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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 Biomedical	Short utterance just showing that he or she understands or is following what the patient has said, e.g., "yeah" or "mhm".			
ыотеан	An utterance providing or seeking only biomedical or procedural information (e.g., about medical tests, appointments, or information from other physicians) <i>without any indication</i> 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 <i>with an explicit indication</i> 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, <i>OR</i> 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	Content	
					function	«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				Provide	Test	Biomedical
	gradually decreases, so				information	results	
	that now after three or						
	four months e it will e						
	(.) well be lower						
	probably						

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 physicianresponses, 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

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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	Response 3b
		probably	

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.

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 be <u>fore</u> 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 [<u>chan</u> ces, >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 <u>that</u> 's ()
1246	Physician	.hhh quite ex- exceptional
1247	Patient	Okay
1248		((Silence))
1249	Physician	.hhh What I (.) <u>hope</u> for, and what I () b- what I be <u>lieve</u> eh
1250	Physician	maybe will happen, and I <u>hope</u> 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

- 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:
- [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] Agledahi KM, Gulbrandsen P, Førde R, Wifstad Å. Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of videorecorded 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 Å, 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. Truthtelling 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.

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- [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.