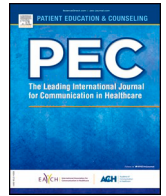




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“If it’s the time, it’s the time”: Existential communication in naturally-occurring palliative care conversations with individuals with advanced cancer, their families, and clinicians

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ABSTRACT

Objective: To explore how patients with advanced cancer, their families, and palliative care clinicians communicate about existential experience during palliative care conversations.

Methods: We analyzed data from the Palliative Care Communication Research Initiative (PCCRI) – a multisite cohort study conducted between 2014 and 2016 involving hospitalized adults with advanced cancer who were referred for inpatient palliative care consultations at two academic medical centers. We used a qualitative descriptive approach paired with inductive content analysis to analyze a random subsample of 30 patients from the PCCRI study (contributing to 38 palliative care conversations).

Results: We found existential communication to be woven throughout palliative care conversations, with key themes related to: 1) time as a pressing boundary; 2) maintaining a coherent self; and 3) connecting with others.

Conclusion: Communication about existential experience is omnipresent and varied in palliative care conversations between individuals with advanced cancer, their families, and clinicians.

Practice implications: Clinicians can recognize that discussion of time, routines of daily life, and relationships in the clinical context may hold profound existential relevance in palliative care conversations. Understanding how patients and families talk about existential experience in conversation can create opportunities for clinicians to better meet these needs.

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1. Introduction

Informed by the pioneering contribution of Dame Cicely Saunders and her attention to the multidimensionality of “total pain,” palliative care has long understood the great significance of patients’ existential experience [1]. Recognizing the fundamental importance of addressing existential concerns in the care of seriously ill individuals, existential aspects of care are identified as one of eight domains in the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care [2]. However, existential experience remains a neglected area in palliative care research and practice [3,4].

Existential experience is broadly understood as a moment or situation in which an individual confronts the boundaries of life and attempts to renegotiate their understanding of the self, life, and death [5]. Recognized in the clinical setting by individuals asking, “Why am I here?,”

“What is the purpose of my life?,” and “What will happen to me after I die?” [3], existential questions are regarded as important for individuals navigating life-limiting illness [6,7]. Although confronting life-limiting illness may serve as an opportunity for personal growth for some [8], others may struggle to find answers to their questions, which can result in debilitating suffering [9,10]. Most likely, these experiences are not exclusionary opposites, with individuals experiencing a dialectical movement between existential suffering and joy [5].

Despite the clinical importance of existential concerns to individuals navigating life-limiting illness and to quality palliative care delivery, clinicians report confusion regarding the conceptual definition and management of existential experience [11,12]. Qualitative research investigating existential experience in advanced cancer has been primarily interview-based, asking individuals to describe their experience living and dying with serious illness [6,13–21]. This research illuminates the complex nature of existential experience and served as the basis for our development of the Conceptual Model of Existential Experience in Adults with Advanced cancer [5], which grounds the present work. Yet, existing evidence does not address

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how existential experience is communicated in the natural clinical setting. The current study therefore explored how existential experience is communicated in palliative care conversations between patients, families, and clinicians. This research provides a foundation for understanding how existential experience is communicated in palliative care conversations, creating opportunities in the clinical context to better meet the needs of individuals with serious illness and their families, and to direct future research.

2. Methods

We used a qualitative descriptive approach [22,23] paired with inductive conventional qualitative content analysis [24,25] to analyze existing data from the Palliative Care Communication Research Initiative (PCCRI). The PCCRI was a multisite cohort study of inpatient palliative care consultations at two large academic medical centers in the United States (2014–2016) [26]. Data includes verbatim transcriptions of audio-recorded naturally-occurring palliative care conversations as well as sociodemographic- and illness-related data acquired via self-report by the patient/proxy participant and the electronic health record. As described more fully elsewhere [26], consent was obtained for 363 recorded conversations in the parent PCCRI study; the cohort includes 231 hospitalized adults with advanced cancer, or proxy participants, and 54 palliative care clinicians. Our study aligns with the aims of the parent PCCRI study and the original consent obtained. The Institutional Review Board at the University of Pennsylvania and the University of Vermont approved this analysis as exempt.

2.1. Sampling

We used a random subsample of 30 patients from the parent PCCRI study [26] for qualitative analysis of palliative care conversations. The initial sample size was chosen based on similar qualitative descriptive investigations of existential experience [27,28]. We continued sampling until meaning saturation was achieved [29].

2.2. Analytic approach

Considering the interactive and co-constructed nature of patient-family-clinician conversation [30], we considered the unit of analysis to be the conversation rather than the individual speaker. We inductively analyzed the entire conversation using conventional content analysis [24,25], paying particular attention to manifestations of existential experience as defined by the Conceptual Model of Existential Experience in Adults with Advanced cancer [5]. Grounded in this model, we considered existential communication as any discussion concerned with confronting mortality or the fragility of existence and the process of facing existential challenges related to the very parameters of existence (body, time, others, and death). We iteratively created a codebook including definitions for each code, category, and theme, with illustrative quotes from the data [31]. To bolster trustworthiness, the first author contextualized the transcribed conversations through reviewing direct observation checklists and field notes from the parent PCCRI study, as well as meeting regularly with members of the research team to discuss and revise the codebook, detailing the process in an audit trail [32,33].

3. Results

The sample included 30 patients from the parent PCCRI study, contributing to 38 palliative care conversations. The characteristics of the patient participants are detailed in Table 1. Data analysis converged around one overarching theme that provided a framework for interpreting how existential communication arises in palliative care conversations and encompassed all other subthemes, which detail more specifically what topics of existential communication were discussed.

Table 1
Patient characteristics (N = 30).

Variable	n (%)
Age in years (Mean \pm SD)	64.3 \pm 13.2
Female	19 (63.3)
Race	
Black/African American	2 (6.7)
White	24 (80.0)
Other	4 (13.3)
Hispanic or Latino ethnicity	3 (10.0)
Highest education	
\geq Bachelors	8 (26.7)
High school/some college	18 (60.0)
\leq High school	4 (13.3)
Financial security	
Secure	15 (51.7)
Partially secure	13 (44.8)
Insecure	1 (3.5)
Cancer type	
Lung	2 (6.7)
Gastrointestinal (non-CRC)	4 (13.3)
CRC/breast/prostate	9 (30.0)
Other	15 (50.0)
Palliative Performance Scale (Mean \pm SD)	4.9 (2.1)
Clinicians' estimate of survival time	
<2 weeks	4 (13.3)
2 weeks to <3 months	10 (33.3)
\geq 3 months	16 (53.3)
Days from enrollment to death (Median (Range))	14 (0–157)
Quality of Life ^a (Mean \pm SD)	4.4 \pm 2.8
Any religious affiliation	
Christianity	22 (73.3)
Buddhism	18 (60.0)
Islam	1 (3.3)
At peace	
Completely	3 (10.0)
Quite a bit	5 (17.2)
Moderately	14 (48.3)
Slightly	1 (3.5)
Not at all	6 (20.7)

Note: CRC = colorectal cancer.

^a Quality of life was assessed using the McGill Quality of Life Global item, asking, "Considering all parts of your life – physical, emotional, social, spiritual, and financial – over the past two days, how would you rate the quality of your life?" (using a 0–10 scale from "Very bad" to "Excellent") [47,48].

3.1. Overarching theme: existential communication was woven within palliative care conversations

Existential communication was rarely expressed explicitly in palliative care conversations. Instead, existential elements intermingled with the more practical, concrete components of palliative care conversations, such as addressing symptoms and treatment decision-making. The subtlety of existential communication in palliative care conversations was exemplified in the following dialog between a palliative care clinician (PCC) and a 62-year-old male patient (P):

PCC: And so, were they going to have an oncologist see you here?

P: I think so. And then he said something else, and I'm not sure. It wasn't specific... know where we're going because I'm going to have to take a leave of absence. We've got some alone time. We need to sit down and talk about it...out of my hands. I said you know, Lord, whatever happens. If it's the time, it's the time...It is what it is. I've got a hot rod I've got to get rid of.

PCC: A hot rod you said?

In this excerpt, discussion of practical aspects of planning for the future are adjacent to a deeper level of planning and sense-making. More overt moments of existential communication, where an individual explicitly discussed their own mortality and reflected on what this meant for them, were rarer. Where explicit existential reflections and the fundamental features of palliative care

conversations most overlapped was in discussion of “what matters most.”.

PCC: What's important to you at this point?

P: I don't know. It sure ain't the value of living.
(53-year-old male).

This line of questioning spotlighted the patient's priorities, opening deeper existential reflections on what the individual found most meaningful, or what no longer held meaning, in their current existence.

Existential communication within palliative care conversations could present a tension and an opportunity. The tension is evident in the following excerpt:

PCC: Right and these are you know what we call advance directives so....

P: Mm hmm.

PCC: ...it's not that we expect them to happen you know today or any time soon....

P: No, I understand.

PCC: ...but planning is important, planning is important.

P: Just like me getting cancer. I didn't expect to get cancer either. For 81 years I was in almost perfect health. I mean I had my problems, but I was never you know sick or didn't take medication or anything and then choo. There you go.

PCC: Now who um is...your husband living?

P: Mm hmm.

PCC: Anybody else living with you or just the two of you?

P: No, no.

(83-year-old female).

The patient's passing existential bid, that she is familiar with the unexpected nature of the universe, was an aside within a larger conversation about advance care planning that the clinician did not engage with. As this excerpt reveals, these moments of existential communication could create a tension, between attending to the often-pressing clinical task at hand and witnessing the patient's existential experience. Existential communication could also provide an opportunity for deepening the conversation, when all conversation participants engaged with this content. For example, one 77-year-old male patient reflected on his father's end-of-life when considering his own treatment decisions:

PCC: Now you may not have thought about anything like this.

P: No, I have. I watched my father um his life was sustained 'til he was 101 years old.

PCC: Mm hmm.

P: And the last two years were absolutely miserable.

PCC: Mm hmm.

P: And uh I knew a few things that they did that kept him alive and one which is a stomach tube for feeding....

PCC: Mm hmm.

P: And I've told him I do not want this kind of treatment feeding.
....

PCC: Is there anything else you learned from what happened to your father at the end of his life?

P: Yeah, he spent two or three years in a nursing home burning through all his money, and he was miserable all the time he was there. So, I don't want that to happen.

In this conversation, the clinician integrated the patient's existential reflections on the perceived suffering and death of his father to learn more about his own visions for end-of-life.

3.2. Subtheme 1: time as a pressing boundary

Time as a precious, finite resource served as the most pressing boundary of existence to be navigated in the conversations. Patients families, and clinicians described time as a way to get oriented, creating a twofold timeline for what they needed to do – a medical timeline and a more personal, existential, timeline. The medical timeline contained pivotal events in the cancer illness experience, such as date of diagnosis, hospital admissions, and the timing of tests and procedures. When an individual considered their medical timeline in relation to their personal timeline of existence, the conversation often became more existential:

P: She sent me to they take a piece of your back there.

Family member (FM): Oh, for a biopsy.

P: A biopsy.

PCC: Yeah.

FM: The [date] of December.

PCC: Yes.

P: And...that's how it started. And then the biopsy and then they keep on talking and finding this and that. So, we came again yesterday and here we are again. You know?

PCC: Yeah.

P: And it's on and on and on. It seems like it doesn't get any better. You know? So, uh...sometimes I wonder are they doing the right things, or I am, I don't know, am I all done, you know, there's nothing you can do for me? I don't know.

(76-year-old male).

The process of crafting a personal timeline in relation to a medical timeline caused individuals to reflect on their mortality in a new way, situating their illness experience within their life course. One 77-year-old male patient said, “I just didn't realize how old I was until this happened.” Commonly, as individuals positioned themselves on their personal, existential, timeline in relation to the medical decisions being considered, they described feeling that they were too early in their life course to be contemplating the end of their life:

PCC: And one of the things that we feel is important to discuss is something called a code status, meaning if you were to get a lot more sick than you are now which is pretty sick. I know you're feeling good but if things were to get worse would you want to go to the ICU? Would you want to be on a breathing machine or if your heart were to stop would you want us to do CPR to try to....

P: Hell yeah.

(laughing).

P: Geez. I'm too young.

(56-year-old female).

Participants also conceptualized time as a precious and dwindling resource. Patients and families described feeling that they'd “lost” time, they didn't want to “waste” any more time, they described treatment decisions as “buying” time, and they shared how they want to “spend” their time to make this time as “rich” as possible. This careful calculus, of how much an individual was willing to go through medically to have a chance at more time personally, was often verbalized through discussions of worth:

FM1: The way that I understood it yesterday with the drug.

PCC: It's not certain if it will work.

FM1: It's not a cure.

FM2: No.

PCC: No.

FM1: It's an extension.

P: Nothing's a cure.

PCC: At best it's an extension.

P: It's just buying time.

PCC: At best it's buying time.

FM3: But it might not buy comfortable time too.

P: Right.

FM3: Is it.

P: Is it worth it?

(80-year-old female).

Participants described time as a rapidly dwindling resource, making these calculations all the more urgent. This could lead to powerful existential reflections of what it meant to be coming to the end of one's timeline:

P: ...I feel blessed. And then from here on out I feel cheated. Not because I'm not being blessed anymore. I hopefully will continue being blessed. It just won't be as much of it as I was planning on.

(70-year-old male).

3.3. Subtheme 2: maintaining a coherent self

Individuals with advanced cancer and their families described striving to maintain a coherent self in the changing landscape of illness and dying. Patients and families told stories during palliative care conversations to give a sense of who the person with advanced cancer really is and was. These stories frequently included accounts of a "fighter," who has "gone through so much...and has lived through so much and survived so much," (family member describing an 83-year-old female patient). Not infrequently, the patient's narrative was one of exceptionalism:

P: I was given 3–9 months to live 6 years ago, and so I'm not proud that everybody else has gone by the wayside, but I'm like one in five million people that are still here with my brain metastases.

(56-year-old female).

In the context of advanced cancer, palliative care conversations frequently included discussion of changes to the patient's physical self. Patients and families described the patient's physical body experiencing increased pain and symptoms, becoming weaker, and getting "cut up." Discussion of a changing body in the setting of advanced cancer often led to reflections on how this changed the person's day-to-day existence:

P: I was an extremely happy person. I did cross country skiing, bicycle riding. I have a couple kayaks and we use them. I have a boat and we're on it all the time. But a lot of that will have to change.

(77-year-old male).

This disruption of daily activities could challenge how an individual understood themselves. As one 83-year-old female patient described, "I can't anymore. I just can't, I just can't live a normal life. I probably never will live a normal life like I used to."

In response to these changes, participants described searching for ways to feel like their "normal self" again. As one 49-year-old patient put it, "I mean I want to start doing something I did that I'm used to and made me feel good." And yet sometimes, patients and families emphasized that it was a struggle to adapt to the changes they were experiencing, and the prospect of more challenges ahead:

P: I don't really have a light at the end of the tunnel to. It seems like every time I see the light it's a freight train coming the other way.

(77-year-old male).

One area where patients and families stressed maintaining a sense of a coherent self was in conversations related to treatment

decision-making. In line with the narrative of the self as a "fighter," many individuals and families emphasized pursuing treatment because this honored the patients' identity. As one family member of an 86-year-old female said, "She's never given in to a fight and now's not going to be the time." In making decisions not to pursue additional life-sustaining treatment, many participants described not wanting to prolong an existence where the patient was no longer themselves. This sentiment was expressed by a family member of a 72-year-old female patient who questioned, "just leave her like this how long? It's not her, you know?"

3.4. Subtheme 3: connecting with others

Patients and families emphasized their connections with others – friends and family, members of the care team, and God – as a source of strength, as well as a potential source of suffering, as they adapted to the changing landscape of illness and dying. Palliative care conversations often revolved around connection with loved ones, in this life and the next. Many participants emphasized the increased importance of these connections in the setting of advanced cancer and a threatened existence.

FM: Because it's not just sitting, I just want to hang out with her.

PCC: Yeah.

FM: Like, I'm like, you're alert, let me feed you, let me give you pills, let me make sure you're clean, let me – you know what I mean? That's just – that's what I'd rather do right now. And somebody else is like, make sure you sleeping. Yeah, I'm sleeping, but right now, I don't know how long she has, so every minute that I can have with her, is a minute I can have with her.

PCC: You're making the most of it.

FM: That's really what's most important to me, you know?

(family member of a 37-year-old female).

For some participants, the idea of maintaining connections with family and friends after death – through the patient's legacy or in the afterlife – brought them solace when struggling with how to say goodbye. As one 70-year-old male patient articulated:

P: You know, I'm, instead of having 20-odd more years here I'm gonna go and be with my father and my younger brother and grandparents and all those people that I love and which is perhaps a little selfish of me, to think that I deserve to stay around longer.

Disrupted connection with family and friends was described as a source of suffering in palliative care conversations. Patients often worried about what they were putting their loved ones through, saying "I just didn't want my family to suffer," (56-year-old female). Looking to the future, patients expressed wanting to make sure everyone was taken care of before their death. As one patient said regarding her husband, "I'm concerned about him and uh there's things I have to settle before," alluding to her impending death (83-year-old female). Grief over the anticipated death of their loved one could lead to powerful reflections on isolation, as one family member of a 37-year-old female patient asked, "Why am I the one left?"

Relationships with the care team were described as an important source of connection in palliative care conversations. Often, palliative care conversations included moments of shared gratitude and admiration; some patients and families went so far as to describe their palliative care team as a source of "spiritual counsel," describing how they "walk[ed] the path" of serious illness together. However, when relationships with the care team were compromised or absent, this could lead to feelings of isolation by patients and families. In relaying a story about seeking care from a previous clinician, and feeling that she had been "blown off," one 56-year-old patient expressed:

P: And um but I knew it's like oh my God, if he's gonna blow me off I don't know what to do. I'm alone and I had no one to talk to. I had nowhere to go.

These stories of feeling neglected by previous clinicians could lead to a “deep internal fear” that they would be abandoned in the future, making patients and families doubt whether their care team could truly support them.

Patients and families described connection with God and their faith as an important relationship, but one that could also be tested in the setting of advanced cancer. For some, these spiritual connections could help them make sense of their threatened existence and offer a sense of peace:

P: I do understand. I don't understand why I have to die but we all have to die. We all...we all face the same thing. It's a time of the season for all things, the Bible says. Out of my house is a flower that blooms, a flower that withers, a flower that dies. And that's the way it is. That's what happens. I see seasons come and go on my farm.
(72-year-old male).

Some patients and families emphasized God and their faith as a profound source of strength.

P: Well, God does it for me. It's the medicine I have.
(67-year-old female).

However, some individuals described their faith being tested during serious illness. As one family member of a 56-year old female patient explained regarding his wife's disconnection with her spiritual beliefs, “she kind of stepped away from it actually when it first happened.”

4. Discussion and conclusion

4.1. Discussion

Our findings highlight key insights about how existential experience is communicated in palliative care conversations. The overarching theme, that existential communication is woven within palliative care conversations, helps explain how existential communication presents, intermingling with the more medical elements of conversation. The three subthemes help to further exemplify the overarching theme (e.g., the existential versus medical timeline) as well as provide clinicians with an expanded set of possibilities for what can be considered expressions of existential experience [34]. Findings add to a growing body of literature regarding what is happening in clinical conversations related to serious illness in patients with advanced cancer [35–38], providing a foundation for future research into existential communication.

The overarching theme, that existential communication was woven within palliative care conversations, supports existing literature on existential and spiritual communication in different populations and settings. For instance, research analyzing home hospice conversations similarly found that spiritual discussions occurred throughout the visit, interspersed with other topics [39]. Related research on end-of-life conversations revealed two broad categories of communication: instrumental dimensions of clinical care conversations, which may be interpreted as “steps to follow,” and the existential dimensions of conversations [40]. Our findings underscore that these elements intermingle in conversation, aligning with prior evidence that talking about dying rarely arises in conversation as a new or isolated topic, but instead emerges as a continuation of patients' previous talk [41]. This finding has implications for how clinicians engage in palliative care conversations, with potential opportunities for clinicians to assess and address existential needs throughout the conversation.

The three subthemes – time as a pressing boundary, maintaining a coherent self, and connecting with others – provide considerable detail regarding exactly what is being communicated related to the breadth of existential experience, with direct implications for clinicians. Our finding that individuals with advanced cancer and their families work to construct a medical timeline and an existential timeline aligns with previous research describing how individuals with advanced illness experience two senses of time, their personal experience of time and the socially constructed norms of time [27,42]. Our finding suggests that everyday expressions (such as “buying” and “spending time”) may carry a different meaning in conversations during serious illness, serving as potential opportunities for clinicians to deepen the conversation about how to make time meaningful. Our second subtheme, maintaining a coherent self, extends previous research by revealing that one way individuals with advanced illness communicate striving for authenticity is through describing their involvement in daily activities that align with their innermost priorities [17,43]. Clinicians can recognize that patients' descriptions of a changing body threatening their day-to-day activities and routines of daily life may hold profound existential relevance during serious illness. The third subtheme, connecting with others, relates to how individuals find belonging in the world while struggling with the key existential challenge of isolation [5,44–46]. Our findings highlight the integral relationship between the patient/family and care team within the social dimension of existence, which we hope encourages clinicians to pause and recognize the important role they play in “walking the path” of serious illness and dying together with the patients and families they serve.

4.1.1. Limitations and future research

Several limitations of this research provide opportunities for future investigation. First, the sample included English-speaking, predominantly White, Christian participants, influencing transferability. Additionally, we reviewed audio-recorded transcriptions and did not have indications of nonverbal behaviors, which could have shaped the way things were said or left unsaid. Furthermore, we considered the conversation to be the unit of analysis given the complex, interactional nature of patient-family-clinician conversation; however, this limited our ability to investigate differences in existential communication according to speaker. Lastly, this study took place in an inpatient environment during one hospital stay, which may be different than conversations in other care settings or conversations that evolve over time. Future research to better understand how existential communication may vary according to speaker, over time, across care settings, and in more diverse patient populations is warranted.

4.2. Conclusion

This study examining naturally-occurring palliative care conversations between individuals with advanced cancer, their families, and clinicians, demonstrates that communication about existential experience is omnipresent and varied. Our findings generate directions for future research working toward the development of more tailored, meaningful communication approaches in service of delivering high-quality, person-centered serious illness care.

4.3. Practice implications

Our findings help to broaden the lexicon for talking about existential experience. Through attending to everyday expressions individuals use to talk about time, routines of daily life, and relationships, clinicians can recognize the deep existential concerns individuals express through seemingly “superficial words of daily living” [43]. By treating these expressions as potential opportunities, rather than tensions in the conversation, clinicians can better meet the needs of patients with advanced cancer and their families.

Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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CRedit authorship contribution statement

Elise C. Tarbi: Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing, Visualization, Project administration, Funding acquisition. **Robert Gramling:** Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Supervision, Project administration, Funding acquisition. **Christine Bradway:** Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing, Supervision, Project administration. **Salimah H. Meghani:** Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing, Supervision, Project administration.

Declaration of Competing Interest

None.

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