How Oncology Fellows Discuss Transitions in Goals of Care: A Snapshot of Approaches Used Prior to Training

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Abstract

Introduction: The moment when a physician raises the possibility of discontinuing palliative chemotherapy at the end of life is a critical moment in the illness, and a difficult conversation. Expert recommendations cite the importance of giving bad news in these situations but there is limited research addressing how physicians should discuss transitions in goals of care from disease-modifying therapy to end-of-life care. While existing research includes survey data and observational studies of oncologist outpatient visits with patient who have advanced cancer, there are no studies that characterize actual physician communication behaviors when the physician tried to initiate a transitions conversation with a patient who has advanced cancer.

Method: In this study, we examined the communication approaches used by oncology fellows discussing transitions with a standardized patient using audiorecordings collected prior to an intensive communication skills workshop. In this preworkshop encounter, each oncology fellow had the task of discussing a transition in goals of care with a patient who was experiencing cancer progression despite treatment with existing evidence-based therapies. We used qualitative methodology to characterize the approaches used by oncology fellows in 20 of these pre-workshop conversations.

Results: We identified two themes in the approaches that fellows used: (1) the limitations of biomedical disease-modifying treatments and (2) the possibility of a new direction for medical care when disease-modifying treatments have been exhausted.

Conclusion: We found that for each theme, fellows tended to emphasize a logical frame or an experiential frame. Understanding these frames could be useful in designing future communication skills training interventions.

Introduction

FOR A PATIENT WITH ADVANCED CANCER, the moment when a physician raises the possibility of discontinuing palliative chemotherapy represents a turning point.¹ Expert recommendations in the medical literature generally emphasize the importance of discussing discontinuing chemotherapy as a transition from therapy focused on modifying the course of the disease to therapy focused on providing comfort, quality of life, and a good death.^{2–4} These recommendations often draw parallels between giving bad news and discussing a transition in goals of care.^{5–7} Transitions conversations have another important function for patients nearing the end of life. These conversations can be part of an introduction to a larger discussion about what the patient wants to accomplish—or

avoid—at the end of life. The presence of a discussion about end-of-life care is associated with better patient outcomes. In one prospective study, patients who answered “yes” to a single question about whether they had discussed with their physician the “kind of care you would want at the end of life” were less likely to die in the intensive care unit (ICU), receive mechanical ventilation before dying, and were more likely to have been enrolled in hospice for longer than 1 week.⁸ These discussions appear to be influenced by the degree of therapeutic alliance between patient and physician.⁹

Existing research has described some aspects of physician communication about transitions with patients who have advanced cancer.¹⁰ Surveys asking patients with advanced cancer about their communication preferences with physicians indicate that approximately 40% wish to negotiate when

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to discuss dying, and end-of-life care.¹¹ Earlier studies of patient–physician communication behaviors focused more on discussions about withdrawal of life-sustaining treatments at the time of death rather than discontinuation of disease-modifying care.¹² For example, resident physicians discussing cardiopulmonary resuscitation with hospitalized patients elicited patient values infrequently, focusing instead on the procedures involved during a resuscitation attempt.¹³

However, there are no studies that directly examine physician communication behaviors during discussions about transitions in goals of care for patients with advanced cancer who have cancer progression despite all evidence-based chemotherapy. Thus in this study, we took advantage of a set of audiorecordings involving oncology fellows collected prior to an intensive communication skills workshop.¹⁴ In these preworkshop encounters with a standardized patient, the oncology fellow had the task of discussing a transition in goals of care with a patient who was experiencing cancer progression despite treatment with existing evidence-based therapies.¹⁵ We used qualitative methodology to characterize the approaches used by oncology fellows in 20 of these preworkshop conversations. The goal of this study was to characterize how oncology fellows approached communicating a transition in goals of care.

Methods

Physician participants

The Oncotalk workshop was a 4-day intensive communication skills workshop conducted in Aspen biyearly from 2001–2006. The curriculum and teaching methods are described elsewhere.^{15,16} Oncology fellows were recruited nationally. All participants were informed about the research aspects of the conference at the time of enrollment, signed

written consent prior to arrival, and all procedures were approved by the University of Washington Institutional Review Board.

Standardized patient encounters

The primary end point for assessing the Oncotalk communication skills workshop were preworkshop and postworkshop standardized patient encounters that were audiorecorded and coded; these analyses have been published elsewhere.¹⁵ Data for the current study were drawn from preworkshop encounters in which each Oncotalk participant had to discuss a transition in goals of care with a standardized patient.¹⁵ For the transitions encounters that were used in this study, participants were randomly assigned to either a case involving a patient with refractory metastatic ovarian cancer or a patient with refractory metastatic colon cancer for the preretreat encounter (Table 1). Standardized patient training was performed by the Center for Clinical Excellence at the University of Colorado Denver.¹⁵

Data collection

Fellow-standardized patient encounters were audiorecorded digitally. For the present study, we randomly selected 20 preretreat transitions encounters from a complete set of 100 preworkshop transitions audiorecordings, representing 20 different oncology fellows. These audiofiles were transcribed verbatim without identifying data.

Qualitative analyses

We used grounded theory to develop a model of how physicians approach transition conversations.^{17,18} The primary analyst (K.M., who was not involved in the case writing, Oncotalk intervention, or content-based coding) listened to all

TABLE 1. TRANSITIONS CASE INFORMATION

Key elements of case information given to fellows immediately prior to their standardized patient encounter are below (not shown below are medication lists, nurses' symptom report, instruction not to perform a physical exam and that the task is to discuss a transition to palliative care).

Case 1

Patient's Name: Mary Parker

Age: 55 years old

History: Diagnosed with stage 2 breast cancer 5 years ago, and had a 3-cm infiltrating ductal cancer with 7 positive nodes; initially treated with a mastectomy and then adjuvant chemotherapy; was disease-free for approximately 2 years.

She then recurred with lung and liver metastases, and has been treated with palliative chemotherapy including cytoxan/adriamycin, taxol, herceptin, and gemcitabine. Although these treatments have, at times, palliated her symptoms, she has never had a complete remission, and on her most recent regimen her liver metastases have clearly progressed.

(This case was used prior to routine use of avastin, lapatinib, and ixabepilone for metastatic breast cancer.)

Family: Divorced, two children; works part time.

Case 2

Patient's Name: James Farber

Age: 65 years old

History: Diagnosed with metastatic non-small-cell lung cancer 11 months ago; initially treated with carboplatin and paclitaxel, had a partial response in 2 large liver metastases on first scan, then had disease progression and was started on cisplatin and gemcitabine, which he has been on for 5 months. Just discharged after hospitalization for neutropenia and fever, now has declining performance status. Just had a computed tomography (CT) scan showing that his liver metastases are progressing.

(This case was used prior to routine use of avastin for first-line therapy of metastatic non-small-cell lung cancer.)

Family: Married with 2 daughters; retired.

the audiofiles in addition to reading the transcripts. Two analysts (K.M., A.B.) devised a preliminary coding scheme designed to identify themes in the way that the physician communicated that represented patterns of presenting the issues salient to the transition. We did not code patient communication because these standardized patients were trained to respond according to a character script. The coding was performed using Atlas.ti software, and involved (1) open coding, to identify specific concepts in the transcripts as categories; (2) axial coding, in which categories are associated by actions and interactions, and (3) selective coding in which conceptual models are developed and refined. One analyst (K.M.) performed primary coding and the other analyst (A.B.) reviewed all the coding; differences were reconciled through discussion and review of transcripts in weekly meetings. A multidisciplinary team representing expertise in oncology, palliative care, qualitative analysis, ethics, communication analysis, and complementary medicine reviewed the coding scheme, reviewed coded output for individual codes, and provided a critical perspective on the themes identified here. Trustworthiness was established by review of the coding scheme by the entire team, and review of all coding by two investigators. After review of coding results for 20 audio-recordings, we concluded that saturation had been reached for the study themes identified so that no additional audio-recordings were analyzed.

Results

Physician participants

Study participants had a median age of 32, were 55% female, 45% Caucasian (Table 2), and 85% were more inclined toward the “social and emotional aspects” of care, as opposed

to the “scientific and technical” aspects. Most had not had communication training about discontinuing palliative chemotherapy during their fellowship, either as part of a conference or during real-time clinical teaching. All had articulated the importance of communication skills in a brief essay submitted as part of the application process for the workshop.

Themes

We identified two major themes in the approaches that oncology fellows used to discuss a transition in goals of care (Table 3). The first theme was “dealing with the limitations of anticancer treatment.” The second theme was “offering new directions for medical treatments when disease-modifying treatments have been exhausted.” For each of these themes, oncology fellows tended to use either what we labeled a logical frame or an experiential frame. The logical frame is based on a biomedical orientation to disease; the experiential frame is based on the patient perceptions of the illness experience.

Dealing with the limitations of anticancer treatment. In dealing with the limitations of anticancer treatments, the logical frame emphasized a biomedical algorithmic approach. These fellows present treatment failure as scientific fact, using a kind of biomedical logic, and describe a treatment algorithm indicating that no further chemotherapy should be given. For example,

Physician: And so we started you off with the standard treatment. . . . We didn't quite see what we wanted with that, we moved on to something else. One thing I just want to make sure you realize is uhm, in cancer, it's not like infectious diseases, or something. We don't save our best, you know, weapons for the end. We use them up front.

TABLE 2. ONCOLOGY FELLOW CHARACTERISTICS

	Oncology fellows (n= 20) ^a
Age, median years (range)	32 (29–46)
# Female (%)	11 (55%)
# Ethnicity (%)	
Caucasian	9 (45%)
African American	0 (0)
Asian or Pacific Islander	3 (15%)
East Indian	6 (30%)
Hispanic or Latino	1 (5%)
Did not answer	1 (5%)
# Recalled teaching as resident or fellow about communicating discontinuing palliative chemotherapy (%)	
Didactic presentation	5 (25%)
Observation and feedback	6 (30%)
# Recalled teaching as resident or fellow about communicating bad news (%)	
Didactic presentation	14 (70%)
Observation and feedback	6 (30%)
# Rated Self as “Well Prepared” or “Very well Prepared” [4 or 5 on 5-point Likert scale] to discuss discontinuing palliative chemotherapy (%)	8 (40%)
# Rated Self as “Well Prepared” or “Very well Prepared” [4 or 5 on 5 point Likert scale] to discuss bad news (%)	10 (50%)
# Recalled number of patients cared for as fellow who died by year of fellowship (range)	
First year	20 (5–300)
Second year	10 (3–100)
Third year	3 (0–20)

^aAll fellows were required for study enrollment to be in a U.S. accredited fellowship.

TABLE 3. THEMES AND FRAMES USED BY FELLOWS IN DISCUSSING TRANSITIONS

Frames	Theme 1: Dealing with limitations of anticancer treatment	Theme 2: Offering a new direction for medical care as death approaches
Logical	Explains biomedical treatment algorithm, treated emotion as a detour	Presents 'options' with pros and cons
Experiential	Focus on patient reaction to treatment failure, with emotion as central to discussion	Elicits patient concerns, then addresses them as new goals

Patient: Mhmm

Physician: So the chances of you responding to other agents, are even less than the chances were with the two other regimens you've already gotten.

A consequence of the logical frame for acknowledging limitations, is that the patient's emotional reactions are treated as a detour. Fellows try to stay on track by offering solutions.

Patient: Just . . . just things like . . . Just things like if I stop the chemo, it's like I'm just giving up, you know.

Physician: I know this is a . . . uhm, for you, we just get another chemo right? Whether we should do this. I just reviewed your chart. Basically, uhm, every time, when you get a chemo treatment, you always had some nausea, as well, right? And I know you were just discharged from the hospital. And you also had some side effects from the previous chemo, taxol. So these things, you know, will affect the quality of life, as well. And you're taking morphine quite often actually, every 8 hours, 15 mg. . . . So, I think, at this time, palliative care is one option. Of course, as a patient, you always think of other options, rather than palliative care, such as, investigational trials. Have you ever heard of clinical trials?

On the other hand, the experiential frame for acknowledging limitations tends to deemphasize biomedical explanations, and move directly to a focus on the patient's reaction and the meaning of treatment failure for the patient.

Physician: So what I mean is that I would like to focus now, not on picking a chemotherapy, because the chemotherapy is no longer working.

Patient: I see.

Physician: But finding other ways to make your quality of life as good as possible. And maximizing each day for you.

Patient: Mhmm.

Physician: And what that's going to mean is you and me kind of navigating our way thought this, now, and figuring out how to best serve you, at this time.

The discussion about meaning is often an exploration:

Physician: All right. Like I started to say before, right now, you're stable. And all things considered, I think you're doing pretty well. Let me take this opportunity though, to get a sense of some of your beliefs and ideas of what you would want to happen, if there came a time when things weren't going so well, ok? What I'm really talking about is basically, if we came to the time where we were toward the end, do you have a sense of what kind of care you'd want to be receiving then?

In the experiential frame, the patient's emotional response is treated as central to the discussion.

Physician: . . . I think it is appropriate to be looking at how we want to shape time now, ok?

Patient: I . . . I . . . I just don't know how I can get through this.

Physician: This is a very difficult conversation and a difficult situation to be in.

Patient: How do I tell my kids? They know I'm sick. I don't think they realize how very sick I am. I gotta tell 'em. How am I gonna do that?

Physician: Well, you don't have to do it alone, if you don't want to. [4-second silence]

Offering a new direction for medical care when disease-modifying treatments have been exhausted. When offering new directions for medical treatments, fellows using the logical frame tend to proceed along the algorithm and present a choice of options to the patient.

Physician: I think we have a couple different options. You've had very good therapy, up to this point, from your previous doctors who gave you very standard chemotherapy. And had some benefit, I think, especially from the first one. Getting some more chemotherapy is a third-line option . . . would be an option. But I need to let you know that I think the likelihood that that would benefit you, in terms of shrinking your tumors or making you feel better or helping you live longer, is pretty small. Another choice would be to really just focus on controlling your symptoms and helping you feel as comfortable as possible.

These options are often weighted with pros and cons:

Physician: So, whatever we do, there's a cost to it. The cost is not only in the form of money. It's also in the form of what you pay, in the form of getting hospitalized, getting complications from the chemotherapy. These are the costs which you pay from the chemotherapy. And now, the way this disease is, in all the small cell lung cancer, it's a tough disease.

And a conclusion is usually suggested by the fellow:

Physician: We have to decide what's more important to you. Is it more important to you to feel better and to be able to do some of the things you want to do with the people you care about? Or, are you . . . or do you want to sort of go for it and take the chemotherapy despite the really very small chances that you're gonna have any further gains from it?

Fellows using the experiential frame generally elicit patient concerns, then present these concerns back to the patient as addressable issues, offering concerns as a potential focus for treatment.

Physician: And it sounds like other things that you've identified that you have been thinking about are how you would die, where that would be and what that would be like.

Patient: Yeah.

Physician: Uhm, tell me a little bit more about what you've thought about, in that regard?

Patient: [audible exhale] Oh, you mean about dying?

Physician: Yeah. Is that a frightening thing for you to think about?

Patient: Well . . . well, I guess I wouldn't want to be in a lotta pain, you know. I don't know, my dad had colon cancer and he

had quite a bit of pain. So I kind of had that experience with him and so just how my children will deal get sicker. It's a lotta things to think about.

Physician: Ok. Well, let's talk about that first, and then maybe we can talk about the kids . . .

Discussion

The aim of this qualitative analysis of audiorecorded encounters between oncology fellows and standardized patients was to characterize the communication approaches that fellows used to communicate about transitions from anticancer treatment to end-of-life care prior to intensive training. With this analysis, we sought to generate new hypotheses about how oncologists conduct transitions conversations that could inform future research and educational interventions—especially given that these communication skills are complex to acquire.¹⁹ In analyzing these conversations, we identified two major themes that the fellows dealt with in discussing transitions: (1) acknowledging limitations of biomedical treatment and (2) offering a new focus for medical treatment when disease-modifying treatments have been exhausted. For each issue, oncology fellows tended to rely on a logical frame stressing biomedical algorithms, or on an experiential frame drawing on concerns that patient had reported. Our use of frames to describe the themes produced by this analysis is related to work by Lakoff and Johnson²⁰ and Goffman²¹ describing mechanisms of the mind that people use to conceptualize experience, and we feel that these frames provide a useful way of describing the communication approaches we observed.

The two major themes identified in this study distinguish the communication task required of oncologists in discussing transitions from the task of giving bad news. The first theme, acknowledging limitations, has not appeared explicitly in expert recommendations for transitions conversations, although it is often identified as bad news.^{4,5,22,23} However, when giving bad news of a cancer diagnosis, physicians are generally relying on biomedical technology to explain to a patient what is happening; whereas, when discussing a transition, physicians must acknowledge the limitations of biomedical technology in reversing the progression of the disease. While patients tend to accept bad news of a cancer diagnosis, at the time of a transition they may question whether the benefits of biomedical interventions have actually been reached for them personally. One hypothesis raised by this point is that the outcome of a transition conversation might depend on how well the physician understands the patient's level of acceptance about the physician's judgment that disease-modifying therapy is at an end. If the patient does not accept the physician's judgment, the patient may not see the relevance of considering a new direction for medical care. A second hypothesis is that the physician's selection of a logical or experiential frame might influence the patient's acceptance of the physician's judgment that disease-modifying therapy is no longer possible.

The second theme, offering a new direction for care when disease-modifying treatments have been exhausted, raises additional hypotheses about how a physician might get stuck during a transitions conversation. Physicians relying on a logical frame to suggest a new direction ("we can no longer do this, so now let's do this") may find that patients hesitate to

follow because they feel the physician has categorized them as a treatment failure rather than thinking of them as a unique individual. On the other hand, physicians relying on an experiential frame ("you're experiencing this, and your goals are these, so let's focus on your goals aside from disease reversal") may find that patients hesitate because the limitations of disease-modifying therapy have not been made clear, or because the physician suggests goals that fail to resonate with the patient. A practical implication of these hypotheses is that physicians may need to shift back and forth between logical and experiential frames during a transitions conversation, to integrate both frames, while they are talking to an individual patient.

These study findings are subject to some limitations. The number of oncology fellows studied is small. The communication behaviors we observed occurred in the context of a simulated patient encounter rather than a real patient encounter, and the patient case was designed to be one in which the patient had done limited prior reflection about their own situation, yet were able to discuss some biomedical and some personal issues; thus these patients may not have elicited the full range of communication approaches used by oncologists seeing real patients. In particular, this data may not capture approaches used by oncologists who had prior relationship with a patient. Finally, using audiorecorded data restricts the study to mostly verbal behaviors.

In summary, this qualitative study identified two themes faced by oncologists communicating a transition in goals of care that distinguish this task clearly from giving bad news. These findings may enable clinicians to become more aware of their own patterns of communicating transitions, which might enable them to try a new direction when they find themselves getting stuck, and provide educators with a new framework for discussing transitions conversations. Future studies could help assess what patients and family members need from transitions conversations.

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