Patient Education and Counseling xxx (xxxx) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pec

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

Berit Hofset Larsen[a,d,1,*], Tonje Lundeby[a], Jennifer Gerwing[b,2], Pål Gulbrandsen[b,c,3], Reidun Førde[d,4]

[a] Department of Oncology, Oslo University Hospital, Oslo, Norway
[b] Health Services Research Unit, Akershus University Hospital, Lorenskog, Norway
[c] Division of Health Services Research and psychiatry, Institute of Clinical Medicine, University of Oslo, Oslo, Norway
[d] Centre for Medical Ethics, University of Oslo, Oslo, Norway

ARTICLE INFO

Article history:
Received 6 September 2021
Received in revised form 8 November 2021
Accepted 9 November 2021
Available online xxxx

Keywords:
Advanced cancer
Existential suffering
Uncertainty
Patient-physician communication
Coping

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

* Correspondence to: Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway.
E-mail addresses: berihla@medisin.uio.no (B.H. Larsen), tonje.lundeby@medisin.uio.no (T. Lundeby), jennifer.gerwing@gmail.com (J. Gerwing), pal.gulbrandsen@medisin.uio.no (P. Gulbrandsen), reidun.forde@medisin.uio.no (R. Førde).
[1] Postal address: Oslo universitetssykehus HF, Avdeling for kreftbehandling, Postboks 4953 Nydalen, 0424 Oslo, Norway.
[2] Postal address: Akershus universitetssykehus, Enhet for helsetjenesteforskning, 1478 LØRENSKOG, Norway.
[3] Postal address: Akershus universitetssykehus, Klinikk for helsetjenesteforskning og psykiatri, 1478 LØRENSKOG, Norway.
[4] Postal address: Universitetet i Oslo, Senter for medisinsk etikk, Postboks 1130 Blindern, 0318 Oslo, Norway.

https://doi.org/10.1016/j.pec.2021.11.010
0738-3991/

Please cite this article as: B.H. Larsen, T. Lundeby, J. Gerwing et al., "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, https://doi.org/10.1016/j.pec.2021.11.010

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

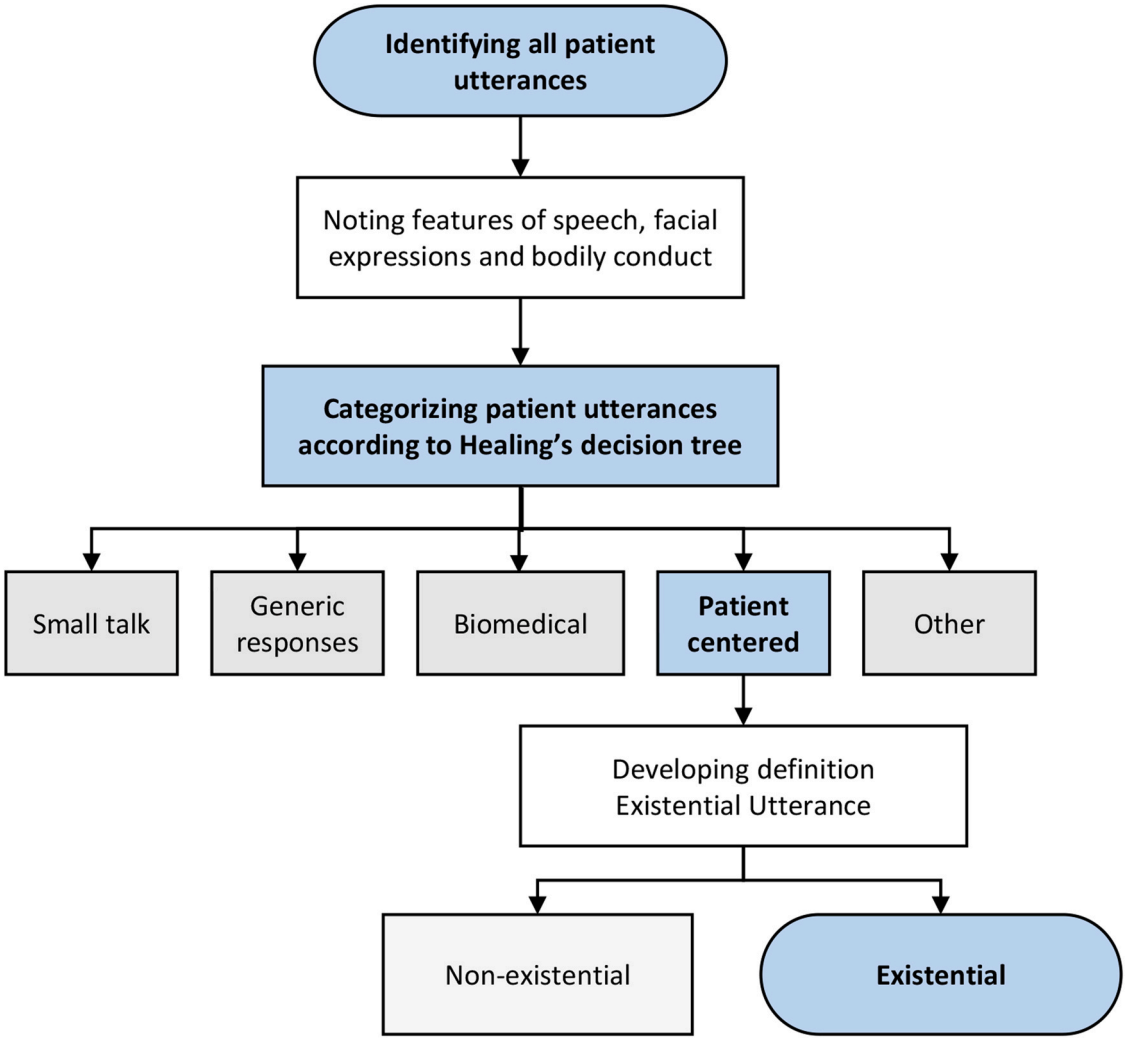

Fig. 1. Inclusion process, patients' existential utterances.

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	Psycho-logical	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.

Funding

This work was supported by South-Eastern Norway Regional Health Authority, Norway [grant number 2018008]. The funding source had no involvement in study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

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.

Acknowledgements

Thanks to Anne Marie Dalby Landmark, linguist and conversation analyst, for pointing to relevant literature on specific aspects of speech delivery. Thanks also to Morten Magelssen, physician and ethicist, for critical reading and constructive feedback on the manuscript.

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.