

Clinician Roles in Early Integrated Palliative Care for Patients with Advanced Cancer: A Qualitative Study

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Abstract

Background: Early palliative care provides better quality of life, increased prognostic awareness, and even improved survival for patients with advanced cancer but how the integrated care model achieves these outcomes has not been completely explained.

Methods: To better understand the clinical approach to early outpatient care from the clinicians' perspective, we conducted focus groups with the palliative care clinicians who had participated in a randomized trial of early palliative care for metastatic lung cancer.

Results: Clinicians described their role in providing early palliative care as having three distinct roles in the outpatient setting: (1) managing symptoms to improve functional status and as a bridge to other issues; (2) engaging patients in emotional work to facilitate coping, accepting, and planning; and (3) interpreting the oncologist for the patient and the patient for the oncologist.

Conclusions: These data lay the foundation for developing training programs for clinicians in early integrated palliative care.

Introduction

EARLY PALLIATIVE CARE provides better quality of life, increased prognostic awareness, and even improved survival for patients with advanced cancer¹⁻⁴ but how the integrated care model achieves these outcomes has not been completely explained. A qualitative analysis of chart notes from a randomized trial of early palliative care for patients with metastatic lung cancer showed that some components of early palliative care are constant throughout the illness trajectory, while other components evolve over time.⁵ For example, symptom management was constant over time, while rapport building was most frequent in initial visits, and end-of-life planning occurred most frequently in late visits. The evolution of clinician work through the patients' disease trajectory is a key feature of early palliative care in the outpatient setting that differs from inpatient palliative care consultation, which typically focuses on acute symptom control and the care of imminently dying patients.⁶⁻¹⁰ For example, in a study of an inpatient palliative care service, the most common symptom for consultation was delirium.¹¹ These differences suggest that palliative care clinicians caring for patients with advanced cancer earlier in the course of their illness may require specific training.

To better understand the clinical approach to early outpatient care from the clinicians' perspective, we conducted focus groups with the palliative care clinicians who had participated in a randomized trial of early palliative care for metastatic lung cancer.¹ The cancer center in which this study took place had already completed one prior early palliative care study in the identical patient population prior to this trial,¹² so the medical oncology and palliative care teams had extensive experience with this care model.¹³ In the randomized trial, outpatient palliative care visits were conducted by clinicians who were either physicians or advanced practice nurses specializing in palliative care. Their approach to study visits was not manualized or scripted. Thus, we conducted this study to identify and describe distinctive aspects of the clinical approach to early palliative care practice that may have contributed to improved patient outcomes.

Methods

In November 2011, we conducted two qualitative group interviews and one qualitative individual interview with eight palliative care clinicians. The goal of the interviews was to understand their clinical approach to caring for patients in the

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ambulatory setting through the course of their illness. We included all the clinicians who participated in the randomized trial and were still practicing in the outpatient palliative care clinic at the institution where the trial was conducted. The sample included board certified palliative care physicians ($n=6$) and advanced practice nurses ($n=2$). We did not include in the sample two attending physicians who had relocated to other institutions, nor palliative care fellow trainees. The trial required that patients have an outpatient visit with either a palliative care physician or advanced practice nurse within 1 month of study enrollment and at least every 3 weeks throughout their illness.

Three authors (A.B., E.P., J.G.) created a semistructured interview guide, which inquired about the clinicians' approach to early palliative care, both initially and over the course of illness. We interviewed respondents in groups as we hypothesized that group interaction during the interviews would enable individual clinicians to see their own perspectives more clearly, leading to more explicit unpacking of the early palliative care clinician perspective. We conducted two group interviews and one individual interview for a respondent who had been unavailable during the group sessions. The interviews were 60–90 minutes in length and were audio-recorded. These audio-recordings were transcribed verbatim and reviewed for accuracy and completion.

We reviewed and discussed the transcripts, identified major themes, and then constructed a content-based coding scheme. Transcripts were coded using the constant comparative method, and themes identified by each analyst (A.B., E.P., J.G.). These themes were reconciled through an iterative process of data analysis and review, and quotes reflective of each theme were chosen.

Results

Clinicians described their role in providing early palliative care as having three distinct roles in the outpatient setting: (1) managing symptoms to improve functional status and as a bridge to other issues; (2) engaging patients in emotional work to facilitate coping, accepting, and planning; and (3) interpreting the oncologist for the patient and the patient for the oncologist. The clinicians described these roles as distinctive aspects of providing early palliative care to this patient population, which they referred to as crisis management. Importantly, the palliative care clinicians felt these were the three key roles that contributed to the improvements in patients' clinical outcomes.

Managing symptoms to improve functional status and bridge to other issues

Palliative care clinicians viewed symptom assessment and management as improving functional status as an important outcome in its own right. One clinician, for example, described how she explicitly related the importance of good symptom control to "tolerating the chemotherapy well" as a way to align her work in palliative care directly with the oncologist's work. They also described symptom management as an important focus of care in initial visits, as the therapeutic relationship with the patient was being built. As one clinician stated, symptom control is "a certain expertise that also helps build rapport."

Yet a second aspect of managing symptoms successfully was that it enabled the palliative care clinician to cultivate

patient trust for difficult discussions about non-physical issues. For example one clinician described starting with something "very concrete—pain, nausea as a 'safe' objective to help you get a full picture of where the patient is at...and get signals of what other topics you can go into." Thus the rapport and trust gained by early "wins" with symptoms enabled these clinicians to bridge from symptom control to conversations about emotional issues that patients were initially reluctant to discuss.

Engaging in emotional work to facilitate patient coping, accepting, and planning

The early palliative care clinicians viewed their role as enabling patients to engage in the emotional work of dealing with their illness. The types of emotional work palliative care included normalizing the situation, forecasting the "tough parts," and fostering the patient's self-understanding of how they could "make it through" the illness. For example, one clinician described how reinforcing patient's feelings had therapeutic value, "I say to them, 'You know what? This is completely unnerving. And you have been a competent, capable person in every other area of your life. And you've never had to be a competent, capable cancer patient, but that will happen too.'"

A key feature of how palliative care clinicians engaged patients in this emotional work was to frame it as a shared concern. As one clinician put it, "It's a lot of 'we'—We are going to look at this together. We are going to figure this out....If there's anything that comes up that I'm not anticipating now, we're in this together and we'll figure it out."

Palliative care clinicians drew on a repertoire of strategies that enabled them to engage patients in difficult discussions. One strategy was containment. One clinician describes this as "setting up what the boundaries are going to be for these conversations...acknowledging that it's a difficult conversation [for a patient to talk about their feelings about being ill], [and] that we don't have to have that difficult conversation every day." The palliative care clinicians were cognizant of the emotional work patients needed to do and expressed to patients that they "don't have to feel like they're going to have these really intense [discussions] all the time." Another palliative care provider likened containment to "opening the box" and "closing the box" to a difficult topic.

A second strategy to engage patients was to acknowledge patient fears, and use the patient's response to guide the next step of the conversation. One provider said "If it feels uneasy, I would name it or ask them, you know 'feels like this is hard' or 'this feels uncomfortable.'" Another provider said, "If [the patient] is pushing away and looking really, really anxious...I just name it, I say, 'What are you worried about?' And sometimes they'll say 'That you'll make me talk about death and dying.' And I'll say, 'Well I'm not going to do that. You get to guide. We partner in this to see what's helpful.'" This strategy was used particularly to enable the patient to discuss prognostic information

A final strategy to engage patients was to provide positive feedback to a patient for engaging in a difficult conversation. A palliative care provider said, "Sometimes I'll say, 'It seems like that was a good amount of work today...even when 'it wasn't that it was going to be a big tearjerker of a conversation'" is a way of reinforcing the patient's participation. The palliative care

TABLE 1. THEMES AND EXAMPLE QUOTES

<i>Theme</i>	<i>Description</i>	<i>Supporting quotations</i>
Managing symptoms to improve functional status and bridge to other issues.	Using symptom control as a safe “starter” topic to show expertise, and build rapport.	<p>“...the answers they give, even to those very concrete questions, tell me a little bit about what they understand about their illness.”</p> <p>“...two things that give me a deeper assessment are...mood and...your spirits...and then you get more vulnerable pieces”</p>
Engaging in emotional work to facilitate patient coping, accepting, and planning.	<p>Preparing for future success in coping and accepting.</p> <p>Containing difficult conversations by explicitly placing boundaries on the conversations.</p> <p>Framing emotional work as a “shared concern.”</p>	<p>“I say to them...you’ve never had to be a competent, capable cancer patient but that will happen too. And this is how it will happen...”</p> <p>“It’s a lot of ‘we’...<i>We</i> are going to look at this together. <i>We</i> are going to figure it out...”</p> <p>“I think it’s really important...setting up what the boundaries are going to be for the conversations, meaning that these are difficult conversations, acknowledging that it’s a difficult conversation and also acknowledging that we don’t have to have that difficult conversation every day...[*] they don’t have to feel like they’re going to have to have these really intense things all the time.”</p>
Interpreting the oncologist for the patient and patient for the oncologist.	<p>Picking up information from the oncologist, visit, or documentation that the early palliative care clinician rediscusses with the patient in a way the patient “can tolerate.”</p> <p>Providing feedback of patient perceptions to the oncologist.</p>	<p>“When I feel like there is a disconnect between what the patient is hearing and what the oncologist is saying they’re telling [that patient], then I suggest we do a joint visit.”</p> <p>“[The patients’] know that we [oncology and palliative care] talk to one another...they see us as being integrated.”</p> <p>“There are things [a patient] will tell us [palliative care] that they won’t tell the oncologist, not because they don’t care about the oncologist but because they worry...they’re going to let the oncologist down or...the oncologist won’t seem them anymore if they don’t want more chemotherapy.”</p> <p>“I will touch base with the oncologist to say, ‘I’m a little concerned about what their understanding’...</p>

provider continued, “Even if you wanted to accomplish two or three other things, if you accomplish one, you make them feel good about that.”

Interpreting the oncologist for the patient and patient for the oncologist

The third role that the palliative care clinicians served was as an interpreter, for both the patient and the oncologist. In one direction, palliative care clinicians interpreted what the oncologist talked about for the patient. For example, a patient might hear his prognosis “from his oncologist. And then part of what we do is we pick that up and then feed it [back]—

reflect it back to them in a way that I think they can tolerate it.” By interpreting the oncologist for the patient, the palliative care clinician enabled the patient to do more emotional work, as in this example the patient was developing a greater ability to discuss and understand his prognosis. “Because sometimes, it’s that [the oncologist] has been saying it but the patient isn’t taking it in...”

Palliative care clinicians also interpreted the patient for the oncologist. For example, if a palliative care clinician sensed that the oncologist was “getting frustrated with the patient,” the palliative care clinician might work with the oncologist separately from the patient. In one example a palliative care clinician described helping an oncologist “tolerate the

extreme hopefulness” of a patient. Occasionally, palliative care clinicians would suggest holding joint visits with oncologist and patient to “help me interpret...and then in the moment, try to bring [them] together.”

Discussion

We conducted this qualitative study to understand clinician approaches to early integrated palliative care that improved patient outcomes. In describing their clinical approach, early palliative care clinicians identified three distinctive roles: (1) managing symptoms to improve functional status, and bridge to other issues; (2) engaging patients in emotional work to facilitate coping, accepting, and planning; and (3) interpreting the oncologist for the patient, and the patient for the oncologist. Taken together, these roles enable early palliative care clinicians to create a bridge between biomedical care and emotional work, and their emphasis on this aspect of their clinical work distinguishes early outpatient palliative care from acute inpatient palliative care. These findings, combined with our earlier study examining chart documentation by clinicians, provide a clear picture of the role of early palliative care clinicians in the care of patients with advanced cancer.

The current themes suggest that the patterns of chart documentation seen in our earlier study⁵ are the product of intentional early palliative care clinical strategies. Our earlier study showed that palliative care documentation in the initial phase of illness focused on relationship building and illness understanding; the late phase of illness focused on end-of-life decision-making. The current study reveals this pattern to be a product of an intentional strategy: early palliative care clinicians begin by focusing on building rapport and symptom control in order to build the patient trust needed for end of life decision making. A different observation involves the turning points identified in our earlier study. Our earlier study showed that early palliative care clinicians documented more psychosocial and coping issues at turning points than oncologists. Again, the current study reveals the intentional early palliative care strategy: early palliative care clinicians deliberately take on a role of interpreting biomedical issues for the patient in order to facilitate decision making, and thus their documentation reflects they interpreted biomedical issues to help patients make sense of their illness, and make medical decisions.

This study also suggests some differences between clinical strategies used for inpatient palliative care consults versus early outpatient integrated palliative care. While inpatient palliative care clinicians typically deal with major shifts in patient status in a single visit, early palliative care unfolds over a longer period of time and multiple contacts. The clinicians in this study spoke of early palliative care as affording a “luxury of time.” Symptom management represents an entry point to developing a patient–clinician relationship, followed by the use of specific strategies to broaden the areas of concern to encompass decision-making and end-of-life planning.

Thus the early palliative care clinician approach may require that clinicians experienced in inpatient palliative care shift their expectations and strategies when working with early palliative care patients. For example, when inpatient palliative care clinicians encounter a patient who is reluctant to discuss prognosis or end-of-life planning, the clinical

urgency of the situation is frequently used to address patient reluctance to engage these issues. In early integrated palliative care, clinical urgency is often not available to use as leverage, and confrontation could result in patient refusal to continue with palliative care follow-up. Thus, communication skills that engage patients in difficult issues and move them in small increments over time are critically important.¹⁴

The longitudinal view of the early palliative care clinician is more about guiding the patient over time than conducting a pivotal goals of care discussion at a turning point in the patients’ illness. This way of thinking can be seen as a threshold concept¹⁵ that represents a substantially different repertoire of clinician roles, intentions, and actions in early palliative care. The implications of considering early palliative care as a threshold concept has relevance for designing training and education for palliative care clinicians, and suggests that training will need to address unlearning of habitual approaches that are highly functional for inpatient palliative care—in particular, the crisis mentality and need for extensive, sweeping decision making. In contrast, the key approaches we identified that are relevant for the design of future training programs include bridging from symptom control to more challenging issues; communication and counseling skills that support coping, planning, and acceptance; and collaborating with specialist colleagues such as oncologists.

This study has several important strengths. The clinicians we studied were a highly experienced group who developed the early palliative care model tested in the randomized study and the roles they described represent a high degree of integration of palliative care and oncology. Additionally, the researchers who interviewed the palliative care clinicians and analyzed the data were not involved in the early palliative care intervention, limiting bias in interviews and interpretation. Last, the study included all of the palliative care clinicians involved in the randomized study who still practice in the outpatient setting at the participating institution.

This study also has some limitations. First, the randomized study was conducted at a single site, which may limit generalization of the experiences of the palliative care clinicians. The small number of clinicians participating in this study means that individual clinician beliefs and practices may be overrepresented. Only physicians and advance practice nurses provided the early palliative care in the study, thus the roles other disciplines may play in caring for patients in the outpatient setting may not be represented in our data. Additionally, the palliative care clinicians had developed close working relationships with oncologists over a period of years, which may be difficult to replicate. Last, the intervention in the randomized study could be considered a “high-dose” intervention involving a median of 10 visits per patient, and lower dose interventions might involve palliative care clinicians differently.

Early integrated palliative care in the outpatient setting has been clearly shown to improve the experience and care of patients with advanced cancer. In this study, we began to unpack the key role that the palliative care clinician plays in caring for patients in the integrated care model. Experienced palliative care clinicians reported managing patients’ symptoms, engaging patients in emotional work, and interpreting between patients and oncologists best describes their role in the outpatient setting. These data lay the foundation for

developing training programs for clinicians in early integrated palliative care.

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