in any way, you do not have to continue with the questionnaire and can stop at any time.

Instructions for completion

When answering the questions, we would like you to focus on the last **two days** of his/her life. Please fill in as much of the questionnaire as you can.

As you go through the questionnaire, please follow the instructions and answer the questions by crossing the most appropriate box, like this:

Here is an example question:

Please look at the following statements and cross the answer box that corresponds most with your opinion.

1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.

Strongly agree	<input type="checkbox"/>
Agree	<input checked="" type="checkbox"/>
Neither agree nor disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>

If, in your opinion, you agreed that there was enough help to meet his/her personal care needs, you would cross the 'Agree' box as in the example. If you would rather not or cannot answer one of the questions, please go onto the next one.

**Your answers will be treated as strictly confidential.
Individuals will not be identifiable in the reports we write.**

Section A: The care received from the nurses & doctors

These questions are concerned with the general care s/he received from the doctors and nurses and, where appropriate the environment in which this care was delivered. The questions apply to the last **two days** of his/her life and relates to the doctors and nurses (including healthcare assistants and / or care agency staff) who were most involved with his/her care during this time.

Please look at the following statements and cross the answer box that corresponds most with your opinion.

1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

2. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed.

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

3. The bed area and surrounding environment was comfortable for him/her.

Not applicable, s/he died at home
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

4. The bed area and surrounding environment had adequate privacy for him/her.

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

5. In your opinion, how clean was the ward area that s/he was in?

Very clean
Fairly clean
Not at all clean

6. Did you have confidence and trust in the nurses who were caring for him/her?

Yes, in all of them
Yes, in some of them
No, not in any of the nurses

7. Did you have confidence and trust in the doctors who were caring for him/her?

Yes, in all of them
Yes, in some of them
No, not in any of the doctors

8. The nurses had time to listen and discuss his/her condition with me.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

9. The doctors had time to listen and discuss his/her condition with me.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Section B: The control of pain & other symptoms

These questions are concerned with the symptoms s/he had and the care s/he received during the last **two days** of his/her life.

10. In your opinion, during the last two days, did s/he appear to be in pain?

- Yes, all of the time
- Yes, some of the time
- No, s/he did not appear to be in pain

11. In your view, did the doctors and nurses do enough to help relieve the pain?

- Yes, all of the time
- Yes, some of the time
- No, not at all
- Not applicable, s/he was not in pain

12. In your opinion, during the last two days, did s/he appear to be restless?

- Yes, all of the time
- Yes, some of the time
- No, s/he did not appear to be restless

13. In your view, did the doctors and nurses do enough to help relieve the restlessness?

- Yes, all of the time
- Yes, some of the time
- No, not at all
- Not applicable, s/he was not restless

14. In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing?

- Yes, all of the time
- Yes, some of the time
- No, s/he did not have a 'noisy rattle' to the breathing

15. In your view, did the doctors and nurses do enough to help relieve the 'noisy rattle' to his/her breathing?

- Yes, all of the time
- Yes, some of the time
- No, not at all
- Not applicable, there was no 'noisy rattle' to his/her breathing

Section C: Communication with the healthcare team

The following questions are about the communication that you, your family members and friends received from the healthcare team who were most involved with his/her care in the last **two days** of his/her life. By **'healthcare team'**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

16. During the last two days, how involved were you with the decisions about his/her care and treatment?

- Very involved
- Fairly involved
- Not involved

17. Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life?

- Yes
- No
- Don't know

18. Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful?

- Yes
- No
- Not applicable, we had these types of discussions

19. Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- They did not explain his/her condition or treatment to me

Section D: The emotional & spiritual support provided by the healthcare team

The following questions are about the emotional and spiritual support that was provided to you and your family member or friend by the healthcare team in the last **two days** of his/her life. By **'spiritual support'**, we mean support relating to important personal beliefs. These beliefs may be connected with a specific religion but may also be personal beliefs about what life means, what provided you or your family member / friend with hope and helped you cope.

20. How would you assess the overall level of emotional support given to you by the healthcare team?

- Excellent
- Good
- Fair
- Poor

22. Overall, my religious or spiritual needs were met by the healthcare team.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

21. Overall, his/her religious or spiritual needs were met by the healthcare team.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Section E: The circumstances surrounding his/her death

The following questions are about the circumstances surrounding his/her death, and your feelings about the way in which the healthcare team treated you and your family member at this time. By **'healthcare team'**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

23. Before s/he died, were you told s/he was likely to die soon?

- Yes
- No

24. Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g. symptoms that may arise)?

- Yes
- No

25. Would a discussion about what to expect when s/he was dying have been helpful?

- Yes
- No
- Not applicable, we had these types of discussions

26. Where did s/he die?

- At home
 - In a hospital
 - In a hospice
 - In a care home / nursing home
 - Other (please specify)
-

27. In your opinion did s/he die in the right place?

- Yes, it was the right place
- No, it was not the right place
- Not sure
- Don't know

28. I was given enough help and support by the healthcare team at the actual time of his/her death.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

29. After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner?

- Yes
- No
- Not applicable, I didn't have any contact with the healthcare team

Section F: Overall impressions

The following questions are about your overall impression of the care s/he received in the last **two days** of life and your experiences during that time.

30. How much of the time was s/he treated with respect and dignity in the last two days of life?

Please answer for both doctors and nurses

	Doctors	Nurses
Always	<input type="checkbox"/>	<input type="checkbox"/>
Most of the time	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>
Never	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>

31. Overall, in your opinion, were you adequately supported during his/her last two days of life?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

32. How likely are you to recommend our Organisation to friends and family?

Extremely likely	<input type="checkbox"/>
Likely	<input type="checkbox"/>
Neither likely nor unlikely	<input type="checkbox"/>
Unlikely	<input type="checkbox"/>
Extremely unlikely	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

32a. When it became clear that s/he was seriously ill and had limited time left to live, did the healthcare team (nurse or doctor) invite you and him/her to a conversation about your wishes for his/her remaining life time?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

32b. Would you have wanted this type of conversation?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Not applicable, we had this type of conversation	<input type="checkbox"/>

Although the focus of this questionnaire has very much been on his/her last days of life, we appreciate there may be other aspects of care or support prior to this time, which you wish to feedback. Please feel free to comment, if you wish to, on any aspect of the overall care and support received:

Section G: Information about you and your relative or friend

We would like to know a little more about you and your relative or friend. This will help us make further use of the information you give us and will remain strictly confidential.

33. What was your relationship to him/her? Were you his/her:

- Husband / Wife / Partner
- Son / Daughter
- Brother / Sister
- Son-in-law / Daughter-in-law
- Parent
- Friend
- Neighbour
- Staff in nursing or residential home
- Warden (sheltered accommodation)
- Other

34. What is your age?

- 18 – 19
- 20 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 – 79
- 80 – 89
- 90+

35. What is your nationality?

Do you have an immigrant background?

- Yes
- No

If yes, from which country (countries)?

36. Are you:

- Male
- Female

37. What is your religious affiliation?

- None
- Christian (all denominations)
- Humanist
- Hindu
- Buddhist
- Jewish
- Muslim
- Sikh
- Any other religion

38. This question is about the illnesses s/he may have had in the last days and hours of life. Here is a list of illnesses which often affect people towards the end of life. Please cross all the illnesses s/he had in the last days of life.

- Cancer (including leukaemia and lymphoma)
- Heart failure
- COPD (chronic obstructive airways disease)
- End-stage renal (or kidney) disease
- Dementia
- Motor Neurone Disease
- Stroke (cerebral hemorrhage)
- Don't know
- Something else

39. What was his/her age when s/he died?

- 18 – 19
- 20 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 – 79
- 80 – 89
- 90+

40. What was his/her nationality?

Did s/he have an immigrant background?

- Yes
- No

If yes, from which country (countries)?

41. Was s/he:

- Male
- Female

42. What was his/her religious affiliation?

- None
- Christian (all denominations)
- Humanist
- Hindu
- Buddhist
- Jewish
- Muslim
- Sikh
- Any other religion
- Don't know

**Thank you very much for taking the
time to complete this questionnaire!**

We ask you to send it to us in the enclosed envelope.



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