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Reframing the Goals of Care Conversation: “We’re in a Different Place”

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Abstract

Purpose: Existing recommendations for communicating with patients with metastatic cancer about redefining goals of care when anticancer treatment is unlikely to provide benefit are based on limited evidence. This study was designed to elicit patient and family views on commonly used communication practices.

Study Design and Methods: Participants were 37 patients with metastatic gastrointestinal cancer and 20 bereaved family members who listened to audiorecordings of oncology fellows instructed to discuss a transition in goals of care with a standardized patient for whom evidence-based palliative chemotherapy was no longer effective. During semistructured qualitative interviews, participants commented on the audiorecordings to give feedback on what they liked or disliked about the oncologist’s communication. These comments were transcribed and analyzed.

Results: Three preferred communication practices were identified from participants’ comments. The first practice involves a necessary disruption of the patient’s expectations about ‘‘trying another chemo’’ (‘‘We’re in a different place’’). The second practice is offering actionable responses to the disruption (‘‘Here’s what we can do now’’). The third practice is to find a new place that acknowledges death is closer yet still allows for ‘‘living forward’’ (‘‘Use your inner wisdom’’).

Conclusion: This study of patient and family feedback indicates that patients and families perceive a conversation about goals of care to require disruption of an existing routine, followed by a process of searching and then reconfiguration, rather than a logical decision process. These findings suggest that assessing quality from patient perspectives must take into account a period of disruption and chaos.

Introduction

The conversation required when a patient with metastatic cancer has progressed despite anticancer treatments is challenging.[1,2] Existing research has emphasized the importance of preserving hope,[3] while at the same time preparing patients for dying—a difficult task when patients often conceptualize hope as an aspiration to fight.[4] The difficulty of these conversations is reflected in clinician discomfort[5,6] and avoidance.[7,8]

The need to address this issue is reflected in outcome studies and position papers. Recent evidence from two randomized trials of early palliative care for patients with advanced cancer demonstrated improvements in symptoms, quality of life, and survival, underscoring the need for excellent communication.[9,10] A qualitative analysis of the chart documentation from one of these studies showed that ending chemotherapy is a ‘‘turning point,’’[9,11] and an ASCO position paper emphasized the need for clinician honesty.[12,13]

A barrier to improving these conversations, however, is that the available evidence to support any particular communication practice is limited. Observational studies show communication with little explicit acknowledgment of patients’ emotions,[14] emphasis of biomedical issues over values,[15,16] and reluctance to acknowledge death.[17,18] In studies, patients cite honesty and caring as important physician qualities,[19] and clinicians cite similar domains,[20] but these data do not reflect their reactions to actual conversations.

To add to the evidence base for specific communication practices, we designed a study that enabled subjects to provide comments without being asked to evaluate their own physician. We sought to identify communication practices that clinicians could use as entry points into conversations about goals of care.

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Methods

Participants and setting

We recruited participants of two types: patients with metastatic gastrointestinal cancers without possibility of cure who had received or were receiving anticancer treatment and were not enrolled in hospice and bereaved family members who had acted as primary caregivers of patients who died of a gastrointestinal cancer in the past 6–24 months. The study was conducted at the Seattle Cancer Care Alliance, a tertiary U.S. cancer center. Potential patient participants were identified by reviewing clinic appointments and were initially approached by their treating oncologist or nurse. Potential family participants were identified by reviewing lists of consecutive deceased patients who had a family member known to a clinic physician or nurse. Participant eligibility required willingness to complete the interview, fluency in English, older than 18, preinterview distress thermometer score of less than 4 of 10, and signed informed consent. All study procedures were approved by the Fred Hutchinson Cancer Research Center/University of Washington Cancer Consortium Institutional Review Board.

Design

The participant sample was designed to examine conversations about transitions in goals of care from two different perspectives. Patients with metastatic cancer provided the perspective of those ‘‘at risk’’ for this conversation in the future. Bereaved family participants provided the perspective of those who had been through these conversations with their loved ones and lived through the consequences.

Both patient and family participants listened to audiorecordings created for a different project of an actual oncology fellow talking to a standardized patient in which the oncologist delivered the news that palliative chemotherapy was no longer effective. The methods have been described in detail elsewhere.[21] The audiorecorded conversations lasted 10–15 minutes and were held in an outpatient setting with a patient who was still ambulatory. The oncology fellows on the recordings had been trained in an approach to redefining goals of care that emphasized eliciting the patient’s values and goals to inform development of a care plan.[2] Participants listened to two audiorecordings in the presence of an experienced qualitative interviewer (E.K.H.) who provided instructions, probes, and judgment on when to pause the audiorecording based on the participant’s words, facial expressions, and body language. Interviews lasted 1.5–2 hours, and most were done in participants’ homes. Interviews were audiorecorded and transcribed verbatim.

Analysis

The interdisciplinary research team included clinicians and researchers representing oncology, palliative care, bioethics, and qualitative methodologies. A qualitative analysis was performed using the constant comparison method. Two members of the team (S.B.T., A.L.B.) developed a coding scheme inductively, and used ATLAS.ti software to code all transcripts.[22,23] Two other team members (E.K.H., K.A.E.) independently constructed a case table that displayed key quotes of what participants liked and disliked about the physicians’ communication. The coding team and case table teams met separately and together throughout the data collection period to discuss emerging themes. We stopped data collection when saturation was reached for the results reported here.[24,25] We then prepared a table of key quotations for each of the major conceptual categories identified through analysis to confirm that the themes were grounded in data. During the last phase of analysis, the interviewer conducted member checks using brief telephone interviews.

Results

Participant demographics

Participant characteristics are shown in Tables 1 and 2. Of the patients, ($n = 37$), 49% were female, 84% were Caucasian, and 30% rated their health as excellent or very good. Of the family members ($n = 20$), 75% of were female, 85% were Caucasian, and 80% were bereaved spouses.

Themes

We have organized participant perceptions about oncologist communication into three general communication practices

Table 1. Participants: Patients with Metastatic Cancer

Participants (patients)	n = *37*	%
Male	15	41
Female	22	59
White	31	84
African American	2	5
Asian/Pacific Islander	3	8
Native American	1	3
Age		
Min	31	
Max	84	
Mean	58	
Married/partnered		
Yes	28	76
No	9	24
Self-reported health status		
Excellent	7	19
Very good	4	11
Good	12	32
Fair	7	19
Poor	7	19
Cancer diagnosis		
Pancreatic	7	19
Colorectal	15	41
Esophageal	2	5
Hepatocellular	6	16
GIST	1	3
Gastric	1	3
Small bowel	2	5
Other	3	8
Treatments		
Surgery	26	70
Any chemoterapy	33	89
Chemotgherapy currently	24	65
Any radiation	18	49
Radiation currently	2	5

GIST, gastrointestinal stromal tumor.

TABLE 2. PARTICIPANTS: BEREAVED FAMILY MEMBERS

Participants (bereaved family)	n = *20*	*%*
Male	5	25
Female	15	75
White	17	85
Asian/Pacific Islander	3	15
Age		
Min	22	
Max	72	
Mean	55.1	
Relationship		
Married spouse	16	80
Parent-in-law	1	5
Sibling	2	10
Adult child	1	5
Self-reported health status		
Excellent	5	25
Very good	6	30
Good	4	20
Fair	4	20
Poor	0	0

that represent entry points into the major components of conversations about redefining goals of care. Although we included both patients living with cancer to give a ''prospective'' view as well as family members who had been a primary caregiver for a patient who died of cancer, their views converged on the practices discussed below.

1. We can't continue with the status quo: "We're in a different place." Participants wanted physicians to be clear that the current medical routine was being disrupted. In the most succinct formulation of this disruption, a participant suggested that the physician start with: ''We're in a different place.'' In the words of this participant:

> ''We're in a different place'' is a way for the physician to signal the patient that trajectory is changing. By describing the current situation as ''a different place'' or a ''crossroads'' or a ''tipping point'' or ''You're at C, you're not at A,'' the oncologist could make clear that ''the strategy changes.''

Participants described this disruption as both necessary and shocking; they voiced that while patients with incurable cancer knew that this moment was getting closer (''like a red barn on the horizon''), knowing it was inevitable did not mitigate the shock of hearing that it had arrived. Naming a ''different place'' also signals going somewhere new, rather than emphasizing the past (e.g., ''chemotherapy has not been working'').

Participants acknowledged that after this signpost, most patients would need more detailed discussion to complete their understanding. Participants wanted the oncologist to offer more discussion that the patient could choose to receive or not. They did not want physicians to leave the responsibility of asking for more to the patient, and several said, ''Don't make the patient ask.'' On the other hand, participants disliked oncologist monologues recounting the past sequence of treatments and how the patient had reached the end of a treatment algorithm (''He's off on a tangent…you kind of lose the one nugget, [that] we need to stop''), and attempts to introduce hospice before the patient had absorbed the fact that the current regimen was not working (''He's yanking her down the path…and she's still standing there going 'whoa, wait a minute!'''). Yet while participants wanted the oncologist to tailor the pace of the conversation to the patient, they also wanted the oncologist at some point to state explicitly that further chemotherapy was unlikely to help: ''State it really clearly and succinctly, and don't leave it open to other interpretations.''

2. It's hard but we're not lost: "Here's what we can do now." The second communication practice, ''Here's what we can do now,'' reflects how participants thought physicians could help patients deal with the uncertainty and fear that grip patients when reality of the disruption has sunk in. The ''different place'' patients were facing after stopping chemotherapy was seen by participants as ''being in limbo,'' ''left out there, dangling in the wind,'' ''reaching out for help''—a place of uncertainty, vulnerability, and chaos.

Given this vulnerability, participants wanted the oncologist to acknowledge that this ''different place'' is hard, and also that he has been through this territory before. As one participant said, ''The patient only has this conversation once in their life. So they're the novice. The doctor…will have it literally hundreds, maybe thousands of times….so [the doctor] needs to be the expert, and they need to guide it.'' When one oncologist introduced this moment by saying, ''This is never what we expect, and never what we plan,'' one participant huffed, ''Pathetic, isn't it?'' because she felt that that the oncologist was pretending to be surprised.

Given this situation of uncertainty and chaos, participants suggested that oncologists could help patients at this point in the conversation by making proactive suggestions about things ''we can do now.'' As one participant said ''[the patient] is working in fight or flight mode…she's brainstem right now…[so] the doctor needs to be her processor and put out ideas.'' Another participant, using the metaphor of the patient having fallen into a fast-moving river, said ''[the oncologist] may not be able to rescue [the patient] from the eventual—where she's going on that river, but [the oncologist] can throw a whole bunch of things out to her.'' Another participant wanted the oncologist to ''take the lead on guiding the patient through'' rather than ''having her sit there, think about it, or process it and then be like, 'So, what else can you do for me?'''

Participants felt that hearing a menu of possibilities that described ''things you could do now' would be preferable to an open-ended question about goals. As one participant said, ''I understand what he [the oncologist] is saying…but to me, a goal is very specific…and this is really not that…it's too specific, too limiting.'' Participants did not feel that patients who were dangling, overwhelmed, and uncertain should be asked to commit to goals that would determine their future care. Instead, participants wanted the oncologist to offer possible directions. ''I like…that the doctor was very expansive in what they were saying. And giving a lot of information, without the patient having to ask a lot of questions or think up what the next question is they should be asking.'' Too much deliberation time was not helpful: ''[the oncologist] just remains silent…I don't understand it. I mean, it's almost pathetic that she's not able to see [the patient's] request for help and information here.'' ''I haven't heard the whole thing,'' one patient paused the recording to say, ''but this doctor seems to be letting the patient make all the decisions. I think it's like letting your child decide when their bedtime should be. Is that doing the best thing for your child? No, it's doing the easy thing for yourself.''

Participants viewed the oncologist's challenge as finding options—things to do now—that were meaningful and specific to that individual person. They appreciated when oncologists made specific concrete offers that reflected something the patient had said earlier, as when one oncologist offered to talk to a patient's children after hearing the patient say earlier in the conversation that she didn't know how to explain to them what was happening. Conversely, participants disliked options that were generic or that sounded ''scripted.'''

In addition, participants emphasized the importance of offering things that were actionable. They endorsed possibilities such as savoring a sense of well-being after stopping chemotherapy, enjoying activities that have been cut short because of time spent in clinic, enjoying loved ones. They contrasted these actions to passively waiting for death: ''What am I supposed to do?'' said one participant, spontaneously putting himself in the shoes of the patient in the audiorecording, ''get my blankets ready for hospice?''

3. Drawing out the patient's "inner wisdom" to find "a new place to land." Given that the first practice calls for disruption, and the second practice attempts to provide direction in the ensuing chaos, the third practice is about reconfiguring how to live when death is closer. Participants viewed the patients in the audiorecordings as trying to find ''a new place to land,'' and felt that emphasizing the patient's own 'inner wisdom' was useful. A participant said ''You would want the doctor, in this situation, to talk…to the patient or a family member about how to help the patient with their inner wisdom about how they'd like to live.'' For example, participants noticed one oncologist's ability to ''pick up the thread'' of issues discussed earlier, and one described the conversation as ''a nice dance, kind of backward and forth between the issues [the patient] was concerned about.'' Another participant commented that ''a key moment for me was when [the patient] was done talking…he'd been rambling a bit…and [the doctor] went back and picked out, in his long narrative there, the exact concerns she needed to address and got those one by one.''

''Finding a new place to land'' is about reconfiguring a new and positive orientation to living, rather than solving the problem of dying. One participant commented: ''[The oncologist] doesn't have a solution to things, but I like the fact that she has left him with, although he is dying, that she is *there* with him, ''We're going to be working on [these issues].'' Participants appreciated having physicians build on cues from the patient, but bristled when physicians tried to tell the patient what to do or how to interpret their situation. For example, upon hearing a physician say to the patient, ''You're a fighter,'' one participant commented, ''I don't know, saying someone is a fighter? What does [the doctor] want him to do? What is [the doctor] offering him to fight with? I want [the doctor] to turn this around so that is isn't that you're fighting the cancer, you're making the most of your life! It's a waste, such negative energy…'' Another participant commented, ''Isn't it the doctor's partial responsibility to help you understand that you are an extraordinary person? Everyone is. So move this [conversation] from the physical to the emotional and spiritual level—then we haven't given up.'' Participants appreciated hearing from oncologists a sense of possibility to ''live forward.'' One participant reflected, ''When [my oncologist] first diagnosed me, [he said] something that has stuck with me. He said, 'You can live to die, or you can live until you die.''' A family participant described life after chemotherapy as ''a lively and unpredictable thing''—what she wanted to tell others in this situation was to ''keep yourself open for the sunshine.''

Discussion

This study used patient and family comments on audiorecorded conversations to identify their preferred clinician communication practices for goals of care discussions. The first communication practice signals disruption of an existing routine, the second offers a repertoire of possible actions, and the third seeks to reconfigure how to live by drawing on the patient's inner wisdom. These findings present a view of goals of care conversations as involving not redirection but disruption and reconfiguration.

Study participants perceived that communication focused on biomedical logic and planning for death did not match their anticipatory worries (for patients), or their experience (for bereaved families). A common practice that participants generally disliked was having the oncologist review the patient's history (e.g., prior chemotherapy regimens) as an opening strategy. Rather, they preferred that the physician be more direct in stating that the status quo was no longer working, and preferred to focus on the future rather than the past. The second common practice that participants disliked was having the oncologist ask the patient to identify ''goals,'' especially early on. Rather, participants preferred to hear options of ''What we can do now.'' The third practice they disliked was an immediate recommendation for hospice. Participants gave mixed views on how much to emphasize hospice, and preferred to focus on how to live with death looming closer. Interestingly, the practices that our participants endorsed resonate with previous research on social rituals. In an anthropological study of rituals that diverse societies used to mark important milestones, van Gennep[26] identified ''rites of passage'' typically consisting of three phases: separation, transition, and reincorporation.[27,28] In our study, the first theme about a ''different place'' can be seen as separation; the second theme as describing a liminal, transitional state; and the third theme, about ''a new place,'' as reincorporation.

What do these findings mean for clinicians? First, a goals-of-care conversation requires disrupting the patient's status quo. This disruption is different from discussing bad news of a new diagnosis because the patient has already adapted to the routine of chemotherapy. ''We're in a different place'' could serve as a reorientation that the status quo is no longer viable. Second, following the disruption is a necessary period of uncertainty, vulnerability, and chaos. Offering ''What we can do now'' may enable patients to find a way through the chaos. However, clinicians should be aware that disruption and chaos upset patients, and this finding might explain other studies showing that communication about difficult topics is not viewed positively.[29,30] Finally, clinicians may find that reminding patients of their own ''inner wisdom'' enables reincorporation to life without chemo.

This study has some unique strengths. The participants included patients with metastatic disease, as well as bereaved family members, for a prospective and retrospective view. The findings are based on participant commentary given in the moment, and their comments were frank and less constrained by social desirability relating to liking their oncologist.

This study also has some important limitations. The standardized patients on the audiorecordings involved outpatients with solid tumors, who were ambulatory and possessed decision-making capacity. The scenarios did not require that physician and patient reach a decision. Using audiotapes meant we were unable to assess body language. Even though participants were interviewed at home, their comments may still have been shaped by biases.

In conclusion, this study suggests that conversations about goals of care should explicitly address disruption and reconfiguration, as opposed to simple questions about ''new goals.'' The goals of care conversation may be a new rite of passage.

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