

Nature of Discussions about Systemic Therapy Discontinuation or Hospice among Patients, Families, and Palliative Care Clinicians during Care for Incurable Cancer: A Qualitative Study

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Abstract

Background: Patient/clinician communication is critical to quality cancer care at the end-of-life (EOL). Yet discussions about systemic therapy discontinuation or hospice as a care option are commonly deferred. Real-time communication about these complex topics has not been evaluated. Palliative care visits may provide useful insight into how communication about EOL care occurs over time.

Objective: To explore the nature of discussions about systemic therapy discontinuation and hospice among patients, families, and palliative care clinicians during care for incurable cancer.

Design: Qualitative study of palliative care visits.

Setting/Subjects: We audiorecorded visits of patients and families who participated in a palliative care trial from diagnosis of incurable lung or noncolorectal gastrointestinal cancer through the course of cancer care ($n=30$).

Measurements: We used thematic analysis to characterize communication patterns in the context of clinical events.

Results: Content and tenor of discussions shifted in relation to patient health status. In the absence of acute medical deterioration, discussions addressed hospice broadly as an EOL care option. Candid exchanges between patients and families and their clinicians supported increasing depth and specificity of EOL care communication. As clinicians identified that patients were not tolerating treatment, the clinicians encouraged contemplation about quality-of-life implications of continuing treatment or the possibility that treatment might harm more than help, in anticipation of change in health status.

Conclusions: Longitudinal relationships with palliative care clinicians functioned through multiple pathways to support patients and families in making complex EOL care decisions. Results inform models and interventions of communication at the EOL.

Keywords: hospice; oncology; palliative care; patient/clinician communication; treatment discontinuation

Introduction

AMONG PATIENTS with incurable cancer, earlier initiation of discussions with clinicians about end-of-life (EOL) care has been linked with earlier referral to hospice.¹ This is important because hospice utilization has been associated with improved symptom management relative to EOL care that does not include hospice.² However, even when patients use hospice at the EOL, most bereaved family caregivers report that discussions about hospice began only within a

month before patient's death or did not occur at all.³ Challenges in broaching EOL care discussions are multifold.³⁻⁷ Clinicians may begin discussing EOL care gradually, wait for the patient or family to initiate discussion, or wait until treatment options are exhausted.^{4,8}

Some research has focused on improving clinician skills for communicating with patients and families about prognosis and EOL care.^{9,10} This work is based in part on social models of learning.^{11,12} The shared decision-making model^{13,14} also has been posited as a critical domain in EOL care communication.¹⁵

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Yet, little is known about the characteristics of EOL care discussions between patients, families, and their clinicians. This information is critical to inform communication interventions and the models upon which they are based.

We aimed to explore the nature of EOL care discussions among patients and families with incurable cancer and their palliative care clinicians. We anticipated that palliative care visits would provide useful insight into EOL care communication, as discussions about EOL care are a core component of guideline-based palliative care.¹⁶ Data were drawn from a randomized controlled trial of early palliative care integrated into oncology care for patients with newly diagnosed incurable lung or noncolorectal gastrointestinal cancer. Primary trial results showed that patients in early palliative care had greater increases in quality-of-life from baseline (<8 weeks from diagnosis) to 24 weeks compared with patients receiving usual oncology care alone.¹⁷ As part of this trial, we audiorecorded the palliative care visits of a subsample of patients, to explore visit characteristics. We focused the current analysis on discussions about hospice and/or systemic therapy discontinuation because the timing of hospice referral before death has been identified as an indicator of quality EOL cancer care.^{2,18} Additionally, in some but not all cases, patients on hospice cannot receive disease-modifying therapy. Yet many patients continue to receive a late referral to hospice and/or systemic therapy during the last two weeks of life.^{19,20}

Methods

Methods and results are reported using the 21-item standards for reporting qualitative research.²¹ Using a thematic analysis approach, we analyzed palliative care visit transcripts from a randomized controlled trial evaluating early palliative care integrated with standard oncology care.¹⁷ The trial team randomly assigned patients with newly diagnosed incurable lung or noncolorectal gastrointestinal cancer to receive either early palliative care integrated with oncology care or usual oncology care alone. The Dana-Farber Cancer Institute/Harvard Cancer Center Institutional Review Board approved the study protocol and all patients provided written informed consent. Family members consented to participate although this was not required for patients to enroll. Consenting patients and family provided additional consent for visits to be audiorecorded. Patients in early palliative care met with a member of the outpatient palliative care team (a board-certified palliative care physician or advanced practice nurse) within four weeks of study enrollment and at least once per month until death. The clinicians conducted the visits based on national guidelines for best practices¹⁶ and documented topics that were discussed using a templated check list. Key topics have been outlined previously.²² The current study utilized data from a subset of early palliative care patients, including self-reported demographics at trial baseline, electronic health record data, and palliative care visit recordings.

Participants

Participants included patients within eight weeks after diagnosis of incurable lung cancer (nonsmall cell, small cell, or mesothelioma) or gastrointestinal cancer (pancreatic, esophageal, gastric, or hepatobiliary) who were scheduled to

receive their care at the Massachusetts General Hospital and who consented to participate in the early palliative care trial ($n=350/480$, enrolled May 2011–July 2015). Patients were ≥ 18 years of age, with an Eastern Cooperative Oncology Group performance status 0–2, and able to complete questionnaires in English or with minimal assistance. Patients were excluded if they were already receiving palliative care services, needed immediate referral to palliative care or hospice, or had significant comorbid disease that precluded study participation.

Data sources

Thirty patients and their family members in the early palliative care intervention arm were invited at the time of study randomization to participate in a substudy, in which palliative care visits were recorded. The subsample size was selected to facilitate thematic saturation while maintaining study feasibility. The study team used purposive sampling for patient age, gender, cancer type, and palliative care clinician, although formal stratification was not conducted. Clinicians audiorecorded their visits with subsample patients and families from first visit until patient death, with exceptions due to recording errors, refusals, clinician forgetting, patient transfer of care, study withdrawal, loss to follow-up, or end of study. We reviewed electronic health records to characterize recent clinical events (e.g., unplanned hospitalization or disease progression on treatment) at the time of each visit.

Analysis plan

We transcribed audiorecorded visits that included patient, family and/or clinician reference to hospice, or discontinuation of systemic therapy (e.g., chemotherapy, oral targeted therapy or immunotherapy), as checked by the clinician in the visit documentation template. We used thematic analysis²³ to identify discussion themes. An inductive thematic approach allowed us to focus on patterns of meaning in the communication content and dynamics, with attention to the timing and clinical context in which each discussion occurred. Several strategies were used to enhance analytic credibility. The study team (oncology, psychology, and palliative care) reviewed initial transcripts to familiarize themselves with the raw data and developed codes that identified key content. The group process helped to minimize overinfluence of any team member's clinical discipline. Two team members (L.T. and C.R.) coded remaining transcripts in an iterative process, with changes or refinements to original codes as needed. The study team then examined and re-examined the coded data to identify overarching themes or patterns of meaning. We refined themes with reference to the raw data and developed an informative statement to describe each theme. We verified results with clinicians and maintained an audit trail to document coding and analysis decisions.²⁴

Results

Substudy patients ($n=30$; Table 1) were primarily White (86.7%), non-Hispanic (90%), and married (86.7%). Four hundred ninety-seven palliative care visits were documented, and 31/497 visits included discussion of hospice and/or systemic therapy discontinuation. Eighteen of 31 visits, representing 9

TABLE 1. SAMPLE CHARACTERISTICS (N=30)

Variable	n (%)
Age, years	
M ± SD	65 ± 12
Range	42–83
Male	16 (53.3)
Race	
White	26 (86.7)
Asian	1 (3.3)
African American/Black	1 (3.3)
Other	2 (6.7)
Ethnicity	
Hispanic	3 (10.0)
Religion	
Catholic	17 (56.7)
Protestant	5 (16.7)
Jewish	1 (3.3)
None	4 (13.3)
Other	3 (10.0)
Married or in a partnership	26 (86.7)
Education	
High school or less	9 (30.0)
Some or completed college	13 (43.3)
Graduate degree	8 (26.7)
Income level	
Less than \$25,000	2 (6.7)
\$26,000–\$50,000	5 (16.7)
\$51,000–\$100,000	5 (16.7)
Over \$100,000	12 (40.0)
Missing	6 (20.0)
Cancer type	
Lung	19 (63.3)
Noncolorectal gastrointestinal	11 (36.7)

patients, were recorded; thematic analysis focused on these recorded visits. A physician (9/18) or nurse practitioner (9/18) conducted each visit, and most (14/18) included both patients and family. At the time of each visit, patients were on chemotherapy (15/18), immunotherapy (1/18), chemotherapy plus an investigational agent (1/18), or targeted therapy (1/18) regimens. Visits included discussion of hospice (10/18), systemic therapy discontinuation (3/18) or both (5/18), and lasted 15–30 minutes (6/18), 31–60 minutes (7/18), or >60 minutes (5/18).

Theme 1: The content and tenor of discussions about systemic therapy discontinuation or hospice moved in phases related to patient health status

In the absence of acute medical deterioration, discussions between patients and families and their clinicians lacked urgency to make concrete decisions about EOL care and focused more on future hospice options. Patients and families asked questions and/or identified preferences related to hospice, whereas clinicians provided information about hospice; explored patient prognostic understanding; and normalized or “tested the waters” for discussing EOL concerns (Table 2). When introducing hospice, clinicians commonly presented it as an anchor of support or protection against suffering, in contrast to giving up hope or giving up on the patient:

TABLE 2. TOPICS OF COMMUNICATION ABOUT SYSTEMIC THERAPY DISCONTINUATION OR HOSPICE BETWEEN PATIENTS AND FAMILIES AND THEIR PALLIATIVE CARE CLINICIANS DURING VISITS THAT OCCURRED IN THE ABSENCE OF ACUTE MEDICAL DETERIORATION

Articulate patient quality-of-life values and goals	Clinician: Is there...any kind of symptom or... harder quality of life that would be a deal breaker for you in terms of treatment? Patient: The [chemotherapy] wasn't easy, but it wasn't intolerable, and if that's going to work, I'm going to do whatever it takes to make it work. [It's] a gut-level, that if it's working, then I go for it.
Address basic information about hospice	Clinician: Oftentimes there's an aide or a volunteer, chaplain, social work, all coming to the home. Medicines getting delivered... a hospital bed or commode. These things getting delivered to try to help patients and families maximize their time at home.
Explore prognostic understanding	Patient: ... The chemo is working so well that the tumor's been shrinking and shrinking. [My oncologist] has given me another six months, or another year, [but]... this is all based on the 'man upstairs'... I mean there is no remission, there is no cure.
Normalize and 'test the waters' for discussing EOL concerns	Clinician: ... Generally at the very final stages of a disease, that's called hospice care... and we can talk more over time about what that looks like or if you want information— Family: Can you explain a little bit now...?
Identify preferences for future EOL care plans, including use of hospice	Clinician: There's the possibility of... having people in your home to care for you that free your family to be less direct in caregiving and preserve the... family role for them. Patient: Yeah. I have considered that... Those are things we need to settle.

EOL, end-of-life.

Clinician: When the balance shifts, even when we say there's not another cancer drug for you, we don't say there's nothing more we can do, because there's always something we really want to help you with.

Acute medical events or worsening health triggered increasingly frank and focused communication between patients and families and their clinicians. Discussions were contextualized more prominently by changes in status than by general timing before death.

Clinician: When I called you a few weeks ago... [your health] had changed so quickly. I was shocked.... I think it even took me a little bit of time to catch how quickly [your health had] changed, so I can imagine [what it must be like for] your family.

At points of medical deterioration, clinicians made more explicit recommendations about timing or type of hospice transition which integrated information they drew from prior visit discussions, appraisal of family resources, and projection of the patient's quality of life into the near future.

Clinician: You've been telling me this for months—the most important thing to you is your family, and being around your kids, and probably being home.... I think this is the time to get you home.

Just before hospice enrollment, discussions focused increasingly on patient and family questions and concerns about access to specific medications or services, coordination of hospice care, family capacity to support home hospice, or other highly personal concerns.

Patient: [Our family] comes from a different background. And we do things a little bit differently in our house... and can [hospice workers] understand about us not being very religious, but at the same time, having a little bit of faith?

Theme 2: Visits included candid, reflective, and intimate exchanges between patients and families and their clinicians, which supported EOL care communication depth and specificity

Patients, families, and clinicians shared personal experiences, anecdotes, dark humor, or reflections on prior conversations, indicating a deepening rapport over time.

Patient: [Grandchild] sat with me and rubbed my back. I said to him, 'Don't do that.' He said, 'Why?' I said, 'because you'll make me cry.' And he rubbed my back... I said to him, 'thank you very much for taking [care of me] Saturday night.' And he says, 'It's no problem, Nana, you've been doing it for me all my life.'

Clinician: Good kid, huh?

Patient: Yeah, real good kid.

All members of the visit moved discussions into and out of topics related to hospice or systemic therapy discontinuation amid symptom management and coping. Patients and families described how symptoms affected quality of life, which highlighted coping styles and daily priorities. In a few instances, when the clinician introduced the topic of hospice, the patient or family member maintained the discussion with additional questions.

Intimate knowledge of the patient's experiences within and outside of cancer care helped clinicians make candid prognostic disclosures as well as recommendations that might diverge from hospice preferences that patients had previously expressed.

Clinician: We talked a long time ago about being home for the end, but it makes me wonder if being [at the hospital] or at the hospice might give your family a little bit more support.

Theme 3: As clinicians identified that patients were not tolerating treatment, the clinicians encouraged patient and family contemplation about quality-of-life implications of continuing treatment or the possibility that treatment might harm more than help, in anticipation of a change in health status

Patients commonly disclosed struggles in adjusting to new states of health or coping with treatment side effects—in some cases, alongside commitment to continuing treatment nevertheless.

Clinician: Do you have any hesitancy about how sick this [chemotherapy] has made you?

Patient: I'm fine with it. I mean, I'm not fine, but I will deal with it... I have a weird kind of comfort. I don't know how to explain... [chemotherapy] has not been easy to tolerate, but I'm still happy to be on it.

Family members expressed distress in witnessing the patient's suffering or deteriorating health, while reflecting on their own hopes or uncertainties about treatment continuation.

Family member: We're still trying to be realistic but positive. I don't want [patient] to have to go through chemo and not have a good quality [of life].

Clinicians used both patient and family disclosures as openings to align with their emotions, clarify prognostic information, and explore motivations for patient decisions. Clinicians elicited or emphasized quality-of-life values, in anticipation that treatment may be stopped at some point in the future.

Clinician: I think that's the trade-off... does [regimen] improve my quality of life? It will give me a little bit more time, but what kind of time is it? And when is it maybe not worth it? And what else is important?

Patient: [Oncologist] said that... we'll give [modified regimen] a try. I say fine.

Clinician: I think that's fine... fingers crossed. I hope this goes easier for you...

When patients pushed back on quality-of-life considerations and/or planned to continue chemotherapy, clinicians appraised the extent to which they felt the decision was reasonable while offering a window into what treatment continuation might be like, naming alternative options, and/or leaving discussions open to shift course.

Patient: No one, except for me, could possibly feel what...having cancer is like.... But here I am. With attitude. Let's do it. Everybody says, let's do it. Let's do it.

Clinician: I think that's a perfectly reasonable thing to do...and I think it's important that if there comes a time when it feels like it's too much, that we can have a discussion about that.

Discussion

This is the first study to characterize discussions about systemic therapy discontinuation and hospice in-depth between patients and families with incurable cancer and their palliative care clinicians. Focusing on early palliative care allowed us to characterize communication in palliative care relationships that began at the time of incurable cancer diagnosis, and without relying on retrospective self-report. Results indicated three overarching themes.

First, the content and tenor of discussions shifted in phases with patient health status. Discussions were contextualized more prominently by health status than by general timing before death. In the absence of an acute medical event or worsening health, the patients, families, and clinicians addressed hospice information or preferences in broad terms. When therapy continuation was a decreasingly possible option, discussions were franker and more focused on the timing of systemic therapy discontinuation or the timing or type of hospice transition. When hospice referral was imminent, patients and families pivoted attention to finalizing a transition plan. These data build on efforts to initiate hospice introductory discussions and visits earlier on in care.²⁵ Results

align with suggestions that enrolling in hospice is a process more than an isolated decision²⁶ and that the end of cancer treatment may be a turning point in hospice decision making.²⁷ Our findings further suggest potential benefits of refining supportive interventions to align with or target the ways in which communication shifts for patients and families and their clinicians in concert with patient health status. This flexibility may support patients with different or unpredictable durations of treatment response, including patients on emerging therapies that change parameters for prognostication.

Second, palliative care visits included candid, reflective, and intimate exchanges, which contributed to EOL care communication depth and specificity. Rapport between patients and families and their palliative care clinicians, including discussions of symptoms, coping, and family life, supported complex decision making by helping to integrate information about family dynamics and other parameter-defining EOL care factors. Prior work has linked earlier initiation of hospice discussions with earlier hospice referral¹ but has not yet established a causal pathway. Findings suggest that, even when patients and families do not discuss hospice explicitly with clinicians, early collaboration may enhance mutual understanding; this in turn may enhance the quality and depth of EOL care discussions and the experience—if not the timing—of transitions to hospice.

Third, as clinicians identified that patients were not tolerating treatment, the clinicians encouraged patient and family contemplation about quality-of-life implications of continuing treatment or the possibility that treatment might harm more than help, in anticipation of a change in health status. Patients and families disclosed struggles with current regimens, alongside feelings about delaying, stopping, or continuing cancer treatment. Clinicians drew on their knowledge of the patient's experiences both within and outside of cancer care to facilitate recommendations—even when decisions remained fraught. When patients pushed back on alternatives to treatment continuation, they allowed the “door to be left open” to future discussion. Results build upon limited prior evidence that the decision to initiate hospice may occur months after chemotherapy is put on hold²⁸ and involves a sharpened or deeper patient or family realization that life is ending.²⁷ Communication about the timing of systemic therapy discontinuation or hospice transition represents a unique intervention target, to assist clinicians in presenting options as decision opportunities¹⁴ before the very EOL.

Current findings inform the application of decision-making models. Results highlight that communication among patients, families, and clinicians is fundamental to EOL care decisions, reflecting a key tenet of shared decision making. Yet formal shared decision making requires both thought and action.¹⁴ The model also focuses on rational processes that may be limited by patient distress.¹⁴ Decisions about hospice or systemic therapy discontinuation reflect less a one-time analytic process and more a complex progression. Prior work has proposed adaptations to shared decision making in serious illness (e.g., incorporating clinician recommendations).²⁹ Current findings further highlight the need to account for diverse points along the illness trajectory in which patients, families, and clinicians may address EOL care options in the context of both uncertainty and certain disease progression. Findings also highlight the importance of additional work to delineate the roles of oncology and palliative care clinicians in EOL care decision making along the disease trajectory.

Current results should be interpreted with attention to study limitations. The sample was drawn from a single academic medical center and primarily comprised non-Hispanic white patients. The palliative care team was highly integrated with the cancer center and had adequate palliative care resources to follow patients from the time of diagnosis with incurable cancer; our themes may not extend to other palliative care settings. The likelihood of discussing hospice with a clinician early after diagnosis of metastatic cancer also has been shown to vary by racial and ethnic identification.³⁰ The study relied on data from a trial of early palliative care; results may not extend to patient/clinician relationships that begin later in cancer care and/or in the inpatient setting. Results also cannot inform our understanding of missed or avoided opportunities to discuss EOL care or patient/family pushback on EOL care discussions. Themes also may not reflect visits that were not recorded, and such visits may have offered new information. Finally, future work should explore whether patient/clinician discussions may differ in the presence or absence of family or may differ between patients with or without options for disease-modifying therapy while on hospice. As patients primarily were on chemotherapy at the time of the visits, future work also should extend to emerging therapies.

Study findings suggest that longitudinal palliative care relationships may function through multiple pathways to support patients and families in making complex EOL care decisions. Findings generate hypotheses about pathways to hospice referral and should be used to inform interventions and models of EOL care communication.

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Author Disclosure Statement

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