Patient autonomy in advanced cancer

A video-based qualitative study of clinical communication in routine hospital visits

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Content

Abstract

This thesis contributes to the discussion about how to enhance patient autonomy in the case of advanced cancer posing an existential threat to all aspects of being. I argue that a narrow focus on patient choice and decision-making may be inadequate, as it does not consider that persons are vulnerable, dependent, and relational. Hence, I advocate a broader and deeper understanding of autonomy that better fits the complex reality of advanced cancer.

Although more people survive their cancer, it is still a dreaded disease causing uncertainty and suffering. This thesis focuses on patients with advanced cancer, that is, cancer that is unlikely to be cured but with which some can live for a long time, sometimes even years. After World War 2 it was a paradigm shift in the patient-physician relationship in the Western World, moving from a traditional paternalistic approach towards the ideal of an active and empowered patient. In the context of a broader democratization process in society at large, the ethical principle of respect for autonomy was born, best known through the influential book of Beauchamp and Childress, *Principles of Biomedical Ethics*. Since then, clinicians, scholars, policymakers and trainers have struggled with how to translate this principle into clinical practice. In several countries, including Norway, the right to information and free choice is established in the health legislation and ethical guidelines for health professionals. In the literature, shared decision-making is a widely promoted approach to secure free and informed choices. However, there is still no consensus on how it is best implemented or when it is appropriate. Moreover, patients' preferences for information and participation vary between individuals and during the course of illness. Besides, the existential experience of advanced cancer involves various losses and threats of loss, including loss of capacity, independence and control, which are features associated with autonomy. For patients receiving palliative cancer care, guidelines recommend a patient-centered approach that comprises all aspects of being, including emotional, relational and existential aspects, and where next-of-kin involvement should be a natural part. However, existential aspects prove to be an underdeveloped and neglected dimension of palliative care. Moreover, there are few observation studies that have investigated next-of-kin involvement in actual practice.

The three articles included in this thesis thus aimed to explore 1) what existential concerns patients with advanced cancer disclose during routine hospital visits and how they

communicate such concerns, 2) how physicians respond to patients' existential concerns, and 3) how next-of-kin contribute to the information exchange during routine hospital visits.

In all three articles, we employed a qualitative research design, studying video-recorded routine outpatient hospital visits involving patients with advanced cancer. In the analytic work, we used principles from "microanalysis of clinical interaction", as this method allows for an inductive, yet structured and systematic approach.

We found that most patients disclosed existential concerns during the consultation. However, existential concerns were hesitant, subtle, and indirect, typically hidden in biomedical terms, suggesting that patients may be unsure whether they can address such concerns with the physician. The physicians habitually responded to these concerns by keeping the agenda around biomedical aspects, resulting in that the existential issues remained unaddressed. In most consultations, the patient was accompanied by a next-of-kin, whom the physicians mostly related to as a "supporter on the sidelines" rather than addressing the couple as a team. When claiming the floor, next-of-kin contributed to secure information that would otherwise have been missing. For example, next-of-kin provided personal and contextual information that can help the physician to see the individual patient when tailoring information and care.

In this thesis I discuss how these findings are relevant for patient autonomy, pointing to that in the context of advanced cancer, the dominating liberal notion of autonomy falls short with its narrow focus on free choice, rationality and independence, as it does not reflect the complex reality of the patient. Drawing on literature that challenges and expands the concept of autonomy, I argue for a broader notion that not only respects patient choice, which aims to restore autonomy and foster coping. Tailoring information and patient-centered care starts with being attentive to the patient's possible underlying concerns. The thesis points to a potential existential neglect in the physician and in the medical culture and discusses how that may be relevant for patient autonomy. Insights from this thesis can inform the discussion about how physicians *can* play a role in attending to existential concerns and restoring autonomy in collaboration with the patient, next-of-kin, and the interdisciplinary team.

Sammendrag [Norwegian abstract]

Denne avhandlingen er et bidrag til diskusjonen om hvordan man kan styrke pasientautonomi ved alvorlig kreftsykdom som utgjør en eksistensiell trussel mot alle aspekter av tilværelsen. Jeg argumenterer for at et snevert fokus på valg og beslutninger kan være utilstrekkelig da det ikke tar hensyn til at personer er sårbare, avhengige og relasjonelle. Følgelig tar jeg til orde for en bredere og dypere forståelse av autonomi som passer bedre til den komplekse virkeligheten ved alvorlig kreftsykdom.

Selv om flere overlever kreft, er det fortsatt en fryktet sykdom som forårsaker usikkerhet og lidelse. Denne avhandlingen fokuserer på pasienter med avansert kreft, det vil si kreft som neppe vil bli helbredet, men som noen kan leve med i lang tid, noen ganger til og med år. Etter andre verdenskrig var det et paradigmeskifte i pasient-lege forholdet i den vestlige verden, fra en tradisjonell paternalistisk tilnærming til idealet om en aktiv og myndig pasient. Samtidig med en bredere demokratiseringsprosess i samfunnet for øvrig, ble det etiske prinsippet om respekt for autonomi født, best kjent gjennom den innflytelsesrike boken til Beauchamp og Childress, *Principles of Biomedical Ethics*. Siden den gang har klinikere, forskere, beslutningstakere og kommunikasjonstrenere strevet med hvordan dette prinsippet skal omsettes til klinisk praksis. I flere land, inkludert Norge, er retten til informasjon og medbestemmelse etablert i helselovgivningen og etiske retningslinjer for helsepersonell. I litteraturen er samvalg en bredt promotert tilnærming for å sikre frie og informerte valg. Det er imidlertid fortsatt ingen konsensus om hvordan det best gjennomføres eller når det er hensiktsmessig. Dessuten varierer pasienters preferanser for informasjon og deltakelse mellom individer og i løpet av sykdomsforløpet. Dessuten er alvorlig kreftsykdom en eksistensiell erfaring som innebærer en rekke tap og trusler om tap, inkludert tap av kapasitet, uavhengighet og kontroll, som er kjennetegn assosiert med autonomi. For pasienter som mottar palliativ kreftomsorg anbefaler retningslinjer en pasientsentrert tilnærming som omfatter alle deler av tilværelsen, inkludert emosjonelle, relasjonelle og eksistensielle aspekter, og hvor involvering av pårørende bør være en naturlig del. Eksistensielle aspekter viser seg imidlertid å være en underutviklet og neglisjert dimensjon ved palliativ omsorg. Det er også få observasjonsstudier som har undersøkt involvering av pårørende i praksis.

De tre artiklene som er inkludert i denne avhandlingen hadde derfor som mål å utforske 1) hvilke eksistensielle bekymringer pasienter med alvorlig kreftsykdom formidler i

polikliniske konsultasjoner og hvordan de kommuniserer slike bekymringer, 2) hvordan leger responderer på pasienters eksistensielle bekymringer, og 3) hvordan pårørende bidrar til informasjonsutvekslingen i slike konsultasjoner. Alle tre artiklene hadde et kvalitativt forskningsdesign hvor vi studerte videoopptak av polikliniske konsultasjoner som involverte pasienter med avansert kreft. I det analytiske arbeidet brukte vi prinsipper fra «micoanalysis of clinical interacion», da det er en metode som muliggjør en induktiv, men strukturert og systematisk tilnærming. Vi fant at nesten alle pasientene avslørte eksistensielle bekymringer under konsultasjonen. Imidlertid ble eksistensielle bekymringer formidlet nølende, subtilt og indirekte, typisk skjult i biomedisinske termer. Dette kan tyde på at pasienter kan være usikre på om de kan ta opp slike bekymringer med legen. Legene reagerte vanligvis på eksistensielle bekymringer ved å holde samtalen til biomedisinske aspekter, noe som resulterte i at de eksistensielle problemene ikke ble adressert. I de fleste konsultasjonene ble pasienten ledsaget av en pårørende, som legene stort sett forholdt seg til som en "supporter på sidelinjen" i stedet for å henvende seg til paret som et team. Når de tok ordet bidro pårørende til å sikre informasjon som ellers ville ha manglet. For eksempel ga pårørende personlig og kontekstuell informasjon som kan hjelpe legen til å se den enkelte pasient ved tilpassing av informasjon og oppfølging til den enkelte.

I denne avhandlingen diskuterer jeg hvordan disse funnene er relevante for pasientautonomi, og peker på at ved avansert kreft, kommer den dominerende forestillingen om autonomi til kort med sitt snevre fokus på fritt valg, rasjonalitet og uavhengighet, da det ikke reflekterer pasientens komplekse virkelighet. Ved å trekke på litteratur som utfordrer og utvider begrepet autonomi, argumenterer jeg for en bredere forståelse som ikke bare respekterer pasientens valg, men tar sikte på å gjenopprette autonomi og fremme mestring. Skreddersydd informasjon og pasientsentrert omsorg starter med å være oppmerksom på pasientens underliggende bekymringer. Avhandlingen peker på en mulig forsømmelse av eksistensielle aspekter hos leger og i den medisinske kulturen og diskuterer hvordan dette kan være relevant for pasientautonomi. Innsikter fra denne avhandlingen kan informere diskusjonen om hvordan leger kan spille en rolle i å møte eksistensielle bekymringer og gjenopprette autonomi i samarbeid med pasienten, pårørende og det tverrfaglige teamet.

List of articles

Article 1

Larsen BH, Lundeby T, Gerwing J, Gulbrandsen P, Førde R. “Eh – What type of cells are these – flourishing in the liver?” Cancer patients’ disclosure of existential concerns in routine hospital consultations.

Patient Education and Counseling. 2021. DOI: 10.1016/j.pec.2021.11.010

Article 2

Larsen BH, Lundeby T, Gulbrandsen P, Førde R, Gerwing J. Physicians’ responses to advanced cancer patients’ existential concerns: A video-based analysis.

Patient education and counseling. 2022. DOI: 10.1016/j.pec.2022.06.007

Article 3

Larsen BH, Lundeby T, Gerwing J, Gulbrandsen P, Førde R. More than an extra set of ears: next-of-kin contribution in routine oncology visits. A video-based analysis.

Manuscript submitted for publication 2023.

Overview articles

Table 1

	Article 1	Article 2	Article 3
Study setting	Routine outpatient visits, large University hospital in Norway	Routine outpatient visits, large University hospital in Norway	Routine outpatient visits, large University hospital in Norway
Participants under study	Patients (13) with advanced cancer, having a poor/ uncertain prognosis, various cancer diagnoses.	Physicians (5) from five different departments with various specialties.	Next-of-kin (10) accompanying patients with advanced cancer. Companions were family members, most were spouses.
Material	Video-recordings (n=13). Transcripts.	Video-recordings (n=13). Transcripts.	Video-recordings (n=10). Transcripts.
Analysis	Microanalysis of clinical interaction.	Microanalysis of clinical interaction.	Microanalysis of clinical interaction.
Unit of analysis (for detailed investigation)	Patient utterances displaying existential concerns, i.e., disclosing the illness/treatment being a threat to the person's physical, psychological, social, or spiritual being.	Physicians' response to patients' existential concerns, i.e., the immediate utterance(s) reacting and orienting to the patient's existential utterance.	Next-of-kin utterances carrying substantive content relevant to the illness/treatment experience.
Aim	To explore what existential concerns advanced cancer patients disclose during routine hospital visits, and how they communicate such concerns.	to explore how physicians respond to patients' uttered existential concerns during routine oncology visits.	To explore how next-of-kin contribute to the information exchange during routine hospital visits involving patients with advanced cancer.
Research questions	1) What existential concerns did patients disclose? 2) How did patients convey such existential concerns?	1) What interactional function did the physician-response serve in the moment? 2) What topics (content) did the response pursue?	1) Who initiated NOK talk? 2) How did NOK contribute to the information exchange? 3) What information did NOK bring into the discussion?
Results	12 out of 13 patients disclosed existential concerns. 127 existential utterances in total, large variations (0-40). *Existential concerns related to*: ○ Threat to life ○ Threat to a good life ○ Threat to identity/self ○ Threat to autonomy ○ Threat to personal relations ○ Threat to social roles ○ Dependency in the patient-physician relation ○ Search for hope ○ Search for meaning Patients revealed uncertainty about future, self and coping; concerns related to separation, dependency, and trust; search for meaning and hope. *How patients disclosed existential concerns*: ○ Uninvited, yet hesitantly ○ Subtle and indirect ○ Wrapped up in bio-medical terms ○ Displaying little emotions	We identified 185 immediate physician-responses to the 127 patient existential utterances. Three types of responses: *Responses giving the patient control over the content* About one-third of responses. ○ Generic responses *Responses providing support* About one-eighth of responses. ○ Acknowledging the patient's emotion/concern/ experience ○ Acknowledging the patient's coping strategies/resources *Taking control over the content* More than half of responses. Physician-responses habitually steered the agenda towards biomedical aspects through what issues they pursued when ○ Educating the patient ○ Exploring pat utterance ○ Reformulating pat utterance Physicians failed to acknowledge and address the patients' existential concerns.	Next-of-kin participation varied but most were largely reticent. 217 utterances in total (3-81). Next-of-kin spoke uninvited. Next-of-kin contribution: *Bringing information into the discussion:* ○ Providing information ▪ Medical/procedural info ▪ Bodily ailments ▪ Concerns/emotional aspects ▪ Patient context, values, and resources ▪ Follow-up and patient-provider relation ○ Requesting information ▪ Disease progression ▪ Treatment plan ▪ Expected outcome ▪ Practical issues *Monitoring and supporting the information process*: ○ Assisting the process of information exchange ○ Interpreting information
Conclusions / Practice implications	Health professionals should be attentive to underlying existential concerns that may be embedded in patients' questions and concerns.	Physicians should be attentive to their possible habit of steering the agenda towards biomedical topics, hence, avoiding patients' existential concerns.	Next-of-kin may be an important resource in the consultation, not only for the patient, but also for the physician, when aiming to tailor information and care.

List of tables and figures

List of abbreviations

ASCO	American Association of Clinical Oncology
CA	Conversation analysis
MCI	Microanalysis of Clinical Interaction
MFD	Microanalysis of Face-to-face Dialogue
NOK	Next-of-kin
NSD	Norwegian Social Science Data Services
REC	Regional Ethics Committee
SDM	Shared decision-making

“To be an autonomous agent is to determine one’s own path in life.
However, this cannot plausibly be seen as a one-off affair. An autonomous agent
does not merely set herself on a particular course and then lock the steering
wheel in place, so to speak, but must maintain some form of ongoing control over
her direction in life—must keep her eyes on the road and her hands on the
wheel.” (Steven Weimer) (1) (p. 211)

1 Introduction

In most Western countries, current medical practice is governed by a focus on the ethical principle ‘respect for patient autonomy’ as a core value and holy grail of health professionals’ ethics (2-4). However, how this principle translates into clinical practice is not straight forward, especially when caring for patients facing existential threats due to severe illness like advanced cancer. From my perspective, being a cancer nurse working with clinical ethics, the current understanding and practice represents a narrow vision of autonomy, with its unilateral focus on autonomous choice and individual rights. This approach takes for granted that patients are free, rational, able, and independent, which is not always the case in real life. I will alternate between the pronouns she/he/they to refer to a patient in general throughout the thesis for inclusivity.

The notion that one respects patient autonomy simply by valuing personal preferences in medical decision-making is an oversimplification of a complex reality for a number of reasons. Firstly, the composite nature of patient involvement in treatment decisions, which has been demonstrated through the difficulties of implementing shared decision-making into clinical practice (5-7). Secondly, truly free choices may be scarce in advanced cancer (8). Third, determining one’s path in life does not only involve medical treatment decisions, but a wide range of choices related to other aspects of life. Forth, the complex nature of the human condition, as vulnerability, dependence, and belonging are inevitable and natural ingredients in human life (9-11) , especially when faced with severe illness (12). Hence, being seen and recognized as an individual in the world can give strength to face the hardships of life and may be just as vital as free choice. Fifth, the complexity of communication must not be overlooked (13). The multidimensional process of information exchange and meaning making has many obstacles.

As Weimer states, quoted in the introduction to this section, being an autonomous agent is 'to determine one's own path in life' and cannot be seen as an 'one-off-affair' (1) (p. 211). Rather, it is an on-going process to retain some control over the direction of one's life. I would like to add that to 'keep her eyes on the road and her hands on the wheel' (1) (p. 211) requires sufficient capacity and certain skills from the patient. She could also need guidance when entering unknown territory. Moreover, she may want to hand over the steering wheel to someone else when her powers are failing, and the ground is shaky. That too is an autonomous act. Holding the steering wheel for someone part of the way involves keeping the direction toward that person's goals.

Life-threatening illness like advanced cancer poses an existential threat to all dimensions of being and may affect persons' capacity to fully exercise their autonomy. That does not imply that this key principle should be ignored when caring for severely ill patients, however, a different approach may be needed based on the individual patient's needs. The physician is in a key position to foster autonomy and coping in collaboration with the patient and the family. Traditionally in clinical practice, existential aspects have largely been overlooked, or defined as outside the scope of medical responsibility. If noted, it has mainly been a task assigned for the chaplaincy. However, ignoring the patient's deepest concerns may be a lost opportunity when aiming to restore patient autonomy (12). With this thesis, I wish to contribute to a broader and deeper understanding of autonomy that better matches the complex reality of severe illness.

My current view on patient autonomy is not the same as the one I had before I started this Ph.D. journey. The process of working with this project has shaped and developed my own understanding of the concept, with a growing recognition of its complexity. My experience of working in a cancer hospital for two decades, also from being a member of the hospital's clinical ethics committee for almost as long, as well as being part of the academic environment at the Centre for Medical Ethics for the past six years has undoubtedly informed my thinking. While working as a cancer nurse, I met daily with patients and their families. Giving high doses of intravenous chemotherapy, with the potential for heavy side-effects, was routine work. As colleagues, we frequently discussed what is the right level of care; when should we continue intensive treatment, and when should we withdraw due to poor or uncertain effect, troublesome side effects, or due to the patient's wishes. The nurses were often concerned about overtreatment and that patients were not always given an opportunity to refrain from treatment due to biased information. For example, the physicians were sometimes overselling the benefits and downplaying the drawbacks. Decisions about life-prolonging treatment is also a recurring theme in the ethics committee(s), both locally and nationally. This piqued my interest, so when I did my master's thesis in nursing science nearly ten years ago, I interviewed physicians and nurses about their experiences of involving patients and their next-of-kin in decisions about limiting life-prolonging cancer treatment. What I learned was that both too much and too little weight on patient autonomy resulted in more treatment; that is, the patients' wishes were more often respected when they wanted to continue treatment than when they did not. Previous research has confirmed that it is always easier for physicians to do more than less when uncertain and there is much at stake (14, 15). So, when I started this Ph.D. journey, I planned to investigate these decision-making processes. However, when I started to study video-recordings from patient-physician interactions, the data took me in a different direction. Instead of studying shared decision-making in practice, as I thought I should, I became interested in exploring other aspects of patient autonomy, which are perhaps just as important, but much less studied and acknowledged. In the method section I elaborate on the reasons for this shift.

Hence, this thesis is a contribution to the discussion about how to translate the principle of respect for autonomy into clinical practice when the patient is seriously ill. It is an argument for a broader and deeper understanding of patient autonomy that better fits the basic conditions of human life and the complex reality in advanced cancer.

2 Background

2.1 Living with advanced cancer

The Norwegian Cancer Registry received reports of nearly 37,000 new cancer cases in 2021 (16) in a population of 5.4 million (17). Approximately one third of the population in Norway is expected to get cancer during their lifetime, the incidence increasing with age. Today, nearly three out of four people live for five years or longer after a cancer diagnosis. Still, there are almost 11,000 cancer deaths annually in Norway (16). In 2020, the estimated number of new cancer cases was more than 19 million worldwide, with 10 million people dying from cancer in the same year (18). Cancer is not a single disease but spans a wide range of conditions with different origins (type of cell or organ), symptoms, prognosis, and treatment (19). This thesis focuses on patients with advanced cancer, that is, cancer that is unlikely to be cured (20). Sometimes, however, advanced cancer can be controlled over a long period of time and be considered an ongoing or chronic disease, and the prevalence of patients living with advanced cancer is increasing (21).

Cancer treatment usually involves surgery, radiotherapy, or drugs (e.g., chemotherapy or immunotherapy), often in combination (19). The course of treatment is often lengthy, as for example radiation and chemotherapy are typically given in a series over weeks or months. The goal may be to cure, prolong life, or relieve symptoms, depending on the circumstances. Generally, it is not known until after some time whether the desired effect will be achieved. Moreover, when cancer has occurred once, there is always a risk of relapse. Common symptoms of cancer include pain, nausea, weight loss, fatigue, breathing problems, and function loss, however, they vary depending on the cancer type and stage (21). In addition, the treatment causes side-effects and it is not always clear which symptoms are due to progression of the disease or the treatment. All these factors may create uncertainty and influence the patients' quality of life. Much of the treatment takes place at the hospital, however, hospital stays are becoming increasingly shorter, and many patients live at home while receiving treatment (22). Consultations at the hospital are often brief and have a clear agenda: evaluating the disease progression and undertaken treatment and planning further treatment and/or follow-up.

2.2 Historical retrospective: the emerge of the ideal of patient autonomy

Respect for personal autonomy was not always a guiding principle for health professionals. Traditionally, moral ideals like care, to do good, and do not harm were more influential (23). However, since World War II there has been a paradigm shift from a paternalistic approach in the patient-physician relationship to the ideal of the active and empowered patient, leading to radical changes in the patient role, as well as the roles of the physician and the family (23). The crimes committed by Nazi doctors during World War II, were confronted in the postwar trials and increased the focus on medical ethics. As a result, voluntary consent became a central principle in the Nuremberg Code (1947) of conduct for human experiments (24) and in the Helsinki Declaration (1964) adopted by the Word Medical Association (25). The formalization of informed consent in research ethics became a precursor to implementing the same principle in clinical ethics. This moral revolution was influenced by social movements and events in the US during the 1960s and 1970s, before spreading to other Western countries, including Norway.

2.2.1 Activist movement in the US during 1960s and 1970s

Following the industrial revolution, a democratization process took place in Western countries, leading to the formation of unions, as well as political parties, and voting rights for all men. The social activist movement during the 1960s and 1970s took these developments a step further by promoting civil rights like liberty and labor, women's liberation, anti-discrimination of gay people, anti-war, as well as advocating for patient rights. In this period, all authorities were challenged, including the medical profession (26).

Prior to this, the dominant view of the patient-physician relationship was informed by Talcott Parson's legendary book, *The Social system (1951)* (27). The physician's role was to be the medical expert responsible for the patient's welfare, while the patient's responsibility was to enter the sick role, seek competent help, and to "follow the doctor's order" (23). The call for full patient-to-physician obedience was reflected in the first Code of Ethics adopted by the newly established American Medical Association in 1847, in the section *Obligations for Patients to their Physicians* (28). The rise of new technology also contributed to a more passive patient as the doctor now had instruments to collect "objective observations" and thus became less dependent on the patient's reporting of symptoms. Moreover, as hospitals replaced the homes as the locus of medical care, its rules and routines increasingly encouraged patient passivity (28).

According to Baker, patients started to rebel against the doctor-knows-best ethos as a response to cases that had become known to the public demonstrating malfunction in the patient-physician relationship (23). One example was the story of Donald “Dax” Cowart, a Vietnam veteran who was severely injured in a gas explosion, whose doctors did not respect his refusal of treatment referring to their duty to treat both his wounds. Another example was the story of Karen Ann Quinlan, a twenty-one-year-old woman who, following months in a coma, was in a persistent vegetative state with no prospect of recovery. When her parents asked the physicians to discontinue ventilator support for their daughter, the physicians refused. Quinlan's parents took legal action and, after several cases, eventually won in the Supreme Court. Public opinion was that their request should have been respected on the outset and not required such legal action. In addition to the battles of individuals, people joined forces in groups and organizations to fight for the cause of patient rights. For example, the feminist Boston Women’s Health Book Collective published the highly influential book *Our Bodies, Ourselves (1970),* in which they listed requested patient rights and rebelled against the medical establishment’s practice of prioritizing clinical and scientific knowledge over personal and experiential knowledge (23).

During this period, the interdisciplinary field of bioethics was conceived. This was a result of an alliance of patients, intellectuals, philosophers, lawyers, theologians, and reform-minded physicians advocating for patient’s and families’ right to self-determination in health care (23). This coalition became influential and offered ethical advice to healthcare professionals, healthcare organizations, and governmental bodies. Following this, in 1979 Beauchamp and Childress published the first edition of their book *Principles of Biomedical Ethics* (29), presenting what has become known as the ‘four-principle ethics’, which includes respect for autonomy.

2.2.2 Patient autonomy in the Norwegian context

In the Norwegian setting, democratization, internationalization, and increased education levels in the population were the strongest driving forces for the shift from patient obedience to equality and participation (30). Besides, trust in doctors had weakened after World War II. Since the late 20th century, the number of areas of life which are regulated by laws in Norway has continually increased. This includes health care services, which has resulted in the rising status of patient rights (30). The Doctors’ Act (1980), which was later replaced by the Health

Personnel Act (1999) (31), imposed numerous duties on doctors which incorporated corresponding rights for patients in the Patients' Rights Act (1999) (32), including the right to participation and information (Chapter 3). These ideals were also in the ethical codes of conduct for doctors (1962) (3). In addition to the changes at the individual level, structural measures were established, such as compensation schemes, ombudsmen, and user committees (30). In this context, the Norwegian welfare model developed, based on a principle of universal access to healthcare (33). Post-war feminism contributed to these changes, as women's liberation had consequences for equality in general. Further, as women had traditionally taken responsibility for health and care in the family a new role for women contributed to the change in patient role (30).

In summary, the ideal of respect for autonomy was born in the context of major societal changes in the postwar era with increasing democratization and focus on civil rights.

2.3 Patient autonomy in clinical practice

How to operationalize and implement patient autonomy into clinical practice has been conceptualized in various ways in academic literature, including patient involvement, participation, empowerment, consent, and self-determination; yet shared decision-making is the most promoted approach (7).

2.3.1 Guidelines and recommendations

National and international oncology guidelines share the ideal of individualized care and a well informed and empowered patient (21, 34-36). For example, a recent Lancet report on the integration of oncology and palliative care states that physicians are legally and ethically obligated to promote patient participation, and to provide information in a way that enables patients to be active and informed partners in the decision-making process (21). Further, the report claims that honest and person-centered discussions about treatment goals are most appropriate within the framework of shared decision-making. In the Norwegian context, shared decision-making is a priority in all areas of health care services (37-39), including cancer care (40).

The Norwegian Medical Association states the following in their ethical rules for physicians regarding the patient-physician relation, participation, and information (3) (§ 2 and § 3):

> *"The doctor must safeguard the interests and integrity of the individual patient. The patient must be treated with care and respect. The collaboration with the patient should be based on mutual trust and should, when possible, be based on informed consent." (§ 2).*
>
> *"The patient has the right to information about his own state of health and treatment and, in general, the right to access his own medical records. The patient must be informed to the extent that the patient wishes. Information that can be expected to be particularly burdensome must be given with caution." (§ 3).* [my translation]

2.3.2 Research on patient involvement

The research literature provides broad support for patient involvement, especially through *shared decision-making* (SDM), which is increasingly advocated for as the preferred model to engage patients in the process of deciding medical inquiry, treatment or follow-up when more than one reasonable option is available (7). Still, it is not part of mainstream practice (5, 6, 41, 42), the recommended stepwise procedure is followed to a limited extent (7), and there are multiple models and accounts of what SDM is and what it is not (43-47). Surveys have revealed that physicians often align with the idea of SDM as the preferred approach, but do not include it in their daily work (48, 49). One survey found that most physicians presented different treatment options, including pros and cons as recommended, but fewer made clear that a decision had to be made or explored with the patient's involvement (48).

According to a systematic review, the most reported barriers for SDM were time constraints and lack of applicability due to patient characteristics and the clinical situation (5). An interview study found the most important barriers to be biased information about treatment and physicians assuming to know what patients want (14). Some physicians believed that SDM was not in the patient's best interest because the patient lacks adequate medical understanding, while others may find it difficult to adopt SDM (42). In an interview study, oncologists thought it was challenging to meet the patients' different preferences for involvement (50). A systematic literature review reported that oncologists often found discussions about ending treatment to be particularly difficult and emotionally demanding (15). There is still some ambiguity regarding in which situations SDM might be appropriate (51).

A systematic review showed that patients with advanced cancer were less involved than they wanted (52). Two out of three wanted to participate in treatment decisions to some extent, however, the proportion decreased with increasing disease burden. A study of patients with incurable cancer showed that almost all received information about diagnosis, treatment, and causation, while less than half were involved in decisions about limiting life-prolonging treatment (53). Patients who agreed with their doctor's preferences for treatment were more often involved in the decisions. A systematic review found that patient reported barriers were predominantly related to patient knowledge and power imbalance, and that patient power is difficult to attain (42). A study of patients with advanced cancer reported that half of the respondents preferred to be involved in SDM, whereas the remaining half were almost equally divided between wanting to make decisions independently and letting the physician solely make decisions (54). Corresponding findings were reported in another study, where half of the cancer patients preferred shared decision-making responsibility, whereas a third preferred to leave the decision to the physician (55). Older and more distressed patients were more likely to want the physician to make the decision. Growing evidence suggest that patients may not always be ready to participate in SDM (56).

Scholars advocating SDM have learned that successful implementation requires knowledge and awareness among both professionals and patients as well as tools and skills training (7), but also a shift in attitudes and organizational support (6). Implementation of SDM in cancer care is considered to be complex, with many elements of uncertainty (57). In various contexts, the use of decision aids is found to create increased knowledge, greater patient engagement, and decisions more consistent with patients' preferences (58). The literature on outcomes of SDM in palliative care is scarce and findings are inconclusive (21, 59) .

2.4 Existential aspects in oncology and palliative care

According to the World Health Organization's definition of palliation, it also encompasses the spiritual and existential aspects of treatment and care for patients (60), and it is widely agreed that spiritual care should be implemented (21). "Spiritual care" is a collective term for the staff's approach and efforts in relation to the patient's existential and spiritual challenges. The term, as often used in the literature, can give too narrow or incorrect associations to religion (36), which is one way people can experience spirituality, and thus a subset of human spirituality as a whole (61). The Norwegian action program for palliation in cancer care (36) adopts the European Association For Palliative Care's (EAPC) definition (62):

> *"Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred."*

The EAPC elaborates on this definition by pointing to three dimensions of the spiritual realm (From the Norwegian action program for palliation in cancer care (36)):

1) ***Existential challenges*** *(i.e., questions related to identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom, and responsibility, hope and despair, love, and joy).*
2) ***Values and attitudes*** *(what is important to each individual, such as the relationship with oneself, family, friends, work, things, nature, art and culture, ethics and morality, and life itself).*
3) ***Religious and ideological anchoring*** *(faith, conviction and practice, the relationship with God, the ultimate reality or the transcendent).* [My translation]

Research findings suggest that the existential cancer journey involves having to navigate unknown territory (63), and includes a state of fundamental uncertainty, vulnerability, lack of power (12), and suffering (64). There is growing evidence that spiritual care is important to patients, that cancer patients often desire to discuss existential concerns as part of clinical care (61, 65-67), and that such care may have positive effects on patients' quality of life (65, 68). However, a multisite study in the US context found that most patients with advanced cancer had never received any form of spiritual care from their oncology nurses or physicians, and that most nurses and physicians had not received any training in providing such care (67). Also in the European context, evidence suggests that spiritual care remains an underdeveloped and neglected dimension of palliative care (65), and that physicians may lack confidence and training in how to discuss existential issues in their daily practice (21, 66, 67).

2.5 Next-of-kin involvement in cancer care

According to WHO, palliative care is by nature family-oriented, being 'an approach that improves the quality of life of patients and that of their families who are facing problems associated with life-threatening illness' (60). An American Society of Clinical Oncology (ASCO) guideline on integration of palliative care into standard oncology care states that building a relationship with family caregivers may be an essential component of care (35). For patients with advanced cancer in the outpatient setting, the guideline encourages providers to initiate tailored support for family caregivers. A Lancet report advocating early integration of palliative care declares that the role of family and caregivers is important in the SDM process throughout the disease trajectory (21). A national guideline on palliation in cancer care appoints next-of-kin to be an important resource for the seriously ill and dying patient, as they usually know the patient well and can provide important information to healthcare personnel (69). Specific next-of-kin guidelines, which applies to the entire health service in Norway, provide numerous recommendations regarding next-of-kin involvement (70), including: to facilitate predictable dialogue; always offer general information; listen to, and follow up on next-of-kin concerns; provide information in a considerate manner; facilitate next-of-kin participation when the patient is unable, and obtain information from next of kin when assessing the patient's need for assistance.

A study investigating patient preferences found that three out of four patients with advanced cancer wanted next-of-kin to be present when information is given (71), and two out of three wanted family involvement in decision making, however, one third did not have this preference met (72).

Family members, as informal caregivers, are often the patient’s main source of emotional and practical support (21). Simultaneously, they experience their own challenges with the illness of a loved one (73). Reduced quality of life, distressing symptoms (e.g., insomnia, fatigue, anxiety, and depression), and financial stress are common among caregivers (35). Further, spouse caregivers of patients with advanced cancer are at high risk of developing depression (74). The strain on caregivers might have increased in the past years because cancer care has shifted towards outpatient and home-based care (21). Interventions for caregivers such as psychoeducational, skills training, and therapeutic counseling have been shown to reduce caregiver burden, and improve their coping, self-efficacy, and quality of life (75).

According to a systematic review of triadic medical visits, the proportion of patients bringing a companion vary greatly, with most companions being family members, most frequently the spouse (76). One review study found that an average of one in three adult patients with various diagnoses brought a companion to their routine medical visits (77). In oncology visits, rates varied from around a quarter (78) to more than four out of five in consultations where ‘bad news’ was disclosed (79). In general, accompanied patients were more likely to be older, female, less educated, and in worse physical health; however, companions of cancer patients were more likely to attend the consultation irrespective of patient's demographic characteristics or functional status (76). The most commonly reported roles of companions were to provide the patient with logistical assistance, informational support, and emotional support, whereas some companions spoke about their own needs (76). Street et al. (80) found that most companions took a passive observer role. Cancer patients generally perceived companions as a source of support in decision-making and communication with the physician (76). They appreciated the companion's informational support, such as asking questions, gathering information, taking notes, and recalling details (76, 81). Patients reported that companions helped increase their understanding (82) and helped improve the information exchange (83, 84). Some patients found it easier to discuss difficult topics at the consultation when accompanied (82). Most patients want to involve their partners in decision-making, cancer patients significantly more so than patients with less serious conditions (76).

Physicians have reported companion's input to be mostly helpful, for example in sharing medical information (76, 85, 86). However, some oncologists thought that including a companion increased complexity to the consultation (85), and some experienced companion dominance as a barrier in the decision-making process (87). Companions of oncology patients believed it was important that they were involved in the consultation (83, 88, 89) and did not perceive it as a burden (83, 90). Some companions reported that they avoided influencing the patient's final decision (91).

Previous studies have focused primarily on perceptions (from interviews, focus groups, or surveys) rather than observations of real-life consultations (76). What companions do in medical visits is rarely investigated (92, 93).

3 Theoretical perspectives and core concepts

3.1 The patient-physician relation

The question 'what should the ideal physician-patient relationship be?' has been much debated in recent decades. Emanuel and Emanuel (94) outlined four models, emphasizing different understandings of, 1) the goals of the interaction, 2) the physician's obligations, 3) the role of patient values, and 4) the conception of patient autonomy (p. 2221). Table 2 compares the four models.

Table 2. Comparing the four models

	Informative	Interpretive	Deliberative	Paternalistic
Patient values	Defined, fixed, and known to the patient	Inchoate and conflicting, requiring elucidation	Open to development and revision through moral discussion	Objective and shared by physician and patient
Physician's obligation	Providing relevant factual information, and implementing patient's selected intervention	Elucidating and interpreting relevant patient values as well as informing the patient and implementing the patient's selected intervention	Articulating and persuading the patient of the most admirable values as well as informing the patient and implementing the patient's selected intervention	Promoting the patient's wellbeing independent of the patient's current preferences
Conception of patient's autonomy	Choice of, and control over, medical care	Self-understanding relevant to medical care	Moral self-development relevant to medical care	Assenting to objective values
Conception of physician's role	Competent technical expert	Counselor or adviser	Friend or teacher	Guardian

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The authors argue that the deliberative model is the ideal for the patient-doctor relationship although different approaches may be appropriate in different clinical situations (94). They believe that both the patient's and the doctor's values are relevant in medical decisions. Moreover, they claim that freedom of choice and control over decisions are not enough to safeguard the patient's autonomy.

3.2 The ethical principle “Respect for autonomy”

The concept of patient autonomy is best known through the groundbreaking book *Principles of Biomedical Ethics* by Beauchamp and Childress, which has been published in eight editions over five decades, most recently in 2019 (2). Their framework is known as the four principle ethics, and includes the principles of beneficence, non-maleficence, and justice. The principles are general and non-hierarchical and must be specified and balanced in each case. During the various editions, their description of respect for autonomy has evolved in an ongoing discourse about how the principle ought to be understood and implemented.

In their view, personal autonomy is an extension of political self-rule to self-governance by the individual (95). They distinguish between autonomous persons and autonomous choices, as autonomous persons make non-autonomous choices, and non-autonomous persons make autonomous choices. Their model emphasizes autonomous choices, highlighting acts like consenting and refusing. They build on the two conditions that are agreed to be essential to autonomy, liberty and agency, which they operationalize into three criteria, deeming an action to be autonomous when a person acts intentionally, with understanding, and without controlling influences that determine the action (2) (p. 102).

They consider intentionality an either-or criterion, as an action is either intentional or not. Understanding, however, can be satisfied to a greater or lesser extent, meaning that there is a broad continuum from fully present to entirely absent. They claim that one should only require substantial satisfaction rather than total, as people’s actions are rarely, if ever, fully autonomous. Hence, their analysis is based on ‘normal choosers’ as they recognize that demand for ideal choosers is unrealistic (2) (p. 102).

Respect for autonomy consists of two opposite features, a negative duty to avoid controlling constraints, including coercion, and lying about or withholding information, and a positive obligation to enhance autonomy. Due to the unequal distribution of knowledge between patients and professionals, the latter have ‘a prima facie obligation to disclose information to ensure understanding and voluntariness, and to foster adequate decision making’ (96)(p. 73).

3.3. Shared decision-making

The phrase ‘sharing of decision-making’ was first used in 1972 by Veatch (97)(p. 7), in his paper *Models for Ethical Medicine in a Revolutionary Age: What physician-patient roles foster the most ethical relationship?* (7). However, the concept of shared decision-making was not introduced in the literature until 1997, when Charles and Gafni published their landmark paper *Shared Decision making in the medical encounter: what does it mean? (Or: it takes at least two to tango)* (98).

Shared decision-making aims to strike a balance between too much and too little patient power and responsibility, thus placing itself between the paternalistic model and the informed model (99), similar to the deliberative model (cf. Emanuel and Emanuel’s models). The essential feature of this approach is collaboration. The physician and the patient share all stages of the decision-making process simultaneously, and there is a two-way exchange of information. The physician provides evidence-based information about relevant treatment options, including no treatment, as well as the pros and cons. The patient communicates what he knows about his illness and various treatment options. In addition, he shares information about his life situation, as well as values and preferences that may influence the perception of which treatment will be the best for him. Both parties express their treatment preferences and their rationale for these, while trying to build a consensus for the most suitable option. Originally, the model was developed to fit the clinical context of potentially life-threatening disease, where important decisions must be made at key points in the course of illness, and where there are several treatment options and considerable uncertainty (99).

3.4 Actual autonomy

What autonomy means in the clinical setting is an ongoing debate, in which George J. Agich has contributed significantly. In his book *Dependence and Autonomy in Old Age (2003)* (100), he examines the concept of autonomy in long-term care for old people in contrast to acute care settings. Agich challenges the dominant liberalist view on autonomy which is based on the abstract ideals of independence and self-determination. Instead, he argues for a more nuanced concept of ‘actual autonomy’ (101)(p. 83-) that is more appropriate in the concrete reality of the long-term care context where interdependence, rather than independence, takes place. Agich claims that ‘attention to the phenomena of choice and decision-making has had the unfortunate consequence of rendering otiose other features of autonomy’ (100) (p.

7). Liberal notions of the concept emphasize autonomy as a negative freedom, meaning that individual freedom is realized by non-interference from others. This standard view of autonomy implicitly assumes a robust concept of individual capacity. Agich argues that in real-world situations, especially in long-term care, people only achieve autonomy through interaction with others, as illness and incapacities may compromise a person's ability to function independently or to choose rationally (100) (p. 1). Also, he challenges current assumptions, for example, the idea that decision-making primarily is a rational process and that society, or the state, poses a threat to the integrity of the self. He also questions that individual beliefs are given primacy over other goods and values (100) (p. 10). Agich uses space, time, communication, and affectivity as a thematic framework for exploring and conceptualizing central issues for autonomy in long-term care (100)(p. 125). Building on insights from phenomenology, with its focus on the lived experience of subjects, he encourages caregivers to consider the emotional (affective) aspects of experienced phenomena (e.g., fatigue), not only the physical aspects. Agich criticizes the liberal notion of autonomy for one-sidedly focusing on decision-making in unusual situations, while ignoring the routines and decision-making of everyday life, as actual autonomy is a process of being in the world. Hence, Agich argues that the standard liberalist, political and legal concept of autonomy, as represented in the concept of consent, is inapplicable in real-life situations, especially in the context of long-term care. Still, he believes that autonomy should remain a central ethical concept in this context, but only if it can be 'refurbished' to better fit its complex reality (100)(Preface, p. VIII). His conceptualization of 'actual autonomy' involves a shift of attention from independence to the concrete manifestations of autonomy in everyday world life.

3.5 Relational autonomy

Feminist theorists in general have been critical of the concept of autonomy, accusing it to be inherently masculinist (100, 102). Catriona Mackenzie and Natalie Stoljar claim that this viewpoint assumes that personal autonomy is fundamentally individualistic and rational, a conviction that they challenge (102). The anthology edited by them, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self (2000)*, is a collection of essays exploring the social and relational dimensions of personal autonomy (103). With this collection, the editors offer an alternative account, what they call 'relational autonomy' (102), rather than rejecting the concept of autonomy altogether. The contributors draw on feminist critiques of autonomy to reconceptualize and refigure the concept of individual autonomy from a feminist perspective. Mackenzie and Stoljar consider relational autonomy to be an umbrella term, including a range of related perspectives rather than being a single, unified conception of autonomy (102). They build on and enrich contemporary debates about agency, identity, and moral responsibility by rethinking central accounts of autonomy in the existing literature. For example, they challenge ruling notions of autonomy: in the liberal political theory, where autonomy is considered an individual right, construed as a negative liberty (non-interference); in rational choice theory, where autonomy is equated with voluntary, rational choice; and in bioethics, where autonomy is often equated with informed consent. In various ways, the authors investigate connections between autonomy and other aspects of the agent which are usually neglected, including self-conception, self-worth, memory, and the imagination.

The notion of relational autonomy has gained increasing influence. Yet, it has been argued that it needs further clarification to be adequately operationalized for clinical practice. Gómez-Vìrseda and colleagues (104) examined the meaning, foundations, and uses of relational autonomy in the specific literature of end-of-life care ethics. They concluded that relational autonomy tends to be more a reaction against an individualistic interpretation of autonomy rather than be a positive concept itself; that it is a rich and complex concept; and, that there is a need for dialogical developments in decision making in end-of-life situations. As a response to the shortcomings in the mainstream interpretation of autonomy when applied to the lived reality of end-of-life practices, the authors proposed a specific procedure to implement relational autonomy, which incorporates multidimensional, socially embedded scalar, and temporally extended aspects of relational theories of autonomy (105).

3.6 Existential experience in advanced cancer

For centuries, philosophers, theologians, and others have tried to unpack the complex nature of the human condition, some in a religious framework, others in a secular one. In their extensive literature review, Boston and colleagues (106) list some of the most influential philosophers associated with the movement of existentialism, who have contributed significantly to our understanding of existential suffering, such as Søren Kierkegaard (107), Victor Frankl (108), Jean Paul Sartre (109), Martin Heidegger (110), and Irving Yalom (11).

What the authors find most significant is the absence of any fixed definition within their teachings. In the Nordic context, the following scholars have had great influence: Søren Kierkegaard, the Danish philosopher and theologian who paved the way for existentialism (107); Knud Ejler Løgstrup, the Danish theologian and ethics professor who had great impact with his book *The Ethical Demand* (9); Peter Wessel Zapffe, a Norwegian philosopher who claimed that human life is tragic as meaning and justice does not exist (111); Bjørn Holgernes, a Norwegian philosopher who has interpreted the work of Sartre (112), Tillich (113), Kierkegaard and Yalom (114) for the Norwegian audience; Kari Martinsen, a Norwegian care philosopher who has built on Løgstrup's work, applying it to the field of nursing (10); Katie Eriksson, a Finnish nurse and philosopher whose authorship and teaching has focused on the suffering human being (115).

The complexity and indefinite nature of existential suffering is also evident in the wide range of definitions used in the research literature. In the review by Boston et al., they found 56 different definitions used in palliative care settings, none of which were stringent or rigorous (106). However, the authors identified various expressions associated with existential suffering; for example, fear of death, fear of the future, physical decline, loss of self, loss of autonomy, loss of dignity, loss of relations, loss of social roles, dependency, lack of power, lack of trust and lack of/search for hope, meaning and purpose in life. Existential aspects of being are physical, social, psychological, and spiritual (12). For analytical reasons, it was helpful to sort the expressions identified in the Boston review (106) into these four domains, see table 'Definitions of existential suffering' (Appendix 1).

There are examples of scholars who have created systems for applying some of the insights from existentialists into the clinical realm. For example, expanding on the work by Yalom (11), Kissane created a typology of existential distress to help clinicians to recognize and address human suffering related to severe illness (64). He summarized the major forms of existential challenge to include death anxiety, loss and change, freedom of choice, dignity of the self, fundamental aloneness, altered quality of relationships, search for meaning, and the mystery of what seems unknowable (64). Kissane also described common symptoms related to each challenge and what would be an adaptive versus maladaptive patient response (64)(p. 1502), in addition to proposing appropriate actions from the doctor. Others have emphasized more optimistic aspects of existential experience when seriously ill, such as an increased sense of meaning and purpose, quality of life and existential health improvement (68), including the possibility of 'existential maturity' (116).

While we worked with the first article studying patients' expressions of existential concerns, Elise C. Tarbi and Salimah H. Meghani published a comprehensive concept analysis to explore and clarify the full spectrum of existential experience in adults with advanced cancer, as a response to the conceptual ambiguity in the literature 'leading to neglect in the clinical realm' (117) (p. 540). They describe the existential experience as a dialectic movement between existential suffering and existential health, with the capacity for personal growth (117). When confronted with their own mortality, patients need to consolidate their existence in relation to body, time, others, and death. Coping strategies may assist individuals in facing existential challenges and moving toward existential health. Tarbi and Meghani developed the following figure (Figure 1) illustrating this dynamic movement.

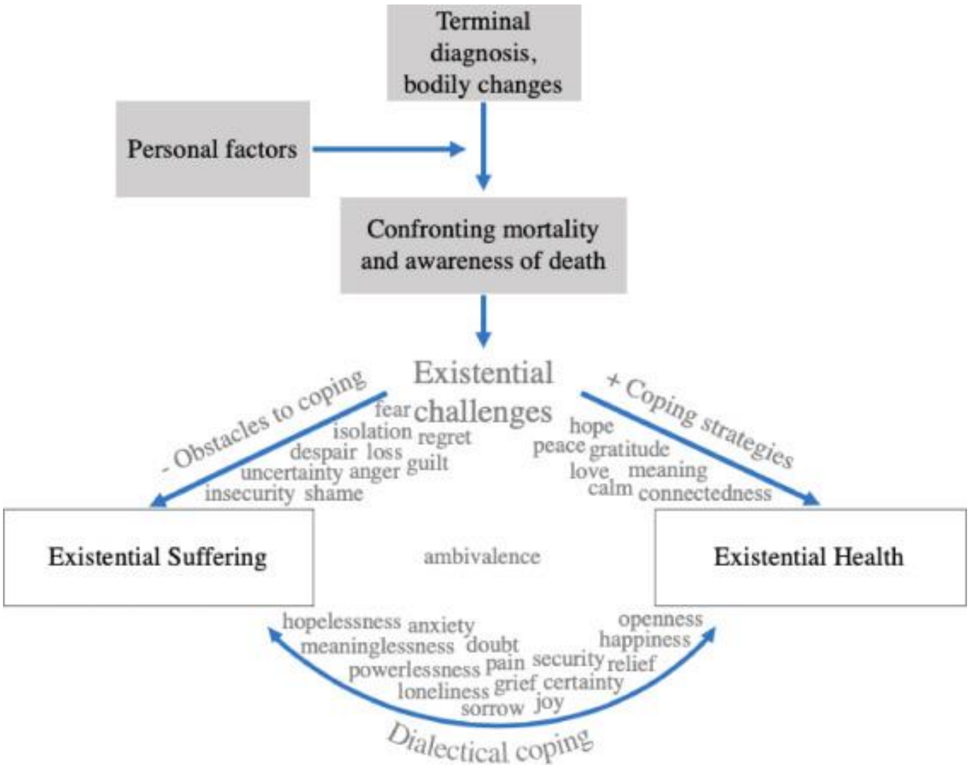

Figure 1: Model of existential experience in advanced cancer is reprinted from *Nursing outlook*, Vol. 67 (5), Tarbi, Elise C. and Meghani, Salimah H., A concept analysis of the existential experience of adults with advanced cancer, pp. 540-557, Copyright (2019), with permission from Elsevier.

4 Aims and research questions

4.1 Aims

The overall aim of this thesis is to explore how the concept of patient autonomy can (best) be understood in the case of advanced cancer through studying clinical communication in routine oncology visits.

The specific aims for each article were as follows:

Article 1: to explore what existential concerns patients with advanced cancer disclose during routine hospital visits, and how they communicate these concerns.

Article 2: to explore how physicians respond to advanced cancer patients' existential concerns during routine oncology visits.

Article 3: to explore how next-of-kin contribute to the information exchange during routine hospital visits involving patients with advanced cancer.

4.2 Research questions

The following research questions guided the studies in this thesis.

1) What existential concerns did advanced cancer patients disclose in the consultation with the physician? (Article 1)
2) How did patients convey such existential concerns? (Article 1)
3) What interactional functions did the physicians' responses (to patients' existential concerns) serve in the dialogue? (Article 2)
4) What topics (content) did the physicians' responses pursue? (Article 2)
5) Who initiated next-of-kin talk in the consultation? (Article 3)
6) How did next-of-kin contribute to the information exchange between the doctor and patient? (Article 3)
7) What information did next-of-kin bring into the discussion? (Article 3)

5 Research design and methods

In this section, I will first present the overall methodological strategies that the three articles share, including reasons for choosing the selected research design and methods. Then, I will explain some of the specific assessments we made for each sub-study. In Chapter 8, I further discuss the methodological approaches, including limitations and quality assessments.

5.1 Empirical study

This study is placed at the intersection between several disciplines: oncology, palliative care, clinical communication, and clinical ethics. These domains are all practice oriented and lean heavily on empirical evidence, which is based on observation or experience rather than theory or pure logic (118). Empirical studies thus generate knowledge through systematic investigations of real-world phenomena and practices, like the present study which is based on observations of communication practices within oncology. Coming from the practice field myself, doing an empirical study involving patients in a vulnerable situation due to severe illness felt like the natural choice. It was also strategic: while I was curious about how patient autonomy plays out in these real-world situations, I was particularly interested in how that harmonizes with the ideals promoted in theories, research literature, laws, and guidelines.

5.2 Qualitative research design

The study employs an inductive approach, moving from the specific to the general, that is, starting with and from the data, generating categories and themes through the analysis rather than using pre-defined categories and theories (119), whilst also applying relevant concepts from the literature when appropriate. When numbers are presented, these are supplementary to provide an overview of the material. The study thus has an explorative research design based on qualitative analyses of the material, as qualitative research methods provide strategies for 'exploring experiences, practices, and phenomena in sociocultural worlds' (120) (p. 322). Therefore, it was the appropriate approach for aiming to understand communication processes in routine oncology visits. Also, an explorative approach allowed for an in-depth investigation of phenomena that were previously poorly described. The literature points to the need for more sufficient descriptions of communication processes. For example, 'qualitative studies on the actual processes of how existential suffering is communicated and managed within the patient and caregiver encounter' have been called upon (106) (p. 609), as well as studies exploring the role and contribution of next-of-kin (76).

5.3 Changes in the project

During the project, based on what we saw in the data material, we made two major changes to the original plan. The first change was a shift in focus from autonomy as freedom of choice to other aspects of autonomy. The second change was, instead of using three different datasets and methods (analysis of videos, interviews, and written information), we decided to do more in-depth analyses of the videos and base all three articles on those. The flexible nature of the qualitative research design made it possible to adjust when the data opened opportunities we had not foreseen. In the next section, I will describe these processes more thoroughly, including the reasons for these adjustments.

5.3.1 From freedom of choice (voluntariness) to other aspects of autonomy

There were two main reasons for the shift in focus from exploring autonomy as freedom of choice (operationalized in the concept of shared decision-making) to other aspects of autonomy. Firstly, although treatment choices were sometimes part of the consultation, discussions around these were not at the fore in most of these visits. Secondly, the absence of talk about how severe illness affected the patient, the family, and their needs, given the severe situation these patients found themselves in, was striking. This absence piqued our curiosity as to whether the patient and the next-of-kin made any attempts to address such issues, and how the physicians responded. This shift in focus was thus not due to reducing the importance of freedom of choice, rather, it was an upgrading of other aspects of autonomy, including agency and the importance of support from others.

Hence, we concluded that we, in these videos, had scarce material to work with to contribute meaningfully to the field of shared decision-making, to which others have contributed extensively. However, we saw a unique opportunity to explore aspects of autonomy that have been largely neglected.

5.3.2 From mixed-method to video-based study only

The two main reasons for the shift from analyzing three different data sources to only analyzing videos were as follows. First, a benefit of using video-based observation is that it provides rich data. Qualitative analysis also has the potential for extracting rich data and provides flexibility. Thus, when we realized the richness of the data, we wanted to exploit that opportunity. Second, analyzing what the patients conveyed during the encounter made us curious about the contribution of the other two interlocutors: the responses from physicians to patients' existential concerns and the role of next-of-kin. An additional, practical reason was that we were in the middle of the Covid-19 pandemic, which made it difficult to meet in person and so to conduct the intended interviews. Technically, it would have been possible to do interviews digitally, as most people quickly adapted to the newfound need for virtual meeting. However, for the group of patients we had planned to interview, patients with incurable pancreatic cancer, we were reluctant to do so because of their vulnerable situation. Moreover, we would touch on personal, sensitive topics and the reactions of the interviewees may be more difficult to notice through digital communication.

5.4 Video-based observation

We employed video-based observation because the material was available from a former project that had video-recorded numerous medical encounters (see section 5.5 Study setting). Such videos provide a durable, verifiable record of the encounter, making it possible to investigate phenomena that would otherwise be difficult to notice or reflect upon (121-123). Having access to existing videos provided a unique opportunity to scrutinize the interactions in detail, in their natural context. We could watch the videos repeatedly, go back and forth, and develop insights as the analytic work progressed. Further, several research team members could, and did, watch the same videos. For me, who had no previous experience in doing video-based analysis, it was extremely valuable to be able to discuss the selected phenomena with more experienced researchers based on observations of the same material. Additional benefits of using video over audio are that it captures both audible and visual communication behaviors (e.g., facial expressions, body postures and gestures) and that it provides a view of the physical environment (93). This view gave us researchers an important contextual understanding of the interaction, giving us greater comprehension than if we had used only audio. Significantly, the fact that video captures more detail about the participants introduces some additional concerns regarding ethical considerations and data protection, so one should only use it when necessary to answer the study aim (93). For this study, the visual information was crucial in the interpretation of the meaning-making. A final point is that, unlike participant observation, we as researchers have not directly influenced the participants or disrupted the interaction, although we cannot rule out that they may have been influenced by being aware that they were recorded.

5.5 Study setting

The study was conducted at Akershus University Hospital, a large hospital in the capital area of Norway, serving a population of around 500,000. In a previous project studying patient-physician-communication, 497 authentic medical encounters were videotaped during 2007-08 (124), thus capturing real-life practices. For the original project, participants were recruited widely, the physicians belonged to various departments, had different background and specialties, and varying experience. Other health professions were not included. The patients were adults (>18 years) with various diagnoses and had to be competent to consent to be included. Next-of-kin were present in some of the encounters but were not the focus of investigation; as a result, they were sometimes outside or only partially inside the scope of the camera lens. That is, we could only partly see gestures and facial expressions, but the sound was equally good as for the patients. The video recordings were from both inpatient and outpatient encounters. The physicians involved participated in a communication training program, and the videos were collected either before or after training. Moreover, they were naturally aware that they were recorded during the encounters, implying that they may have been particularly mindful about their own communication style and behaviors. We did not know whether the physicians had attended the training yet at the time the video recording was made. However, we considered this to be of little relevance, as our objective was not to evaluate the effectiveness of this training program.

5.6 Selection of videos

In the present study, we examined a sub-set of all recordings involving cancer outpatients, which was 33 videos. One of my co-supervisors (PG) was the principal investigator for the original project and could point out the videos in which cancer patients were involved. We were most interested in outpatient visits because these are brief and may be the only contact between the patient and the healthcare system until the next consultation, which could be in weeks or even months. Meanwhile, the patient continues living at home with the challenges that may arise. In this context, it is particularly important that the patient's needs are identified and addressed during this brief encounter.

Together with my main supervisor (RF) I inspected all 33 videos involving outpatient cancer patients. We discussed which ones to include based on the inclusion criteria, that is, videos involving cancer patients with a poor or uncertain prognosis, meaning that they either had an incurable diagnosis or were experiencing a cancer relapse. The reasoning for this selection was that patient autonomy may be particularly challenged in the event of severe illness due to the inherent vulnerability of the situation. Recordings including patients in a phase of remission or long-term disease control were thus excluded. Thirteen videos met the inclusion criteria.

The assessment of the patients' prognostic situation was partly based on information that emerged in the consultation and partly on data that had been collected in connection with the original project. It was rarely expressed explicitly in the consultation. During this process, it was advantageous that I am an experienced cancer nurse and that my main supervisor, who participated in the selection process, has a background as a practicing medical doctor. When needed, we checked the relevant national guidelines, for example, the action program for colon cancer (125), for additional information on the specific cancer types to guide the assessment. One example could be specific treatments that are used in a palliative setting.

5.7 Transcripts

Although studying the videos was the primary access to the data, I realized that I needed to transcribe them as well. There were two main reasons for this. Due to privacy considerations, we were only able to watch the videos at the communication lab where the videos were stored on a secure server. Although the access to this lab was good, it was not unlimited, so the transcriptions allowed me to analyze the data outside of access times. Further, due to the ethical commitments that had been given to the participants in the consent letter, the videos were to be deleted by a certain date (31.12.21), and I would need to refer to the data after that date. Also, when I spoke with experienced scholars at an annual workshop for clinical communication researchers, OCHER (Oslo Communication in Healthcare Education and Research group), the unanimous advice was to transcribe the data. Although some of the videos were already transcribed, I did all the transcribing myself so that I had control over the structure and level of detail etc. This decision gave me a unique opportunity to familiarize myself with the data. In addition, I could switch between the videos and the transcripts, make notes related to specific events, and discuss with other research team members when we could not meet in the lab.

In an early phase of my Ph.D. period, before I had concluded which method to use for the analysis, I joined an inspiring five-day course on conversation analysis (CA), an established tradition for doing inductive analysis of human interaction (126, 127). Conversations with a communication researcher and linguist, Anne Marie Landmark, had made me curious and enthusiastic about the method. However, I concluded that for this project I did not need the level of detail that CA provides. Further, I realized that to become an expert in CA would require being in a research group and years of practice. I also wanted to make use of the visual data, for which I found the method microanalysis (accounted for later) to be even more appropriate. However, during the CA course, I learned the Jeffersonian system for transcribing vocal conduct in talk-in-interaction (128), which I found to be useful. I decided to employ a simplified form of this system to be able to note not only the words spoken, but also how they were presented, including gaps, pauses, intonation, pitch, speed, breath, laughter, loudness and overlap between speakers, when this was useful for the research questions. The Jeffersonian system is designed to capture these various features that are fundamental to how interlocutors produce specific actions and respond to the actions of others (128). Hence, I transcribed the whole interaction except during the physical medical examination. I noted features of speech, facial expressions, and bodily conduct when these provided additional information relevant for meaning making related to the research questions. The transcripts were thus supporting the analysis.

5.8 The use of Excel for transcripts and analysis

I used Microsoft Excel for transcription and analysis. Excel is a digital spreadsheet program, designed to create tables, calculate, and analyze data. It is most often used for numerical data, for example for accounting, but can be used for organizing other data types. It is practical due to its flexibility. I created a master file where I noted all the data, transcribing each video on a separate spreadsheet within that file. In one column, I noted the spoken words, one turn-of-speech or meaning unit per row. I assigned each speaker separate letter colors, so it was easy to distinguish between them (patient=blue; physician=black; next-of-kin=green), which was useful when navigating large data sets. The shortest consultation had 166 rows (meaning units), whereas the longest had 1788 rows (in total=7291; mean=560). Then I created columns for noting row number; time (minutes); speaker; bodily conduct and facial expressions (e.g., posture, gestures, gaze); annotations (my impressions/reflections); content (topic, sub-category, category, domain); interactional function (e.g., seek info/ provide info); speech delivery (e.g., explicit/implicit); emotions; prompted/not.

When I had selected the utterances for detailed investigation, like patient existential utterances, I copied them and collected them in a separate joint spreadsheet. I included the dialogue prior to and after each utterance to retain the context. Then, I hid the adjacent rows to retain visual overview, but I could easily unhide them when needed. Also, I could effortlessly move back and forth between the joint sheet where the data was merged and the sheets from each individual video. As the analysis progressed, I could cut and paste rows to collect utterances related to each derived category.

5.9 Microanalysis of clinical interaction

Elisabeth H. Golembiewski et al (93) have shown that researchers use a range of different approaches when doing video-based analyses, both within quantitative and qualitative study design. Using an existing quantitative coding scheme, for example Roter Interaction Analysis System (RIAS) (129), the Verona Coding system (130), or the OPTION scale (Observing Patient Involvement in Decision Making) (131) may be beneficial in several ways, such as when comparing or evaluating practices. However, for this project we had decided that a qualitative approach was most fruitful and wanted to employ a method that allowed to work inductively with the data. Microanalysis of Clinical Interaction (MCI) is an inductive, systematic, comprehensive, and flexible method for generating knowledge about different aspects of patient-provider communication (132). MCI is based on microanalysis of face-to-face dialogue (133), adapted to the clinical setting, with interdisciplinary collaboration expected among interaction analysts, practitioners, and medical educators (134). We used this approach for all three studies, although, in the first two articles we refer to the method as microanalysis of face-to-face dialogue, as the MCI-method was not yet formalized. The historical roots of MCI stem from early video-based communication studies in the fifties and sixties and subsequent studies that have contributed to the constant development of the field driven forward by influential pioneers and research groups (132).

MCI is based on the following theoretical foundations and assumptions, that dialogue:

- is context-bound and thus must be interpreted in its context;
- is multi-modal, that is, a complex combination of words, movements or use of space;
- is collaborative and reciprocal;
- is learned, not inborn, and therefore different for each culture;
- consists of words, gestures, and prosody, which are integrated (coordinated and mutually influential) and thus must be studied together, not separately;
- is patterned and therefore analyzable.

Doing MCI is an iterative, not linear, process for recognizing and describing phenomena of interest within clinical dialogue, and it involves ‘a myriad of analytical micro-decisions’ (132) (p.23). This process includes deciding what would be the phenomenon of interest, recognizing when it happens in the material, building an operational definition, and deciding whether entry points in the material could point to where the phenomena would be likely to happen. Then, identifying the phenomenon in specific behaviors, collecting exemplars (obvious ones, contrasting ones, grey area ones that might not be recognizable at first glance), discerning inclusion and exclusion criteria, and characterizing the specific behaviors based on qualitative, descriptive features that show its variation in the material (e.g., based on content, function, formulation, timing). Decisions on what are the most interesting and useful characteristics should be guided by the overall rationale for the project. MCI allows for quantifying the phenomenon, for example, one can generate results for how frequent a phenomenon occurs, for instance how many patient utterances conveyed existential content, based on the operational definition. In line with MCI-methodology, we aimed for an exhaustive collection. We were selective in the sense that we did not study all phenomena but remained comprehensive in that we collected all the instances of the selected phenomenon.

5.10 Specific analytic choices for each sub-study

5.10.1 Article 1

In the initial, exploratory stage, my main supervisor (RF) and I watched the 13 videos repeatedly to discern what could be the phenomena of interest: how might aspects of patient autonomy emerge in this material? We individually noted our first impressions, and when discussing our observations afterwards, we agreed that treatment decision-making was rarely the central focus in the consultations. What piqued our interest was the apparent absence of talk about existential issues, given the patients’ situation. This directed our focus to search for patients’ attempts to address existential aspects with the physician.

How to recognize an utterance that conveyed existential issues was not obvious from the outset. In an early phase of building an operational definition to help us identify such expressions, I created a mind map (Appendix 2) of my initial thoughts of how advanced cancer can pose an existential threat to different aspects of life, using my own lived experiences and what we had observed so far in the material. I then followed an iterative process between the ongoing data analysis, the literature (See 3.6 Existential experience in advanced cancer), and discussions within the research team, to build and refine the operational definition, which ultimately looked like this:

> *An utterance containing information about the illness/treatment being a threat to the person's physical, psychological, social, or spiritual being, that is; loss or threat of loss of something/someone significant to the person OR expressions of illness related concerns, fears, or uncertainty OR information about the person's hopes, dreams, goals, or search for meaning.*

Before developing the operational definition, we had already applied Healing's definition for identifying patient centered utterances (See Codebook 1, Appendix 3, p. 6). We decided that this was the natural entry point for further analysis, as we expected to find existential utterances within those defined as patient centered. We used the operational definition actively to identify existential utterances and to collect exemplars. During this process, we were able to develop the following inclusion criteria, of which all three had to be met to be included in the final sample:

a) Content criterion: according to definition, AND
b) Significance criterion (heaviness): considered significant to the person, AND
c) Relevance criterion: related to the illness experience (including treatment).

The significance criterion was vital because not all losses or threats of loss are significant. However, it was also the most difficult to assess, so we developed separate rules for that, described in Codebook 1. When we had selected all existential utterances, we described them and grouped them according to the interactional function they served, how they were delivered, and what the utterance related to (content). Codebook 1 (Appendix 3) describes the analytic process and choices made in more detail.

5.10.2 Article 2

Working with the patients' existential utterances made us curious about how the physicians responded to those utterances. Building the operational definition was less complicated this time, and the entry point for analysis was more self-evident, as the utterances identified in Article 1 were the obvious sequences to focus on. We discovered that we could not limit the selection to the physician's first utterance following an existential utterance from the patient, as we might miss later responses relating to it. Hence, the final definition was as follows:

Physicians' response to patients' existential concerns, i.e., the immediate utterance(s) reacting and orienting to the patient's existential utterance.

When we had selected all physician-responses, we described them according to their interactional function and content. For content, we applied Healing's definitions again to sort the responses into rough, initial categories, differentiating between those that included patient-centered versus biomedical information. Then, we studied the responses in more detail to decide what topics the physicians chose to pursue and which they did not. Codebook 2 (Appendix 4) provides a more detailed description of the analytic process and choices.

5.10.3 Article 3

At the outset of this project, the role of next-of-kin was not my focus. We observed that next-of-kin did not typically speak much, so we became interested in what they focused on in their contributions, and its effect on the interaction. Hence, the phenomenon of interest was all instances where next-of-kin spoke. However, for detailed analysis we were not interested in small talk or minimal responses (such as nodding or saying m-hm in response to the primary participants' utterances), so the operational definition we built to guide the selection of next-of-kin utterances, was as follows:

Next-of-kin utterances carrying substantive content relevant to the illness/treatment experience.

This selection process was not complicated, so we did not need specific criteria for deciding which utterances to include. For this analysis, we were also interested in who initiated next-of-kin talk, to see if they were actively invited to speak. Then, we described each utterance according to its function and substantive content, including whether the utterance was contributing something new. Again, we found that Healing's definitions (135) were useful for distinguishing between biomedical and patient-centered utterances in addition to deriving more specific content categories. Finally, we combined the interactional function and content generating categories based on what themes and issues next of kin raised, and how.

5.11 Research team

The interdisciplinary research team, which has been involved in the entire project, includes two physicians and two psychologists in addition to the Ph.D. candidate (me) previously being a cancer nurse. Together, we cover different specialties: oncology, palliative care, clinical ethics, interaction analysis, and communication training for health professionals. All team members, except myself, have previous experience in doing video-based qualitative research, one being an expert on the specific method of microanalysis in clinical communication research. Hence, the research team is well equipped to ensure methodological robustness as well as breadth of expertise and perspectives, which has been an asset at all stages of the research process.

5.12 Ethical and privacy considerations

The original project (124) in which the videos were recorded was approved by The Regional Committee for Medical Research Ethics (REC) of South-East Norway (1.2007.356), and the privacy measures were accepted by the Privacy Ombudsman for Research in Norwegian universities (NSD approval 16423/2007) (124). Since 2011, REC has considered studies of these recordings as being outside the Health Research Act and thus beyond the scope of their mandate. In connection with the original project, participants in all videos provided broad consent for use of the videos in further communication studies. As we had planned to do interviews as well, we submitted the whole project to REC of South-East of Norway and received ethical approval (project number 2018/474 D) (Appendix 5).

We followed the requirements for handling data and personal information from the Norwegian Agency for Shared Services in Education and Research (SIKT), formerly known as Norwegian Social Science Data Services (NSD). The video recordings were stored in a secure server at the hospital where the recordings were conducted, and all observations were carried out at this site. Transcripts are encrypted by password, free from personal information that could identify any of the participants, and accessible to the research team only. Patients were given pseudonyms and all physicians are referred to as ‘she’ to protect their identity.

Using visual data has ethical implications due to its unique privacy and confidentiality concerns, giving researchers a responsibility to ’carefully weigh the intended benefits and uses of video recordings against the risks to patients and clinicians’ (93) (p. 57). Voluntariness is mandatory, as in all research (25). Consent practices within communication studies using audio-visual recordings commonly focus on the patient (136), however, clinicians may be more worried about being video recorded than patients (137). Exposing their professional practices (involving complex tasks) to others' scrutinizing gaze puts them in a vulnerable position (136, 138). We were therefore very careful about not describing differences in the physicians' personalities and communication styles, although that may be relevant as they can bring out different things in the patient.

5.13 User involvement

As part of the process of trying to keep the project rooted in what is relevant to the research subjects, I met with different persons and groups. They all gave valuable input to the project and the interpretation of data.

The Health Services Research Unit at Akershus University Hospital has a user panel including representatives from patients and next of kin, health personnel, and patient organizations. I visited the user panel twice (2018 and 2019) to present the project and get input on the project overall, including the project aim, patient selection, methodological and ethical issues, as well as more specific questions relating to the definition of existential challenge and the relation between existential aspects of severe illness and autonomy.

I also contacted the Board of Pancreas Cancer Network in Norway. I had several meetings with the head of the board, Caroline Verbeke, met with the board once, and attended seminars organized by the network. The main message I retrieved from the board meeting was the importance of next-of-kin, especially in the case of severe illness. Unfortunately, illness and pandemic restrictions led to the cancellation of further meetings.

My main supervisor and I also had a digital meeting with Thomas Hylland Eriksen, a scholar in the field of social anthropology, who gave talks about what mattered to him as a patient based on his personal experience from living with pancreatic cancer. We were especially interested in his perspectives on patient autonomy in that setting. His unique combination of personal experience and professional background made his reflections very valuable as he put his own and fellow patients' situations into a wider context.

6 Main results and summary of papers

In this chapter I present a summary of the results from the three papers included in this thesis. The investigated consultations involved three participants: the patient, the physician, and the next-of-kin, each with a different set of roles and contributions.

6.1 Participants

The patients included in this study (n=13) had various cancer diagnoses, including kidney cancer, prostate cancer, colon cancer, myelomatosis, lung cancer, pancreatic cancer, and head and neck cancer. What they had in common was that their prognosis was poor or uncertain, due to relapse, lack of disease control, or failing treatment effect. All patients had undergone extensive treatment with surgery, radiation, or chemotherapy, or a combination of those. The average age was 62 years, which means that they were relatively young considering that most patients will get cancer after the age of 65. The range spanned from early twenties to more than eighty years, but most were in their sixties or seventies. More details about the patients are in Article 1 (Table 4 in the article).

The physicians (n=5) belonged to five different departments with various specialties, three males and two females.

Next-of-kin accompanying the patients (n=10) were all family members, two male and eight female: six spouses, one mother, and one daughter-in-law. The latter was the only one not living with the patient.

6.2 Article 1

The first article focuses on the patient. In this sub-study we aimed to explore what kind of existential concerns patients with advanced cancer disclose during a routine hospital visit, and how they communicate such concerns. We identified a total of 1967 patient utterances in the 13 video-recorded consultations, 658 of those were patient centered, that is, concerns, questions, or statements relating to how the illness affected their life. Within the group of patient-centered utterances, 127 were coded existential. We found existential utterances in nearly all encounters, however, the amount per consultation varied greatly (0-40). Categories derived from the data are italicised in this section

6.2.1 Existential concerns disclosed by patients

Patients disclosed how the illness and its consequences posed a threat to all dimensions of their being, as they experienced various losses and threats of loss of something significant to them. Above all, the illness posed a *threat to life* itself, as patients disclosed concerns about disease progression, tumor growth and spread of the cancer. Additionally, the cancer posed a *threat to a good life* as patients conveyed concerns related to current or future symptoms, side-effects, and function loss. Some patients disclosed that the illness entailed a *loss of self*, as bodily changes prevented them from being the person they used to be. Across the encounters, patients revealed that the cancer experience included *loss of autonomy, independence,* and *control*. Also, it affected their confidence in their own coping and decision-making capacity. The illness also constituted a *threat to personal relations* and *social roles.* All patients faced the possible prospect of separation from their loved ones without this being explicitly addressed, however, some patients expressed concern for their closest ones. Some experienced changes in close relations due to their increased need for help and support. One patient expressed worry about losing the opportunity to work. The patients' awareness of their *dependency in the patient-physician relation* sometimes became apparent. They demonstrated confidence in the current physician, but some expressed a *lack of trust* in other health professionals. Patients rarely explicitly conveyed their hopes, dreams, goals, or their search for meaning. Their expressions of hope were closely related to available treatment options, that is, disease control, and/or symptom control. No patient conveyed religious beliefs or convictions.

6.2.2 How patients disclosed existential concerns

Patients usually disclosed existential concerns *uninvited, yet hesitantly*, observable through features of speech and body gestures (including facial expressions) displaying discomfort. Indicators of discomfort were taking a breath or clearing the throat before speaking, stuttering, speaking rapidly, pausing within own turn of speech, sitting uneasily, frowning, or gazing away. Sometimes, the patients displayed existential concerns with increasing clarity: they used subtle or indirect questions at first, and then gradually became clearer and more specific when encouraged to elaborate (which was unusual).

Existential utterances were most often *subtle and indirect*. For example, no patient explicitly stated fear of death or dying, instead they chose other wordings, like expressing concern about not getting well or sadness when there was no curative treatment available. We found that patients commonly disclosed their existential concerns *wrapped up in biomedical terms*, and often through what information they requested from the physician. Concerns about disease progression and how it would affect the patient's life were typically embedded in questions about test results, tumor growth, or available treatment options.

Although there were a few exceptions, the patients were *displaying little emotions*. Rather, they commonly downgraded their emotional distress, for example through understatements, even when it was clear that the patient was suffering greatly. Another phenomenon observed in some of the encounters was the occurrence of laughter when talking about serious topics.

6.3 Article 2

In this sub-study, we aimed to explore how physicians respond to patients' uttered existential concerns during routine oncology visits. We identified 185 immediate physician-responses to the 127 patient existential utterances previously identified (Article 1). The responses demonstrated three approaches: giving the patient control over the content, providing support, and taking control over the content. The latter was by far the most common, through which the physicians habitually kept the discussion around biomedical aspects.

6.3.1 Giving the patient control over the content

Generic responses (e.g., "yeah", "mhm", often accompanied with nodding) demonstrated that the physician was paying attention to what the patient said. Such responses accounted for almost one-third of the immediate responses following an existential utterance and provided space for the patient to continue uninterrupted and, thus, an opportunity to control the agenda.

6.3.2 Providing support

Supporting responses were few, as they accounted for just over one-eighth of physician-responses and occurred in less than half of the consultations during which existential concerns were uttered. Like generic responses, these were not directing the content of the subsequent dialogue. We identified three types of supporting responses. One was *acknowledging the patient's emotion, concern, or experience.* Another was *acknowledging the patient's coping strategies or personal resources*. The third type was *giving advice* for how the patient could cope, which was rare.

6.3.3 Taking control over the content – steering the agenda towards biomedical topics

More than half of the physician-responses served to direct the content of the subsequent dialogue, steering the agenda more actively. We identified three types of such responses, based on their interactive function: educating, exploring, and reformulating. For each of these functions, we present how they were distributed between biomedical and patient-centered content.

Educating was the most common physician-response that functioned to control the content and was the most frequent response to patients' existential concerns overall. Educating responses refer to the physician providing new information aiming to increase the patient's knowledge about a topic. Most educating responses provided biomedical information explaining medical facts related to their disease, tests, or medical treatment. Few educating responses were patient-centered, that is, information about the illness' implications for the individual patient's life, for example the expected course of illness or future follow-up.

Few responses were *exploring*, responses where the physician explicitly invited the patient to elaborate on something. When asking the patient to elaborate, the physicians tended to ask the patient about biomedical aspects rather than patient-centered aspects. None of the exploring responses invited the patient to elaborate on existential concerns.

Reformulating responses were utterances paraphrasing something the patient had said, revealing how the physician had interpreted the meaning of the preceding patient utterance and what content the physician emphasized. Such responses were uncommon; however, they remain significant as they served to direct the subsequent dialogue in more subtle ways. Reformulations were rarely direct repetitions using the exact same wording. Although most reformulating responses were patient-centered, the physicians redirected the dialogue away from the existential concern by omitting or adding information, or slightly altering what the patient had said. For example, when a patient expressed "fear" related to the need for additional therapy, the physician transformed it into an issue of "energy" and "tiredness", thus, keeping the discussion focused on physical aspects and biomedical content.

6.4 Article 3

In this sub-study, we aimed to explore how next-of-kin contribute to the information exchange during the consultation. Next-of-kin participation varied greatly, most were largely reticent and rarely spoke, while a few were more active. In total, we included 217 next-of-kin utterances (3-81).

6.4.1 Who initiated next-of-kin talk?

When companions spoke, it was rarely following an explicit invitation from the physician or the patient. More typically, they entered the discussion unsolicited, usually with brief comments and questions. Occasionally, the patient included the companion with an implicit invitation whereupon the companion contributed, typically by providing information. The physicians, however, rarely approached the next-of-kin as a source of information. Rather, they primarily related to them as a supporter on the sideline and did not address the couple as a team.

6.4.2 How did next-of-kin contribute to the information exchange?

We identified two main types of next-of-kin contribution, featured by various clusters of communication behavior. The most frequent type was *bringing information into the discussion*, and the second was *monitoring and supporting the information process.*

Next-of-kin brought information into the discussion either directly by providing information or indirectly by requesting information, usually from the physician. Surprisingly, they provided information far more often than they requested it. Next-of-kin sometimes complemented the patient by filling in some informative gaps. Other times they amplified what the patient had said or provided context on the patient's life situation. When requesting information, they usually posed questions. However, at times they elicited information more indirectly by displaying a state of not-knowing. About as often as they requested new information, next-of-kin asked clarifying questions (e.g., asking the physician to specify or explain something).

The second type of contribution related to the information process, to which companions contributed by assisting the process of information exchange and by interpreting information. For example, companions encouraged the patient to provide or request information (prompting) or they pre-empted or fixed difficulties in the information exchange (repairing). Also, next-of-kin contributed to the processing and interpretation of information by commenting and/or reflecting on the meaning of the shared information.

6.4.3 What information did next-of-kin bring into the discussion?

We arranged the information provided by next-of-kin into five categories: *medical and procedural information*; *bodily ailments; concerns and emotional aspects*; *patient context, values, and resources;* and *follow-up and patient-provider relation.* Next-of-kin often assisted the patient by filling in specific details related to the illness, examinations, or treatment. Hence, they contributed to a more accurate overview of the medical history and practicalities related to the administration of health care. Next-of-kin also reported on disease burden and treatment tolerability, especially the physical ailments caused by symptoms, side effects and function loss. However, they displayed very little emotion and rarely reported on their own strains. When disclosing emotional distress or concern, it was often related to disease progression and uncertainty about future. Occasionally, next-of-kin provided contextual information about the patient or family that was relevant to the treatment or illness experience, such as family and work situation, previous healthcare experience, patient values, resources, and personal qualities. Some companions expressed their views on the follow-up in and outside the hospital and on the relationship to health professionals. Through sharing their experiences, they disclosed a need for caregivers whom they can trust, while also revealing the fragile nature of trust.

Information requested by next-of-kin was placed into four categories. Disease related questions were largely about disease progression, whereas treatment related questions were mainly about the treatment plan, expected outcome, and practical issues. More than half of the companions requested information about disease progression, that is, the growth, malignancy and/or spread of the cancer. Companions rarely asked directly about the expected effect of treatment. Most questions about the treatment outcome related to the negative aspects of treatment, including expected side effects. Questions addressing practical issues were often about medical procedures taking place at the hospital and sometimes about treatment related activities that the patient and next-of-kin had to administer at home.

7 Discussion of findings and their implications

7.1 Patient autonomy in advanced cancer

7.1.1 The relation between existential experience and autonomy

The patients in this study disclosed how the illness experience included loss and threats of loss that are strongly associated with existential suffering, including threat to life, heavy symptom burden and function loss, loss of self, loss of capacity, loss of control, loss of independence, threat to personal relations, dependence, and fragile trust in the patient-provider relation. Through these expressions, patients revealed uncertainty about the future and insecurity about self and coping. These are aspects that may be relevant for autonomy, depending on the applied notion of the concept. Several scholars have argued that the existential experience of advanced cancer includes a perception of lost autonomy (64, 106, 117, 139). For example, Kissane (64) claims that our desire for personal liberty, is accompanied with fear of loss of control, dependency, becoming a burden to others, and a fear of loss of dignity as the illness dominates life.

In the literature review by Boston and colleagues (106), expressions associated with existential suffering included components related to autonomy, such as uncertainty, vulnerability, reduced freedom of choice, loss of control, fundamental aloneness, dependence, loss of relations, lack of power, lack of trust, and feeling ungrounded. Others have described existential suffering as a process of 'Longing for Ground in a Ground(less) World' (140) and 'navigating unfamiliar territory between a homeworld and an alienworld' (63)(p. 375), narratives that contrast to the ideals of autonomy. Studies on existential suffering found that physical decline was associated with loss of autonomy due to loss of independence (141, 142). For some patients, the need for someone to assist them in daily activities such as personal hygiene implied a loss of self, testifying that, "I don't recognize myself." (142)(p. 4).

7.1.2 Freedom of choice

One of the two pillars in Beauchamp and Childress' concept of autonomy is voluntariness (95). Freedom of choice, understood as non-interference, was what the rebels demanded in the moral revolution, expressed through slogans like "Nothing about me, without me" (23). This liberty aspect of autonomy also dominates in ethical (3, 4) and professional guidelines (21, 34), policy making (37-40, 143), and healthcare legislation (32).

Although medical decision-making sometimes was part of the consultations in this study, it was rarely the center of attention. When treatment decisions were discussed, none of the patients were subjected to oppression or pressure, however, it can be questioned to what extent they had freedom of choice. One example was Carl who had a large tumor in his kidney that the physician recommended to remove surgically. Carl was skeptical and worried that the operation could reduce his physical capacity. The physician made great effort to convince Carl that the surgery was necessary, otherwise the tumor would spread, and Carl would be in more pain. Another example was Karen who was given the choice between two types of chemotherapy, which were similar in terms of effect but different in terms of side effects, an ideal situation for shared decision-making. Karen and her husband were reluctant to accept the alternative that the physician recommended because a previous physician had informed them that it could cause terrible and irreversible neuropathy (painful nerve injury). A third example was Olav who was told that there was no effective treatment for his metastatic cancer, so no options were available.

It may have been good medical practice to convince Carl and Karen about the best option from a medical point of view. Still, the examples above illustrate that the liberalist ideal of free choice does not always work with the clinical reality of advanced cancer, which is far more complex and encumbered with several hidden premises. For example, when a choice is presented to the patient, a series of medical decisions have already been made, and the options are defined within a narrow framework set by the physician in advance (8).

In the context of advanced cancer not all decisions are well-defined with clear options. Moreover, decision-making does not only include major medical decisions in what Agich calls unusual events (100), such as newly discovered disease or relapse, rather it spans a wide range of choices, including minor routine medical decisions and choices related to every-day life (44, 144). The focus on freedom of choice and decisions that should be shared may have clouded the awareness that there might be situations where free choice is unrealistic or even unwanted. Elwyn and colleagues are strong advocates of shared decision-making, however they warn that it is paramount to acknowledge its limitations to avoid dismissing it as an impossible ideal altogether (51). They argue that the limits of SDM occur when wider interests override individual wishes, evidence of benefit is insufficient or absent, lowered decision-making capacity is present, or profound existential uncertainty exists.

7.1.3 Agency

The second pillar in Beauchamp and Childress' concept of autonomy is agency, which refers to an agent's capacity for autonomous choice, including sufficient understanding (95). None of the patients in this study lacked competency to consent or decision-making capacity in the legal sense (32) (§ 4-3). Also, they received ample and comprehensive medical information and were allowed to share information about their personal life in line with the principles of shared decision-making (7, 98, 99). Thus, they are congruent with the liberalist notion of an autonomous agent.

Still, I will argue that Agich's (100) account of actual autonomy in long-term care for the elderly is relevant in the context of advanced cancer. Admittedly, the two groups differ in several ways, as the patients in this study were all competent, and they did not receive any healthcare services in their everyday lives, unlike many elderly people in long-term care. However, they were dependent on long-term follow-up from the hospital, with the prospect of increased need for healthcare services in the future. Moreover, capacity is not only about intellectual capacity but also includes physical and emotional aspects which may be affected as part of the illness experience (12). An example from this study is John, who had lost a lot of weight and was suffering from heavy symptom burden. When the physician invited him to discuss further treatment, more tumor targeted treatment or symptom-relieving only, he seemed overwhelmed and said that he did not have the energy to even think about that. In the liberal view of autonomy, decision-making is regarded as a rational process, 'emphasizing information exchange and the legal doctrine of informed consent' (100) (p. 10). Shared decision-making presupposes that the patient shares his values and preferences with the physician (98, 99), assuming they are well-defined and explicit, which is not always the case (8), neither in these consultations. Moreover, people do not always make choices by analyzing all the options and comparing them with a given set of values, norms and preferences (144). Nor can one assume that everyone finds freedom of choice to be liberating. A fairly large proportion of cancer patients want to hand over decision-making responsibility to the physician (54, 55, 145), more-so with increasing disease burden (52). Also, patients with advanced cancer want to involve their partners in decisions more often than patients with less severe conditions (72, 76).

7.1.4 (In)dependence

Independence is a central ideal in the liberalist view of autonomy. Agich and others have criticized this notion of autonomy for being abstract, assuming an ideal view of persons, and for ignoring the complex reality for persons in need of long-term care (100, 144, 146). Existential philosophers who have had great influence in the field of healthcare, for example, Løgstrup (9), Martinsen (10) and Eriksson (115), have emphasized that dependence on others is a fundamental condition of human life. This becomes particularly apparent in the case of serious illness or impairment for other reasons, for example, chronic diseases or old age (144, 146, 147).

The patients in this study depended on help and support from their nearest in various ways. For example, Miriam, a young woman living with her parents, was no longer able to help at home as she was now the one needing support in her daily activities, such as cooking and exercising. Frank, who had brain metastases, received help from his wife to keep track of his medication and other practicalities related to the treatment plan. John, who was very weakened, needed much help from his wife, including preparing meals that he was able to digest. The patients were also dependent on the physician, as the doctor had the medical expertise and could provide the healthcare and information that the patients needed. For example, how information is presented can be important for the patients' understanding and opportunity to exercise their autonomy (8), as mentioned earlier (7.1.2 Freedom of choice).

This study showed that existential concerns raised by the patient were hesitant, subtle, or indirect, often hidden in biomedical terms. This may be understood as an expression of perceived lack of power, as a sign of modesty, as not feeling in a position to set the agenda, or insecurity about whether it is acceptable to impose personal issues on the doctor. This interpretation is supported by studies showing that patients often find it hard to speak up due to the power imbalance inherent in the patient-provider relation, which is also considered a barrier to shared decision-making (42).

Given the interdependent nature of human existence, it has been argued that discussions of autonomy should not be restricted to the unrealistic ideals of independence and non-interference (144, 148). Dekkers (144) argues that there is a need to rethink the common notion of autonomy as the opposite of dependence. Building on Agich's notion of actual autonomy as well as Seneca's view of human finiteness, that corporal beings are mortal by nature, Dekkers introduces the concept ‘Socratic autonomy’ (144)(p. 186), stating that an individual who denies his or her mortality is dependent, whereas persons who can acknowledge and give meaning to the limitations of bodily life are independent. These are aspects that clinicians working with severely ill patients should bear in mind when aiming to respect autonomy.

7.1.5 The need for a broader notion of autonomy in advanced cancer

The discussion above illustrates some of the shortcomings of the liberalist view of autonomy, with its unilateral focus on the individual, independence, rationality, and choice, based on premises that can be questioned in advanced cancer. There are numerous factors challenging patient autonomy in the case of advanced cancer, including that the existential experience involves loss and threats of loss. Importantly, this does not make respect for autonomy any less significant, nor does it make the patient's values and wishes irrelevant, rather that it may call for a different approach. Perspectives from Agich (100) and others are valuable when translating the concept of autonomy into the real-world context of advanced cancer, advocating for a broader account rather than dismissing it altogether. Moreover, an increasing amount of scholars that are embracing shared decision-making have acknowledged the need for a broader notion of SDM, compared to the early ideas focusing on information exchange and treatment choice (46). For example, chronic care decisions may need a problem-solving approach rather than weighing pros and cons regarding specific treatment options (149). And, as illness may cause existential problems that may affect a person’s capacity, providing information and exploring preferences may not be sufficient, rather, care should aim for restored autonomous capacity and acknowledge emotional and relational dimensions (12). Moreover, it is equally important to recognize when sharing decisions may not be the appropriate approach (51).

7.2 Restoring patient autonomy - the role of the physician

> *"A wise clinician will listen with eyes […] as well as listening to sounds and words uttered. But there are deeper layers to listening too. As the Chinese symbol for listening portrays, one listens with undivided attention and with one's heart, one's whole being." (Ilora Finlay) (150).*

The patients in this study were met by friendly physicians, and the patient-physician dialogue was a two-way process in that the patients to a large extent were allowed to ask questions and share information, including personal points. However, the physicians habitually kept the discussion focused on biomedical aspects and rarely pursued the patients' existential concerns, resulting in these factors remaining unaddressed, contrary to the recommendations and guidelines (21, 36, 62). Agledahl (151) studied a larger sample from the same body of videotaped encounters (n=101) and found that the doctors' politeness concealed their neglect of patients' existential concerns. The medical encounters in Agledahl's study were a broad and representative selection from non-psychiatric departments, meaning that the patients had various diagnoses and severity. It is worth noting that even in the selected cases of advanced cancer, patients' existential concerns still seem to be overlooked by the physicians'. Agledahl and colleagues (151) discussed how ignoring the patient's existential concerns is a way of disregarding the patient's humanity, which in turn can cause moral harm, even though the physicians are likely unaware how their lack of responsiveness may affect the patient. Moreover, such neglect can be perceived as a rejection and thus increase the feeling of fundamental aloneness following existential suffering (64); it can be a lost opportunity to support the patient in the movement towards existential health (117). If we accept that existential suffering includes loss of autonomy, as discussed in the previous section, then including the existential concerns in a holistic approach may be a way to counteract some of the loss (12). In what follows, I will discuss how physicians can play a role in restoring patient autonomy in advanced cancer and point to factors that may be relevant in this respect.

7.2.1 Someone to trust is someone who cares

Of the patients in this study, six knew the doctor a little, one knew the doctor well, and six did not know the doctor at all. Irrespective of their previous acquaintance, both the patients and next-of-kin seemed to have great trust in the physician they were present with. However, some complained about other health professionals in whom they had lost confidence for various reasons; one because the department had not detected a relapse, another because the general practitioner did not follow up the patient's psychological problems well enough. These examples illustrate the importance of trust but also its ephemeral nature (9, 10). A trusted health professional has been associated with someone who shows empathy and honesty, encourages questions, and clarifies individual understanding and information needs (152). Agich (100) emphasizes that affection is important for how we connect with others and that commitment to another person involves affective bonds that are usually developed over time. Karen was one of the patients who knew the doctor a little and she was the one whose relapse was not detected at first. Her husband demonstrated the importance of the relation to the physician, declaring, "Just so you know, you are the one holding her hand". Continuity in the patient-physician relation should be the standard when caring for patients in a vulnerable life-situation like advanced cancer. Although continuity may not always be achievable in practice, physicians should still invest in the relation to the patient and family, showing genuine interest in the person(s) they encounter at any given time, not only in the information exchange (47, 153). They should also not underrate the power imbalance embedded in the patient-physician relation and how that may affect the other(s) in the interaction, for example, fear of disclosing existential concerns or occupying consultation time.

Building on Emanuel and Emanuel's four models of the patient-physician relation (94), Falkum and Førde (154) investigated Norwegian physician's attitudes towards patient autonomy and found that physicians were far more paternalistic than they themselves acknowledged. The authors concluded that the applied approach must be adapted to the clinical situation. Some situations require the professional to take the patient's hand and lead him or her through unknown territory. It is a common misunderstanding that sharing decisions involves leaving ultimate responsibility to the patient (21), which is indeed an abandonment. Efforts to respect patient autonomy, and fear of being too paternalistic, must not lead healthcare personnel into the unfortunate pitfall of abdicating from their professional responsibilities.

7.2.2 Talk less - listen more

> *"In clinical practice in recent years there has been a tendency to focus on communication in terms of conveying information to patients – and with their permission, to those important to them. But all too often such communication has gone wrong because the fundamental steps of listening has had less importance in curricula than verbal construct." (Ilora Finlay) (150).*

Even though the patients in this study were in situations that shared resemblance, they were nevertheless very different. Each of them had their own personality, history, familial context, values, resources, vulnerabilities and so on. We can learn from research about the variety of human experience, but the person(s) in front of us is always unique. Kissane and colleagues comment on this in the preface to their textbook *Communication in Oncology and Palliative Care*: 'Personalized medicine aims to tailor therapies to the uniqueness of each patient's disease by genetic profiling of the tumor. The same level of individualized care is essential in responding humanely to each person' (155). Moreover, patient-centered care should not be restricted to biomedical aspects but should encompass psychological, social, and spiritual aspects (12, 21, 60, 106, 156). Agich argues that care for vulnerable persons clinicians should aim to combine respect for autonomy with a holistic approach, that is, instead of falling back into inappropriate paternalism, he advocates for 'parentalism', referring to the kind of supportive care one receives from a good parent (100) (p.45).

Patient-centered communication is key to improving oncology and palliative care (21, 155) but should not be a one-way process. Communication aiming to restore autonomy starts with being attentive to the individual patient's informational, emotional, and relational needs (12). Moreover, patient-centered care includes being responsive to individual needs and values. Findings from this study suggest that the physician should actively explore the patients' concerns, as they may not disclose them without invitation. Tools like 'The four habits model' (157) and 'Ask-tell-ask model' (158) can be useful for training skills in patient-centered communication. When exploring the patient's needs, physicians should investigate how actively the patient wants to be involved in decision-making, as patient preferences may vary between individuals and may change during the course of illness (21). Regardless of the patient's ability and willingness to participate actively, the physicians should always seek to include the patient's values in decision-making.

7.2.3 The right information in the right doses

> *"Cancer remains one of the most dreaded diagnoses because of the enormous threat it brings to the well-being and survival of the patients it afflicts. Challenged to adapt with courage and cope with complex treatment, patients and their families need support from the whole multidisciplinary team to deal optimally with their predicament. Communication is at the heart of the effective delivery of this care." (Kissane et al.) (155).*

According to Beauchamp and Childress (95), the negative aspect of respect for autonomy is the obligation of non-interference, that is, respecting an agent's free choice. The positive feature is the duty to enhance autonomy by providing information that will enable the agent to make decisions based on understanding. The physicians in this study did educate the patients reasonably well, however, the education was largely restricted to biomedical aspects, which they often explained in considerable detail. Of course, patients can benefit from understanding how the disease spreads or how the chemotherapy works, and sometimes the patients request such information. The question is, is detailed medical explanations always what the patient needs, and is it necessarily the right 'medicine'? The Norwegian ethicist Knut Erik Tranøy (159) stated that information is as potent as other medical interventions, meaning that it must be delivered with the same level of caution. If we follow this metaphor, there are several things to consider. Firstly, the indication, or the purpose of the information. Given that the goal is to enable participation in decision-making, the patients need sufficient information to understand what the alternatives entail to be able to assess which course of action will best safeguard their values (99). However, if the goal is coping with challenges following advanced cancer, whether they are related to physical, psychological, social, or existential experiences, then the information must be tailored to meet the specific needs. According to Antonovsky's influential coping theory, people need a sense of coherence (160). The illness experience represents a breach of coherence in many ways (161), and new questions may arise, including what the future holds. The patients in this study rarely received any information to support their coping, other than how to deal with physical symptoms, nor did they receive information preparing them for the time ahead or any reassurance that they will not be alone in their experience. Olav, for example, was told that there was no treatment available for him, and he got a thorough explanation for why various options were not applicable, which he appreciated. Then he asked the physician whether the cancer cells in his liver were of the fast-growing or slow-growing type, to which the physician explained that there was no clear answer. Olav asked how the physician would follow up on him, as he would probably get more symptoms over time. When he left the encounter, Olav had received no information about the expected course of illness, which symptoms may develop, how those could be relieved, who he could talk to if he or his family needed any support, or where he could turn to if he got symptoms or other needs.

The second consideration is the appropriate dose of information. John, who suffered from heavy symptom burden, was provided with a lot of information about chemotherapy that he could try at a later stage if his general condition improved. John seemed overwhelmed by this information and signaled that he could barely manage the day to day. One could question whether John received the right information in the right dose in this situation. This leads to the third consideration, the need to evaluate the effects and side-effects of information sharing, as it may not always lead to the intended result and could have adverse effects. Inappropriate information or information overdose may thus create powerlessness instead of empowerment or increase the burden rather than easing it.

A reflection in this regard is that practice seems very much governed by legal requirements. The obligation to inform is formulated as a directive in the Norwegian health legislation, which states that the patient must receive information about his condition and health care (32), resulting in doctors possibly being afraid of not fulfilling their obligations. The ethical rules for Norwegian physicians formulates this duty slightly differently, “the patient must be informed to the extent that the patient wishes” (3)(§ 3), suggesting that there is room for adjustment based on ethical and professional judgement. A good starting point is to explore the patient’s and family’s preferences for how they want to receive information (21). Another measure to limit information overdose, which I learned from a wise colleague, is to give limited information at first and then let the patient control the level of detail through enquiry. This cautious approach applied to children with cancer, but in my experience, it works well with adult patients as well.

7.2.4 Responding to patients' existential concerns

The physicians in this study habitually responded to the patient's uttered existential concerns with more information on biomedical aspects. As discussed in Article 2, a possible reason for this could be that the patients often concealed their concerns in biomedical terms. However, the same pattern took place when the concerns were explicit. So, what would be an appropriate response to patients' existential concerns, and how can physicians support patients in the movement from existential suffering towards existential health (117). Or should physicians even enter this domain? There are conceivable arguments why physicians should not, including that emotional and existential concerns belong to the private sphere and should be managed with support from family and friends, perhaps with additional aid from a chaplain or a religious community. Moreover, physicians can be afraid of imposing difficult topics on the patient. However, studies have shown that talk about serious subjects such as death and dying is usually not stressful or harmful for patients (139), and that patients want to discuss existential concerns with their healthcare providers (61, 65-67). The fact that the patients in this study disclosed existential concerns, although subtle and indirect, suggests that they would value a conversation about it. One cannot take for granted that all patients talk to their loved ones about difficult topics (162), nor that loved ones feel equipped to deal with these issues. Besides, the physician may be the patient's only contact with the healthcare system. For example, all the patients in this study still lived at home and did not yet receive any care services, meaning that if the physician did not identify or respond to their concerns, these issues might remain unaddressed entirely. Moreover, information about the expected course of illness and how future symptoms can be handled may be what the patient needs to feel confident and prepared, information that the physician can typically provide. Hence, beyond the fact that it is recommended in guidelines, there are many valid reasons why physicians should include existential concerns when caring for patients with advanced cancer (21, 36, 62). Responding to the patient's existential concerns is the humane thing to do, as it may relieve suffering (64, 163), foster coping (36, 160), and improve quality of life (65, 68). Whereas, not responding can be perceived as a rejection and dehumanization of the patient (151) and may become a source of suffering in itself (164).

If patients with advanced cancer can benefit greatly from a holistic approach that includes the existential aspect, why is it rarely implemented in medical practice? One suggested barrier is time-constraints (165). However, I argue that responding to patients' existential concerns need not necessarily take more time, as it is not about performing additional tasks rather than applying a different approach. One can achieve much by seeing and recognizing the whole person and by adapting communication to individual needs. For example, reducing extensive and detailed biomedical explanations, unless on patient request, and talking more about the patient's worries about the future. Some patients, however, may have maladaptive responses to existential challenges and may thus need specialized measures (99). A literature review showed that most of the interventions targeting existential concerns were psychological interventions with some form of therapy with designs that were perceived as too time consuming for daily routine practice (139). In such cases, the physician at the outpatient clinic may admittedly have neither the time nor the expertise to accommodate the patient's needs. Conversely, in most cases, existential concerns are natural reactions to a difficult situation and pathological reactions are exceptional.

Another barrier for including existential aspects in medical encounters is that physicians may not be confident to talk about existential issues, for example, due to lack of training (66, 67). An additional barrier may the medical culture, as the lack of training can be perceived as a symptom that existential aspects have not been considered an important and natural part of medical practice. General practitioners have interpreted their individual barriers in the light that they are socialized into dominant biomedical and secular cultures that are 'solution focused' and 'faith frightened' (166) (p.108).

So, how can physicians overcome these barriers to include existential aspects of cancer care? A good start is to become aware that 'there are deeper layers to listening', as attentive listening involves the listener's eyes, her heart, and her whole being (150). An attentive listener who is sincerely curious about the person beyond the illness is more likely to identify when something may be at stake for the patient, both because the listener is more open to what may arise and because the patient may be more confident in sharing with someone who shows genuine interest and empathy (152).

Resources exist that can help doctors meet patients' existential needs. Some guidelines offer practical advice for how to meet patients' spiritual needs (167). Norwegian guidelines for palliative cancer care suggest specific questions that can be helpful, including: "How is it for you to experience what is happening to you now? What is important to you now? What are you hoping for? What are you worried about? Is there anything that can help you get through what has just happened? What has helped you earlier in life when you experienced difficult things? Many people have a faith that can help them when life gets difficult. Can you relate to that?" (my translation) (36). HOPE[1], a tool that can help structure a conversation about existential topics, has additional suggestions for questions that may be relevant (168, 169). Kissane (64), who developed a taxonomy for existential suffering, also provided specific suggestions for how physicians could accommodate maladaptive responses to such suffering. As a response to physicians' lack of training, Hvidt and colleagues (66) developed a one-day course program in Denmark that has been shown to increase doctors' confidence in the ability to carry out existential communication. In Norway, the Norwegian Association for Palliative Medicine and the Regional Centers of Competence for Palliative Care organize courses in palliative care where communication about existential concerns is a natural aspect (36). Although doctors are important in identifying and responding adequately to existential concerns, it is natural that they collaborate with others in the interdisciplinary team who may have more time and expertise to provide good existential care to those in need (170). Such collaboration may require efforts to improve the working culture as health care professionals' perceptions of themselves and others in the interdisciplinary team has been identified as a possible barrier (171). Additionally, some patients may benefit from participation in support groups, mastery courses or counseling services for cancer patients, for example, arranged by the Norwegian Cancer Society (172).

7.2.5 Involving next-of-kin

Ten out of thirteen patients in this study brought a companion to the consultation. Although the numbers obviously are too small to yield statistical robustness, we note that the proportion of patients bringing next-of-kin was notably higher in these visits compared to previous research studying medical visits in general (mean 37.6 %) (77), and in the upper end of the range reported in previous studies on oncology visits (76). The patients in this study did not need practical assistance due to function loss and had not lost their decisional capacity, suggesting that the need for accompaniment was not primarily related to having someone to compensate for impairment. However, as discussed earlier, they all had a poor or uncertain

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[1] HOPE: Sources of **H**ope, meaning, comfort, strength, peace, love and connection - **O**rganized religion - **P**ersonal spirituality/practices – **E**ffects on medical care and and-of-life issues.

prognosis, facing loss and threats of loss that are strongly associated with existential suffering (106, 117). As the existential journey of severe illness is associated with vulnerability (12, 117), fear of the future (106, 173), loss of autonomy (12, 106, 117), and fundamental aloneness (64, 106, 117), advanced cancer may reinforce the need for belonging (173, 174) and non-abandonment (175). Cancer patients have reported that seeking support from family, friends, and health professionals is a strategy for coping with existential challenge (117). In contrast to routine medical visits involving patients with other chronic diseases, companions were more likely to be present in oncology visits irrespective of the patient's demographic characteristics and functional status (76). Moreover, in a study where 'bad news' was disclosed, the companion presence rate was as high as 86 % (79), suggesting that the need for support is perceived to be greater when existentially threatened. Cancer patients have reported to appreciate companion involvement as a source of emotional support, informational support, and support in decision-making (76).

As in previous studies, next-of-kin participation varied greatly, however most companions were largely restrained (76). This reticence contrasts with companions reporting that they see their own contribution as important (90, 176). One explanation could be fear of occupying valuable time and attention from the patient or, as was found in one study, deliberately avoiding having too much influence (91). The fact that the companions rarely displayed emotions nor disclosed their own concerns may indicate that they did not want to take up space for the sake of the patient. Another explanation could be due to a feeling that it was expected of them to adopt a passive role. The physicians' habit of not inviting companions to contribute may have left them with the impression that their contribution was not wanted. Companions have previously reported being actively excluded by healthcare professionals or feeling superfluous in the consultation (88).

When speaking, next-of-kin contributed both substantively and to the process of information exchange, securing information that might otherwise have been missing. Moreover, they provided information more than they were requesting it, meaning that they took on a more active role than "being an extra set of ears" (Article 3), which is the role they are often assigned in both guidelines and clinical practice. For example, next-of-kin drew attention to issues like disease burden, concerns, context, values, and resources, as well as practical issues. As discussed in Article 3, the findings from this study suggest that next-of-kin may be an important resource in the consultation for the patient, but also for the physician if the aim is to tailor information and care to the individual and make it more person-centered.

Guidelines unanimously advocate for next-of-kin involvement, recommending building a relationship with next-of-kin and initiating tailored support for family caregivers (35, 177), involving them in decision-making (21), providing information and listening to their concerns, and facilitating next-of-kin participation when the patient is not able (70). The video-recorded consultations in this project suggest that the family-oriented approach recommended in the guidelines is not necessarily integrated into medical practice and culture. One could argue that the videos were recorded prior to these guidelines, however, recommending next-of-kin involvement is not a new phenomenon (78, 178, 179).

Barriers to next-of-kin involvement include the notion that it is too time-consuming. Yet, that is not necessarily the case, as a study of oncology outpatients found that the duration of accompanied visits was on average 3 minutes longer (78). Additional barriers could be physicians' fears of increased complexity (85) or dominant companions (87). From that perspective, their non-involvement of next-of-kin can be perceived as an expression of respect for the patient. However, in the consultations in this study there was little indication of next-of-kin dominance. A study from an oncology setting did not find that next-of-kin presence led to a more passive patient (180), suggesting that such fear may be exaggerated. Moreover, there is solid evidence that many patients appreciate their next-of-kin's contribution (76, 81-84).

In addition to personal and professional barriers, the strong push for an individual approach in society and in health legislation and guidelines may contribute to next-of-kin becoming peripheral. Although there is an increasing focus on family involvement, the overall tone in guidelines is that next-of-kin is an important supporter for the patient and that they may need support themselves, therefore being assigned a passive role. To a limited extent they are regarded as an active participant and a resource for the physician, unless the patient himself is indisposed. For example, family members are recognized as the patient's main source of emotional and practical support (21). This is reflected in these consultations in that the next-of-kin provided and requested information about practical issues, and some of them took on a reasonable amount of responsibility for supporting everyday life with illness. Such next-of-kin behavior in the consultation gave the impression that the two functioned as a team at home. However, in the consultation they were rarely treated as a unit, as the physicians habitually primarily addressed the patient, resulting in the next-of-kin having to interrupt the patient-physician dialogue when they wanted to speak. The way the physicians related to next-of-kin in these consultations did not testify to a view of autonomy as something relational.

So, how to improve next-of-kin involvement in cancer care? Relating to the patient and the companion as a team could be a good start. Acknowledging the next-of-kin’s supportive role by seeing them as a resource in the consultation may encourage next-of-kin to contribute more actively. However, it makes demands of the physician's attention and skills. Laidsaar-Powel and colleagues (181) have developed the first comprehensive guidelines for oncology physicians and nurses on how to involve family caregivers of adult patients in consultations and patient care (TRIO Guidelines-1) and how to manage challenging interactions with family caregivers (TRIO Guidelines-2), which has been evaluated as helpful. However, guidelines alone may not be sufficient, as effective implementation will require targeted efforts, including training.

8 Discussion of methodological approach, quality, and limitations

In Chapter 5, I presented the research design and methods and the reasons for selecting them. In this chapter I will further discuss some aspects of the methodological approaches and choices including limitations, and quality assessments. I will start by discussing which knowledge traditions this project is building on and therefore influenced by.

8.1 Ontological and epistemological positions (preconception)

As explained in the method section (Chapter 5), this project originates from empirical research traditions, generating knowledge from what can be observed and experienced in real-world situations. In this project, we produce knowledge from what can be observed, supported by the procedures within the MCI-methodology (132). This type of knowledge production is based on a vision that there are some phenomena that are accessible to us without needing to envision the patients' perspective (182). That is, we adopt an outside perspective in contrast to, but not in competition with, phenomenology which takes an inside perspective and is concerned with how a phenomenon is experienced by those directly experiencing it (182). Moreover, there are some qualities of the situation that are true regardless of how the participants experience them. For example, the physicians may have habits in their communication style that they are not necessarily aware of. Further, patients facing death are in an existentially vulnerable situation and dependent on others irrespective of their awareness of this, it is not defined by their experience alone. They could be in denial, although I do not believe that the patients in this study were. Therefore, how people experience a situation of existential threat and how they cope with it is individual, whilst the phenomenon of existential challenge has elements that are universal (99).

Importantly, empiricism is often considered to coincide with positivism (118), a claim I do not subscribe to. Although the study is descriptive in the sense that we aimed to portray clinical practice as closely to reality as possible, that does not imply that I adopt a positivist world view, assuming that one objective truth exists independent of the observer (118). Rather, I subscribe to the view that the inherent meaning of social phenomena is interpreted in an interplay between the data (including contextual factors), myself as researcher, the literature explored, and discussions within the research team. More about what may have influenced my analysis during the research process is in section '8.4.1 Reflexivity' (p. 72).

8.2 The limitations and risks of video-observation

When using video observation, there is an inherent selection bias for participants who agree to be recorded versus those who do not (93). For the original project, in which the videos were recorded, the acceptance rates were high; more than 90 % of the approached patients (183) and more than 70 % of the physicians (124) consented to participate. Video recordings do not provide access to the participants' inner lives, such as, thoughts, emotions, motivations, and so on (132, 133). Hence, what a participant meant by what they said or did was necessarily associated with some uncertainty. When doing participatory observation, however, the researcher may, and often does, interview the participants afterwards with the opportunity to ask them to explain or elaborate on something that was said or happened in the consultation (184). In the present study, we did not have that opportunity, so we had to interpret participants' meaning with great caution. Moreover, if we had been in the room with the participants we may have noticed things that cannot be captured on camera, for example smells or the atmosphere in the room. Still, we believe that video-recordings were very well suited for this project, for reasons accounted for in the method section (Chapter 5), for example, the non-interference on the interaction.

Although we as researchers did not directly influence the participants or the consultation as we were not in the room, the presence of a camera might conceivably have done so. So, did we see any signs that the camera had any impact on the interaction? All participants had given consent and were of course aware of the camera and what the purpose of its presence was. Some mentioned it briefly, usually at the onset of the consultation, but overall participants did not pay it much attention as the consultation progressed. When patients commented on the camera they usually did so in neutral or positive terms, for example saying that they endorsed this type of research so that it could be learned from, which is in line with previous research (185). This also applied for next-of-kin, however, there was one instance where the next-of-kin gave the patient the hush sign while glancing at the camera. This happened while the physician absent and the patient introduced an issue to his wife. What the wife did not want to put on camera is unknown to us because we could not hear what they spoke about in that moment, as they lowered their voices. However, we cannot rule out that the camera may have contributed to them not addressing something with the doctor that they would otherwise have done. The physicians were mostly focused on the patient and were not visibly occupied with the camera. However, one physician commented on it after acknowledging that they had talked too much (the physician's own words), then noting, whilst laughing, that her babbling did not look good on camera. The examples above suggest that we cannot rule out the possibility that the camera may have affected the participants and the interaction to some extent.

A review by Parry et al. (186) investigated acceptability and risks entailed in video-based research on healthcare communication. They found that there has been little empirical research on the acceptability of video recording in healthcare settings for the purposes of research. One qualitative interview study (185) had explored the views of 31 hospice patients after one of their consultations had been video-recorded. The vast majority had a positive view towards the use of videos with the aim to improve communication and said that they would agree to another recording in the future. Parry et al. (186) investigated three common concerns related to video-recordings: effects on communication and thus patient care; threats to privacy and confidentiality; and coercion of participants. Some of the included studies showed that participants orient to and comment on the presence of the camera, most often from the start. Although the recording necessarily affects the interaction to some extent, they concluded that 'concerns that recording could be detrimental to healthcare delivery are not confirmed by existing evidence' (186)(p. 1271). None of the hospice patients in the interview study felt that the video recording had made the consultation less confidential or made them feel nervous or less willing to talk (185).

8.3 Was the microanalytic lens necessary?

The MCI-methodology is fine grained and can be quite time consuming, especially when new to the method, as I was in the beginning. At times, I discussed with my main supervisor (RF) about the balance between being thorough and the risk of getting lost in the details. What appealed to me with the method was that it is systematic and detail-oriented, but it took some time to get used to it and to feel that I mastered the craft. This left my supervisor with two reasonable concerns: one was related to the progress due to time limits in the Ph.D. project, and the other was related to the risk that I could lose sight of what were the unique "gold" in this material if digging too deep into details. Fortunately, she was patient enough to respect my need to take the steps at my own pace, while at the same time constantly reminding me of the purpose and the direction. Looking back, if I were to start again, I would naturally avoid some of the unnecessary detours I had in the beginning. However, the more I have learned about microanalysis and communication research the more I have been convinced that using the microanalytic lens has added valuable insights and nuances. Other analytic lenses could obviously have worked on this data material as well, but it would have resulted in something else. For example, I would not have been able to recognize and describe the subtle ways patients displayed existential concerns, or how physicians almost unnoticeably steered the agenda towards biomedical aspects, or how next-of-kin assisted the patient-physician dialogue with their comments and questions.

8.4 Trustworthiness and quality assessments

Evaluating the quality of research is essential if findings are to be incorporated into clinical practice (187). What terms are most appropriate when assessing quality in qualitative research, however, is an ongoing discussion (187) with no accepted consensus about the standards by which such research should be judged (188). Some have suggested to adopt and modify terms that are commonly used to assess quality in quantitative research, such as validity (188-190) and reliability (190, 191). Others have offered alternative criteria for demonstrating rigor within qualitative research, for example, Lincoln and Guba (192) suggested truth value, consistency and neutrality, and applicability. Trustworthiness, to what extent we can trust the research findings, is a core concern shared by numerous scholars (188, 189, 193, 194) although they may differ in how they label quality criteria and measures for obtaining trustworthiness. I will adopt the terms reflexivity, transparency, and transferability to describe some of the measures we employed to foster quality and trustworthiness in this project. However, 'research is only as good as the investigator' (190)(p. 17), meaning that quality does not only concern what researchers do, equally important is who the researchers are, their outlook, self-demands, and ingenuity (194)(p. 596). Integrity in qualitative research is an all-encompassing issue throughout the entire research process (194), including how questions are formulated, data selection, interpretation and analysis, reporting, and the researchers themselves.

8.4.1 Reflexivity

The belief of a neutral observer is falsified. Modern knowledge theory recognizes that a researcher's position and perspectives will necessarily influence the knowledge production (193)(p. 484). For example, Donna Haraway (195) claimed that the perspective of the observer is always limited and determines what can be seen. She challenged the prevailing perception of objectivity, emphasizing the need to recognize that knowledge is partial and situated (195). This means that researchers may approach the same subject in various ways, accessing different, although equally valid, aspects of the situation, resulting in an increased understanding of complex phenomena not in a failure of reliability, unless the effect of the researcher is ignored (193). However, biases must be accounted for and cannot always be eliminated. Reflexivity refers to critical self-reflections, including own biases, personal preconceptions, and preferences (194). Malterud (193) adopts the metaphor 'the knower's mirror', defined as an 'attitude of attending systematically to the context of knowledge production, especially to the effect of the researcher, at every step of the research process' (p. 484).

According to Malterud (193), reflexivity starts by identifying what preconceptions were brought into the project based on the researcher's personal and professional experiences, beliefs about how things are and what is to be investigated, their motivation and qualifications for exploration of the field, and their perspectives and theoretical foundations related to education and interests. Malterud (193) calls such preconceptions the 'researchers backpack' (p. 484). So, what was in my backpack, what preconceptions did I bring into this project, what are my potential biases, and what did we do to counteract unwanted or hidden skewedness?

My professional background as a cancer nurse has undoubtedly contributed to my interest in clinical communication, in fact, I see communication as my most important tool when encountering patients and their families. Meeting persons where they are, trying to understand their perspectives and how they experience their situation are important goals for me, reflecting my personal and professional values. Nursing and doctoring differ when it comes to values, roles, and responsibilities, which may explain why I react negatively when, in my opinion, the focus is too much on biomedical aspects and too little on human aspects. Having an external perspective may make it easier to criticize and it may be that I underestimate the complexity of the physicians' tasks. That said, the two doctors in the project were often more critical of their colleagues than I was.

Through my clinical work I am accustomed to discuss difficult aspects of the illness experience. My personal faith as a Christian may also influence how I perceive existential issues.

Moreover, at the cancer hospital where I worked, next-of-kin were seen as an integral part of the patient's life, and they were often present at the ward. Also, in clinical ethics committee work next-of-kin are assigned an important role. These experiences have probably shaped my ideals regarding next-of-kin involvement.

To avoid biased interpretations of the data, we constantly looked for competing conclusions, what Malterud (193) calls establishing meta-positions or 'the participating observer's sidetrack' (p. 484). Additionally, inherent in being part of an interdisciplinary group was that meta-positions came naturally in the discussions. Conclusions that seemed self-evident to me were not always evident to other team members. Then, I had to re-think, establish a more convincing argument, or reject the conclusion. Also, having video-recordings and transcripts allowed other team members to audit them, which is another recommended strategy (193). Bringing in user perspectives (accounted for in the method section, Chapter 5) was also a way of establishing meta-positions. My change in view of autonomy exemplifies what such reflexive activities have resulted in.

8.4.2 Transparency

A key question when assessing trustworthiness in qualitative research is: 'is the process of knowledge generation open to outside scrutiny?' (189) (p. 85). Transparency should be sought throughout the whole research process, from data collection to reporting. For example, researchers should implement a transparent and systematic procedure in the interpretation and analysis of data (193). That includes being open about what theories, models, and notions are applied for understanding and interpreting the data. Malterud (193) stresses that although qualitative researchers work inductively, as we did in this project, knowledge never emerges from data alone but from the relation between empirical substance and theoretical frame of reference, as these are 'the analyst's reading glasses' that unavoidably affect the analytic process and conclusions made (p. 484). The theoretical concepts and frameworks that we applied in this project are described in the theory section (Chapter 3). For example, the overarching term that has guided this project from the start is patient autonomy. From the outset, my understanding of autonomy was largely shaped by Beauchamp and Childress' influential literature on the concept (2). During the process, reading competing notions of autonomy and other literature while working with the data and discussing with colleagues, my understanding developed, which in turn has affected what questions I asked, what I noticed, and how I interpreted what I saw.

As part of a transparent process, the researcher should also reveal the style of analysis used (193). Miller and Crabtree (196) present three styles of analysis, that is, immersion/ crystallization (intuitive), editing (data-based), and template (theory-based). The approach we used in the studies included in this thesis mostly resembles the editing (data-based) analysis style where the researcher identifies units in the text that form the basis for data derived categories, which are used to reorganize the text so that its meaning becomes clear. The analytic process for each study is accounted for in the articles and in the method section of this thesis. For study 1 and 2, which involved more complex analytic choices, more details are provided in the corresponding codebooks (Appendix 3 and 4).

By being transparent throughout the research process, we welcome others to judge whether the methods used are appropriate for investigating the study objectives, referred to as internal validity (193), that is, whether the study investigates what it is meant to. However, absolute transparency is a difficult to achieve in qualitative research as the participants are few, and detailed descriptions may reveal their identity. Hence, due to privacy considerations, we do not make the raw data publicly available for inspection (only on reasonable request). However, to obtain transparency in the reporting of results, we make abundant use of quotations (not linked to identifiable persons) to support the validity of the results.

8.4.3 Transferability

The overall aim of research is to produce knowledge that can be shared and applied beyond the study context; however, no study can provide universally transferable findings (193). Especially in qualitative research, the findings ‘are not thought of as facts that are applicable to the population at large, but rather as descriptions, notions, or theories applicable within a specified setting’ (193) (p. 486). Transferability refers to the extent to which the findings can be transferred to other settings (192), also known as external validity (193). In each article, as well as in the method section of this thesis, we have described the participants, the consultations, and the study context in reasonable detail to enable readers to assess for which situations the findings can provide valid knowledge.

9 Conclusions

The aim of this thesis was to explore how the concept of patient autonomy can be understood in the case of advanced cancer. Through studying clinical communication in routine oncology visits, we found that most patients disclosed existential concerns during the consultation. However, existential concerns were hesitant, subtle, and indirect, typically hidden in biomedical terms, suggesting that patients may be unsure whether they can address such concerns with the physician. We also found that the physicians habitually responded to existential concerns by steering the agenda towards biomedical aspects, resulting in that the existential issues remained unaddressed. The existential illness experience involves various losses and threats of loss related to autonomy, including loss of capacity, independence and control. Addressing these issues may thus be an opportunity to restore autonomy. In most consultations, the patient was accompanied by a next-of-kin, whom the physicians mostly related to as a "supporter on the sidelines" rather than addressing the couple as a team. Next-of-kin were largely reticent but when claiming the floor, they contributed both substantively by bringing information into the discussion and by assisting the patient-physician dialogue. Next-of-kin provided far more information than they requested it, and they typically drew attention to topics such as disease burden, patient concerns, values, resources, and context, information that can be important for the physician when aiming for patient-centered care.

In this thesis I discuss how these findings are relevant for patient autonomy, pointing to that in the context of advanced cancer, the dominating liberal notion of autonomy falls short with its narrow focus on free choice, rationality and independence, which simply does not reflect the complex reality of the patient. Hence, I argue for a broader notion of autonomy that not only respects patient choice but aims to restore autonomy and foster coping by tailoring information and holistic care based on individual needs. To succeed in this task, communication must start with being attentive to and curious about what the patient tries to disclose in the dialogue. This thesis can draw attention to a potential existential neglect in the medical culture that may be relevant for patient autonomy. Moreover, insights from this study can inform the discussion about how physicians *can* play a role in relieving existential suffering restoring autonomy and fostering coping with severe illness.

Implications for practice, training and research

Findings from this thesis suggest that physicians should be attentive to underlying existential concerns that might be embedded in patients' questions and concerns about medical issues and to their possible habit of neglecting existential challenges. Knowledge of how patients communicate existential concerns will hopefully help clinicians recognize such expressions when they arise in the dialogue. Once identified, the physician and patient can explore these concerns together and discuss how the latter can be helped in dealing with them, including what kind of information and support the patient needs. The findings will hopefully also raise awareness to the important contribution of next-of-kin, as they may support both the patient and the patient-physician dialogue. However, physicians should be aware that next-of-kin may withhold their own needs. Further, we hope the findings from this thesis will inspire physicians to reflect on how they can collaborate with others in the interdisciplinary healthcare team in fostering patients' existential health, coping and autonomy.

Communication training for physicians should not only focus on free choice and shared decision-making but reflect that patient autonomy in advanced cancer may need a broader and more holistic approach. How to communicate about existential aspects of the illness experience should be incorporated into education programs for physicians caring for patients with advanced cancer, as lack of confidence and training is an identified barrier for physicians. There are programs that are shown to be helpful. Future research should further develop and evaluate methods for this purpose.

References

1. Weimer S. Evidence-Responsiveness and the Ongoing Autonomy of Treatment Preferences. HEC Forum. 2018;30(3):211-33.
2. Beauchamp TL, Childress JF. Principles of biomedcal ethics 8th ed. Oxford: Oxford University Press; 2019.
3. Rådet for legeetikk CfME. Etiske regler for leger [Ethical Rules for Doctors]: Den norske legeforening [Norwegian Medical Association]; 2015 [Available from: http://legeforeningen.no/Om-Legeforeningen/Organisasjonen/Rad-og-utvalg/Organisasjonspolitiske-utvalg/etikk/etiske-regler-for-leger/.
4. Council on Ethical & Judicial Affairs (CEJA). Code of Medical Ethics: American Medical Association; [Available from: https://code-medical-ethics.ama-assn.org/.
5. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. Patient Educ Couns. 2008;73(3):526-35.
6. Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. BMJ. 2017;357:j1744-j.
7. Stiggelbout AM, Pieterse AH, De Haes JCJM. Shared decision making: Concepts, evidence, and practice. Patient Education and Counseling. 2015;98(10):1172-9.
8. Agledahl KM, Førde R, Wifstad A. Choice is not the issue. The misrepresentation of health care in bioethical discourse. J Med Ethics. 2011;37:212-15.
9. Løgstrup KE. The ethical demand. Oxford: Oxford University Press; 2020.
10. Martinsen K. Fra Marx til Løgstrup : om etikk og sanselighet i sykepleien [From Marx to Løgstrup: on ethics and sensuousness in nursing]. 2. utg. ed. Oslo: Universitetsforl.; 2003.
11. Yalom ID. Existential psychotherapy. New York: Basic; 1980.
12. Gulbrandsen P, Clayman ML, Beach MC, Han PK, Boss EF, Ofstad EH, et al. Shared decision-making as an existential journey: Aiming for restored autonomous capacity. Patient Education and Counseling. 2016;99(9):1505-10.
13. Kissane DW, Bultz BD, Butow PN, Bylund CL, Noble S, Wilkinson S. Oxford textbook of communication in oncology and palliative care. 2nd edition. ed: Oxford University Press; 2017.
14. De Snoo-Trimp JC, Brom L, Pasman HR, Onwuteaka-Philipsen BD, Widdershoven GA. Perspectives of Medical Specialists on Sharing Decisions in Cancer Care: A Qualitative Study Concerning Chemotherapy Decisions With Patients With Recurrent Glioblastoma. Oncologist. 2015;20(10):1182-8.
15. Clarke G, Johnston S, Corrie P, Kuhn I, Barclay S. Withdrawal of anticancer therapy in advanced disease: a systematic literature review. BMC Cancer. 2015;15(1):1-9.
16. Cancer-Registry-of-Norway. Cancer in Norway 2021. 2022.
17. Statistisk Sentralbyrå [Statistics Norway]. Befolkning i Norge [Population in Norway] [Available from: https://www.ssb.no/en/befolkning/folketall/statistikk/befolkning.
18. Global-Cancer-Observatory. Cancer Today: International Agency for Research on Cancer, World Health Organization; [Available from: https://gco.iarc.fr/.
19. National-Cancer-Institute. Understanding Cancer: United States government; [Available from: https://www.cancer.gov/about-cancer/understanding.
20. American-Cancer-Society. Understanding Advanced and Metastatic Cancer [Available from: https://www.cancer.org/treatment/understanding-your-diagnosis/advanced-cancer/what-is.html.
21. Kaasa S, Loge JH, Aapro MS, Albreht T, Anderson R, Bruera E, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. 2018.
22. Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care. Nat Rev Clin Oncol. 2016;13(3):159-71.
23. Baker R. The Structure of Moral Revolutions: Studies of Changes in the Morality of Abortion, Death, and the Bioethics Revolution London, England: Massachusetts Institute of Technology; 2019.

24. Shuster E. Fifty Years Later: The Significance of the Nuremberg Code. New England Journal of Medicine. 1997;337(20):1436-40.
25. World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. JAMA. 2013;310(20):2191-4.
26. Kline W. Bodies of knowledge : sexuality, reproduction, and women's health in the second wave. Chicago: University of Chicago Press; 2010.
27. Parsons T. The social system. London: Tavistock; 1952.
28. Hoffman BR. Patients as policy actors. New Brunswick, N.J: Rutgers University Press; 2011.
29. Beauchamp TL. Principles of biomedical ethics 1st ed. Childress JF, editor. New York: Oxford University Press; 1979.
30. Nylenna M. Fra lydighet til likeverd – pasientmedvirkning i et historisk og helsepolitisk perspektiv [From obedience to equality - patient participation in a historical and health policy perspective]. Michael Journal. 2020;17:15-42.

31. Lov om helsepersonell m.v. LOV-1999-07-02-64, (1999).
32. Lov om pasient- og brukerrettigheter LOV-1999-07-02-63, (1999).
33. Saunes IS, Karanikolos M, Sagan ANHSRHSiT. Norway Health System Review. Norwegian Institute of Public Health and European Observatory on Health Systems and Policies; 2020.
34. Peppercorn JM, Smith TJ, Helft PR, Debono DJ, Berry SR, Wollins DS, et al. American society of clinical oncology statement: toward individualized care for patients with advanced cancer. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2011;29(6):755-60.
35. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, et al. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. J Clin Oncol. 2017;35(1):96-112.
36. Helsedirektoratet [Norwegian Directorate of Health]. Palliasjon i kreftomsorgen - handlingsprogram. Nasjonal faglig retningslinje. [Palliation in cancer care - action program. National professional guidelines].
37. Meld. St. 7 (2019–2020). Nasjonal helse- og sykehusplan [National Health and Hospital Plan] 2020–2023. In: Care] H-ooNMoHa, editor.: Norwegian Government; 2019.
38. Folkehelseinstituttet [Norwegian Institute of Public Health]. Samvalg [Shared Decision making] [Available from: https://www.fhi.no/kk/oppsummert-forskning-for-helsetjenesten/samvalg/.
39. Helse Norge. Samvalg – du kan være med og bestemme [Shared Decision Making - you can participate in the decision: HelseNett [Norwegian health network, Public Webpage]; [Available from: https://www.helsenorge.no/samvalg/.
40. Helse-og-Omsorgsdepartementet [Norwegian Ministry of Health and Care Services]. Leve med kreft. Nasjonal kreftstrategi [Living with Cancer. National cancer strategy](2018-2022) Norwegian Government; 2017.
41. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, Widdershoven GAM, Stiggelbout AM, Pasman HRW. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. Health Expect. 2017;20(1):69-84.
42. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education and Counseling. 2014;94(3):291-309.
43. Kunneman M, Montori VM, Castaneda-Guarderas A, Hess EP. What Is Shared Decision Making? (and What It Is Not). Acad Emerg Med. 2016;23(12):1320-4.
44. Hargraves I. Beyond involvement: multiple methods and purposes of shared decision making. J Comp Eff Res. 2019;8(16):1345-7.
45. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision making: multistage consultation process. BMJ. 2017;359.
46. Entwistle VA, Watt IS. Broad versus narrow shared decision making. Oxford: Oxford: Oxford University Press; 2016.

47. Montori V, M. , Ruissen M, M. , Hargraves I, G. , Brito J, P. , Kunneman M. Shared decision-making as a method of care. BMJ Evidence-Based Medicine. 2022:bmjebm-2022-112068.
48. Driever EM, Stiggelbout AM, Brand PLP. Shared decision making: Physicians' preferred role, usual role and their perception of its key components. Patient Education and Counseling. 2020;103(1):77-82.
49. Shepherd HL, Tattersall MHN, Butow PN. The context influences doctors' support of shared decision-making in cancer care. Br J Cancer. 2007;97(1):6-13.
50. Shepherd HL, Butow PN, Tattersall MHN. Factors which motivate cancer doctors to involve their patients in reaching treatment decisions. Patient Education and Counseling. 2011;84(2):229-35.
51. Elwyn G, Price A, Franco JVA, Gulbrandsen P. The limits of shared decision making. 2022.
52. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. Soc Sci Med 2005;61(10):2252-64.
53. Winkler EC, Reiter-Theil S, Lange-Riez D, Schmahl-Menges N, Hiddemann W. Patient involvement in decisions to limit treatment: The cricial role of agreement between physician and patient. . J Clin Onkol 2009;27:2225-30.
54. Noguera AMD, Yennurajalingam SMDMS, Torres-Vigil ID, Parsons HAMDMS, Duarte ERMD, Palma AMD, et al. Decisional Control Preferences, Disclosure of Information Preferences, and Satisfaction Among Hispanic Patients With Advanced Cancer. J Pain Symptom Manage. 2014;47(5):896-905.
55. Schuler M, Schildmann J, Trautmann F, Hentschel L, Hornemann B, Rentsch A, et al. Cancer patients' control preferences in decision making and associations with patient-reported outcomes: a prospective study in an outpatient cancer center. Support Care Cancer. 2017;25(9):2753-60.
56. Keij SM, Lie HC, Laidsaar-Powell R, Kunneman M, de Boer JE, Moaddine S, et al. Patient-related characteristics considered to affect patient involvement in shared decision making about treatment: A scoping review of the qualitative literature. Patient Education and Counseling. 2023;111:107677.
57. Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and evaluating shared decision making in oncology practice. CA: A Cancer Journal for Clinicians. 2014;64(6):377-88.
58. Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. The Cochrane database of systematic reviews. 2014;1:CD001431.
59. Hauser K, Koerfer A, Kuhr K, Albus C, Herzig S, Matthes J. Outcome-Relevant Effects of Shared Decision Making A Systematic Review. Deutsches Ärzteblatt international. 2015;112(40):665-71.
60. World Health Organization. Palliative Care [Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care.
61. Best M, Butow P, Olver I. Do patients want doctors to talk about spirituality? A systematic literature review. Patient Educ Couns. 2015;98(11):1320-8.
62. European Association of Palliative Care. EAPC Task Force on Spiritual Care in Palliative Care: European Association of Palliative Care; [Available from: https://eapcnet.eu/.
63. Hvidt EA. The existential cancer journey: Travelling through the intersubjective structure of homeworld/alienworld. Health (London, England : 1997). 2017;21(4):375-91.
64. Kissane DW. The Relief of Existential Suffering. Archives of Internal Medicine. 2012;172(19):1501-5.
65. Gijsberts M-JHE, Liefbroer AI, Otten R, Olsman E. Spiritual Care in Palliative Care: A Systematic Review of the Recent European Literature. Med Sci (Basel). 2019;7(2):25.
66. Hvidt EA, Ammentorp J, Sondergaard J, Timmermann C, Hansen DG, Hvidt NC. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. Scandinavian journal of primary health care. 2018;36(2):142-51.

67. Balboni MJ, Sullivan A, Amobi A, Phelps AC, Gorman DP, Zollfrank A, et al. Why Is Spiritual Care Infrequent at the End of Life? Spiritual Care Perceptions Among Patients, Nurses, and Physicians and the Role of Training. J Clin Oncol. 2013;31(4):461-7.
68. Cohen SR, Mount BM, Tomas JJN, Mount LF. Existential well-being is an important determinant of quality of life: Evidence from the McGill Quality of Life Questionnaire. Cancer. 1996;77(3):576-86.
69. Helsedirektoratet. Rapport om tilbudet til personer med behov for lindrende behandling og omsorg mot livets slutt - å skape liv til dagene2015.
70. Helsedirektoratet [Norwegian Directorate of Health]. Pårørendeveileder [National Guideline Next-of-kin]. 2017.
71. Pardon K, Deschepper R, Stichele RV, Bernheim J, Mortier F, Deliens L. Preferences of advanced lung cancer patients for patient-centred information and decision-making: A prospective multicentre study in 13 hospitals in Belgium. Patient Educ Couns. 2009;77(3):421-9.
72. Pardon K, Deschepper R, Stichele RV, Bernheim JL, Mortier F, Bossuyt N, et al. Preferences of Patients with Advanced Lung Cancer Regarding the Involvement of Family and Others in Medical Decision-Making. J Palliat Med. 2010;13(10):1199-203.
73. Stenberg U, Ekstedt M, Olsson M, Ruland CM. Living Close to a Person With Cancer: A Review of the International Literature and Implications for Social Work Practice. J Gerontol Soc Work. 2014;57(6-7):531-55.
74. Mikulincer M, Rydall A, Walsh A, Braun M, Rodin G. Hidden Morbidity in Cancer: Spouse Caregivers. J Clin Oncol. 2007;25(30):4829-34.
75. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. CA Cancer J Clin. 2010;60(5):317-39.
76. Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, et al. Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. Patient Education and Counseling. 2013;91(1):3-13.
77. Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review. Soc Sci Med. 2011;72(6):823-31.
78. Labrecque MS, Blanchard CG, Ruckdeschel JC, Blanchard EB. The impact of family presence on the physician-cancer patient interaction. Soc Sci Med. 1991;33(11):1253-61.
79. Eggly S, Penner LA, Greene M, Harper FWK, Ruckdeschel JC, Albrecht TL. Information seeking during "bad news" oncology interactions: Question asking by patients and their companions. Soc Sci Med. 2006;63(11):2974-85.
80. Street RL, Gordon HS. Companion participation in cancer consultations. Psycho-Oncology. 2008;17(3):244-51.
81. Lee LE, Greene K, Venetis MK, Bontempo AC, Catona D, Buckley de Meritens A, et al. Aligned and Divergent Perceptions of Support Persons' Role in Triadic Gynecologic Cancer Communication. Qual Health Res. 2022;32(4):710-24.
82. Rosland A-M, Piette JD, Choi H, Heisler M. Family and Friend Participation in Primary Care Visits of Patients With Diabetes or Heart Failure: Patient and Physician Determinants and Experiences. Med Care. 2011;49(1):37-45.
83. Kimberlin C, Brushwood D, Allen W, Radson E, Wilson D. Cancer patient and caregiver experiences: communication and pain management issues. J Pain Symptom Manage. 2004;28(6):566-78.
84. Hubbard G, Illingworth N, Rowa-Dewar N, Forbat L, Kearney N. Treatment decision-making in cancer care: the role of the carer. J Clin Nurs. 2010;19(13-14):2023-31.
85. Beisecker AE, Moore WP. Oncologists' Perceptions of the Effects of Cancer Patients' Companions on Physician-Patient Interactions. Journal of psychosocial oncology. 1994;12(1-2):23-39.
86. Barone AD, Yoels WC, Clair JM. How Physicians View Caregivers: Simmel in the Examination Room. Sociological perspectives. 1999;42(4):673-90.

87. Shepherd HL, Tattersall MHN, Butow PN. Physician-Identified factors Affecting Patient Participation in Reaching Treatment Decisions. Journal of Clinical Oncology. 2008;26(10):1724-31.
88. Morris SM, Thomas C. The carer's place in the cancer situation: where does the carer stand in the medical setting? Eur J Cancer Care (Engl). 2001;10(2):87-95.
89. Sinfield P, Baker R, Agarwal S, Tarrant C. Patient-centred care: What are the experiences of prostate cancer patients and their partners? Patient Educ Couns. 2008;73(1):91-6.
90. Petronio S, Sargent J, Andea L, Reganis P, Cichocki D. Family and Friends as Healthcare Advocates: Dilemmas of Confidentiality and Privacy. Journal of social and personal relationships. 2004;21(1):33-52.
91. Srirangam SJ, Pearson E, Grose C, Brown SCW, Collins GN, O'Reilly PH. Partner's influence on patient preference for treatment in early prostate cancer: PARTNER's INFLUENCE ON TREATING EARLY PROSTATE CANCER. BJU international. 2003;92(4):365-9.
92. Clayman ML, Morris MA. Patients in context: Recognizing the companion as part of a patient-centered team. Patient Education and Counseling. 2013;91(1):1-2.
93. Golembiewski EH, Espinoza Suarez NR, Maraboto Escarria AP, Yang AX, Kunneman M, Hassett LC, et al. Video-based observation research: A systematic review of studies in outpatient health care settings. Patient Education and Counseling. 2023;106:42-67.
94. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. JAMA. 1992;267(16):2221.
95. Beauchamp TL, Childress JF. Respect for autonomy. Principles of biomedical ethics. 8th ed. ed. New York: Oxford University Press; 2019. p. 99-154.
96. Beauchamp TL, Childress JF. Principles of biomedical ethics 3rd ed. Oxford: Oxford University Press; 1989.
97. Veatch RM. Models for ethical medicine in a revolutionary age. What physician-patient roles foster the most ethical realtionship? Hastings Cent Rep. 1972;2(3):5-7.
98. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). Social Science & Medicine. 1997;44(5):681-92.
99. Charles C, Gafni A. Shared treatment decision-making and the use of decision-aids. In: Kissane DW, Bultz BD, Butow PM, Finlay IG, editors. Handbook of Communication in Oncology Care and Palliative Care. Oxford: Oxford University Press; 2010.
100. Agich GJ. Dependence and autonomy in old age : an ethical framework for long-term care. 2nd , rev. ed. Agich GJ, editor. Cambridge, UK New York: Cambridge University Press; 2003.

101. Agich G. Actual autonomy. United Kingdom: United Kingdom: Cambridge University Press; 2003. p. 83-124.
102. Mackenzie C, Stoljar N. Introduction: Autonomy refigured. . In: Mackenzie C, Stoljar N, editors. Relational autonomy : feminist perspectives on automony, agency, and the social self. New York: Oxford University Press; 2000. p. 3-31.
103. Mackenzie C, Stoljar N. Relational autonomy : feminist perspectives on automony, agency, and the social self. New York: Oxford University Press; 2000.
104. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. BMC Med Ethics. 2019;20(1):76-.
105. Gómez-Vírseda C, De Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: A contextualized approach to real-life complexities. BMC medical ethics. 2020;21(1):50-.
106. Boston P, Bruce A, Schreiber R. Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. Journal of Pain and Symptom Management. 2011;41(3):604-18.
107. Westphal M. Søren Kierkegaard. Danish Philosopher: Encyclopaedia Britannica; [Available from: https://www.britannica.com/biography/Soren-Kierkegaard.
108. Frankl V. The doctor and the soul: From psychotherapy to logotherapy. Aylesbury, UK: Hazell, Watson and Viney Ltd.; 1952.
109. Sartre J. Being and nothingness. New York: Washington Square Press; 1966.

110. Heidegger M. Being and time. . Oxford, UK: Blackwell; 1997.
111. Grepstad J. Peter Wessel Zapffe: Store Norske Leksikon; [Available from: https://snl.no/Peter_Wessel_Zapffe.
112. Holgernes B. Dømt til frihet : de menneskelige vilkår i Jean-Paul Sartres Væren og intet. Kristiansand: Høyskoleforl.; 2010.
113. Holgernes B. Mot til å leve : et møte med Paul Tillichs tanker og tro. Oslo: Cappelen Damm akademisk; 2013.
114. Holgernes B. Angst i eksistensfilosofisk belysning : en studie i Irvin D. Yalom og Søren Kierkegaard. Kristiansand: Høyskoleforl.; 2004.
115. Eriksson K. Det lidende menneske [The suffering man]. 2. udg. ed. København: Munksgaard; 2010.
116. Emanuel LL, Reddy N, Hauser J, Sonnenfeld SB. "And Yet It Was a Blessing": The Case for Existential Maturity. J Palliat Med. 2017;20(4):318-27.
117. Tarbi EC, Meghani SH. A concept analysis of the existential experience of adults with advanced cancer. Nursing outlook. 2019;67(5):540-57.
118. Godfrey-Smith P. Theory and reality : an introduction to the philosophy of science. Chicago, Ill: University of Chicago Press; 2003.
119. Polit D, Beck CT. Qualitative Data Analysis. In: Polit D, Beck CT, editors. Nursing Research Generating and assessing evidence for nursing practice Wolters Kluwer & Lippincott Williams & Wilkins; 2012. p. 557-81.
120. Moen K, Middelthon A-L. Chapter 10 - Qualitative Research Methods. In: Laake P, Benestad HB, Olsen BR, editors. Research in Medical and Biological Sciences (Second Edition). Amsterdam: Academic Press; 2015. p. 321-78.
121. Sacks H. Notes on methodology. Cambridge University Press; 1985. p. 21-7.
122. Menichetti J, Henselmans I, Noordman J, Landmark AM, Gerwing J, Hillen M, et al. Methods for analyzing actual communication: A shared decision making consultation under multiple methodological lenses. Patient education and counseling. 2021;104(10):2598-600.
123. Lie HC, Gerwing J, Bondevik H, Bostad I, Ellingsen D-M, Frühholz S, et al. Studying clinical communication through multiple lenses: The underused potential of inter-disciplinary collaborations. Patient education and counseling. 2022;105(6):1673-5.
124. Fossli Jensen B, Gulbrandsen P, Dahl FA, Krupat E, Frankel RM, Finset A. Effectiveness of a short course in clinical communication skills for hospital doctors: Results of a crossover randomized controlled trial (ISRCTN22153332). Patient Education and Counseling. 2011;84(2):163-9.
125. Helsedirektoratet [Norwegian Directorate of Health]. Kreft i tykktarm og endetarm – handlingsprogram [Colon and rectal cancer – action programme] [Available from: https://www.helsedirektoratet.no/retningslinjer/kreft-i-tykktarm-og-endetarm-handlingsprogram.
126. Antaki C. Applied Conversation Analysis : Intervention and Change in Institutional Talk. Antaki C, editor. Basingstoke: Palgrave Macmillan; 2011.
127. Sidnell J, Stivers T. The handbook of conversation analysis. Chichester, U.K. Malden, Mass.: Wiley-Blackwell; 2013.
128. Hepburn A, Bolden GB. The Conversation Analytic Approach to Transcription. In: Sidnell J, Stivers T, editors. The handbook of conversation analysis Oxford: Wiley-Blackwell; 2012. p. 57-76.
129. Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. Patient Educ Couns. 2002;46(4):243-51.
130. Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, De Haes H, Eide H, et al. Coding patient emotional cues and concerns in medical consultations: The Verona coding definitions of emotional sequences (VR-CoDES). Patient Education and Counseling. 2011;82(2):141-8.
131. Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing M, Cheung W-Y, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. Health Expect. 2005;8(1):34-42.

132. Gerwing J, Healing S, Menichetti J. Microanalysis of Clinical Interaction (MCI). In: Rossi MG, Bigi S, editors. A pragmatic agenda for healthcare: fostering inclusion and active participation through shared understanding: John Benjamins; 2023. p. xx (under review).

133. Bavelas J, Gerwing J, Healing S, Tomori C. Microanalysis of Face-to-face Dialogue. An Inductive Approach. In: Van Lear CA, Canary DJ, editors. Researching Interactive Communication Behavior : A Sourcebook of Methods and Measures. Los Angeles, California: SAGE; 2016. p. 128-57.

134. Henry SG, White AEC, Magnan EM, Hood-Medland EA, Gosdin M, Kravitz RL, et al. Making the most of video recorded clinical encounters: Optimizing impact and productivity through interdisciplinary teamwork. Patient Educ Couns. 2020;103(10):2178-84.

135. Healing S. Development of a Method of Analysis for Identifying an Individual Patient's Perspective in Video-recorded Oncology Consultations [Master og Science]. Victoria, Canada: University of Victoria; 2007.

136. Themessl-Huber M, Humphris G, Dowell J, Macgillivray S, Rushmer R, Williams B. Audio-visual recording of patient–GP consultations for research purposes: A literature review on recruiting rates and strategies. Patient Educ Couns. 2008;71(2):157-68.

137. Henry SGMD, Fetters MDMDMPHMA. Video Elicitation Interviews: A Qualitative Research Method for Investigating Physician-Patient Interactions. Ann Fam Med. 2012;10(2):118-25.

138. Gelbart B, Barfield C, Watkins A. Ethical and legal considerations in video recording neonatal resuscitations. J Med Ethics. 2009;35(2):120-4.

139. Henoch I, Danielson E. Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. Psycho-Oncology. 2009;18(3):225-36.

140. Bruce A, Schreiber R, Petrovskaya O, Boston P. Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering. BMC Nursing. 2011;10(1):2.

141. Murata H, Morita T. Conceptualization of psycho-existential suffering by the Japanese Task Force: The first step of a nationwide project. Pall Supp Care. 2006;4(3):279-85.

142. Gaignard ME, Hurst S. A qualitative study on existential suffering and assisted suicide in Switzerland. BMC Medical Ethics. 2019;20(1):<xocs:firstpage xmlns:xocs=""/>.

143. Sør-Øst H. Regional delstrategi for innføring av samvalg i Helse Sør-Øst. Innsatsområder og tiltak. 2023-2026.: Helse Sør-Øst; 2023 [Available from: https://helse-sorost.no/Documents/Helsefaglig/Samvalg/Delstrategi%20for%20innf%C3%B8ring%20av%20samvalg.pdf.

144. Dekkers WJM. Autonomy and dependence: chronic physical illness and decision-making capacity. Med Health Care Philos. 2001;4(2):185--92.

145. Kunneman M, Laidsaar-Powell R, Lie H, de Boer J, Moaddine S, Stiggelbout A, et al. O.4.3 - Patient readiness for shared decision making: A scoping review of qualitative literature: Presenter(s): Sascha Keij, Leiden University Medical Center, Netherlands. Patient education and counseling. 2023;109.

146. Mol A. The logic of care : health and the problem of patient choice. London: Routledge; 2008.

147. Agich GJ. Introduction. Dependence and autonomy in old age : an ethical framework for long-term care. Cambridge, UK New York: Cambridge University Press; 2003. p. 1-11.

148. Agich G. The liberal theory of autonomy. United Kingdom: United Kingdom: Cambridge University Press; 2003. p. 13-50.

149. Hargraves IG, Montori VM, Brito JP, Kunneman M, Shaw K, LaVecchia C, et al. Purposeful SDM: A problem-based approach to caring for patients with shared decision making. Patient Educ Couns. 2019;102(10):1786-92.

150. Finlay I. Foreword. In: Kissane DW, Bultz BD, Butow PN, Bylund CL, Noble S, Wilkinson S, editors. Oxford textbook of communication in oncology and palliative care. Oxford textbooks in palliative medicine: Oxford University Press; 2017.

151. Agledahl KM, Gulbrandsen P, Førde R, Wifstad Å. Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. Journal of Medical Ethics. 2011;37(11):650-4.
152. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. J Pain Symptom Manage. 2007;34.
153. Hargraves I, LeBlanc A, Shah ND, Montori VM. Shared decision making: The need for patient-clinician conversation, not just information. Health Aff (Millwood). 2016;35(4):627-9.
154. Falkum E, Førde R. Paternalism, patient autonomy, and moral deliberation in the physician–patient relationship: Attitudes among Norwegian physicians. Soc Sci Med. 2001;52(2):239-48.
155. Kissane DW, Bultz BD, Butow PN, Bylund CL, Noble S, Wilkinson S. Preface. In: Kissane DW, Bultz BD, Butow PN, Bylund CL, Noble S, Wilkinson S, editors. Oxford textbook of communication in oncology and palliative care. Oxford textbooks in palliative medicine: Oxford University Press; 2017.
156. Saunders C. The evolution of palliative care. J R Soc Med. 2001;94(9):430-2.
157. Frankel R. Getting the Most out of the Clinical Encounter: The Four Habits Model. The Permanente Journal. 1999.
158. Shapiro J, Robins L, Galowitz P, Gallagher TH, Bell S. Disclosure Coaching: An Ask-Tell-Ask Model to Support Clinicians in Disclosure Conversations. J Patient Saf. 2021;17(8):E1364-E70.
159. Tranøy KE. Medisinsk etikk i vår tid [Medical ethics in our time]. 4. utg. ed. Bergen: Fagbokforlaget; 2005.
160. Antonovsky A. Health, stress, and coping. San Francisco: Jossey-Bass; 1979.
161. Benner PE, Wrubel J. The primacy of caring: Stress and coping in health and illness. Reading, MA, US: Addison-Wesley/Addison Wesley Longman 1989.
162. Kristvik E. Livsviktig og underkjent; om det å være nærstående til ein som er alvorleg sjuk [Indisensable and under-recognized; about being close to someone who is seriously ill]. Syn og segn. 2012.
163. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet. 2003;361(9369):1603-7.
164. Cassel EJ. The Nature of Suffering and the Goals of Medicine. N Engl J Med. 1982;306(11):639-45.
165. Amonoo HL, Harris JH, Murphy WS, Abrahm JL, Peteet JR. The Physician's Role in Responding to Existential Suffering: What Does It Mean to Comfort Always? Journal of palliative care. 2019:825859719839332-.
166. Assing Hvidt E, Søndergaard J, Hansen DG, Gulbrandsen P, Ammentorp J, Timmermann C, et al. 'We are the barriers': Danish general practitioners' interpretations of why the existential and spiritual dimensions are neglected in patient care. Commun Med. 2017;14(2):108-20.
167. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. J Palliat Med. 2009;12(10):885-904.
168. Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. American family physician. 2001;63(1):81-9.
169. Blaber M, Jone J, Willis D. Spiritual care: which is the best assessment tool for palliative settings? Int J Palliat Nurs. 2015;21(9):430-8.
170. Cobb M, Puchalski CM, Rumbold B. Oxford textbook of spirituality in healthcare. Oxford: Oxford University Press; 2012.
171. Lundeby T, Wester T, Loge J, Kaasa S, Aass N, Grotmol K, et al. Challenges and Learning Needs for Providers of Advanced Cancer Care: Focus Group Interviews with Physicians and Nurses. Palliative Medicine Reports. 2020;1(1):28-215.
172. Kreftforeningen. Our Services. [Norwegian Cancer Society]. [Available from: https://kreftforeningen.no/en/our-services/.

173. Saeteren B, Lindström UÅ, Nåden D. Latching onto life: living in the area of tension between the possibility of life and the necessity of death: Latching onto life. Journal of clinical nursing. 2011;20(5-6):811-8.
174. van Deurzen E. Structural Existential Analysis (SEA): A Phenomenological Method for Therapeutic Work. In: Schulenberg SE, editor. Clarifying and Furthering Existential Psychotherapy: Theories, Methods, and Practices. Cham: Springer International Publishing; 2016. p. 95-113.
175. Kristvik E. "Grasping for the missing thread" On the (non-)issue of systematic discontinuity in the treatment of patients at the end of life In: Steele S, Caswell G, editors. Exploring issues of care, dying and the end of life. E-book: Inter-Disciplinary Press; 2011. p. 135-42.
176. Beisecker AE, Brecheisen MA, Ashworth J, Hayes J. Perceptions of the Role of Cancer Patients' Companions During Medical Appointments. Journal of psychosocial oncology. 1996;14(4):29-45.
177. Ferrell B, Wittenberg E. A review of family caregiving intervention trials in oncology: Family Caregiving in Oncology. CA: a cancer journal for clinicians. 2017;67(4):318-25.
178. Boehmer U, Clark JA. Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. Psycho-Oncology. 2001;10(2):147-55.
179. Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing Information and Decision Preferences of Men With Prostate Cancer and Their Partners. Cancer Nurs. 2002;25(1):42-9.
180. Eggly S, Harper FWK, Penner LA, Gleason MJ, Foster T, Albrecht TL. Variation in question asking during cancer clinical interactions: A potential source of disparities in access to information. Patient Educ Couns. 2010;82(1):63-8.
181. Laidsaar-Powell R, Butow P, Boyle F, Juraskova I. Facilitating collaborative and effective family involvement in the cancer setting: Guidelines for clinicians (TRIO Guidelines-1). Patient Educ Couns. 2018;101(6):970-82.
182. Polit D, Beck CT. Evidence-Based Nursing: Translating Research Evidence into Practice. In: Polit D, Beck CT, editors. Nursing Research Generating and assessing evidence for nursing practice Wolters Kluwer & Lippincott Williams & Wilkins; 2012. p. 25-47.
183. Gulbrandsen P, Jensen BF. Post-recruitment confirmation of informed consent by SMS. J Med Ethics. 2010;36(2):126-8.
184. Polit D, Beck CT. Data Collection in Qualitative Research. In: Polit D, Beck CT, editors. Nursing Research Generating and assessing evidence for nursing practice Wolters Kluwer & Lippincott Williams & Wilkins 2012. p. 533-55.
185. Hargreaves PN, Peppiatt R. Is videotaping of consultations acceptable to patients attending a hospice day centre? Palliat Med. 2001;15(1):49-54.
186. Parry R, Pino M, Faull C, Feathers L. Acceptability and design of video-based research on healthcare communication: Evidence and recommendations. Patient Education and Counseling. 2016;99(8):1271-84.
187. Noble H, Smith J. Issues of validity and reliability in qualitative research. Evid Based Nurs. 2015;18(2):34-5.
188. Rolfe G. Validity, trustworthiness and rigour: quality and the idea of qualitative research. J Adv Nurs. 2006;53(3):304-10.
189. Porter S. Validity, trustworthiness and rigour: reasserting realism in qualitative research. J Adv Nurs. 2007;60(1):79-86.
190. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification Strategies for Establishing Reliability and Validity in Qualitative Research. International journal of qualitative methods. 2002;1(2):13-22.
191. Tjora A. Kvalitative forskningsmetoder i praksis [Qualitative research methods in practice]. Oslo: Gyldendal Akademisk; 2010.
192. Lincoln YS. Naturalistic inquiry. Guba EG, editor. Beverly Hills, Calif: Sage; 1985.

193. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet. 2001;358(9280):483-8.
194. Polit D, Beck CT. Trustworthiness and Integrity in Qualitative Research. In: Polit D, Beck CT, editors. Nursing Research Generating and assessing evidence for nursing practice Wolters Kluwer & Lippincott Williams & Wilkins; 2012. p. 582-601.
195. Haraway D. Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. Feminist Studies. 1988;14(3):575-99.
196. Miller WL, BF C. Clinical research: a multimethod typology and qualitative roadmap. In: Crabtree BF MW, editor. Doing qualitative research. 2nd ed: Thousand Oaks: Sage Publications; 1999. p. 3-30.

Appendices

Article 1-3

Appendix 1	Definitions existential suffering
Appendix 2	Mind map existential challenge
Appendix 3	Codebook 1
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Appendix 5	Ethics approval from the Regional Ethics Committee

Article 1

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“Eh – What type of cells are these – flourishing in the liver?” Cancer patients’ disclosure of existential concerns in routine hospital consultations

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ABSTRACT

Objective: Advanced cancer poses a threat to all aspects of being, potentially causing existential suffering. We explore what kind of existential concerns patients with advanced cancer disclose during a routine hospital consultation, and how they communicate such concerns.

Methods: We analyzed thirteen video-recorded hospital consultations involving adult patients with advanced cancer. The study has a qualitative and exploratory design, using procedures from *microanalysis of face-to-face-dialogue*.

Results: Nearly all patients disclosed how the illness experience included losses and threats of loss that are strongly associated with existential suffering, displaying uncertainty about future and insecurity about self and coping. Patients usually disclosed existential concerns uninvited, but they did so indirectly and subtly, typically hiding concerns in biomedical terms or conveying them with hesitation and very little emotion.

Conclusions: Patients may have existential concerns they want to address, but they may be uncertain whether these are issues they can discuss with the physician.

Practice implications: Health professionals should be attentive to underlying existential messages embedded in the patient’s questions and concerns. Acknowledging these existential concerns provides an opportunity to briefly explore the patient’s needs and may direct how the physician tailors information and support to promote coping, autonomy, and existential health.

1. Introduction

Severe illness, such as advanced cancer, poses a threat to all aspects of being, and thus brings existential suffering to the ones affected [1–3]. This has implications for what kind of information and support the patients need to cope and to remain autonomous agents in their lives [4,5]. Person-centered care involves attention to the whole person, including existential concerns [6–8]; however, cancer patients report unmet existential needs [9].

Existential aspects of the illness experience involve not only the spiritual domain, but also the physical, psychological, and social dimensions of being [10]. An extensive literature review by Boston et al. found 56 different definitions of existential suffering used in palliative care settings, none of which was stringent or rigorous [11]. However, the authors identified various expressions associated with

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Table 1
Operational definitions.

Analytical concept	Definition
Patient utterance (=unit of analysis)	The smallest meaningful verbal expression from the patient, from as short as a single word to as long as a full sentence in the transcripts.
Patient centered utterance (Adopted from Sara Healing's framework for sorting patient utterances into five categories; small talk, generic response, biomedical, patient centered or other)	A question asking for information or implicitly asking the physician to confirm that the patient is understanding OR [a statement] containing information with an explicit indication from the patient whether or how the illness, treatment, side-effects, or symptoms are either (1) affecting the patient's life, (2) interfering with the patient's activities, or (3) tolerable to the patient, OR including information about the patient's hopes, dreams, plans, goals, preferences, decision-making-preferences, wishes, concerns or fears.
Existential utterance (Developed through research team discussions based on the emerging observations and the literature)	An utterance containing information about the illness/treatment being a threat to the person's physical, psychological, social or spiritual being, that is; loss or threat of loss of something/someone significant to the person OR expressions of illness related concerns, fears, uncertainty or vulnerability OR information about the person's hopes, dreams, goals or search for meaning.

existential suffering; for example, fear of death, fear of the future, physical decline, loss of self, loss of autonomy, loss of dignity, loss of relations, loss of social roles, dependency, lack of power, lack of trust and lack of/search for hope, meaning and purpose in life. Building on previous work by Yalom [12], Kissane summarized the major forms of existential challenge in a typology that includes death anxiety, loss and change, freedom with choice, dignity of the self, fundamental aloneness, altered quality of relationships, search for meaning, and mystery about what seems unknowable [1]. Others have emphasized more uplifting aspects of existential experience when seriously ill, such as increased sense of meaning and purpose and improved existential health, affecting quality of life in a positive way [13], as well as the possibility of "existential maturity" [14].

Due to its complex nature and conceptual ambiguity in the literature, Tarbi and Meghani conducted a comprehensive concept analysis to explore and clarify the full spectrum of "existential experience" in adults with advanced cancer [15]. They describe the *existential experience* as a dialectic movement between existential suffering and existential health, preceded by being confronted with one's own mortality and with the capacity for personal growth. Patients need to redefine their existence in relation to body, time, others, and death. Coping strategies may assist individuals in facing existential challenges and moving toward existential health, which is associated with positive thoughts and emotions such as hope, peace, gratitude, love, meaning and connectedness. Lack of coping, however, is associated with negative thoughts and emotions such as fear, uncertainty, regret, shame, hopelessness, anxiety, powerlessness, grief and loneliness [15].

Previous research has provided valuable insights through interview studies in which patients were asked explicitly about their existential experience following severe illness. To assist individuals in coping, clinicians need knowledge of how cancer patients communicate existential concerns in a clinical context [16,17]. We know from communication studies that patients in oncology consultations reveal fear, uncertainties and hopes indirectly and with minimal emotion [18], and that patients across diagnoses tend to raise their concerns using hints and cues, rather than explicit talk [19]. However, cancer patients' disclosure of existential concerns during routine medical encounters is still poorly investigated. The aim of this study is therefore to explore what existential concerns patients with advanced cancer disclose during a routine hospital consultation, and how they communicate those concerns.

2. Materials and methods

We analyzed video-recorded consultations involving patients with advanced cancer. The study has a qualitative and exploratory design, using analytical principles and procedures from *micro-analysis of face-to-face-dialogue (MFD)* [20], which enables a focused, inductive approach while being structured and systematic in the detailed examination of observable communicative behavior. MFD is based on two theoretical assumptions, that interlocutors use "both visible and audible communicative resources, which are tightly integrated with each other" and that "their actions must be understood as coordinated and mutually influential" [20].

2.1. Participants and study setting

In a previous project studying patient-physician-communication, 497 medical encounters were video-recorded [21] during 2007–08 at a large university hospital in the capital area of Norway, serving a population of around 500.000. In connection with this project, contextual information was collected (eg., whether the patient knew the doctor from before). The present study is situated in a broader program aiming to explore aspects of patient autonomy in case of advanced cancer, including patients' need for information and support. Two members of the research team (BHL and RF) inspected a sub-set of all recordings involving cancer outpatients (n = 33) and, for this study, decided to include only videos involving adult cancer patients having a poor or uncertain prognosis (n = 13); that is, the patients were in an incurable situation or in a situation with relapse.

2.2. Analysis

2.2.1. Transcripts, analytic unit, selection process, and definitions

The first author (BHL) transcribed the videos verbatim, additionally noting features of speech (e.g., gaps, pauses, breathing, laughter, emphasis), facial expressions and bodily conduct when these provided relevant additional information. We did analysis from both videos and the transcripts. The unit of analysis was each *patient* utterance.We interpreted the utterances in their immediate communicative context against the backdrop of what had been said so far, reflecting on why this patient is saying or asking this now.

To select relevant utterances, we applied Healing's inductively-derived definitions for types of information patients provide in utterances during oncology consultations: *patient-centered* vs. *biomedical* vs. *small talk* vs. *other*[20,22]. We focused subsequent analysis on patient-centered utterances, within which we expected to find existential information.

The operational definition used for identifying *existential utterances* was developed during research team discussions based on the emerging observations and review of the literature. See Table 1 for operational definitions and Table 2 for inclusion criteria. Fig. 1 illustrates the inclusion process.

The first author (BHL) was the primary analyst. To ensure analytical consistency, the second author (TL) coded the data independently, first identifying patient-centered utterances using one randomly selected video, then identifying existential utterances

Table 2
Inclusion criteria, existential utterance.

Criteria existential utterance	Example	Coding/assessment	Included
a) Content criterion: *according* to definition, AND b) Significance criterion (heaviness): considered *significant* to the person, AND c) Relevance criterion: *related* to the illness experience (including treatment)	*(No, I) don't want to be in hospital either, I just see that now (.) I' m having trouble (.) Yeah, it's awful when it…*	a) Yes: Loss of independence, need hospitalization b) Yes: Express trouble, wish to avoid hospital stay, may be long term/permanent c) Yes: Related to illness, symptom burden and function loss	Yes
	Then I was afraid that I might have eh become very (.) [D: addicted], addicted [D: yes] but I managed quite well	a) Yes: Loss of control, addiction b) No: Temporary, was worried (past), managed well, not worried now c) Yes: Related to treatment/ symptom management (morphine for pain)	No

Illustration of how we coded utterances according to the inclusion criteria for existential utterance. D = doctor. *We developed rules for assessing what emerged as significant to the individual patient, accounted for in the codebook.

using all 13 videos. We discussed all minor inconsistencies until arriving consensus. The first author translated quotes used for illustration from Norwegian to English and then two co-authors and a bilingual research assistant checked them for accuracy.

2.2.2. Analytic steps

We analyzed all existential utterances along two lines: according to *content* and according to *function and speech delivery*. For content, we first labeled existential utterances according to the topics raised on a *literal level* (e.g., malignant tumor, sense of not making it). Then we categorized them according to what emerged as significant to that specific patient in the context, that is the existential, often unstated *implications* (e.g., fatal disease, loss of control), and grouped those into main categories at a more *abstract level* (e.g., threat to life, threat to autonomy). Finally, we grouped the existential utterances according to *domain* (physical, psychological, social and spiritual).

For function and speech delivery, we categorized existential utterances according to whether the patient was *providing information* or *seeking information* from the physician. Then we noted details of *speech delivery.* These descriptive labels were not necessarily

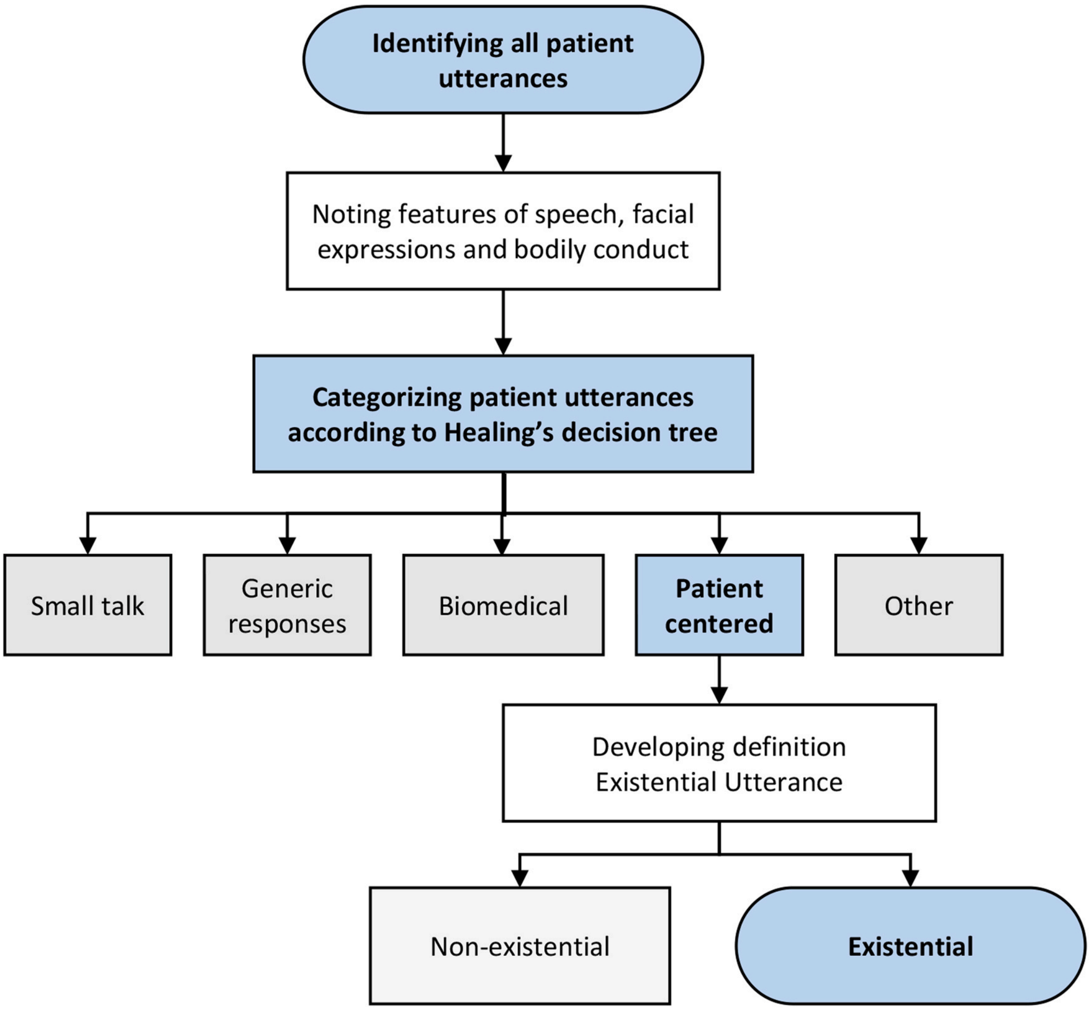

Fig. 1. Inclusion process, patients' existential utterances.

Table 3
Analytic steps, existential utterances.

WHAT existential concerns patients disclosed (content)					HOW patients disclosed existential concerns			
Patient utterance (Quote)	Topic (Literal level)	Sub category (Existential implications)	Category (Abstract level)	Domain	Function	Features of speech	Elicited by physician (yes/no)	Expression of emotions (yes/no)
Yeah 'cause it is malignant, isn't it,	Malignant tumor	Fatal disease	Threat to life	Physical	Seek info	In-direct Biomedical	No	No
(.) but e (.) just a few days ago I felt that (.) I won't make it,	Sense of not making it	Loss of control	Threat to autonomy	Psychological	Provide info	Explicit Pauses	No	No
No (.) I'm not disappointed (.) the way you think (.) but eh I'm just sad because (.) it was not possible to do anything	Sadness related to lack of treatment options	Fatal disease	Threat to life	Physical	Provide info	Explicit emotion Pauses	Yes	Yes (sad)

mutually exclusive. We also noted whether the existential utterance was *elicited by the physician*, and whether it was accompanied with any verbal or non-verbal *expression of emotion* (e.g., crying). Table 3 illustrates the analytic steps.

The analytic work was an iterative process between parts and whole, which provided increasingly deeper insight [23]. Throughout the process, we sought a reflective and critical attitude towards our own interpretation. As part of this process, the first author met with different groups of colleagues (from varying disciplines and practice orientations), a group of researchers who conduct inductive video analysis of clinical interactions using MFD-methodology. We developed a codebook describing the analytic process in more detail (available from the first author on request).

2.3. Ethical and privacy considerations

The study is part of a project that was approved by the Regional Committees for Medical and Health Research Ethics (REC) of South East Norway (project number 2018/474 D). Participants in all videos provided broad consent for use of the videos in further communication studies. All physicians are referred to as "she", and patients are given a pseudonym to protect their identity.

3. Results

The patients, ten male and three female, had various forms of advanced cancer, all living at home. Six patients did not know the doctor from before, six knew the doctor a little, and one patient knew the doctor well. The consultations lasted an average of 22 min and 14 s, and focused primarily on disease control and/or treatment assessment. See Table 4 for details about participants and contextual factors.

We identified a total of 1967 patient utterances in the encounters. As presented in Table 5, 658 were *patient centered*, showing that the patients actively displayed concerns, posed questions, and shared with the physician how the illness affected their life. High numbers of *generic responses* reflect that the patients also *received* a considerable amount of information. Few utterances being *small talk* and *other* indicate that the time was mainly used for discussing illness related topics. Within the category of patient-centered utterances, 127 fit the definition of *existential utterances.* Although the amount per consultation varied considerably (0–40), we identified existential utterances in all encounters except one. Table 5 provides an overview of different categories of patient utterances.

3.1. Existential concerns disclosed by patients

During these routine hospital consultations, patients disclosed how the illness constituted a threat to all aspects of being. As expected, none of the patients used the terms "existential", "threat" or "suffering", however, they expressed various losses and threats of loss of something significant to them, resulting from the illness or treatment and its consequences. Table 6 provides quotes and examples of existential topics raised by the patient.

The most prominent patient concerns were related to the illness being a *threat to life* itself. It also became apparent that illness posed a *threat to a good life*, as several patients expressed concern about current or future ailments. Some patients conveyed that symptoms like pain, nausea or breathlessness reminded them of their dire situation. Patients also expressed worry related to function loss or changed appearance (weight loss, sexual dysfunction, hair loss and fatigue) preventing them from being the person they used to be, thus disclosing a *loss of self.* Across the encounters, there were utterances testifying to *loss of autonomy, independence, and control,* as patients who were accustomed to relying on themselves now expressed insecurity about their ability to cope. One patient explicitly expressed that the illness affected his decision-making capacity (Table 6, Example 12).

Patient utterances testified that the illness also posed a *threat to personal relations* and *social roles.* Some patients expressed worry about their loved ones, without explicitly mentioning the impending separation. Others revealed that close relationships had been altered due increased dependence on their next-of-kin. One patient expressed concern about the possible prospect of not being able to work. The patients' awareness of their *dependency in the patient-physician relation* sometimes became apparent through their requests for information and support (Table 6, Example 19). Several patients expressed that having trust in the physician was profoundly important to them, yet not something they took for granted. None of the patients displayed any mistrust in the current physician. However, several patients expressed a *lack of trust* in other health personnel or institutions due to previous experiences.

Few patients explicitly expressed their hopes, dreams, goals or search for meaning. Still, many of them disclosed a hope for (better) *disease control*, and/or *symptom control.* Thus, hope was closely related to available treatment options. None of the patients expressed how religious beliefs or other convictions affected their perceptions of life and death, or their coping.

3.2. How patients disclosed existential concerns

3.2.1. Uninvited, yet hesitantly

Although there were examples of physicians eliciting existential concerns, it was more common for patients to bring them up. Yet, they often did so with some degree of hesitation, observable through *features of speech* and *body gestures.* Examples of such speech delivery were: taking a breath or clearing the throat before "claiming the floor", stuttering, speaking rapidly, pausing within own turn of speech, whispering/using a low voice or suddenly cutting off, followed by restarting or abandoning own utterance. Similarly, *body gestures* displaying discomfort, like: sitting uneasily, frowning, pulling hand over face or gazing away. Such non-verbal signs were

Table 4
Patient characteristics.

Pseudo-nym	Age	Diagnosis and received therapy	Reason for attendance and contextual factors
Miriam	20–29	Cancer in head and neck area Radiation Chemotherapy	Control after oral infection (due to cancer treatment). Fatigue and swallowing difficulties affects her daily life. Miriam disclosed worry about the need for additional radiation. Lives with her parents.
Carl	80–89	Kidney cancer	Assessment for surgical removal of large renal tumor, which the physician strongly recommends. Carl is skeptical. He now lives an active life and he is worried that complications will affect his condition.
Peter	60–69	Cancer prostate Radiation	Control after radiation, stopped the treatment before it was completed due to side-effects. Peter is worried about test results. Fatigue and impaired sexual function affect his well-being.
John	60–69	Gastric cancer, bone metastases Radiation Surgery (?)	Discussion about further treatment. Undergone radiation with less effect than one hoped for. Clear signs of advanced cancer. John suffers from severe weight loss, pain, nausea and fatigue. He feels that he won't tolerate more cancer treatment, and he is worried that he can no longer manage himself.
Christian	60–69	Colon cancer, liver metastases Surgery Chemotherapy	Assessment for further treatment. Christian has noticed tumor growth lately, he is concerned because it has grown rapidly. Physician recommend radiation although it will only shrink the tumor temporarily.
Karen	40–49	Colon cancer, lung metastases Surgery Radiation	Assessment for chemotherapy tablets, newly detected lung metastases. Severe intestinal side-effects after radiation. Karen is concerned about the effect of treatment and the risk of further side-effects. She is worried about function loss and looking ill. Wants to protect her child from talk about the disease.
Roger	60–69	Lung cancer Surgery Chemotherapy	Control of cancer progression. Roger is fully aware that his condition is fatal, is concerned with living as normally as possible. Just got back from a vacation with his wife and friends.
Olav	70–79	Colon cancer, liver metastases Surgery	Control of cancer progression. Is informed that the liver is full of metastases. Asks a lot about available treatment options but learns that there are none. John express worry about the time ahead, future symptoms, and how the doctor will follow him up. He is concerned about his wife and son.
Eric	70–79	Myelomatosis Chemotherapy	Control, assessment of further treatment. May reduce treatment due to disease regression, however, high probability that the disease will progress again. Eric has bothersome symptoms and side-effects; dyspnea, persistent runny nose, jaw pain, poor appetite, and problems drinking.
Thomas	50–59	Lung cancer Surgery Chemotherapy	Control after surgery. Severe diagnosis, stable now, but high risk of relapse. Thomas experience fatigue, sleeping problems, and shortness of breath, otherwise in good condition. He asks many questions about the disease and what is normal.
Anne	50–59	Pancreatic cancer, adrenal gland metastases Chemotherapy	Control, assessment of further treatment. Anne reveals early that she knows tumor is growing, linking it to increasing back pain. Concerned about her increased need for pain killers and what to do with the tumor.
Frank	70–79	Colon cancer, brain metastases Surgery, colon and brain	Control, additional radiation is already decided. Communication primarily between physician and Frank's wife about medical and practical issues. Frank is very quiet, but occasionally he breaks in with relevant comments.
Roy	60–69	Kidney cancer, bone and lung metastases Surgery Chemotherapy	Control, consideration of changing therapy. Roy is very grateful that bone metastases have receded, he feels privileged. Roy wants to switch therapy due to intensely bothersome side effects in skin. Physician is skeptical due to risk of reduced effect.

notably less present when the utterance contained more neutral information. In some cases, the patients displayed existential concerns with increasing clarity; as if they were "trying the floor" with subtle or in-direct questions at first, and then gradually becoming clearer and more specific when encouraged to elaborate. A quote from Karen can illustrate this. While the physician and Karen's husband engaged in small-talk and jokes about people from his home country, Karen interrupted with a question disclosing her concerns about her future prospects (Table 6, Example 4).

3.2.2. Subtle and in-direct

Existential utterances were rarely explicit and unequivocal; rather, they were often implicit, subtle, and indirect. For example, none of the patients explicitly expressed fear of death or dying, instead they chose other words when touching upon their uncertain future. Karen, for example, expressed concern about the possibility of *"not getting well"*. When Olav, atypically, uttered an explicit expression of grief, he chose the words, being *"sad because (.) there was nothing to do about it*", referring to the lack of treatment options.

3.2.3. Wrapped up in biomedical terms

Although we found all the existential utterances within the ones coded patient-centered, many of them were still wrapped up in biomedical terms. We also found that patients often displayed their existential concerns through what information they sought from the physician. Concerns about disease progression and how it would affect the patient's life, typically became apparent through questions about test results, tumor growth, or treatment options. Olav for example, frequently used medical terms in his questioning, as in this example, "*Eh (.) what type (of cells) are these, and (.) which one of those (.) eh flourishing in the liver is this, is it the most dangerous, or is it the mildest ones, or (.)?"*. Given the grave news he just received about multiple liver metastases, one can fairly assume that his question is not primarily rooted in an academic interest about cellular growth. Additionally, his use of the term "dangerous" positions cellular growth in relation to himself (dangerous *to him*), disclosing a concern about his future prospects. Olav rephrases his questions in various ways, repeatedly signaling a need to know what will happen to him and what to expect in the future: how quickly his condition will progress, how much time he has left, how the physician intends

Table 5
Overview of patient utterances.

Categories of Patient utterances	Short definition	No	(%)
Biomedical	Neutral information about illness, symptoms, treatment or procedures	284	14
Patient-centered	Questions, concerns, or information about how the illness affect their life	658	34
Existential	Information about the illness being a threat to any aspect of the patient's life, (threat of) loss of something significant, concerns, fears, hope	(127)	(6)
Generic response	Showing that (s)he understands or is following what the other speaker said, e.g. *"aha", "yeah", "mm"*	792	40
Small talk	E.g. talking about the weather or where you were born	75	4
Other	Incomplete meaning units or utterances not fitting any other definition	158	8
Total		**1967**	**100**

Table 6
Quotes - illustrations[1] of existential categories.

Main category	Sub category	Quote (patient utterance)	Ex. No
PHYSICAL BEING – UNCERTAINTY ABOUT FUTURE			
Threat to life (being alive)	Fatal disease	*Yeah ‘cause it is malignant, isn’t it,*	1
		I'm a little excited (anxious) about those blood tests and see if it has (.) [D: e yes] if it has gone down (.) [D: yes] the p- [D: yes] the PSA (tumor marker) so,	2
		So:: (.) what to do then (.) to (.) to (.) keep this in check for as long as possible, are these types of (.) of ehm eh of cells that multiply fast? (.) Will it go slowly (.) is there any (.) hope of treatment with something (.) that is at the research stage (.) that is coming?	3
		But e:: (.) I just have to ask because, he eh (.) ((Clears her throat)) there is one thing I've thought about a lot, and that is eh he (Surname) said that eh one of the tu- yeah. The biggest tumor wasn't more than eh one and a half centimetres something like that [D nods].hhh and that's nothing, (.) he says [D nods].hhh e e is it e (.) >I just have to ask like< a::re the:re e >any chances that I will get well?< (3 s) chances, >I’m not saying that I will< get well, but are there any chances that I will get well?	4
Threat to a good life	Symptom burden	*Well, I can’t handle much more nausea now than what I’ve had, it (.) It goes without saying*	5
		because as this develops over time, I will get (…) get eh (.) hmm (.) get eh (.) symptoms of it (.).	6
		(The pain) it reminds me of it, it keeps me in-	7
	Loss of function/ physical decline	*And tha::t (.) I don’t like very much_ I struggle a lot to try to maintain weight. Nothing has any flavor and (…) and e (.) yeah (…) (I) almost get a bit discouraged*	8
		(.) so e e there were many who had so much tingling (chemotherapy induced neuropathy) and who lost mobility in their fingers and toes, (.).hhh that they became disabled .hhh and so I think (.) will I be disabled in addition to maybe not getting well? I don’t want that.	9
PSYCHOLOGICAL BEING – UNCERTAINTY ABOUT SELF AND COPING			
Threat to identity/self	Loss of self	*(cause), e when I take medicine as a medicine, I feel that (.) I’m sick*	10
		So (I’m) not used to (.) or what, (usually) very good (sexual function) ((laughter)) [Doc: yes]. (It is) with me too you know [Doc: Yes (.) right] and if e it becomes like- (…) [Doc: yes] (…) gone then e that affects (you) mentally too	11
Threat to autonomy	Loss of capacity	*No:: we haven’t really done that (thought about further treatment), cause (.) I haven’t thought any further than from day to day, and- I’ve (.) hardly had the energy for that […] But I don’t kno- don’t know what to think about really (.) Wha::t*	12
	Loss of control	*(.) but e (.) just a few days ago I felt that (.) I won’t make it,*	13
	Loss of independence	*No, it's not good (…) so (…) eh I'm (…) I'm a little worried really because I see that I can’t can’t handle it myself*	14
SOCIAL BEING – SEPARATION, DEPENDENCY AND FRAGILE TRUST			
Threat to personal relations	Separation	*Well, well, well, well (.) there are someone at home who are very anxious too you know (Referring to his wife and son)*	15
	Altered relations	*And I (.) who is (usually) driving my mom around, here and there and all such things, you know [D: Yes] So:: (cannot drive anymore due to opioid use)*	16
Threat to social roles	Work life	*So, if I can handle working, then I can work? (Repeatedly returning to this issue)*	17
Dependency and fragile trust in pat-provider relation	Dependency	*No, I (.) was about to say (.) do I (.) do I need help from the hospital (.) to (.)?*	18
		Yes (.) I would prefer to (.) continue to come to you (for follow up) (.) (.) if you’re willing	19
	Lack of trust	*.hhh I'll <u>never</u> ever go there (hospital department)*	20
SPIRITUAL BEING – SEARCH FOR MEANING AND HOPE			
Search for hope	Hope related to disease control	*Hmm (3–4 s) I had hoped for that (surgery) because (name of the surgeon) told me that they had found some like that in (.) the (.) eh right (liver)lobe*	21
	Hope related to symptom control	*I had somehow hope- (.) had a hope that it would get better (.) [D: yes] less pain and things like that, but that didn’t (.) work out yet*	22
Search for meaning	Acceptance	*Well, well (.) We:: eh (.) we’ve got to be happy with what we have (.)*	23
	Perspective	*Well, well (.) It's probably worse for people sitting here who are fifty years younger*	24

[1] All illustrative utterances considered existential based on the inclusion criteria (accounted for in the method Section 2.2.1. and the codebook) and the context in which the utterance was expressed. [2]Explanation of signs: (.) = micro-pause;.hhh = in-breath; > word < = speeding up; < word > = speeding down; a:: = prolongation of sound; wor- = cut off.

to follow-up, and how future symptoms will affect him (Table 6, Example 3 and 6).

3.2.4. Displaying little emotions

Despite their grave situation, the patients displayed very little emotion and none cried openly. There were a few exceptions; for example, John explicitly said he was worried, Miriam expressed fear, and Olav reported that the situation made him sad. More typically, patients commonly *downgraded* their emotional distress, for example, through what could be considered understatements from the context, as John when he states, “*It’s no fun*”, or, *“I’m a little worried”* while it was obvious from the context that he was suffering greatly. Another example is Miriam, who despite all her ailments, smiles a lot and repeatedly reduces her complaints, “*Otherwise, it’s going well”,* and, “*It’s not that bad”.*

Another phenomenon, observed in some of the encounters, was the occurrence of laughter when talking about serious topics. For example, in this case when the physician (atypically) invited a patient with lung cancer to reflect on his situation by declaring, “*It is-, after all, it is a serious illness*”, and the patient responds, “*Yeah, it is lethal ha ha (laughter)”.*

4. Discussion and conclusion

4.1. Discussion

In routine hospital consultations, the patients in this study revealed how the cancer experience affected all aspects of life, leading to losses and threats of loss that are strongly associated with existential suffering [11,15]. Only a few patients conveyed how they reoriented in search for new meaning and hope (e.g., Table 6, Example 23 and 24), which is associated with coping [1] and existential health [15]. Existential utterances were usually patient-initiated. However, rather than being explicit and unequivocal, they were indirect and subtle. Patients disclosed them in biomedical terms, stated them with hesitation, displaying very little emotion.

4.1.1. Uncertainty about future, self and coping

In previous research, patients have described terminal diagnosis as an “existential turning point” leading them to become mindful that their life is threatened and that existence is no longer secure [15]. Cancer patients have also reported that symptoms or side effects disrupted their daily life and activities, and reminded them of their “fragile situation and impending death“ [24](p. 587). For clinicians, this is something to bear in mind when patients ask about tumor growth, test results and other signs of disease progression or disclose concerns about symptoms and function loss.

Patients in this study revealed that physical changes (e.g, weight loss, hair loss, impaired sexual function, and fatigue) affected how they viewed themselves. Such profound loss “of the person we know ourselves to be” may lead to uncertainty, meaningless, grief, and loneliness [25] (p. 141). Challenges related to identity and being unable to cope may cause existential suffering, and “disturb the entity of body, soul and spirit” [9](p.816). The fact that severe illness may affect autonomy was evident in John’s statement, disclosing that he lacked the energy to think beyond day-by-day (Table 6, Example 12). Being expected to participate in treatment decision-making did not seem to enhance his sense of being empowered; rather, he seemed quite overwhelmed and confused. There are two basic conditions for autonomous choice: voluntariness and agency [26]. Severe illness may affect both, as freedom of choice may be limited [27] and decision-making capacity may be reduced [5]. Importantly, this is not an argument against shared decision-making in case of advanced cancer. Although John lacked the energy to think of treatment options, his values and preferences were not less relevant. He had stated that his highest priority was better symptom control, important information available for the physician to include in her judgement without leaving the decision responsibility to him. Patients in this study revealed uncertainty about future, about self and coping. This related to both contextual and personal factors, as illness brought them into a situation of non-control, simultaneously experiencing loss of independence.

4.1.2. Communication about existential concerns

It is previously known that patients often raise their concerns indirectly and with minimal emotion [18], using hints and cues [19], as observed in these encounters. What our study adds to former observations is the patients’ often hesitant revealing of existential concerns and their tendency to wrap them up in biomedical terms. In natural conversations, hesitation markers such as pauses and small words like *uh*, *hmm* or *umm* interrupting or delaying the flow of speech, typically occur when speakers struggle with the cognitive planning of their own turn of speech [28]. Simultaneous occurrence of laughter, seen in some of the encounters, is also a known indicator of delicate topics [29]. This study does not provide clear answers to why patients hesitate. One explanation, however, may be that they are unsure whether these are issues they can discuss with a physician. Patients reporting of existential neglect from health personnel [9] supports this notion. The traditional, yet still dominant, structure of the medical interview, with the physician collecting the information needed to diagnose and treat the patient [16,17], may leave the patient with the impression that there is little room for issues that do not fit into this pattern. The patients’ tendency to raise existential concerns wrapped up in biomedical terms and questions may point in that direction. The power imbalance embedded in the physician-patient relationship may cause the patients to feel not in a position to set the agenda [30], and fear of being rejected may increase their sense of vulnerability.

Living with severe illness, with bothersome symptoms and various losses, most likely heading towards an impending death (without knowing when or how), is a scary journey in unfamiliar territory [3]. Coping when on this journey, still remaining in the driver’ seat in one’s own life, requires new understanding and new skills [4]. Physicians may play an important role in this respect, for example as providers of information, as knowledge helps promote mastery [1,31]. Learning about the expected course of illness, including the dying process, and available help and support along the way, may promote hope and courage, and thus help the patient prepare for death and time ahead [1]. Interview studies has shown that patients want to discuss these issues with health personnel [9,25]. However, as patients’ needs may vary and change during the course of illness [32], tailoring such communication to the individual patient’s current needs is crucial. Reflecting on, “Why is the patient asking or saying this now?”, and “What might he actually be worried about?” may increase awareness about the patient’s underlying worries. The physician showing interest in or recognizing what the patient is sharing may be, in itself, healing. Acknowledging existential concerns enables the physician to explore the patient’s needs, simply by asking. While some patients may get the support they need from family and friends, others may want the physician to provide information about the time ahead, or may wish to speak with a professional with expertise supporting patients who are dealing with emotional and existential distress (e.g., a chaplain or a psychiatric nurse).

4.1.3. Strengths and limitations

This study is based on video-recordings from one single hospital, with patients living independently at home; we do not claim our findings fit all cancer patients across geographical and cultural boarders. Of the 13 patients, only one had minority background. Since the videos were collected, there has been an increasing focus on communication and ethics in the education of medical students and doctors. Nevertheless, how patients communicate existential concerns has still received little attention in Norway. There is little reason to believe that patients' communication behavior has changed significantly. Due to the lack of an established definition of what constitutes “existential information” in this context, we developed an operational definition based on research to date, which we found to capture the existential experience of severe illness, without being too comprehensive for practical use. When doing analysis of video-recordings, there is an inherent danger of over interpretation, which we addressed by taking several measures (accounted for in the method section and the codebook). By using both videos and transcripts, we could revisit utterances repeatedly in context, sort and compare according to analytical decisions, and discuss any doubts and ambiguities. The repeated alternation between parts and the whole provided increasing and deeper understanding.

4.2. Conclusion

Patients with advanced cancer face existential challenges due to various losses and threats of loss. This study provides novel insight on the nature of how patients communicate their existential concerns to physicians during routine consultations. Existential utterances were often indirect and subtle, typically hidden in biomedical terms, often delivered with hesitation, displaying very little emotion. Our findings suggest that patients may have existential concerns they want to address, but they may be uncertain whether these are issues they can discuss with the physician.

Future research is needed to identify possible barriers to raising existential concerns in medical consultations. Consensus on a valid definition of what constitutes “existential” is needed; this article constitutes a contribution on which others can build. How physicians respond to patients' existential utterances is still an open question. Finally, the patients’ voice is needed regarding how they strive for existential health while facing fundamental threats not just to their life, but to who they are.

4.3. Practice implications

Physicians and other health professionals should be attentive to underlying existential concerns that may be embedded in patients' questions and concerns. Acknowledging these existential concerns provides an opportunity to explore the patient's needs, which, even if brief, may help the physiciantailor information and support to promote coping, autonomy, and existential health. When appropriate, the physician can refer to professionals that have expertise in existential and emotional support.

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CRediT authorship contribution statement

Berit Hofset Larsen: Conceptualization, Methodology, Formal analysis, Writing – original draft, **Tonje Lundeby:** Conceptualization, Validation, Writing – review & editing, **Jennifer Gerwing:** Methodology, Validation, Writing – review & editing, **Pål Gulbrandsen:** Conceptualization, Methodology, Resources, Writing – review & editing, **Reidun Førde:** Conceptualization, Analysis, Writing – review & editing, Supervision, Project administration.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

[1] Kissane DW. The relief of existential suffering. Arch Intern Med 2012;172(19):1501–5.

[2] Bruce A, Schreiber R, Petrovskaya O, Boston P. Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering. BMC Nurs 2011;10(1):2.

[3] Hvidt EA. The existential cancer journey: travelling through the intersubjective structure of homeworld/alienworld. Health 2017;21(4):375–91.

[4] Weimer S. Evidence-responsiveness and the ongoing autonomy of treatment preferences. HEC Forum 2018;30(3):211–33.

[5] Gulbrandsen P, Clayman ML, Beach MC, Han PK, Boss EF, Ofstad EH, et al. Shared decision-making as an existential journey: Aiming for restored autonomous capacity. Patient Educ Couns 2016;99(9):1505–10.

[6] Piderman KM, Kung S, Jenkins SM, Euerle TT, Yoder TJ, Kwete GM, et al. Respecting the spiritual side of advanced cancer care: a systematic review. Curr Oncol Rep 2015;17(2):1–9.

[7] Saunders C. The evolution of palliative care. J R Soc Med 2001;94(9):430–2.

[8] Henoch I, Danielson E. Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. Psycho-Oncol 2009;18(3):225–36.

[9] Saeteren B, Lindström UÅ, Nåden D. Latching onto life: living in the area of tension between the possibility of life and the necessity of death: Latching onto life. J Clin Nurs 2011;20(5–6):811–8.

[10] van Deurzen E. Structural Existential Analysis (SEA): a phenomenological method for therapeutic work. In: Schulenberg SE, editor. Clarifying and furthering existential psychotherapy: theories, methods, and practices. Cham: Springer International Publishing; 2016. p. 95–113.

[11] Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. J Pain Symptom Manag 2011;41(3):604–18.

[12] Yalom ID. Existential psychotherapy. New York: Basic; 1980.

[13] Cohen SR, Mount BM, Tomas JJN, Mount LF. Existential well-being is an important determinant of quality of life: evidence from the McGill Quality of Life Questionnaire. Cancer 1996;77(3):576–86.

[14] Emanuel LL, Reddy N, Hauser J, Sonnenfeld SB. "And yet it was a blessing": the case for existential maturity. J Palliat Med 2017;20(4):318–27.

[15] Tarbi EC, Meghani SH. A concept analysis of the existential experience of adults with advanced cancer. Nurs Outlook 2019;67(5):540–57.

[16] Mishler EG. The discourse of medicine: dialectics of medical interviews. Greenwood Publishing Group; 1984.

[17] de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns 2009;74(3):287–94.

[18] Beach WA, Dozier DM. Fears, uncertainties, and hopes: patient-initiated actions and doctors' responses during oncology interviews. J Health Commun 2015;20(11):1243–54.

[19] Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, De Haes H, Eide H, et al. Coding patient emotional cues and concerns in medical consultations: the Verona coding definitions of emotional sequences (VR-CoDES). Patient Educ Couns 2011;82(2):141–8.

[20] Bavelas J, Gerwing J, Healing S, Tomori C. Microanalysis of face-to-face dialogue. An inductive approach. In: Van Lear CA, Canary DJ, editors. Researching interactive communication behavior: a sourcebook of methods and measures. Los Angeles, California: SAGE; 2016. p. 128–57.

[21] Fossli Jensen B, Gulbrandsen P, Dahl FA, Krupat E, Frankel RM, Finset A. Effectiveness of a short course in clinical communication skills for hospital doctors: Results of a crossover randomized controlled trial (ISRCTN22153332). Patient Educ Couns 2011;84(2):163–9.

[22] Healing S. Development of a method of analysis for identifying an individual patient's perspective in video-recorded oncology consultations [master of science]. Victoria, Canada: University of Victoria; 2007.

[23] Polit D, Beck CT. Nursing Research. Generating and assessing evidence for nursing practice. Wolters Kluwer & Lippincott Williams & Wilkins; 2012.

[24] LMSWP Sand, MMSWP Olsson, Strang PMDP. Coping strategies in the presence of one's own impending death from cancer. J Pain Symptom Manag 2009;37(1):13–22.

[25] Adorno G, Brownell G. Understanding quality-of-life while living with late-stage lung cancer: an exploratory study. J Soc Work End Life Palliat Care 2014;10(2):127–48.

[26] Beauchamp TL, Childress JF. Principles of biomedcal ethics. eighth ed. Oxford: Oxford University Press; 2019.

[27] Agledahl KM, Førde R, Wifstad A. Choice is not the issue. The misrepresentation of health care in bioethical discourse. J Med Ethics 2011;37:212–5.

[28] Boonsuk Y, Ambele EA, Buddharat C. Position of hesitation markers in everyday, informal conversation in English. ABAC J 2019;39(3):129–40.

[29] Haakana M. Laughter as a patient's resource: Dealing with delicate aspects of medical interaction. Text Talk 2001;21(1):187–219.

[30] Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. BMJ 2014;348(may14 7). g3178-g.

[31] Hvidt EA, Ammentorp J, Sondergaard J, Timmermann C, Hansen DG, Hvidt NC. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. Scand J Prim Health care 2018;36(2):142–51.

[32] Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. Soc Sci Med 2005;61(10):2252–64.

Article 2

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Physicians’ responses to advanced cancer patients’ existential concerns: A video-based analysis

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ABSTRACT

Objective: In a recent study, we explored what kind of existential concerns patients with advanced cancer disclose during a routine hospital consultation and how they communicate such concerns. The current study builds on these results, investigating how the physicians responded to those concerns.
Methods: We analyzed video-recorded hospital consultations involving adult patients with advanced cancer. The study has a qualitative and exploratory design, using procedures from microanalysis of face-to-face-dialogue.
Results: We identified 185 immediate physician-responses to the 127 patient existential utterances we had previously identified. The responses demonstrated three approaches: giving the patient control over the content, providing support, and taking control over the content. The latter was by far the most common, through which the physicians habitually kept the discussion around biomedical aspects and rarely pursued the patients’ existential concerns.
Conclusions: Although the physicians, to some extent, allowed the patients to talk freely about their concerns, they systematically failed to acknowledge and address the patients’ existential concerns.
Practice implications: Physicians should be attentive to their possible habit of steering the agenda towards biomedical topics, hence, avoiding patients’ existential concerns. Initiatives cultivating behavior enhancing person-centered and existential communication should be implemented in clinical practice and medical training.

1. Introduction

Existential suffering “develops from the threat to life or injury to the self with resultant in distress, grief at loss, emerging helplessness, and likelihood that this situation will endure” [1] (p. 1). Advanced cancer may bring existential suffering to those affected. Uncertainty, vulnerability, and dependency are thus commonly part of the illness experience [2]. Moreover, existential suffering is associated with reduced quality of life, anxiety and depression, suicidal thoughts, and desire for hastened death [3]. Such heavy impact on patient well-being has implications for oncology care.

Existential aspects of life involve all dimensions of being [2,4,5]. In a recent study, we explored what kinds of existential concerns patients with advanced cancer disclose during routine hospital consultations, and how they communicate such concerns [6]. To identify patients’ existential utterances, we had developed an operational definition based on a literature review and the emerging data analysis. In short, we looked for utterances conveying that the illness or treatment posed a

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threat to the person's physical, psychological, social, or spiritual being, i.e., losses or threats of loss of something or someone significant to the person. We identified a total of 127 existential utterances in 12 of the 13 encounters we analyzed [6]. Most existential concerns were related to the illness being a threat to life itself, however, patients also conveyed threats to a good life (e.g., due to symptom burden, function loss), to identity, autonomy, and relations. The patients displayed uncertainty about the future, uncertainty about self and coping, dependency on others, and their search for hope and meaning. Importantly, existential concerns were rarely explicit; instead, patients expressed them hesitantly, subtly, and indirectly, typically wrapped up in biomedical terms and accompanied by little emotional display.

Traditionally in clinical practice, existential aspects of illness have been defined as outside the scope of medical responsibility [7], as a task assigned for the chaplaincy. An increasing number of scholars, however, have argued that physicians can and should play a role in attending to the patient's existential concerns [1, 2, 8–11], as part of person-centered care [12]. For many patients attempting to orient the unfamiliar territory of illness, the physician is an important (perhaps the only) guide. The relief of suffering, in a way that respects patient autonomy and enhances coping, is a salient goal in clinical practice and particularly important in chronic and life-threatening conditions. Communication is at the heart of implementing this care [13]. How physicians respond to patients disclosing their existential concerns constitutes key moments in the dialogue, which has received little attention in research, clinical practice, and medical training. Previous research has shown that early-stage cancer patients who had expressed uncertainty and fear were met with biomedical information in response [14]. Still, we have limited knowledge of how communication around existential concerns play out in consultations involving patients with advanced cancer. Thus, the aim of this study is to explore how physicians respond to patients' uttered existential concerns during routine oncology visits.

2. Methods

The study had a qualitative and exploratory design, using analytical principles and procedures from microanalysis of face-to-face-dialogue (MFD) [14]. This method involves detailed examination of observable communicative behavior and allows researchers to build a structured, systematic, and quantifiable analysis from initial inductive observations.

2.1. *Participants and study setting*

Drawing from a video corpus that had been collected at a large university hospital in Norway during 2007–08 as part of a project studying patient-physician-communication [15], we selected all routine outpatient consultations involving advanced cancer patients with a poor or uncertain prognosis. The selected videos involved 13 patients and five physicians. We have previously described the selection process and the patients in detail [6]. The physicians, three males and two females, belonged to five different departments. The consultations focused mainly on disease control or treatment, with an average duration of 22:14 min (09:22–41:57).

2.2. *Analysis*

MFD is based on the theoretical assumptions that both audible and visible behaviors influence how interlocutors interpret each other [16]. Thus, the first author (BHL) transcribed the videos verbatim (in Norwegian), additionally noting features of speech, facial expressions, and bodily conduct when these provided relevant additional information. The analysis is based on both videos and transcripts. The entry point for analysis was the 127 patient utterances that we had identified as conveying existential information [6]. For the present analysis, we examined the physicians' responses, which we defined as the immediate utterance(s) reacting and orienting to the patient's existential utterance. Excerpt 1 presents such responses to the patient's existential utterance, spanning lines 355, 357, and 359. The blood tests that the patient refers to (PSA) are tumor markers for prostate cancer, and thus indicate progression of a fatal disease.

As demonstrated here, utterances from the patient and the physician could be intertwined, as patients sometimes conveyed their meaning in short instalments, punctuated by brief listener responses. The excerpt includes two such responses ("yes" in lines 356 and 358) and a substantive response spanning lines 360 and 362.

We took a descriptive approach, analyzing the physician-responses along two lines: according to the *interactional function* they served in that moment (e.g., providing information,) and according to *content* (what the physicians chose to pursue). For content, we analyzed in two steps. The first ("topic choice") related the physician's response to what the patient had said along three levels of meaning: the literal (e.g., worry about test results), the existential implications for the patient's life (e.g., potential progression of fatal disease), and the more abstract, existential concept (e.g., threat to life). The second step dealt with the substance of the physician-response, which we categorized according to Sara Healing's framework distinguishing between: small talk, generic responses, biomedical content, or patient centered content [17]. See Table 1 for definitions of these content categories, and Fig. 1 for illustration of analytic steps.

Initially, two members of the research team (BHL and RF) inspected the videos repeatedly. The first author (BHL) conducted all coding and the second author (TL) reviewed all the responses independently. Then, the two discussed coding doubts and ambiguities until they reached consensus. The last author (JG) participated in the last refinement of categories. The whole research team engaged in discussions about the analytic process and the derived categories. BHL documented the analytic choices in a codebook guiding subsequent decisions. The codebook is available from the first author (BHL).

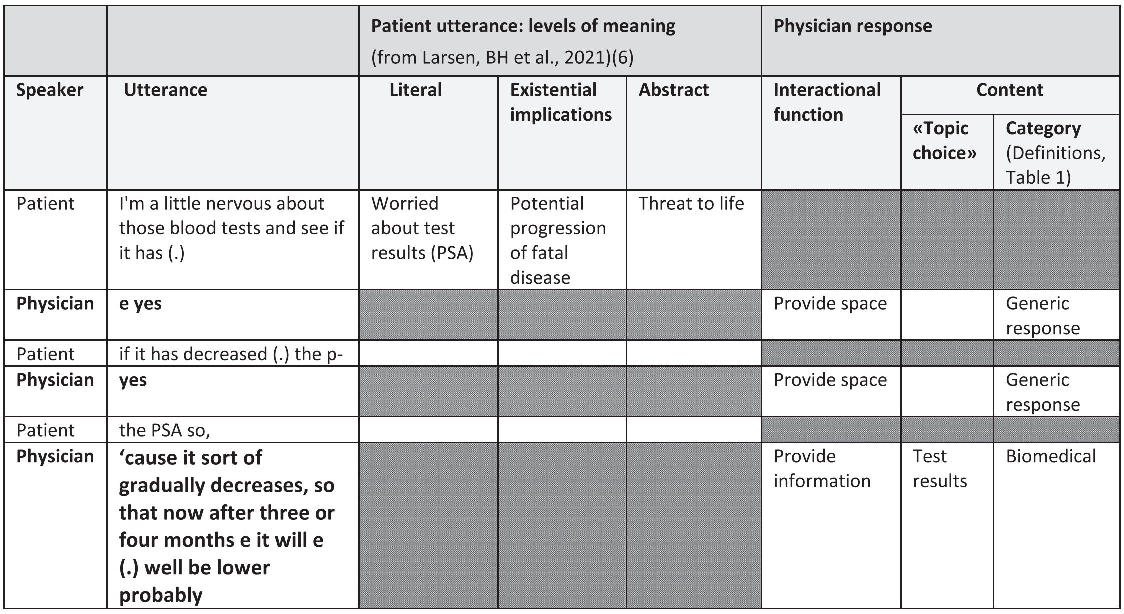
2.3. *Ethical and privacy considerations*

The study is part of a project that was approved by the Regional Committees for Medical and Health Research Ethics (REC) of South-East Norway (project number 2018/474 D). Participants in all videos had provided broad written consent for use of the videos in further communication studies. The video-recordings were stored in a secure server at the hospital. All observations were carried out at this site. Transcripts are encrypted by password, free from personal information identifying the participants, and accessible to the research team only. All

Table 1
Short definitions of content categories.

Small talk	The kind of information that you might give someone when you meet them for the first time, e.g., talking about the weather or where you were born
Generic response	Short utterance just showing that he or she understands or is following what the patient has said, e.g., "yeah" or "mhm".
Biomedical	An utterance providing or seeking only biomedical or procedural information (e.g., about medical tests, appointments, or information from other physicians) *without any indication* whether or how the illness, treatment, side-effects, or symptoms are or will be either[1] affecting the patient's life,[2] interfering with the patient's activities, or[3] tolerable to the patient.
Patient centered	An utterance providing or seeking biomedical information or procedural information *with an explicit indication* whether or how the illness, treatment, side-effects, or symptoms are or will be either[1] affecting the patient's life,[2] interfering with the patient's activities, or[3] tolerable to the patient, *OR* an utterance seeking information about (or commenting on/relating to) the patient's hopes, dreams, plans, goals, preferences, decision-making-preferences, wishes, concerns or fears.

The definitions of content categories are based on Sara Healing's framework for categorizing patient utterances, linguistically modified to fit physician responses [17].



		Patient utterance: levels of meaning (from Larsen, BH et al., 2021)(6)			Physician response		
Speaker	**Utterance**	**Literal**	**Existential implications**	**Abstract**	**Interactional function**	**Content**	
						«Topic choice»	**Category** (Definitions, Table 1)
Patient	I'm a little nervous about those blood tests and see if it has (.)	Worried about test results (PSA)	Potential progression of fatal disease	Threat to life	▨	▨	▨
Physician	**e yes**	▨	▨	▨	Provide space		Generic response
Patient	if it has decreased (.) the p-				▨	▨	▨
Physician	**yes**	▨	▨	▨	Provide space		Generic response
Patient	the PSA so,				▨	▨	▨
Physician	**'cause it sort of gradually decreases, so that now after three or four months e it will e (.) well be lower probably**	▨	▨	▨	Provide information	Test results	Biomedical

Fig. 1. Illustration of analytic steps; the middle columns showing the content analysis of patients' existential utterances as previously reported [6], the right columns showing the current analysis of physician-responses.

physicians are referred to as "she", and patients are given a pseudonym to protect their identity.

3. Results

We identified 185 immediate physician-responses to the 127 patient existential utterances. By combining the analysis of interactive function and content, we found that responses demonstrated three approaches: responses giving the patient control over the content, responses providing support, and responses taking control over the content. No responses fit the category "small talk". Table 2 illustrates the distribution of the various categories of physician-responses.

3.1. Giving the patient control over the content

While the patients were talking, the physicians occasionally uttered generic responses (e.g., "yeah", "mhm"), often accompanied with nodding. Such responses displayed attending to what the patient said (unless the physician directed gaze elsewhere) and offered the patient an opportunity to continue without the physician's influence. Generic responses accounted for almost one-third of the immediate physician-responses, and they occurred both during the patient utterance (overlapping) and afterwards (when the patient paused).

3.2. Providing support

We identified *supporting responses* in five of the 12 encounters during which existential concerns were displayed. Similar to generic responses, these were not directing the content of the subsequent dialogue. The physicians who provided supporting responses did so in three ways. One was *acknowledging the patient's emotion, concern, or experience* (e.g., "I understand" or "It's not strange you feel that way"). Another was *acknowledging the patient's coping strategies or personal resources* (e.g., "That sounds like a good idea" or "I thought that, this is a strong lady"). The third type of supporting responses was *giving advice* for how the patient could cope. These responses were rare.

Excerpt 2 illustrates the first two supporting responses. Karen, a woman in her forties, was recently told that her colon cancer had spread

Table 2
Overview of physician-responses to patients' existential concerns.

Main approaches	Interactional function	Content
Giving the patient control over the content (53/185)	Attending to what the patient said, allowing the patient to continue uninterrupted (n = 53)	Generic response (n = 53)
Providing support (24/185)	Acknowledging the patient's emotion, concern, or experience (n = 10)	Patient centered (n = 10)
	Acknowledging the patient's coping strategies or personal resources (n = 10)	Patient centered (n = 10)
	Giving advice for how the patient could cope (n = 4)	Patient centered (n = 4)
Taking control over the content – steering the agenda towards biomedical topics (108/185)	Educating (providing new information) (n = 85)	Biomedical (n = 77) Patient-centered (n = 8)
	Exploring (inviting the patient to provide more information about something) (n = 16)	Biomedical (n = 10) Patient-centered (n = 6)
	Reformulating (restating or paraphrasing what the patient had said) (n = 7)	Biomedical (n = 2) Patient-centered (n = 5)

Table 2 illustrates the distribution of the various categories of physician-responses according to interactional function and content.

to the lungs. She has now attended the clinic to discuss further treatment. Karen had just told the physician that she will not "lie down" and give in to depression, she would rather keep the possibility of "not getting well" at a distance. She shared with the physician that she finds it distressing when people confront her with her daunting situation, so she tells them that she prefers to avoid talking about it all the time. Her existential utterance is lines 1644–1646.

In this excerpt, we see that the physician both acknowledged the strain of Karen's experience (lines 1648–1649) and her coping strategy (to avoid talking about the illness), using the metaphor putting "it in the drawer and putting the drawer in the dresser" (lines 1651–1653).

One example of giving advice is from Roger's encounter, when he and the physician briefly reflected on the severity of the disease, and Roger uttered, "Yeah, it is fatal (heh heh)". In response, the physician provided the following advice, "It is important that you take care of (.) or (.) use the health you have now at least".

3.3. Taking control over the content – steering the agenda towards biomedical topics

Most physician-responses functioned to steer the agenda more actively, directing the content of the subsequent dialogue. We identified three types of such responses, based on their interactive function: *educating* (providing new information), *exploring* (inviting the patient to provide more information about something), and *reformulating* (restating or paraphrasing what the patient had said). For each of these interactive functions, we present the analyzed content as well, differentiating between patient centered and biomedical content.

Educating was the most common way of taking control of the content and indeed was the most frequent physician-response to existential concerns overall. Most of these responses provided *biomedical* information, typically about disease status, test results, and treatment options. The biomedical information provided in response to existential concerns was sometimes initiated by a request for this information from the patient, but usually not. Few educating responses were *patient-centered*, that is, information about implications for the patient's life. One example is the response to Carl, who had expressed concern about how surgery for his kidney tumor would affect his condition; the physician replied that he would most likely be just as fit as before. Physicians rarely addressed the expected course of illness or what follow up the patient could expect.

We will illustrate educating responses with two examples. Olav, a man in his seventies, had undergone surgery for colon cancer. Now, the physician told him that, unfortunately, they had found multiple metastases in his liver, and that no treatment was applicable. Olav expressed grief over this daunting news. Then, as shown in excerpt 3, he asked about the cells growing in his liver, whether they were of the "dangerous" type or the "mildest ones" (line 130).

The physician's immediate response (lines 131 and 133) educated Olav about the likely connection between the cells found in his liver and his colon cancer. The physician continued by describing thoroughly how the cancer cells spread via the bloodstream, thus offering an explanation about the biomedical facts (lines 135–143). What this information meant for Olav's life, and what the news evoked in him, was not a topic the physician pursued.

Throughout Karen's encounter, she uttered several treatment-related concerns of existential significance; about expected effect, potential side effects and function loss. After nearly thirty minutes, Karen raised the question of whether there might be a chance that she will ever become well, as shown in excerpt 4 (line 1239).

The physician responded by answering Karen's unusually direct question, educating her that the tumor will probably never go away (lines 1245–1246). Then, the physician explained that she hoped the treatment would keep the tumor under control (lines 1249–1251), thus offering some reassurance. Still, the physician kept the discussion focused on biomedical content, without addressing Karen's concern related to the high probability of *not* getting well, and the inherent implications for her life. Nor did the physician explore Karen's thoughts and emotions or offer any partnership taking responsibility for non-abandonment.

Few responses were *exploring*, that is, responses explicitly inviting the patient to elaborate. When eliciting information, the physicians tended to ask the patient for information about *biomedical* aspects rather than *patient-centered* ones. By reviewing the six cases in which the physician explored patient-centered topics, it became apparent that none were invitations for the patient to elaborate on existential matters. Excerpt 5 illustrates this. Peter, a man in his sixties, had recently undergone radiation for his prostate cancer. Due to severe side-effects, he had cancelled the treatment before it was completed. Now, Peter and his wife shared their worry about the disease status (lines 50–55).

The physician's first response was educating them that blood samples will be taken, as is the routine (line 56). Then the physician asked if Peter had noticed anything in his body (line 58).

Beyond educating and exploring, physicians sometimes *reformulated* what the patient had said. These were uncommon, but they played a significant role when occurring, as they displayed the physician's perception of the meaning of the patient utterance. Most reformulating responses were patient-centered, still, they directed the subsequent dialogue in a subtle way, in how they omitted or added information or altered what the patient had said.

Excerpt 6 illustrates some of these findings. Miriam, a young woman in her early twenties, had undergone extensive therapy for her cancer in the head-and-neck area, and she was still taking chemotherapy tablets. Miriam displayed worry and reported heavy symptom burden, both affecting her quality of life. The physician listened attentively to Miriam's narrative. Most of the time, she was facing toward Miriam and allowed her to speak out, uttering generic responses while nodding, and occasionally acknowledging Miriam's strain with a compassionate tone of voice. In this encouraging context, Miriam disclosed the intimidating moment when she was informed about the need for additional radiotherapy, something she had not been prepared for.

Miriam emphasized the significance of this event by choosing the word "worst" (line 76). She abandoned a personal description by cutting off "when I-", and then used a more neutral and distant word "the radiation". The physician encouraged her to continue by nodding (line 77). In her subsequent elaboration, Miriam displayed that the news about radiation was daunting, using the word "fear" (line 84). Her concurrent facial gestures (frowning and adopting a serious expression) and bodily conduct (shuddering) emphasized the display of dread and were particularly notable given that Miriam's baseline facial display throughout the consultation was to smile. The physician's response conveyed empathy; however, the reformulation distorts Miriam's utterance, transforming "fear" into an issue of "energy" (line 85) and "tiredness" (line 88). Despite this unusually explicit expression of fear, the physician did not display any recognition, much less offer to explore it with the patient.

4. Discussion and conclusion

4.1. Discussion

The physicians' immediate responses to patients' disclosed existential concerns demonstrated three approaches; giving the patient control over the content, providing support, or taking control over the content. The latter was by far the most common, through which the physicians habitually kept the discussion around biomedical aspects and rarely pursued the patients' existential concerns. The physicians avoided sensitive issues by routinely selecting biomedical topics when providing information (educating), eliciting information (exploring), or paraphrasing something the patient said (reformulating). Failing to respond to a patient concern or redirecting the conversation has been called "blocking" and is listed among communication behaviors to avoid [18].

Generic responses gave the patients control over the agenda, providing them an opportunity to continue uninterrupted. Previous research has shown that after generic listener responses, storytellers tended to contribute more new information [19]. Allowing silence may have the same function and is a behavior some have recommended to cultivate [18]. During analysis, we noted that gaze and body posture towards the patient seemed to encourage the patient to elaborate (e.g., Excerpt 6), whereas body posture and gaze away from the patient (into the PC-screen or papers), seemed not to. This corresponds with research showing that looking at the patient is an effective way for doctors to show interest [20], arguably a minimal requirement for building trust and relationship.

Providing biomedical information was the most common response to patients' existential concerns. Educating the patient is indeed an important part of physicians' responsibilities. However, delivering medical facts without tailoring it to the patient's concerns may be overwhelming and not necessarily helpful [14,18]. Admittedly, the information provided was sometimes answering specific questions from the patient, but usually not. Moreover, although the patients revealed insecurity about their future and their own coping [6], little information physicians provided in response shed light on the path ahead or conveyed non-abandonment.

4.1.1. *The biomedical culture of avoidance*

One explanation for the non-recognition of patients' existential concerns could be the oftentimes subtle and implicit way patients displayed them [6]. However, avoidance of sensitive topics and difficult emotions *also* occurred when the patients were quite explicit about them, as illustrated in Extract 6. The physicians' evasive responses to existential concerns are similar to those previously shown for emotional concerns [21]. Although existential concerns undoubtedly evoke emotions, they are not the same, but may both arouse uncertainty in the physician. Physicians' reluctance to discuss end-of-life-issues with patients is well known [22–24], leading to inappropriate treatment and care at the end of life [25]. A focus-group-study found that patients, families, nurses, and physicians, *all* tended to avoid or postpone conversations about difficult end-of-life issues and that both individual, interactional, and system-level factors contributed to preserve this culture of avoidance [26]. Lack of continuity in the patient-physician relation was among the reported barriers, which might be a relevant factor in these encounters as only one patient knew the doctor well. While a requirement for efficiency is another recognized barrier [26], in the present study there were few signs of time-constraints: the physicians took plenty of time explaining biomedical matters thoroughly, often in more detail than asked for. This aligns with research showing that physicians' responses to patients' uncertainties and fears were lengthy, spanning a wide complex range of biomedical and technical issues [14], apt to create confusion and alienation [27].

Physicians have shown a tendency to point to barriers outside themselves [28]. Another plausible explanation lies within medical culture and identity, with its inherent biomedical focus [29], which is also reflected in the professional training. Traditionally, the underlying structure of the medical interview, described by Mishler four decades ago, consists of the physician's request for information and the patient's response providing information [30]. Mishler argued that this cyclic information exchange leaves physicians in control of the turn-taking process, enabling them to obtain the information needed to diagnose and treat the patient, which is still the doctor's primary goal [31]. Talking with patients about impending death and lack of effective treatment options is associated with physicians feeling insufficient and failing their mission to heal [22, 23, 32]. Thus, one might ask if providing biomedical information is sometimes employed as a shield of protection against one's own discomfort.

4.1.2. *Physicians' role in the relief of existential suffering*

A recent concept analysis defined the *existential experience* in advanced cancer as a dialectic movement between existential suffering and existential health, preceded by being confronted with one's own mortality and with the capacity for personal growth [33].

Kissane, who provided a taxonomy for existential suffering, highlights the universal nature of existential challenges [1]. Although some patients may need specialized therapies, he claims that the physician can assist the patient in the relief of existential suffering [1], thus, in the movement toward existential health. He suggests that the physician can promote hope and courage that is not rooted in denial or unrealistic expectations to the achievements of medicine, emphasizing that realistic and tailored information can promote acceptance and help patients prepare for time ahead [1]. According to Kissane, such education should include the dying process and focus on optimal symptom control, as these aspects commonly cause fear and uncertainty [1]. In the analyzed encounters, such information was rare. Of equal importance is the right to not know, suggesting that clinicians ask patients about their information needs, rather than routinely sharing biomedical information based on assumptions.

Tailoring information starts with listening to and acknowledging the patient's experience and struggles. Moreover, this listening process itself may have a healing effect [1]. Several tools aim to enhance patient-centered cancer care and may be helpful when refining responses to patients' existential concerns [32,34]. There are also specific course programs shown to enhance existential communication with cancer patients [9]. Early integration of palliative care, with its inherent holistic approach, might also broaden the room for existential aspects. Video-recorded consultations using our analytical lens has a potential in quality improvement of practice and may be used as a schema for reflection by doctors in small groups.

Knowing that patients express existential concerns subtly and hesitantly [6], physicians could ask patients about their concerns and informational needs rather than awaiting patient initiatives. Questions used in Advance care planning conversations [35], may be helpful in the process of tailoring information and care. Our analysis provides a schema for reflecting on responses to patient answers.

Clinicians may feel neither comfortable nor competent help patients to deal with the full spectrum of existential problems that may arise. Avoiding difficult topics, however, can be perceived as a rejection, reinforcing the notion of fundamental aloneness. Instead, when faced with patient-needs that they feel unable to accommodate, physicians could direct the patient to others within the interdisciplinary team, e.g., a hospital chaplain or a psychiatric nurse.

4.1.3. *Strengths and limitations*

This study is based on data from few participants in one hospital. Thus, the findings must be translated into other settings with caution. Video recordings of authentic consultations allow for a repetitive and detailed inspection of what goes on, without being filtered through the "lens" of the participants. However, the data do not provide information about the physicians' motivations, reflections, or assessments, limiting interpretation to observable behavior without extending to these inner aspects. Since the videos were collected, the focus on communication and ethics in medical training has increased. Nevertheless, communication about existential concerns has received little specific attention.

5. Conclusion

Although the physicians, to some extent, allowed the patients to talk freely about their concerns, they systematically focused the discussions on biomedical aspects and rarely explored the patients' uttered existential concerns. Consequently, these aspects mainly remained unaddressed. The patients, who displayed great uncertainty about the future and their own coping, received little information about what awaited them, how they could be helped in dealing with these issues, or what kind of support they could expect.

5.1. Practice implications

Physicians should be attentive to their possible habit of steering the agenda towards biomedical topics, hence, avoiding patients' existential concerns. Initiatives like tools and course programs cultivating behavior that are known to enhance person-centered and existential communication should be implemented in clinical practice and medical training to promote coping, autonomy, and existential health. Video recordings of conversations could be used in quality improvement for example in reflection groups for health care personnel. When appropriate, the physician could invite others within the interdisciplinary team to provide expertise in existential and emotional support.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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CRediT author contribution statement

Berit Hofset Larsen: Conceptualization, Methodology, Analysis, Writing – original draft. **Tonje Lundeby**: Conceptualization, Validation, Writing – review & editing. **Pål Gulbrandsen**: Conceptualization, Methodology, Resources, Writing – review & editing. **Reidun Førde**: Conceptualization, Analysis, Writing – review & editing, Supervision. **Jennifer Gerwing**: Conceptualization, Methodology, Validation, Writing – review & editing.

Competing interests

The Authors declare that there is no conflict of interest. We confirm all patient/personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

Excerpt 1, from Peter's encounter.

Line no	Speaker	Quote	Response
355	Patient	I'm a little nervous about those blood tests and see if it has (.)	
356	Physician	e yes	Response 1
357	Patient	if it has decreased (.) [the p-]	
358	Physician	[yes]	Response 2
359	Patient	the PSA [so,]	
360	Physician	['cause] it sort of gradually decreases,	Response 3a
361	Patient	Yeah, they said so at N1 (other hospital)	
362	Physician	so that now after three or four months e it will e (.) well be lower probably	Response 3b

Explanation of signs: (.)=micro-pause; wor-=cut off; […]=overlap of speech.

Excerpt 2, from Karen's encounter.

Line no	Speaker	Quote
1644	Patient	so everyone asks, you know, like "oh my god, how
1645	Patient	do you handle this", but I say, "do you have any-, do you have any
1646	Patient	suggestions? D-do you have a ch-, do I have any other choices?"
1647	Physician	e but what are you going to do if (.)
1648	Physician	can be very- f- e (.) I can understand that, can imagine
1649	Physician	that it can be very (.) tiring,
1650	Physician	(…)
1651	Physician	.hhh eee say that e (…) "now, now I have put it
1652	Physician	in a drawer and e (.) put that drawer
1653	Physician	[into] the dresser, [I] don't take it out until I have to"
1654	Patient	[yeah] [mhm]

Explanation of signs: (.)=micro-pause;.hhh=in-breath; wor-=cut off; […]=overlap of speech.

Excerpt 3, from Olav's encounter.

Line no	Speaker	Quote
130	Patient	Eh (.) what type (of cells) are these, and (.) which one of those (.) eh flourishing in the liver is this, is it the most dangerous, or is it the mildest ones, or (.)?.
131	Physician	Well, what (.) what we can say with certainty based on the samples (.) that have been taken
132	Patient	yes
133	Physician	is that what is in the liver (.) is exactly the same type as what you had in your gut (colon)
134	Patient	Is that so, well well
135	Physician	So that that there's probably no doubt that this is where it comes from
136	Patient	No, it probably isn't
137	Physician	And it's also the case that (.) the blood supply from the gut goes to the liver
138	Patient	Mhm
139	Physician	(.) eh so that the liver is often the place where it spreads if it actually spreads
140	Patient	Mhm
141	Physician	Yeah, so I guess I'm as sure as I can get about it coming (.) from your gut
142	Patient	It has spread quite fast then (.) relatively?
143	Physician	Well, it's a bit difficult to answer because (.) well the only thing we know (.) (is) that it had spread before you got symptoms from your gut.

Explanation of signs: (.)=micro-pause; word=emphasis.

Excerpt 4, from Karen's encounter.

Line no	Speaker	Quote
1238	Patient	.hhh e e is it e (.) >I just have to ask like<
1239	Patient	a::re the:re e >any chances that I will get well?<
1240		(3 sec pause)
1241	Patient	.hhh [chances, >I'm not saying that I will< get well, but
1242	Physician	[Yes
1243	Patient	are there any chances that I will get well?
1244		((Silence))
1245	Physician	If it disappears completely (.) then that's (…)
1246	Physician	.hhh quite ex- exceptional
1247	Patient	Okay
1248		((Silence))
1249	Physician	.hhh What I (.) hope for, and what I (…) b- what I believe eh
1250	Physician	maybe will happen, and I hope will happen, (…) ((Pat nods))
1251	Physician	is that it shrinks ((Shapes her hands into a ball)), (…)
1252	Patient	((nods))
1253	Physician	and that we can keep it at (.)
1254	Spouse	encapsulate it
1255	Physician	e e yeah in a way (.) [in a way]
1256	Pat	[mhm]

Explanation of signs: (.)=micro-pause;.hhh=in-breath; >word< =speeding up; a::=prolongation of sound; wor-=cut off; word=emphasis; […]=overlap of speech; ((comment)).

Excerpt 5, from Peter’s encounter.

Line no	Speaker	Quote
50	Spouse	Well we have been thinking a bit about about the other thing as well
51	Spouse	[(how this has) developed (.)
52	Patient	[Yeah, we have]
53	Physician	yes,
54	Patient	yes,
55	Spouse	so
56	Physician	Yeah right, ‘cause it will be to follow blood tests and such in the time ahead. It will be sort of a f-fixed scheme
57	Patient	Yeah
58	Physician	right? But have you noticed any bodily afflictions?

Explanation of signs: (.)=micro-pause; […]=overlap of speech.

Excerpt 6, from Miriam’s encounter:

Line no	Speaker	Quote
76	Patient	The worst got to me really when I- (0.5) the radi[ations, (0.5)
77	Physician	[((nodding))
78	Patient	because I had been told that I wouldn’t get it anymore,
79	Physician	Oh.
80	Patient	I was aware that I wouldn’t get [any] more,
81	Physician	[Yeah.]
82	Patient	and when there was (.) a radiation [then e] (0.2)
83	Physician	[yeah]
84	Patient	it was a fear [like-] ((shudders, frowns, serious facial display))
85	Physician	[so you] had portioned out your energy uhm:
86	Patient	[to] the treatment you knew you would get=
87	Physician	[yes]
88	Patient	=and then [it] came even more=yeah that’s tiring.
89	Physician	[yeah],

Explanation of signs: (.)=micro-pause; wor-=cut off; […]=overlap of speech; word= =word=continuation of speech without pause; ((comment)).

References

[1] Kissane DW. The relief of existential suffering. Arch Intern Med 2012;172(19):1501–5.
[2] Gulbrandsen P, Clayman ML, Beach MC, Han PK, Boss EF, Ofstad EH, et al. Shared decision-making as an existential journey: aiming for restored autonomous capacity. Patient Educ Couns 2016;99(9):1505–10.
[3] LeMay K, Wilson KG. Treatment of existential distress in life threatening illness: a review of manualized interventions. Clin Psychol Rev 2008;28(3):472–93.
[4] van Deurzen E. Structural Existential Analysis (SEA): A Phenomenological Method for Therapeutic Work. In: Schulenberg SE, editor. Clarifying and Furthering Existential Psychotherapy: Theories, Methods, and Practices. Cham: Springer International Publishing; 2016. p. 95–113.
[5] Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. J Pain Symptom Manag 2011;41(3):604–18.
[6] Larsen BH, Lundeby T, Gerwing J, Gulbrandsen P, Førde R. “Eh – What type of cells are these – flourishing in the liver?” Cancer patients’ disclosure of existential concerns in routine hospital consultations. Patient Educ Couns 2022;105(7):2019–26.
[7] Assing Hvidt E, Søndergaard J, Hansen DG, Gulbrandsen P, Ammentorp J, Timmermann C, et al. ’We are the barriers’: Danish general practitioners’ interpretations of why the existential and spiritual dimensions are neglected in patient care. Commun Med 2017;14(2):108–20.
[8] Assing Hvidt E, Hansen DG, Ammentorp J, Bjerrum L, Cold S, Gulbrandsen P, et al. Development of the EMAP tool facilitating existential communication between general practitioners and cancer patients. Eur J Gen Pract 2017;23(1):261–8.
[9] Hvidt EA, Ammentorp J, Sondergaard J, Timmermann C, Hansen DG, Hvidt NC. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. Scand J Prim Health care 2018;36(2):142–51.
[10] Agledahl KM, Gulbrandsen P, Førde R, Wifstad Å. Courteous but not curious: how doctors’ politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. J Med Ethics 2011;37(11):650–4.
[11] Amonoo HL, Harris JH, Murphy WS, Abrahm JL, Peteet JR. The Physician’s Role in Responding to Existential Suffering: What Does It Mean to Comfort Always? Journal of palliative care. 2019:825859719839332–.
[12] Saunders C. The evolution of palliative care. J R Soc Med 2001;94(9):430–2.
[13] Kissane DW. Oxford textbook of communication in oncology and palliative care. 2nd edition.,. Oxford University Press; 2017.
[14] Beach WA, Dozier DM. Fears, uncertainties, and hopes: patient-initiated actions and doctors’ responses during oncology interviews. J Health Commun 2015;20(11):1243–54.
[15] Fossli Jensen B, Gulbrandsen P, Dahl FA, Krupat E, Frankel RM, Finset A. Effectiveness of a short course in clinical communication skills for hospital doctors: Results of a crossover randomized controlled trial (ISRCTN22153332). Patient Educ Couns 2011;84(2):163–9.
[16] Bavelas J, Gerwing J, Healing S, Tomori C. Microanalysis of Face-to-face Dialogue. An Inductive Approach. In: Van Lear CA, Canary DJ, editors. Researching Interactive Communication Behavior: A Sourcebook of Methods and Measures. Los Angeles, California: SAGE; 2016. p. 128–57.
[17] Healing S. Development of a Method of Analysis for Identifying an Individual Patient’s Perspective in Video-recorded Oncology Consultations [Master og Science]. Victoria, Canada: University of Victoria; 2007.
[18] Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. CA Cancer J Clin 2005;55(3):164–77.
[19] Tolins J, Fox Tree JE. Addressee backchannels steer narrative development. J Pragmat 2014;70:152–64.

[20] Ruusuvuori J. Looking means listening: coordinating displays of engagement in doctor–patient interaction. Soc Sci Med 2001;52(7):1093–108.

[21] Finset A, Heyn L, Ruland C. Patterns in clinicians' responses to patient emotion in cancer care. Patient Educ Couns 2013;93(1):80–5.

[22] Rogg L, Loge JH, Aasland OG, Graugaard PK. Physicians' attitudes towards disclosure of prognostic information: a survey among a representative cross-section of 1605 Norwegian physicians. Patient Educ Couns 2009;77(2):242–7.

[23] Hancock K, Clayton JM, Parker SM, der Wal S, Butow P, Carrick S, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. Palliat Med 2007;21:507–17.

[24] Peppercorn JM, Smith TJ, Helft PR, Debono DJ, Berry SR, Wollins DS, et al. American society of clinical oncology statement: toward individualized care for patients with advanced cancer. J Clin Oncol: J Am Soc Clin Oncol 2011;29(6): 755–60.

[25] Sallnow L., Smith R., Ahmedzai SH, Bhadelia A., Chamberlain C., Cong Y., et al. Report of the Lancet Commission on the Value of Death: bringing death back into life. The Lancet.

[26] Pavlish C, Brown-Saltzman K, Fine A, Jakel P. A culture of avoidance: voices from inside ethically difficult clinical situations. Clin J Oncol Nurs 2015;19(2):159–65.

[27] Kristvik E. For whom and for what? Exploring the question of 'informed consent' in treatment decision making processes.". Med Antropol 2012;24(1):149–64.

[28] Lundeby T, Wester T, Loge J, Kaasa S, Aass N, Grotmol K, et al. Challenges and learning needs for providers of advanced cancer care: focus group interviews with physicians and nurses. Palliat Med Rep 2020;1(1):28–215.

[29] Illich I. Limits to medicine: medical nemesis: the expropriation of health. Enl. ed. ed. London: Marion Boyars; 1995.

[30] Mishler EG. The discourse of medicine: Dialectics of medical interviews. Greenwood Publishing Group; 1984.

[31] de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns 2009;74(3):287–94.

[32] Campbell TC, Carey EC, Jackson VA, Saraiya B, Yang HB, Back AL, et al. Discussing prognosis: balancing hope and realism. Cancer J 2010;16(5):461–6.

[33] Tarbi EC, Meghani SH. A concept analysis of the existential experience of adults with advanced cancer. Nurs Outlook 2019;67(5):540–57.

[34] Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. Oncologist 2000;5(4):302–11.

[35] Thoresen L., Lillemoen L., Sævareid TJL, Gjerberg E., Førde R., Pedersen R. [Guideline. Advance care planning; joint planning of the time ahead and end-of-life health care for patients in nursing homes] Centre for medical Ethics; 2017. Available from: https://www.med.uio.no/helsam/forskning/prosjekter/forh%C3%A5ndssamtaler-i-sykehjem/acp-veileder271117–.pdf.

Article 3

Appendices

Appendix 1

Table Definitions of existential suffering

Physical	Psychological	Social	Spiritual
Bodily needs and capacities	Identity - views about self	Belonging	Meaning/purpose - faith/beliefs
Connectedness to nature Fear or terror of dying Fear of facing death **Fear of death** Death anxiety Annihilation Loss of temporality Thoughts about the future **Physical decline** and its consequences Thoughts about the dying process Living is painful Burden **Fear of the future** Life is over	Connectedness to self **Disruption of personal identity** Feeling emotionally irrelevant **Loss of autonomy** (independence, control over the future, continuity of self) Self-transcendence Dignity of the self A semantic philosophy of life and being Evaluating elements of self **Loss of dignity** Alienation **Uncertainty** **Vulnerability** Freedom with choice Loss of control Freedom Loss of pleasurable activities	Connectedness to others **Feelings of loneliness** A sense of isolation **Loss of social role functioning** **Dependency** Fear of being a burden on others Grief over imminent separation **Impending separation** Relations with close relatives Relations with significant others **Loss of relations (with others)** Communion and mutuality Loneliness Connectivity Fundamental aloneness Altered quality of relationships Loss of social significance Being a financial burden Homelessness Existential loneliness/isolation **Lack of power** (Lack of trust,	Meaning making Loss of meaning or purpose in life Finding meaning Seeking answers to the questions ○ Why am I here? ○ What is the purpose of my life? ○ What will happen to me after I die? Connectedness to the significant or sacred Hope **Hopelessness** Meaninglessness Life after death Faith Love and purpose in life Meaning **Lack of meaning** Finding meaning, purpose and fulfilment Finding meaning in life events Groundlessness Unfinished business A sense of purpose, freedom and authenticity in life Why-me-questions Transcendence with a higher being Loss of personal meaning Loss of purpose in life Search for significance and meaning Search for meaning and purpose Mystery about what seems unknowable Expressions of meaning and purpose Search for meaning to one's life Living of one's understanding of meaning

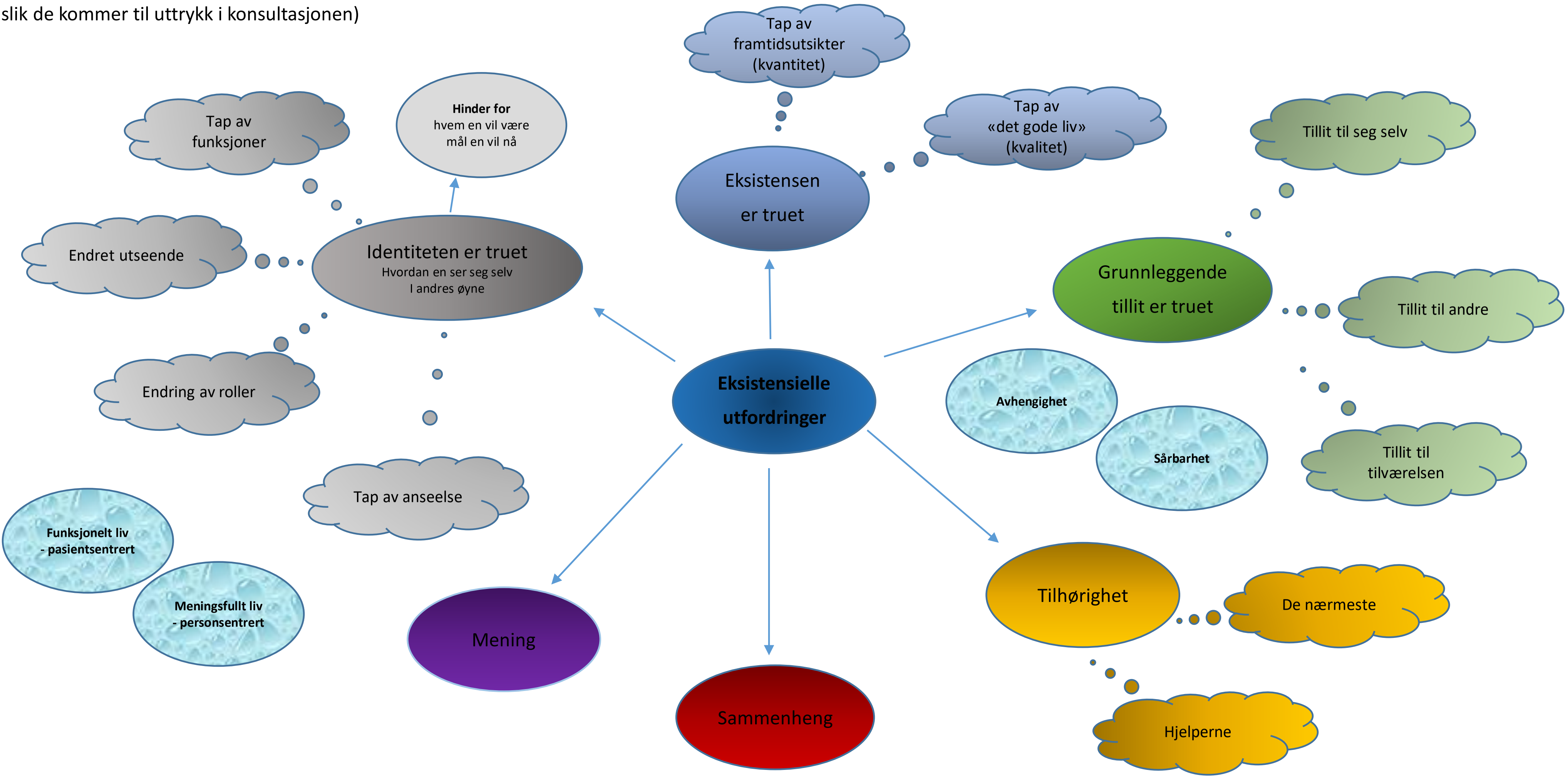
Expressions of existential suffering from the literature review by Boson et al*, sorted into the physical, psychological, social and spiritual domain by the PhD candidate.

*Boston P, Bruce A, Schreiber R. *Existential Suffering in the Palliative Care Setting: An Integrated Literature Review*. Journal of Pain and Symptom Management. 2011;41(3):604-18.

Appendix 2

Hvilke eksistensielle utfordringer møter pasienten?

(slik de kommer til uttrykk i konsultasjonen)



Appendix 3

9/6/2021

Codebook: “Eh - what type of cells are these - flourishing in the liver”

Cancer patients’ disclosure of existential concerns in routine hospital consultations

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Contents

Introduction

The aim of this study is to explore what existential concerns patients with advanced cancer disclose during a routine hospital consultation, and how they communicate those concerns. The analysis is based on all utterances from the patient. Patient utterances identified as *existential utterances* (ExU) are the ones who were selected for detailed examination. This Codebook describes the analysis and choices made during the analytic process, and thus functioned as a workbook, as decisions made early in the process, functioned as guidelines for subsequent and similar choices in order to achieve uniformity and consistency in the coding.

The first step of coding is based on Healing's decision tree for identifying patient utterances being *patient centered* (1). Next, we expanded the decision tree, creating a subset of *existential utterances* within the group patient centered (page 10). During this process, we developed a definition of existential utterance. Examples will follow, with reference to video number (x/) and line number (/x) in the transcript. Note that most examples come from one consultation (100/) as this was the first video we analyzed.

Transcripts and procedures for analysis

- All the dialogue in the videos, except talk during medical examination, were transcribed verbatim into excel worksheets
- Features of speech, facial expressions and bodily conduct was noted when these appeared to provide relevant additional information.
- A simplified form of Jefferson's system for transcribing vocal conduct in talk-in-interaction (2) was employed to capture details of how the utterance was presented (e.g., gaps, pauses, intonation, pitch, speed, breathing, laughter, loudness and overlap between speakers), when providing relevant additional information.
- Columns were created in each excel sheet for notation of: line number, minutes, speaker, utterance, speech delivery (non-verbal-signs), annotations, category according to Healing's decision tree, Existential utterance (yes/no), criteria (1+2+3), topic , sub category, category, domain, action (provide /seek information), expressed emotion, ExU elicited (yes/no).

Unit of analysis

We define a patient utterance as the smallest meaningful entity expressed by the patient. Often, the utterance constitute a sentence including subject and verb, and possibly an object. Sometimes, a single word may constitute a meaningful utterance, but must usually be interpreted in its context. Thus, in the coding we chose to look at the utterances from the patient in connection with utterances from other speakers (physician or next-of-kin) when necessary to produce a complete and meaningful unit of speech. One example is when the *doctor says, "Tired"* and the patient reply, *"Yes"* (100/18-19). Simply looking at the patient's response, would not make any sense. However, the message from the patient is the primary focus of the analysis. Further, a meaning unit can also be a fusion of several utterances from the patient himself, when necessary to make a (more) complete point, or when an utterance is followed by a comment like *yeah* simply reaffirming the patient's previous statement, e.g. (171/15-20. D=doctor; N=Next-of-kin/daughter in law; P=patient):

> *D: This is eh (.) your daughter?*
> *N: Daughter in law*
> *D: [Daughter in law] daughter in law it is*
> *P: [Daughter in law]*
> *D: Yeah*

P: Yeah

Quite often, the utterances are overlapping and intertwined with another speaker, e.g. (100/37-41):

P: Like m eating it eh (.) with my mouth and get it in somehow
D: [Yeah, all the chemotherapy like]
P: [taste no-   yeah]
D: you got when you were home you [mean]
P: [yeah]

Examples of analytic units

Example 1

D: Yes, there have been a lot of hospital (stays) for you lately P: Yeah, a lot of toil (100/15-16).

We interpreted the patient utterances in its communicative context; as the patients’, “a lot of toil” (16) is linked to the doctors’; “a lot of hospital stays” (15). The patient is building on the statement from the doctor.

Example 2

D: You've just been admitted to us now too? P: Yeah (.) I don’t like the hospital anylong- much (100/20-21)

Interpreted in communicative context; as “*Yeah (.) I don’t like the hospital anylong- much” (21)* is linked to D’s pointing out that the patient has just been admitted. Here also, looking at the patient’s utterance in connection with the doctor’s creates a richer meaning.

Example 3

D: You don’t like hospitals that much (23). No, I can easily understand that (24). P: but eh I think it was quite okay really (25). D: You think so? (26) P: eh yeah (27). (100/23-27)

Marked as one joint meaning unit as the patient’s, *“but eh I think it was quite okay really” (25*) is linked to the doctor’s, *“You don’t like hospitals that much” (23).* Further, the patient’s, *“eh yeah” (27)* is a response to the doctor’s question, *“You think so?” (26),* and a verification of the statement in line 25; *“but eh I think it was quite okay really.” Key message: (Although I don’t like hospitals that much), it was quite okay really.*

Although (20-21) could be merged together with (23-27) as D’s, *“You don’t like hospitals that much” (23*) is a response to *P’s, “Yeah (.) I don’t like the hospital anylong- much” (21),* we have chosen not to because “*but eh I think it was quite okay really” (25*), brings in a new piece of information.

Decision tree from Healing

Healing's decision tree is an analytic tool for sorting patient utterances into the following categories; small talk, generic response, biomedical, patient centered or other.

Definitions

Small talk

Is this utterance small talk? Is this the kind of information that you might give someone when you meet them for the first time? E.g. talking about the weather or where you were born? YES: Small talk

Generic response

Is this utterance a generic listener's response? Is the patient just showing that he or she understands or is following what the physician or family member has said? E.g. saying things like "yeah" or "Mhm". YES: Generic response

Biomedical

Is the information in the utterance biomedical centered? Does it contain only biomedical or medical procedural information (e.g about medical tests, appointments, or information from other physicians) *without any explicit indication* from the patient whether the illness, treatment, side-effects, or symptoms are (1) affecting the patient's life, (2) interfering with the patient's activities, or (3) tolerable to the patient?

Patient Centered

Is the utterance a question? Is it asking for information or implicitly asking the physician to confirm that the patient is understanding? YES: Patient centered

Is this utterance patient centered? Does the utterance contain biomedical information or medical procedural information *with an explicit indication* from the patient whether or how the illness, treatment, side-effects, or symptoms are either (1) affecting the patient's life, (2) interfering with the patients activities, or (3) tolerable to the patient? *OR does the utterance include information about the patient's hopes, dreams, plans, goals, preferences, decision-making-preferences, wishes, concerns or fears?* YES: Patient centered

Analytic choices in the coding process

Symptoms and side-effects can, in principle, be assessed both biomedical and patient centered, so when should it be judged to be the one or the other. We have chosen to define it as *biomedical* when the utterance simply is a neutral description of whether a symptom or side effect is present and/or how it manifests. We have assessed it *patient centered* when the description of the symptom and/or side effect is followed by *"an explicit indication from the patient whether or how the illness, treatment, side-effects, or symptoms are either (1) affecting the patient's life, (2) interfering with the patients activities, or (3) tolerable to the patient",* as described in the decision tree.

Repetition of information, which at first seems to be neutral, indicate that it might be of significance to the patient, see example with tooth extraction in a young woman.

"Yes", "yeah", "mm" etc., will often be assessed as generic responses. Sometimes, however, these confirming responses function as a *verification of a statement, suggestion or question* from another speaker. When the content is assessed as neutral information about illness, treatment, procedures etc. the meaning unit is coded biomedical, e.g. D: *Did you get an appointment? P: Yes (100/138-139).* When the patient is verifying information consistent with the definition of *patient centered*, the meaning unit was coded in accordance with that, e.g. *D: Tired P: Yes* (100/18-19).

Examples

Examples of coding Small talk

Greetings

“Hi”, *“Good morning”* or *“Good bye”* (100/4)

Presentations

Name or relation to patient (mother, husband, daughter in law etc.) (100/8)

Courtesy statements

“Thank you” or *“thanks”* for example in response to “Sit down” (100/14) or “Good luck” (328/306)

Examples of coding Generic response

Response to information or explanation from other speaker

Doc: It might be that you will get more rounds like that, when we in a way (.) thought we would be finished, and then Pat: Yeah (100/101-105).

Response to other speaker’s checking they have the same perception

Doc: you’re coming to me today (s)- only for a control after your last admittance, right Pat: eh yeah (100/123-124).

The patient’s *“Yeah”* is not interpreted as the patient taking a position, only confirming common understanding, or accepting what the physician just said.

Response to other speaker’s checking that P has perceived information

(*Doc: We don’t need to put you up for another appointment here if you have a control appointment at N1 Pat: eh Yes) Doc: OK? Pat: ((nodding))* (100/169-170).

Doc’s *“OK?”* may be interpreted so that she is asking if the pat is okay with not putting up a new appointment. However, Doc’s utterance in the previous line is formulated more like a statement than a question. Thus, the pat’s nodding is not interpreted a verification of her being okay with it, simply that she has grasped the message.

Examples of coding Biomedical

Verification or denial of biomedical statement, suggestion or question from another speaker

Doc: *Did you get an appointment? P: Yes (100/138-139).*

Doc: And you have continued with the Thalidomid P: Yes, correct (777/26-27)

Neutral descriptions of symptoms, symptom management or function

Pat: and so I've been on morphine now lately, [] e because of the throat, (100/203)

Pat: and it’s come a lot of slime, (.) which is dry Doc: mm P: and sticky and (100/327-329)

Doc: what color is it then? Pat: yellow color (100/330-331)

Providing information about treatment, tests and/or test results

Pat: and that’s why the doctor took eh Ct of the lungs, but he didn’t find anything (100/340)

Examples of coding Patient centered

Verification or denial of patient centered statement, suggestion or question from another speaker

Doc: so you had portioned out your energy to the treatment you knew about. Pat: yes (100/85-87).

Expression of opinions

Pat: I don't like the hospital anylong- much (100/21)

Preferences

Pat: no, but I'm glad I'm getting the treatment, Doc: m Pat: I am (100/111-113)

Emphasis of apparently neutral information

(Talk about appointment for control) *P: and and I was going to pull out my teeth as well (100/147)*

The first time tooth extraction was mentioned (100/133), it was judged biomedical. When it was brought up repeatedly, it was coded patient centered.

Doc: It (the surgery) is in narcosis, and it will take an hour or two, (.) eh and that is of course, a load when you are eh (.) well, you have passed eighty Pat: Yeah (.) even more than eighty (171/305-307). (No: åtti og vel så det)

Apparently a neutral information about age*,* but with the point made that he is even more than eighty, and in the context of how this affects his tolerance to surgery, it's not interpreted as neutral.

Expression of emotions, explicitly and/or implicitly (non-verbal) - often in combination

Pat: and when (.) the radiation came up then eh Doc: Yes Pat: it was a fear ((frowning, serious facial expression and shiver in her body)) *(100/82-84).* This is an example of the patient also showing negative emotions with her facial expression and body gesture.

Pat: I was more curious about the one (blod test) I delivered (100/238).

In this context *curious* can also mean worried or anxious

Positive or negative descriptions of something valuable to the patient (judgements)

Pat: .hhh (.) so eh it's been (.) it's been really hard (.) when I got home (100/60).

In breath before speaking (.hhh), the use of *eh* before starting and *mini pause (.)* before restarting the sentence, indicating a need to give herself time to think, suggesting hardship in finding the correct words and/or the courage. *Really hard*, emphasizing the hardship.

Pat: yeah, cause right there and then (.) I felt like I'm kind of on the right track, now I'm doing fine ((straightening up her back)) Doc: Yes Pat: and then comes this hard blow again ((hunched body posture)) (100/89-92)

Pat: but eh (.) it took several days, (.) before I got on my feet D: Yes P: It was yesterday (.) ((turning her head towards her mom)) first time I got up and helped out at home (100/66-68).

Could be interpreted as a neutral description of her recovery. However, the combination of *first time* and her turning to her mom, suggests that *not helping out at home* is a departure from what she would normally do. The patient in this case is not a native Norwegian, but speaks the language well. A Norwegian way of speech is, "*It was first yesterday …*" meaning, "*It wasn't until yesterday...*" If we interpret her expression in this sense, it strengthens the notion of this being something *affecting her life (2)* and *interfering with her activities (3)*, and thus, patient centered.

Emphasis

Pat: and then I stopped (with morphine) during that time when I got home (.) and then I really felt a need for it (100/205-208)

Expressions of coping

Pat: but I managed quite okay (100/216),

Pat: but I took a few small Paracet doses, Doc: mm Pat: to like five milliliter just to eh (.) calm myself (100/217-219).

Telling about daily life, function or life situation (or responding to other speaker mapping out)

Doc: Yeah, but don't you guys eat a lot of that lens eh dahl - stuff and, Pat: Ye:ah (100/276-279).

Doc: What have you been doing (professionally)? Pat: Driver (171/278-279)

Irony

Doc: maybe not making it too spicy Pat: Eh yeah, right ((Laughing)) (100/284-286).

Pat's reaction to Doc's suggestion of less spicy food as a solution to her difficulties swallowing indicates that she doesn't find it easily adapted into her family's food traditions.

Adherence to a suggestion

Doc: You'll just have try out different stuff (food) NoK: Yes Pat: Yes (100/ 301-303).

Acceptance of invitation

Doc: So eh (0.2) would you like to see it in this image? (0.5) Pat: Yeah (171/73-75)

Implicitly asking the physician to confirm that the patient is understanding

*NoK: They said that he swelled up from the radiation (.) was one of those who didn't tolerate_*
Pat: It's probably one of those side-effects (.) that someone get I guess (311/34-35)

Examples of coding Other

Not complete meaning units

Doc: Yellow color Pat: but now- Doc: How long have you been coughing? (100/331-333).

Overlap in speech, resulting in the patient not completing the utterance she started.

Comments on things not related to the illness or treatment

Pat: a wire or something slipped out (100/354). Referring to the video equipment

Not interpretable utterances because of weak or noisy sound

NoK: (?) Pat: hm? NoK: (?) Pat: (?) (100/361-364)

Response to instructions

Doc: You can lie down here Pat: eh yes (171/264-265)

Practical issues related to treatment

Doc: I'm not that good at (.) Pat: No, but I have a phone number where one can order it (taxi to radio therapy) (328/259-260).

No explicit indication from the patient about how it affects life.

Coding the patient's existential utterances (ExU)

In the next analytical step, we reviewed all *patient centered* utterances again in search for *existential utterances*, as we expected to find those within that category. Existential utterances are thus a *subset of patient centered utterances*.

Definition Existential utterance

A literature review on definitions used in palliative care settings revealed that strict definitions in this field is non-existent (3). The authors, however, identified various expressions associated with existential suffering. We found that common denominators were loss and threats of loss of something or someone significant to the person, e.g. fear of death, fear of the future, physical decline, loss of self (disruption of personal identity), loss of autonomy (independence and control), loss of dignity, loss of relations, impending separations, loss of social role functioning, dependency, lack of power, lack of trust and lack of (search for) hope, meaning and purpose in life. Kissane's taxonomy of existential suffering (4) and Tarbi and Meghani's concept analysis of existential experience following advanced cancer (5) also informed our interpretation. For analytical purposes, it was fruitful to group the existential utterances into the following four domains: the physical, psychological, social and spiritual, as illness constitute a threat to all aspects of life (6). In order to identify existential utterances and to ensure consistency in the inclusion process, we adopted an operational definition, developed through an iterative process between the ongoing data analysis and the literature review in a discussion within the research team:

> *An utterance containing information about the illness/treatment being a threat to the person's physical, psychological, social or spiritual being, that is; loss or threat of loss of something/someone significant to the person OR expressions of illness related concerns, fears or uncertainty* OR information about the person's hopes, dreams, goals or search for meaning.*

Inclusion criteria

Table 2 (in manuscript): Inclusion criteria, existential utterance

Criteria existential utterance	Example	Coding/assessment	Included
a) Content criterion: *according* to definition, AND b) Significance criterion (heaviness): considered *significant* to the person, AND c) Relevance criterion: *related* to the illness experience (including treatment)	*(Nei, jeg) vil heller ikke være på sykehus, jeg bare ser det at nå (.) har jeg trøbbel med å (.) ja, det er fælt når det å …* *(No, I) don't want to be in hospital either, I just see that now (.) I' m having trouble (.) Yeah, it's awful when it…*	a) Yes: Loss of independence, need hospitalization b) Yes: Express trouble, wish to avoid hospital stay, may be long term/permanent c) Yes: Related to illness, symptom burden and function loss	Yes
	da var jeg redd for at jeg kanskje var e blitt veldig (.) [D: avhengig], avhengig [D: ja] men jeg klarte det ganske greit *Then I was afraid that I might have eh become very (.) [D: addicted], addicted [D: yes] but I managed quite well*	a) Yes: Loss of control, addiction b) No: Temporary, was worried (past), managed well, not worried now c) Yes: Related to treatment/ symptom management (morphine for pain)	No

Illustration of how we coded utterances according to the inclusion criteria for existential utterance. D=doctor..

*Uncertainty in this context is not the same as lack of knowledge per se, i.e. not primarily the cognitive aspect of uncertainty (e.g. uncertainty about the effects of a specific treatment). Here, we focus on perceived uncertainty, i.e. the emotional and existential aspects (shaky ground). Lack of knowledge can cause perceived uncertainty, but it is not the same.

**Significance (b) was the hardest criterion to determine with certainty. Sometimes it was *made explicit by the patient*, other times not. In general, one should be extremely cautious in interpreting other persons' perceptions. Nevertheless, some utterances were judged significant *by implication* based on assumptions/taken-for-(almost)-granted-arguments, as for example staying alive and escape from severe symptom burden/ suffering is significant to most people, although there are exceptions (none observed in these encounters). *Severity* was considered weighty in this context, for example, strong, unbearable pain is more likely to cause suffering than slight pain. *Temporality* also played a role, as for example losses or burdens that are expected to be temporary, are more likely less threatening than those who are expected to be final/ absolute (death/separation from loved ones). *Manageability,* the patient's (expressed) perception of the loss/ threat being inside or outside the patient's range of coping "repertoire" or sense of control, was also part of the assessment. Expressed emotions is often considered a sign of significance. We used features of speech and non-verbal signs as complementary information, supporting the interpretation, never as single signs of their own. Contextual factors, such as previous utterances from the patient sometimes supported the assessment whether or not an utterance met the significance criterion. One example is an elderly male patient commenting on the physician's statement that he will be just as fit after the surgery, "Oh, I will be just as fit?" (with a smiley voice). Standing alone, this utterance would not necessarily be judged significant. However, earlier in the consultation it became clear that the patient had been skeptical to surgery. In addition, when the physician states that the risk of complications may be somewhat increased due to his high age, the pat emphasize that he is even more than eighty. The patient is currently in a good condition, living an active live, despite severe illness. Complications from surgery constitute a threat to the life he currently lives and appreciates.

Guidelines to support the assessment/inference of significance

1) Signs from the patient
    - Previous patient utterances during the consultation supporting or contradicting
    - Emotions, e.g. fear, grief, uncertainty, vulnerability, alienated, abandoned, powerlessness (However, emotions ≠ existential threats)
    - Speech delivery, e.g. emphasis, repetitions, speed, speech overlap (interruption), choice of words etc.
    - Body gestures and facial expressions, e.g. leaning forward, gazing, gesturing, looking worried etc. (putting emphasis to the utterance)
    - Manageability, inside or outside the patient's (expressed) coping or sense of control
2) By implication
    - Severity (weight), e.g. short life expectancy, level of symptom burden/suffering
    - Temporality, expected to be temporary or final/absolute

Example 1 - male in his sixties (Existential):

a) Substantial: Impaired sexual function (threat to physical, psychological and social being). "Haven't been much activity"
b) Significance: The patient confirms that a functional sex-life is significant to him; sexual dysfunction affects him mentally and prevents him from being who he wants to be
c) Relevance: Related to radiation for prostate cancer (side-effect)

Non-verbal: sitting uneasy in his chair pulling his hand over his face, glancing at his wife etc. suggest the patient being quite uncomfortable talking about it.

Example 2 - young female in her early twenties (Not existential):

a) Substantial: Changed appearance because of pigment spots in the face and neck (a possible threat to identity) "Will these spots stay there permanently?"
b) Significance: Not significant (pat ask about the spots in a curious, neutral way - after her mother reminds her about it at the end of consultation. Doesn't seem to be bothered by it, more like, “Oh, by the way ...")
c) Relevance: Related to radiation for head- and neck cancer (side-effect)

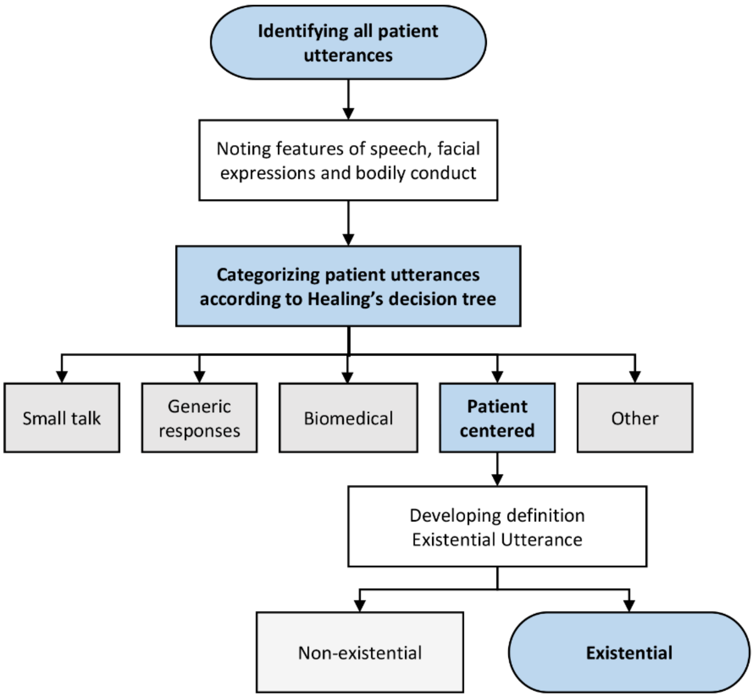
Example 3 - same female (Not existential):

a) Substantial: "I am Pakistani" (laughter) Clear expression about identity, response to the physician's suggestions for food that might be easy to swallow when sore throat (f.ex. porridge - not typical for the Pakistani kitchen), but not threatened
b) Significance: Significant
c) Relevance: Not relevant, as it is not threatened by illness or treatment

Example 4 - male in his sixties (Existential):

a) Substantial: "What kind of cells are these, do they grow slow or fast?" (interpreted as: “How much time do I have left?) Short life expectancy, imminent death, uncertainty about future.
b) Significance: Significant (to most people, and he is still in good condition with no burdensome symptoms or function loss) + repeatedly asks in various ways about how fast the tumor cells grow)
c) Relevance: Related to tumor growth and no available treatment options

Figure 1: Inclusion process, patients' existential utterances



Analytic steps in coding existential utterances

We analyzed all existential utterances along two lines: according to *content* and according to *function and speech delivery*. For content, all the included utterances were analyzed in four steps representing different levels of abstraction, increasing from 1-4: (1) topic, (2) subcategory, (3) category, and (4) domain.

(0) Quote

The exact rendering of the utterance, e.g. "*Eh (.) what type (of cells) are these, and (.) which one of those (.) eh flourishing in the liver is this, is it the most dangerous, or is it the mildest, or?*"

(1) Topic (literal level)

Description of the topic(s)/issue(s) raised by the patient, a condensed reproduction of the explicit content/meaning, and thus, close to the data, e.g. malignant tumor, sense of not making it.

(2) Subcategory (Existential implication)

Interpretation of the implicit meaning of the utterance, what it represents in the patient's life, e.g. fatal disease, loss of control.

(3) Category (Abstract level)

This step represents a higher level of abstraction describing existential loss/threat in more general terms, e.g. threat to life, threat to identity, threat to autonomy. Existential expressions used in the literature was employed when appropriate.

(4) Domain

All utterances were divided into four domains, depending on the utterance being an expression of a threat to either physical, psychological, social or spiritual being. Some utterances fit into multiple domains, e.g. the utterance about impaired sexual function due to radiation for prostate cancer was assessed as a threat to both physical, psychological and social being. However, it was not considered so automatically, but based on the patient's own explicit statements, e.g., "*When that's not working (sexual function), it affects you mentally too, you know",* or other signs displaying relevance, for example his glancing at his wife when he comments on trying medication for erectile dysfunction, "*Well, we could give it a try*".

For function and speech delivery, we categorized existential utterances according to whether the patient was *providing information* or *seeking information* from the physician. Then we noted details of *speech delivery.* These descriptive labels were not necessarily mutually exclusive. We also noted whether the existential utterance was *elicited by the physician*, and whether it was accompanied with any verbal or non-verbal *expression of emotion* (e.g., crying).

Table 3 (in manuscript): Analytic steps, existential utterances

WHAT existential concerns patients disclosed (content)					**HOW patients disclosed existential concerns**			
Patient utterance (Quote)	**Topic** (Literal level)	**Sub category** (Existential implications)	**Category** (Abstract level)	**Domain**	**Function**	**Features of speech**	**Elicited by physician (yes/no)**	**Expression of emotions**
Yeah 'cause it is malignant, isn't it,	Malignant tumor	Fatal disease	Threat to life	Physical	Seek info	In-direct Biomedical	No	
(.) but e (.) just a few days ago I felt that (.) I won't make it,	Sense of not making it	Loss of control	Threat to autonomy	Psycho-logical	Provide info	Explicit Pauses	No	

Features of speech, facial expressions and bodily conduct was noted when providing relevant additional information. Microanalysis of face-to-face-dialogue (MFD) is based on two theoretical assumptions; that interlocutors use "both visible and audible communicative resources, which are tightly integrated with each other" and that "their actions must be understood as coordinated and mutually influential". Conversation Analysis (CA) is widely used in communication studies. Jefferson's system for transcribing vocal conduct in talk-in-interaction is the most common system used in CA-studies. We employed a simplified form of the system in the transcripts, which enabled us to note not only what was said, but also details of how it was presented, e.g.; gaps, pauses, intonation, pitch, speed, breathing, laughter, loudness, stuttering, overlap between speakers etc.

By holding together the content, speech delivery, and *the context* of the utterance, we were able to capture underlying meaning that was not necessarily expressed explicitly. By studying the context, we mean both (1) asking, "What happens in the conversation prior to the utterance?", and "Why is the patient saying or asking this right now?" and (2) looking at the patient's situation as a whole, e.g. when the patient asks, "What type of cells are these (in the liver), …?". These words coming from a patient whose life is dependent on what kind of cells it is and how fast they grow, makes the meaning quite different than coming from a medical student having an academic interest in understanding the biological properties.

References

1. Healing S. Development of a Method of Analysis for Identifying an Individual Patient's Perspective in Video-recorded Oncology Consultations [Master og Science]. Victoria, Canada: University of Victoria; 2007.
2. Hepburn A, Bolden GB. The Conversation Analytic Approach to Transcription. In: Sidnell J, Stivers T, editors. The handbook of conversation analysis Oxford: Wiley-Blackwell; 2012. p. 57-76.
3. Boston P, Bruce A, Schreiber R. Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. Journal of Pain and Symptom Management. 2011;41(3):604-18.
4. Kissane DW. The Relief of Existential Suffering. Archives of Internal Medicine. 2012;172(19):1501-5.
5. Tarbi EC, Meghani SH. A concept analysis of the existential experience of adults with advanced cancer. Nursing outlook. 2019;67(5):540-57.
6. van Deurzen E. Structural Existential Analysis (SEA): A Phenomenological Method for Therapeutic Work. In: Schulenberg SE, editor. Clarifying and Furthering Existential Psychotherapy: Theories, Methods, and Practices. Cham: Springer International Publishing; 2016. p. 95-113.

Appendix 4

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Codebook: Physicians’ responses to advanced cancer patients’ existential concerns: A video-based analysis

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Contents

Introduction

In a recent study, we explored what kinds of existential concerns patients with advanced cancer disclose during a routine hospital consultation, and how they communicate such concerns (1). The current study builds on these results and focuses on how physicians responded to those concerns. The analysis of all patient utterances including *existential utterances (ExU)* is described in Codebook 1, whereas the analysis of the *physicians' responses* is described here in some more detail than in the article manuscript.

We apply interaction analysis of video-recorded consultations. The study has a qualitative and exploratory design, using principles from *microanalysis of face-to-face-dialogue (2)*, as this method allow for an inductive approach while being structured and systematic in the detailed examination of observable communicative behavior.

The first author (BHL) transcribed the videos verbatim (in Norwegian), additionally noting features of speech, facial expressions and bodily conduct, when this provided relevant additional information. The theoretical basis for that is the assumption that both visible and audible communicative resources affect how meaning is interpreted and understood by the interlocutors (2). The analysis is based on both videos and transcripts. Anonymized transcripts made it possible to study the data also when not present in the communication lab where the videos were stored. We used Microsoft Excel for the coding and had separate columns for each analytic step. In addition we had separate columns for noting non-verbal signs (facial expressions and body gestures) and annotations.

Initially, two research members (RF and BHL) watched the videos together, individually taking notes, and discussed our observations afterwards. Next, BHL watched the videos repeatedly, winding back and forth, to be able to observe details in the interaction, focusing particularly on the key moments where we had identified existential utterances. BHL conducted all coding and the second author (TL) coded parts of the data independently. The two discussed coding differences until they reached a consensus decision. All research members participated in studying parts of the data and in the discussions around analytic choices and the derived categories.

Decisions made early in the analytic process, functioned to guide subsequent and similar choices in order to achieve uniformity and consistency in the coding. The codebook is primarily a workbook assisting the coder(s) to keep track on the analytic choices made during the process.

Coding physician-responses

We repeat the definition of patient existential utterance here, as this is the entry point for the current analysis.

Definition Existential utterance

We had developed and applied the following operational definition to identify *existential utterances*:

> *An utterance containing information about the illness/treatment as a threat to the person's physical, psychological, social or spiritual being, that is; loss or threat of loss of something/ someone significant to the person OR expressions of illness related concerns, fears, uncertainty or vulnerability OR information about the person's hopes, dreams, goals or search for meaning.*

More about the selection process and the inclusion criteria in Codebook 1.

Analytic unit: Physician-responses

By *physician-response* we mean *the immediate physician-utterance reacting to the patient's existential utterance* (ExU), i.e., what the physician said and did immediately after. Although we noted non-verbal features (e.g., pauses and nodding), we only coded verbal responses. Sometimes there were more than one response relating to the patient utterance. Hence, we included all *immediate responses orienting to* the existential utterance. Consequently, the physician may have responded to an existential utterance later in the consultation, but these potential responses were not included in the analysis. However, after studying all the material repeatedly we have not been able to identify any "late responses". Excerpt 1 presents such physician-responses to the patient's existential utterance (spanning lines 355, 357, and 359). The blood tests that the patient refers to (PSA) are tumor markers for prostate cancer, and thus indicate progression of a fatal disease.

Excerpt 1 illustrating analytic units

Line no	**Speaker**	**Quote**	**Response**
355	Patient	I'm a little nervous about those blood tests and see if it has (.)	
356	Physician	e yes	Response 1
357	Patient	if it has decreased (.) [the p-]	
358	Physician	[yes]	Response 2
359	Patient	the PSA [so,]	
360	Physician	['cause] it sort of gradually decreases,	Response 3a
361	Patient	Yeah, they said so at N1 (other hospital)	
362	Physician	so that now after three or four months e it will e (.) well be lower probably	Response 3b

As demonstrated in this example, utterances from the patient and the physician could be intertwined, as the patients sometimes conveyed their meaning in short instalments, punctuated by brief listener responses. The excerpt includes two such responses ("yes" in lines 356 and 358) and a substantive response spanning lines 360 and 362.

We took a descriptive approach (not normative), analyzing the physician-responses along two lines: according to the *interactional function* they served in the moment and according to *content*.

Analyzing the interactional function of the physician-responses

The first line of analysis focused on what kind of function the physician-response served in that particular moment of the dialogue. The analytical question was, "What did the physician *do* in response to the ExU?" We identified five different function categories: attending (providing space), supporting, educating, exploring, and reformulating.

Attending (providing space)

Using generic listener's responses, showing that the physician's attention is directed toward the patient, that (s)he understands/follows what the patient said, e.g., *"yeah"* or *"mhm"* (in these encounters, often accompanied with nodding). This is a well-known concept in the literature, and the definition of generic responses we used is retrieved from Sara Healing's framework (presented below). These responses may work as so-called "continuers" (another term from the communication literature), a recommended behavior (passively) allowing/encouraging the patient to continue, by holding back own turn of speech, thus, providing space for the patient's narrative.

Supporting (providing support)

Responses supporting the patient in various ways other than (beyond) bringing new information. Although providing information may be a way to support the patient, patient education is a complex intervention with multiple goals, so we decided to keep these two as separate categories. We derived three sub-categories from the analysis of supporting responses:

- **Acknowledging/validating the patient's emotion, concern, or experience**
  Examples: *"I understand",* and *"It's not strange you feel that way".*
- **Acknowledging/validating the patient's chosen coping strategies or personal resources**
  Examples*: "That sounds like a good idea"* or *"You're just like I remember you [...] I thought that, This is a strong lady".*
- **Giving advice, making suggestions for solutions or how the patient could cope**
  "It is important that you take care of (.) or (.) use the health you have now at least".

Educating (providing information)

Responses educating the patient by providing information considered new to the patient (new content/ knowledge or new understanding). When the provided information was answering a question from the patient (including statements requesting information), this was noted. Educating responses was divided into subcategories according to content (Definitions below).

Exploring

Responses eliciting or seeking more information about something from the patient, that is, responses explicitly/ actively asking the patient to elaborate. The *exploring-responses* were divided into subcategories depending on what type of information the patient was asked to elaborate (content).

Reformulating (formulation)

Responses where the physician is restating or paraphrasing something the patient has said, completely or partially. The response may work as "holding up the mirror" to the patient, but also displays the physician's perception of the patient's expression. Formulating responses did not occur very often, but we chose to include this category because the physician's understanding of the patient's utterance is relevant for the designing of the next response. The four subtypes of formulating responses described here build on work by Korman et al. on formulations (3).

Preserve: Content and wording is identical to the original patient utterance
Alter: Different wording, but (some of) the content is preserved
Omit: Some of the original content is missing
Add: New content is added

The categories were not mutually exclusive at this level, as a single formulation could simultaneously alter, omit, or add information.

Figure 1, analyzing the interactional function of physician-responses

Speaker	**Utterance**	**Interactional function**
Patient	I'm a little nervous about those blood tests and see if it has (.)	▨
Physician	**e yes**	Attending/ providing space
Patient	if it has decreased (.) the p-	▨
Physician	**yes**	Attending/ providing space
Patient	the PSA so,	▨
Physician	**'cause it sort of gradually decreases, so that now after three or four months e it will e (.) well be lower probably**	Educating / providing information

Analyzing the content of the physician-responses

For content, we used two approaches. The first ("topic choice") related the physician's response to what the patient had said along three levels of meaning: the literal (e.g., worry about test results), the existential implications for the patient's life (e.g., potential progression of fatal disease), and the more abstract concept (e.g., threat to life).

Topic choice

The first line of analysis related to the content, we called *topic choice*. The analytical question was, "Which of the topics embedded in the patient's existential utterance did the physician choose to pursue, and which topics did they not choose?"
All existential utterances had been labeled according to the topics raised on a propositional/literal level (e.g., tumor growth, symptom burden, loss of function, lack of treatment options) and categorized according to the topics raised on the more abstract level of the existential implications (e.g., threat to life, threat to QoL, threat to identity, loss of autonomy, search for meaning and hope), shown in the categories and subcategories.

Figure 2, analyzing the content of physician-responses

		Patient utterance: levels of meaning (from Larsen, BH et al., 2021)			**Physician response: Content**	
Speaker	**Utterance**	**Literal**	**Existential implications**	**Abstract**	**«Topic choice»**	**Category** (Definitions, Table 1)
Patient	I'm a little nervous about those blood tests and see if it has (.)	Worried about test results (PSA)	Potential progression of fatal disease	Threat to life	▨	▨
Physician	**e yes**	▨	▨	▨		Generic response
Patient	if it has decreased (.) the p-				▨	▨
Physician	**yes**	▨	▨	▨		Generic response
Patient	the PSA so,				▨	▨
Physician	**'cause it sort of gradually decreases, so that now after three or four months e it will e (.) well be lower probably**	▨	▨	▨	Test results (literal level)	Biomedical

Illustration of analytic steps; the middle columns showing the content analysis of patients' existential utterances as previously reported (1), the right columns showing the current analysis of physician-responses. In the article manuscript Figure 1 and Figure 2 is merged, visualizing both function and content categories.

Content categories

The second approach analyzing content dealt with the substance of the physician's response, which we categorized according to Sara Healing's framework distinguishing between: small talk, generic responses, biomedical content, or patient centered content (4). See Table 1 for definitions of these four content categories, and Figure 2 for illustration of analytic steps.

Table 1, short definitions of content categories

Small talk	The kind of information that you might give someone when you meet them for the first time, e.g., talking about the weather or where you were born
Generic response	Short utterance just showing that he or she understands or is following what the patient has said, e.g., "yeah" or "mhm".
Biomedical	An utterance providing or seeking only biomedical or procedural information (e.g., about medical tests, appointments, or information from other physicians) without any indication whether or how the illness, treatment, side-effects, or symptoms are or will be either (1) affecting the patient's life, (2) interfering with the patient's activities, or (3) tolerable to the patient.
Patient centered	An utterance providing or seeking biomedical or procedural information *with an explicit indication* whether or how the illness, treatment, side-effects, or symptoms are or will be either (1) affecting the patient's life, (2) interfering with the patient's activities, or (3) tolerable to the patient, *OR* an utterance seeking information about (or commenting on/relating to) the patient's hopes, dreams, plans, goals, preferences, decision-making-preferences, wishes, concerns or fears.

The definitions of content categories are based on Sara Healing's framework for categorizing patient utterances, linguistically modified to fit physician responses (4).

Examples

Examples of educating responses according to content

Biomedical: Providing information with (neutral) biomedical or procedural content, e.g., information explaining causal relationships or effect of a drug.

Patient centered: Information about probable implications for the patient's life or available support.

Existential: A subcategory of patient centered information addressing the existential issue raised

Examples of exploring responses according to content

Biomedical: Asking for (neutral) biomedical information, for example how symptoms acted out, without eliciting from the patient how the illness, treatment, side-effects, or symptoms were (1) affecting the patient's life, (2) interfering with the patient's activities, or (3) tolerable to the patient. Responses eliciting procedural information (about medical tests, appointments, or information from other physicians), e.g., "When did you have the last CT-scan?", or "When is your next appointment?" was coded biomedical.

Patient centered: Responses eliciting the patient's perspective, e.g., emotions, values, preferences, views on how illness/treatment affect their life (including tolerability of such effect), or the patient's hopes, dreams, plans, goals, wishes, concerns, or fears.

Existential: Responses explicitly asking the patient to elaborate on the existential issue(s) raised.

Table 2, Overview: Physicians' responses to patient existential utterances

ENCOUNTER	100	171	201	311	328	507	616	679	777	806	874	897	905	TOT
ExU	7	3	12	15	3	18	2	40	1	4	14	0	8	**127**
RESPONSES														
Attending	**14**	**0**	**8**	**3**	**0**	**9**	**0**	**8**	**0**	**0**	**6**	**0**	**5**	**53**
Supporting	**2**	**0**	**5**	**1**	**0**	**7**	**2**	**5**	**0**	**0**	**0**	**0**	**2**	**24**
Acknowledge*	2		2			3		2					1	10
Support coping / resources**			1	1		4	1	2					1	10
Give advice***			2				1	1						4
Educating	**2**	**4**	**7**	**8**	**3**	**14**	**1**	**29**	**2**	**4**	**10**		**1**	**85**
Biomedical	2	3	7	8	3	12	1	29	2	4	6	0	1	78
#Answer question	0	1	2	1	1	6	0	15	1	2	2	0	0	31
Patient centered	0	1	0	1	0	2	0	0	0	0	4	0	0	8
○ Existential						(1)								(1)
Exploring	**1**	**0**	**1**	**3**	**0**	**2**	**0**	**3**	**0**	**0**	**1**	**0**	**5**	**16**
Biomedical	1	0	1	2	0	0	0	0	0	0	1	0	5	10
Patient centered	0	0	0	1	0	2	0	3	0	0	0	0	0	6
Existential														-
Reformulating	**3**	**0**	**0**	**3**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**7**
Preserve														
Alter	1			3							1			
Omit	2			2							1			
Add	1			2										
Total responses	**22**	**4**	**21**	**19**	**3**	**33**	**3**	**45**	**1**	**4**	**18**	**0**	**13**	**185**

*Acknowledging/validating the patient's emotion, concern, or experience
** Acknowledging/validating the patient's chosen coping strategies or personal resources
*** Giving advice, making suggestions for solutions or how the patient could cope
#The educating response was answering a request for information from the patient

References

1. Larsen BH, Lundeby T, Gerwing J, Gulbrandsen P, Førde R. "Eh – What type of cells are these – flourishing in the liver?" Cancer patients' disclosure of existential concerns in routine hospital consultations. Patient Education and Counseling. 2021.
2. Bavelas J, Gerwing J, Healing S, Tomori C. Microanalysis of Face-to-face Dialogue. An Inductive Approach. In: Van Lear CA, Canary DJ, editors. Researching Interactive Communication Behavior : A Sourcebook of Methods and Measures. Los Angeles, California: SAGE; 2016. p. 128-57.
3. Korman H, Bavelas J, De Jong P. Microanalysis of Formulations in Solution-Focused Brief Therapy, Cognitive Behavioral Therapy, and Motivational Interviewing. Journal of Systemic Therapies. 2013;32(3):31-45.
4. Healing S. Development of a Method of Analysis for Identifying an Individual Patient's Perspective in Video-recorded Oncology Consultations [Master og Science]. Victoria, Canada: University of Victoria; 2007.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Hege Cathrine Finholt, PhD	22857547	17.04.2018	2018/474 REK sør-øst D
			Deres dato:	**Deres referanse:**
			13.02.2018	

Vår referanse må oppgis ved alle henvendelser

Pål Gulbrandsen
Universitetet i Oslo

2018/474 Pasientautonomi ved langtkommet kreft.

Forskningsansvarlig: Universitetet i Oslo, Oslo universitetssykehus HF, Akershus universitetssykehus HF
Prosjektleder: Pål Gulbrandsen

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 21.03.2018. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektleders prosjektbeskrivelse

Hensikten med studien er å undersøke om kreftpasienter ved norske sykehus får tilstrekkelig og tilpasset informasjon slik at de har en reell mulighet til å medvirke i beslutninger, og til å mestre livet med livstruende sykdom. Undersøkelsen har et kvalitativt og utforskende design bestående av tre delstudier. I del 1 vil vi intervjue pasienter med kreft i pankreas for å få kunnskap om deres behov og preferanser for informasjon, samt deres opplevelse av om viktige informasjonsbehov er møtt. I del 2 vil vi analysere skriftlig pasientinformasjon om livsforlengende cellegiftbehandling ved pankreaskreft, ved hjelp av et verktøy som er utviklet for å kvalitetsvurdere skriftlig pasientinformasjon ved behandlingsvalg. I del 3 vil vi studere hvordan muntlig informasjon gis til pasienter med kreft ved å analysere videoopptak av autentiske samtaler mellom kreftpasienter og deres behandlende lege på sykehuset. I denne delstudien er ikke utvalget begrenset til en bestemt gruppe kreftpasienter

Vurdering

Det omsøkte prosjektet har som siktemål å vurdere om kreftpasienter får tilstrekkelig informasjon som gjør at de kan være med å ta beslutninger om behandling, og til at de får hjelp til å mestre livet med en livstruende sykdom. Studien har tre deler, og det er del en som det her søkes om REK godkjenning for. I denne delen skal det foretas intervjuer av pasientene og det vil kunne bli meddelt helseopplysninger.

I komiteens vurdering ble det vektlagt at måten en pasient blir møtt på vil ofte ha betydning på vedkommende sin helse og hvordan pasienten har det. Videre vektlegges det at pasienter kan påvirke behandlingen av seg selv dersom de blir inkludert i beslutningsprosessene angående behandlingen. På bakgrunn av dette mener flertallet av komiteens medlemmer at prosjektet vil kunne føre til ny kunnskap om helse og sykdom, og det faller derfor innenfor helseforskningslovens virkeområde.

Vedtak

Med hjemmel i helseforskningsloven § 9 jf. 33 godkjenner komiteen at prosjektet gjennomføres.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2022. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2027. Forskningsfilen skal oppbevares atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

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

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

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Komiteens avgjørelse ble fattet mot en stemme.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Hege Cathrine Finholt, PhD
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