

Oncologist Factors That Influence Referrals to Subspecialty Palliative Care Clinics

By Yael Schenker, MD, MAS, Megan Crowley-Matoka, PhD, Daniel Dohan, PhD, Michael W. Rabow, MD, Cardinale B. Smith, MD, MSCR, Douglas B. White, MD, MAS, Edward Chu, MD, Greer A. Tiver, MPH, Sara Einhorn, and Robert M. Arnold, MD

University of Pittsburgh Cancer Institute; University of Pittsburgh, Pittsburgh, PA; Feinberg School of Medicine, Northwestern University, Chicago, IL; Institute for Health Policy Studies; Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, CA; and Tisch Cancer Institute, Icahn School of Medicine at Mount Sinai, New York, NY

Abstract

Purpose: Recent research and professional guidelines support expanded use of outpatient subspecialty palliative care in oncology, but provider referral practices vary widely. We sought to explore oncologist factors that influence referrals to outpatient palliative care.

Methods: Multisite, qualitative interview study at three academic cancer centers in the United States with well-established palliative care clinics. Seventy-four medical oncologists participated in semistructured interviews between February and October 2012. The interview guide asked about experiences and decision making regarding outpatient palliative care use. A multidisciplinary team analyzed interview transcripts using constant comparative methods to inductively develop and refine themes related to palliative care referral decisions.

Results: We identified three main oncologist barriers to subspecialty palliative care referrals at sites with comprehensive palliative care clinics: persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy, a predominant belief that providing palliative care is an integral part of the oncologist's role, and a lack of knowledge about locally available services. Participants described their views of subspecialty palliative care as evolving in response to increasing availability of services and positive referral experiences, but emphasized that views of palliative care as valuable in addition to standard oncology care were not universally shared by oncologists.

Conclusions: Improving provision of palliative care in oncology will likely require efforts beyond increasing service availability. Raising awareness of ways in which subspecialty palliative care complements standard oncology care and developing ways for oncologists and palliative care physicians to collaborate and integrate their respective skills may help.

Introduction

Palliative care is defined as medical care for patients with serious illness aimed at improving quality of life for both patient and family.¹ Accumulating evidence indicates that subspecialty palliative care provided concomitantly with standard oncology care improves clinical outcomes for patients with advanced cancer.²⁻⁴ In response, professional oncology guidelines have been revised to recommend earlier integration of subspecialty palliative care services.⁵⁻⁹

However, significant provider-level variation exists in the use of subspecialty palliative care.¹⁰⁻¹² In a recent survey of oncologists, pulmonologists, and internists caring for patients with lung cancer in New York City, nearly half reported referring less than 25% of their patients to palliative care services.¹¹ Surveys of oncologists in Canada and Europe similarly indicate a wide range of practices regarding the frequency and timing of palliative care referrals, suggesting that factors beyond patient needs, service availability, and professional guidelines motivate use.^{10,12} To date, there has been little in-depth exploration of provider factors that influence palliative care referral decisions at academic cancer centers across the United States, where outpatient palliative care services are rapidly expanding.^{13,14} Understanding oncologists' views on referrals to palliative care

clinics is critical to inform efforts to improve integration and uptake of these services.

Our goal in this study was to elucidate how oncologists at academic cancer centers in the United States make decisions about referring patients to outpatient, subspecialty palliative care. We interviewed oncologists practicing at three centers with well-established palliative care clinics in order to maximize participants' exposure to these services. In this analysis, we explore oncologist factors that influence referral decisions.

Methods

Study Design, Setting, and Subjects

We conducted a multisite qualitative interview study at two National Cancer Institute-designated comprehensive cancer centers (University of Pittsburgh Cancer Institute [UPCI] and the University of California, San Francisco Helen Diller Family Comprehensive Cancer Center [UCSF]) and one academic center (Mount Sinai Tisch Cancer Institute [TCI]) with outpatient palliative care clinics. These clinics, named the Cancer Pain and Supportive Care Clinic (UPCI), the Symptom Management Service (UCSF), and the Hertzberg Palliative Care Clinic (TCI), were established between 2002 and 2005 and are

supported by a combination of billing (all), institutional support (all), philanthropy (UCSF and TCI), and research grants (UCSF). Subspecialty-trained palliative care physicians provide treatment and counseling for physical and emotional symptoms, assistance with advance care planning, and family and spiritual support.

Eligible participants were attending-level, fellowship-trained medical oncologists with an outpatient clinical practice of at least one half day per week. We sought to include an equal number of participants from each site to maximize our ability to understand a spectrum of practice patterns in different settings. We chose to focus on medical oncologists because they generate the majority of palliative care referrals at these cancer centers and are thus most likely to be “information rich” with respect to the phenomenon of interest.¹⁵ We included only medical oncologists with active outpatient practices to ensure that all participants had the opportunity to refer patients to subspecialty palliative care clinic.

Enrollment and Data Collection

We generated a random-order list of potential participants at each site and sent an introductory e-mail from a local investigator describing the purpose of the study. The study coordinator followed up with potential participants through e-mail and telephone contact to schedule interviews. All interviews were conducted between February and October 2012 by a single experienced interviewer (G.A.T.) either in person (UPCI) or over the phone (UCSF and TCI). The institutional review board at each site approved the research protocol. All participants provided verbal informed consent.

Our interview guide included open-ended questions with follow-up probes to elicit oncologists’ experiences with outpatient palliative care services. We asked participants to reflect on particular patients whom they had and had not referred to their local palliative care clinic, as well as a brief hypothetical patient vignette. We included a hypothetical vignette because asking physicians about individual practice patterns is a potentially sensitive topic that may be better explored using this complementary qualitative research technique.¹⁶ Interviews lasted an average of 20 minutes (range, 8 to 44 minutes). After each interview, participants completed a demographic questionnaire. The interview guide is included as a Data Supplement.

Qualitative Data Analysis

All interviews were recorded and transcribed verbatim. The interviewer (G.A.T.) reviewed all transcriptions to verify quality. We developed the coding framework using constant comparative methods, a qualitative analytic technique used to inductively develop coding themes when existing frameworks are inadequate.^{17,18} Eight investigators from diverse backgrounds identified preliminary themes through independent coding of a subset of six transcripts. These themes were modified through review and discussion of concepts and questions identified in additional transcripts at a series of investigator meetings. A coder trained in qualitative analysis (S.E.) applied

the final framework to all transcripts. We assessed reliability by having a second investigator (G.A.T.) code 80 representative passages from 38% of the interviews. We use a quasi-statistical analysis style to summarize patterns in the data¹⁹ and respondent validation (“member checking”), creation of an audit trail documenting the data analysis process, and attention to negative cases to enhance the validity of our findings.²⁰

Results

We contacted 95 oncologists for participation. Of these, five did not meet eligibility criteria, and 16 did not respond to our invitation or declined to participate. A total of 74 oncologists completed the interview (n = 25 at UCSF, 24 at UPCI, and 25 at TCI), for a response rate of 82%. Participants were 68% male, reflecting the gender breakdown of medical oncologists in the United States.²¹ Participants had been in practice for a mean of 17 years, in both hematologic malignancy and solid tumor specialties (Table 1). The most common reason for referral to palliative care was for management of pain symptoms (Table 2).

The qualitative analytic process proceeded without difficulty. Kappa statistics for the codes that compose our main analysis ranged from 0.87 to 0.95, indicating excellent interrater reliability.

Views of Palliative Care

A significant minority (22 of 74) participants viewed palliative care primarily as an alternative to cancer therapy (Table 3). This view was expressed by participants at all sites, more commonly by those who had been in practice longer. As one participant explained, “if a patient is a chemotherapy candidate, they’re not a palliative care candidate.” Oncologists with this view noted that their referral decisions were dictated primarily by a patient’s illness stage and treatment options. They reported using subspecialty palliative care infrequently and late in the disease course. One oncologist referred patients “whose overall quality of life has diminished to the point that quantity is no longer an issue.” He added, “When we’re no longer thinking of what . . . new agent to use for treatment of the disease, I think it [palliative care] is appropriate then.”

Some participants described palliative care as a different philosophy of care that may not be compatible with aggressive, disease-modifying therapy. They noted that there tended to be a focus in oncology on either treating the disease or treating symptoms, and not both. A fear that palliative care physicians might create a conflict for patients receiving chemotherapy by contradicting oncologists or giving more dismal prognostic estimates was a barrier to referrals. Oncologists also worried that a referral too early would be viewed by their patients as abandonment or giving up. “I know that the patients want to be treated actively and get better,” another oncologist said. “That’s why they come to me or any doctor taking care, not to have palliative care.”

Other participants expressed a more comprehensive view of palliative care as complementary to cancer therapy (Table 3).

Table 1. Participant Demographic Characteristics (N = 74)

Characteristic	No.	%
Site		
UPCI	24	
UCSF	25	
TCI	25	
Age, years		
Mean	47.9	
SD	11.3	
Sex		
Male	50	68
Female	24	32
Race/ethnicity		
White	56	76
Asian	15	20
Other/no response	3	4
Latino/a or Hispanic	2	3
Religion		
Christian/Catholic	27	36
Jewish	20	27
Muslim/Hindu/Buddhist/other	5	7
Agnostic/atheist/no religion	22	30
Years practicing oncology (including fellowship)		
Mean	17.3	
SD	11.7	
Range	2-61	
Disease site specialty (multiple responses allowed)		
Brain	3	
Breast	14	
Colon and gastrointestinal	9	
Head and neck	4	
Leukemia and lymphoma	22	
Liver	2	
Lung and esophageal	8	
Melanoma	7	
Ovarian and gynecologic	2	
Prostate and urologic	9	
Other	32	
Tumor type specialty		
Solid tumors	45	61
Hematologic malignancies	24	32
Both solid tumors and hematologic malignancies	5	7
Half days in oncology clinic		
Mean	3.9	
SD	2.2	
Palliative care fellowship training	1	1

Abbreviations: SD, standard deviation; TCI, Mount Sinai Tisch Cancer Institute; UCSF, University of California, San Francisco Helen Diller Family Comprehensive Cancer Center; UPCI, University of Pittsburgh Cancer Institute.

For these oncologists, referral decisions were dictated largely by patient needs—predominantly pain symptoms—and the perceived value of palliative care. They reported referring patients more frequently and earlier in the disease course. As one partic-

Table 2. Outpatient Palliative Care Referrals (N = 74)

Parameter	No.	%
Most common reason for outpatient palliative care referral		
Pain symptoms	51	69
Nonpain symptoms	2	3
Psychosocial support	9	12
Family support	4	5
Goals of care discussion	1	1
Has never referred to outpatient palliative care	7	9
Perceived likelihood of making outpatient palliative care referrals compared with colleagues		
More likely	28	38
About the same	31	42
Less likely	10	14
No response	4	5

ipant said, “We try to refer [to palliative care clinic] early in the process of treating them, so we don’t end up with this very awkward thing, saying. . . ‘there’s nothing available’ . . . It’s a far smoother transition if you do it very early.” Another oncologist commented that palliative care clinics were more helpful in forming therapeutic relationships with sick patients than were anesthesiology-based pain services.

Several participants described their views of palliative care as evolving in response to increasing availability of services and positive referral experiences, though none mentioned recent professional society recommendations as influencing their referral patterns. They noted a changing culture around palliative care, while emphasizing that views of palliative care as complementary to cancer therapy were not necessarily shared by colleagues. One oncologist thought that physicians were “hopefully learning” to move beyond a “still pretty embedded” view of palliative care as simply meaning “that your patient is dying, end-of-life.” She went on to say, “We have a lot of oncologists who grew up before palliative care was a part of complete care for these patients, so I think there is that culture, but I think it’s changing.”

Self-Defined Professional Roles

Many oncologists viewed providing palliative care as an integral part of their professional role, noting that this was a barrier to involving subspecialty palliative care (Table 4). “I think you should know,” one participant said, “that oncologists are territorial and they tend to view this [indicating clinic area] as their complete domain. And that they’re responsible for the care of their patient from day one to last day. And they tend not to be very . . . receptive to [having] other physician interfere with their care.” Several participants reported that they began practicing oncology at a time or place where subspecialty palliative care did not exist. “Historically,” one oncologist explained, “I have done all of the palliative care myself when I was at [prior institution]. Meaning, that we didn’t really have a service of palliative care folks. . . So when I got here, I was initially a bit

Table 3. Oncologists' Views of Palliative Care

View	Representative Quotes
Alternative to cancer therapy	<p>If they have symptoms, and they're ready to stop treatment, they get referred [to palliative care clinic].</p> <p>The reason that people are referred to us . . . is to participate in clinical trials. And to try to take a more aggressive . . . to try to make them live longer, for lack of a better word. . . if you refer a person to palliative care, in a sense you're saying that . . . you know, maybe you don't think that outcome will actually happen. And maybe you should concentrate on taking care of the symptoms better. Now, I know that . . . it's not a zero-sum game. It's not like you can't take care of symptoms and also . . . you know, improve their outcomes. Like make them live longer, whatever it is that you're trying to do: shrink the tumor down. . . . You could do both at the same time. But I think partly it's a selection thing. . . people come to us because . . . they're not concerned about their pain so much, they're concerned about beating the melanoma or shrinking the melanoma. And we are responding to that, what patients want us to do.</p> <p>I avoid the referral [to palliative care]. Like I said, until there's some signal from the patient that they're ready for it. But I try to avoid the signals by constantly reemphasizing to them that, "Now is not the time to quit. Now is not the time to give in." . . . "There's still an opportunity here to effect a good result." And sometimes that's very difficult to do when someone else is giving the opposite signals. You know? . . . whether it's intended or not . . . don't misunderstand me, I'm not particularly saying that I think people in the palliative care program are telling them to go out and buy their burial plots or anything like that. But, I think patients pick it up that way. They just start thinking, you know, that the entire situation is changing, that I or the people that are actually treating them for their acute illness may be too optimistic, you know, that sort of thing. So I try to avoid that conflict, as much as I can, in their minds.</p>
Complementary to cancer therapy	<p>I think it's kind of putting it in context: it's not like I'm abandoning you because your problem is too hard, it's basically saying, you know, "You have cancer, you see an oncologist. When you have pain or you have symptom-control issues, that aren't being managed simply, then it's time for you to see a specialist in regards to that.</p> <p>Well, I would say I would send the person to the symptom management clinic slash palliative care clinic if she's having symptoms that I'm having difficulty controlling. And I wouldn't necessarily be sending her to help with end-of-life decision making, although that may play into it. So I think that palliative care doesn't necessarily mean it's end-of-life, and in this case, the patient's disease and other things would sort of dictate that.</p> <p>If the patient has . . . is undergoing a primary therapy, but has severe pain symptoms that are . . . you know, where they're . . . we're having difficulty managing pain. Then under those circumstances, I would consider referring the patient to palliative care for help with symptom relief.</p>
Evolving views of palliative care	<p>This particular patient, with the palliative care involvement and some therapy from my side, has done very well and actually ended up living for two years. And she had excellent quality of life and the family was very appreciative of such approach. It was one of my first patients that I involved palliative care on such level, because in the past I usually involved palliative care without additional therapy for cancer. So that was basically stopping therapy and going to palliation. She was one of the first ones that I realized that I don't have to stop, and actually, this patient lived very well and obviously everyone was very happy with that.</p> <p>You know . . . since the Massachusetts General trial, I've found myself kind of earlier and earlier offering it up. And you know, if someone is basically doing well and they're just starting on therapy, something may tweak my brain to say, "maybe I'll just mention this to them, if they have that overriding concern about neuropathy, and how am I going to deal with that?" You say, "Well, you know, there are some other physicians that could help us in the future. And maybe you should see them early to kind of get tuned in and so on and so forth."</p>

Table 4. Oncologists' Self-Defined Professional Role

Role	Representative Quotes
Includes providing palliative care	<p>I guess I should start by saying that we are trained as oncologists to think of pain management and palliative care as part and parcel of what we do every day. So, we take a lot of . . . you know, I think, proactive initiative in terms of addressing some of the issues that arise around the supportive care of patients at various stages of their disease . . . So when it comes to the management of . . . their psyche as they go through the different disease states, that's . . . I consider that as important to my practice as prescribing chemotherapy.</p> <p>Everyone draws a line of what they will do themselves because we are all palliative care-ists, to some degree. Everything I do is to palliate these patients.</p> <p>I do feel though, as an oncologist, a lot of what I do should . . . include a lot of palliative . . . care. So, I do feel that referring someone to palliative care is not always necessary . . . if I feel that I can adequately provide for the patient's needs in the palliative care realm.</p>
Focused on anticancer therapy	<p>I probably focus more . . . on their medical care, like the ins and the outs of their medication, lab monitoring, what to do about the cancer. And I have a limited amount of time to spend on what I think is equally important, which is the psychological impact of the cancer on their life and their family's life . . . And I think, in my past experience with palliative care, it's been a nice adjunct to help them deal. And I've gotten very positive feedback from patients. So, for this particular patient, I thought he would benefit from being able to devote like an entire visit to talk about what's going on in their life and how the cancer's impacting the family dynamics and their life, et cetera.</p> <p>I can do my job a little bit better—which is to talk about prostate cancer and the treatments of prostate cancer and how we can try to slow down the cancer—and have others help out with the symptom management needs.</p>

uncomfortable with letting go of that." Others viewed referring patients to palliative care as passing off difficult tasks or shirking their professional responsibility. As one participant said, "Some people, even for end-of-life discussions, some people will send patients to palliative care. I don't. I feel like I shouldn't dump that on somebody else. If I've been following that person, it's

my obligation to have that discussion." Oncologists expressed concern that referrals might lead to confusion about who was handling different aspects of a patient's care, or that patients might receive mixed messages. One participant explained, "You know, I think sometimes there's a little bit of 'too many cooks stirring the pot' kind of thing. And patients might be kind of

confused, who do they go to if there are issues or questions or medications they need or things like that?"

A minority of oncologists (18 of 74) described their primary role as providing cancer therapy, not palliative care. As one participant acknowledged, "Frankly, again, we are focused on one thing, and this is basically fighting that cancer. And the other things can slip, you can just not think about it." Another noted, "Being an oncologist, you obviously have some palliative care skills, because you manage pain, shortness of breath, adverse effects of chemotherapy. But also, a large part of what we do is aimed at treating cancer. . . the mindset of an oncologist, in my opinion, is more therapeutically driven." These participants saw a clearer role for subspecialty palliative care and appreciated the service for allowing them to focus more on their primary responsibilities. As one oncologist said, "It's basically saying, you know, you have cancer, you see an oncologist. When you have pain or you have symptom-control issues, that aren't being managed simply, then it's time for you to see a specialist in regards to that." Many participants noted that palliative care was as important as cancer therapy, but that there was simply not time for oncologists to do everything.

Knowledge of Available Services

A handful of oncologists at each site (11 of 74) described a lack of knowledge about local outpatient palliative care services as a barrier to referral. As one participant said, "Because I didn't know that we had outpatient services, I did not refer. But there are many patients that do need palliative care services, and I didn't know that we had outpatient." Another oncologist at a different institution noted that he was not clear who was eligible for palliative care: "I don't know if I refer patients to palliative care whether they can still be on treatment or they have to be off care. For example, if you send someone to hospice, they have to be off treatment. You cannot offer them treatment. I'm still not clear whether palliative care services will allow me to keep treatment, or does it mean I have to stop treatment." A few participants expressed confusion about the difference between a palliative care clinic and a pain clinic. For these oncologists, incomplete awareness of available services precluded use. Nine percent (7 of 74) of participants reported that they had never referred a patient to their local palliative care clinic.

Recommendations

Although not a focus of the interview, several oncologists offered suggestions for how to improve integration of outpatient palliative care services at cancer centers. These included raising awareness, clarifying roles, improving communication between palliative care clinicians and oncologists, and embedding palliative care in oncology practices (Appendix Table A1, online only).

Discussion

Using in-depth interviews, we have identified three oncologist barriers to subspecialty, outpatient palliative care referrals: persistent impressions of palliative care as an alternative philosophy

of care incompatible with cancer therapy, the belief that providing palliative care is an integral part of the oncologist's role, and lack of familiarity with available local services. Oncologists described their views of subspecialty palliative care as evolving in response to increasing availability of services and positive referral experiences but emphasized that views of palliative care as valuable in addition to standard oncology care were not universally shared by colleagues.

This study contributes depth to current knowledge about palliative care referrals in oncology by elucidating factors beyond service structure, name (palliative care *v* supportive care) and availability that impact subspecialty palliative care use.^{14,22-25} A recent survey of oncologists in Canada identified lack of access to palliative care services, especially for patients receiving chemotherapy, as a primary barrier to timely referrals.¹² Our findings build on this work by demonstrating that even at cancer centers in the United States where outpatient palliative care services are well-established and accept patients receiving all cancer treatments, oncologists' views of these services influence referrals.

In light of new professional guidelines supporting the expanded use of subspecialty palliative care services in oncology,⁵⁻⁹ improved uptake of subspecialty palliative care services is needed. These data support three potential targets of efforts to improve palliative care referrals at US cancer centers. First, local provider education is needed to increase familiarity with available services. Whereas passive dissemination of guidelines is unlikely to change physicians' referral practices, more active educational programs involving consultants have shown promise as interventions to improve referral practices in other settings²⁶ and should be a focus of efforts to expand referrals to outpatient palliative care. As one of the participants in this study noted, simply having the palliative care team introduce themselves at an oncology clinic could do much to improve awareness of available services.

Second, continued efforts are necessary on a systemic level to raise awareness about what palliative care means, what it does not mean, and what it can offer patients. The fact that some oncologists view palliative care as an alternative to standard oncologic care for patients near the end of life reflects, in part, the history of palliative medicine in the United States as a new medical specialty that grew out of the hospice movement. Palliative care has only recently begun to emphasize ways in which it is different from hospice care,²² and more work is needed to differentiate the eligibility criteria and approach of these two services for referring clinicians. However, even among oncologists who understand these differences, persistent perceptions of palliative care as incompatible with being treated or "getting better" indicate a need to more clearly define and promote what palliative medicine offers patients and ways in which subspecialty palliative care services may complement standard oncology care. Collaboration with professional organizations such as ASCO to promote uptake of their own recommendations is appropriate.

Finally, the fact that most oncologists view providing palliative care as an integral part of their own role signals the need to

develop and test innovative practice models that allow oncologists and palliative care physicians to collaborate and integrate their respective skills.²⁷ An important challenge facing the field is to identify aspects of palliative medicine that should be handled by oncologists and those that necessitate a palliative care specialist.²⁸ Subspecialty palliative care must be provided in ways that improve patient outcomes and also promote trust among referring providers, avoid conflicts, and maximize scant resources. Facilitated communication between oncologists and palliative care specialists and rapid identification and evaluation of suboptimal experiences cited by participants in this study—for example, when a palliative care physician contradicts an oncologist's prognostic estimate or leads a patient to question the benefit of an oncologist's treatment plan—may help to achieve these goals.

Our study has strengths and weaknesses. By conducting interviews at multiple sites with medical oncologists from a range of specialties, we were able to elicit a diversity of views regarding palliative care. These findings may not generalize to sites where palliative care is less available, less well established, or provided via different delivery models. Similarly, our findings may not generalize to physicians from other disciplines such as surgical oncologists or radiation oncologists. We would expect the barriers to palliative care referral that we describe to be even more pronounced among providers who have less access and/or experience with these services. Given the design of our study, we were unable to measure actual referral practices.

In summary, we found that provider factors play an important role in influencing subspecialty palliative care referrals, even at cancer centers where outpatient palliative care services are well established. Current conceptions of palliative care have not fully penetrated academic oncology, and it is clear that provider views do not appropriately reflect recent guidelines. Improving the provision of palliative care in oncology will re-

quire efforts beyond expanding access to these services. Additional work is needed to define, develop and promote ways in which outpatient palliative care services complement standard oncology care to improve outcomes for patients with cancer and their families.

Acknowledgment

Supported by the National Center For Advancing Translational Sciences of the National Institutes of Health under Award No. KL2TR000146, and by a Junior Scholar Award from the Department of Medicine at the University of Pittsburgh (Y.S.). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

We would like to acknowledge Denise Rousseau, PhD, for her contributions to the interview guide.

Authors' Disclosures of Potential Conflicts of Interest

The author(s) indicated no potential conflicts of interest.

Author Contributions

Conception and design: Yael Schenker, Megan Crowley-Matoka, Daniel Dohan, Michael W. Rabow, Cardinale B. Smith, Douglas B. White, Edward Chu, Robert M. Arnold

Collection and assembly of data: Yael Schenker, Michael W. Rabow, Cardinale B. Smith, Douglas B. White, Greer A. Tiver

Data analysis and interpretation: Yael Schenker, Megan Crowley-Matoka, Daniel Dohan, Cardinale B. Smith, Douglas B. White, Edward Chu, Greer A. Tiver, Sara Einhorn, Robert M. Arnold

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Yael Schenker, MD, MAS, Division of General Internal Medicine, University of Pittsburgh, 230 McKee Place, Suite 600, Pittsburgh, PA 15213; e-mail: schenkery@upmc.edu.

DOI: 10.1200/JOP.2013.001130; published online ahead of print at jop.ascopubs.org on December 3, 2013.

References

- Kelley AS, Meier DE. Palliative care—a shifting paradigm. *N Engl J Med* 363:781-782, 2010
- Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
- Rabow MW, Dibble SL, Pantilat SZ, et al: The comprehensive care team: A controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 164:83-91, 2004
- Bakitas M, Lyons KD, Hegel MT, et al: Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA* 302:741-749, 2009
- Smith TJ, Temin S, Alesi ER, et al: American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Oncol* 30:880-887, 2012
- Levy MH, Adolph MD, Back A, et al: Palliative care. *J Natl Compr Canc Netw* 10:1284-1309, 2012
- Ferris FD, Bruera E, Cherny N, et al: Palliative cancer care a decade later: Accomplishments, the need, next steps – from the American Society of Clinical Oncology. *J Clin Oncol* 27:3052-3058, 2009
- Levy MH, Back A, Benedetti C, et al: NCCN clinical practice guidelines in oncology: Palliative care. *J Natl Compr Canc Netw* 7:436-473, 2009
- Peters S, Adjei AA, Gridelli C, et al: Metastatic non-small-cell lung cancer (NSCLC): ESMO clinical practice guidelines for diagnosis, treatment and follow-up. *Ann Oncol* 23:vii56-64 (suppl 7), 2012
- Cherny NI, Catane R, European Society of Medical Oncology Taskforce on Palliative and Supportive Care: Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: Report on a survey by the

European Society of Medical Oncology Taskforce on Palliative and Supportive Care. *Cancer* 98:2502-2510, 2003

- Smith CB, Nelson JE, Berman AR, et al: Lung cancer physicians' referral practices for palliative care consultation. *Ann Oncol* 23:382-387, 2012
- Wentlandt K, Krzyzanowska MK, Swami N, et al: Referral practices of oncologists to specialized palliative care. *J Clin Oncol* 30:4380-4386, 2012
- Rabow MW, Smith AK, Braun JL, et al: Outpatient palliative care practices. *Arch Intern Med* 170:654-655, 2010
- Hui D, Elsayem A, De la Cruz M, et al: Availability and integration of palliative care at US cancer centers. *JAMA* 303:1054-1061, 2010
- Patton MQ: *Qualitative Research and Evaluation Methods* (ed 3). Thousand Oaks, CA, Sage Publications, 2002
- Barter C, Renold E: The use of vignettes in qualitative research. *Social Research Update* 1999. <http://sru.soc.surrey.ac.uk/index.html>
- Charmaz K: *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London, United Kingdom: Sage Publications, 2006
- Grbich C: *Qualitative Data Analysis: An Introduction*. London, United Kingdom: Sage Publications, 2007
- Miller WL, Crabtree BF: Primary care research: A multimethod typology and qualitative road map, in Crabtree BF, Miller WL (eds): *Doing Qualitative Research*. Newbury Park, CA, Sage, 1992, pp 3-28
- Mays N, Pope C: Qualitative research in health care. Assessing quality in qualitative research. *BMJ* 320:50-52, 2000
- Association of American Medical Colleges: 2008 physician specialty data. <https://www.aamc.org/download/47352/data>

22. Meier DE: Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Q* 89:343-380, 2011
23. Ahmed N, Bestall JC, Ahmedzai SH, et al: Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 18:525-542, 2004
24. Rhondali W, Burt S, Wittenberg-Lyles E, et al: Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study. *Palliat Support Care* 10:1-8, 2013
25. Dalal S, Palla S, Hui D, et al: Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *Oncologist* 16:105-111, 2011
26. Akbari A, Mayhew A, Al-Alawi MA, et al: Interventions to improve outpatient referrals from primary care to secondary care. *Cochrane Database Syst Rev* 4:CD005471, 2008
27. Yoong J, Park ER, Greer JA, et al: Early palliative care in advanced lung cancer: A qualitative study. *JAMA Intern Med* 173:283-290, 2013
28. Quill TE, Abernethy AP: Generalist plus specialist palliative care - Creating a more sustainable model. *N Engl J Med* 368:1173-1175, 2013



Appendix

Table A1. Oncologists' Recommendations for Improving Use of Outpatient Palliative Care Services at Academic Cancer Centers

Recommendation	Representative Quotes
Raising awareness	I think the palliative care team maybe coming to our clinic, palliative care team introducing their services to the . . . to the organization, and also involving the treating physicians with their research-like this survey here-it'll bring the awareness when I go to clinic. So, all these things help.
Clarifying roles	<p>There are some concerns I have about the . . . the delineation of the roles. I think there are many physicians, many mid-level practitioners, who just are unclear as to who's who . . . I think it would be fairly easy to get a good audience [to] spend five minutes at a medical staff meeting to identify who's who and how to go about doing things.</p> <p>I think educating physicians about the role of . . . palliative care and explain to them how can this be worked in an integrative manner with their practice, would be far better way to approach this.</p> <p>I suppose it would be to emphasize over and over again that it's not really hospice. I guess that would be one thing.</p>
Improving communication	<p>I'm just thinking about if I'm to be asked how to make this process better, I would say that . . . it would be nice if the palliative care physician that I refer my patient to picks up the phone and calls me, even before they see my patient. . . . I feel like one, lengthy, in-depth conversation between the oncologist and the palliative care person—just one—the earliest possible in . . . the transfer of the patient to their services [would] probably significantly improve . . . the entire experience.</p> <p>It would be nice just for continuity of care, if the same palliative care person always saw my patients. And maybe that happens; I'm just maybe not aware of that. Then they could be part of the daily clinic meetings, and we could just sit down together and go over things, instead of just saying, "Okay, Mrs. Smith: getting Gemzar next week, cycle 4, day 8. Platelets low, pain management, blah, blah, blah." Then somebody from palliative care would say, "Oh yeah, so here's the pain management issues, here's the nutrition issues . . ." But that's an ideal world, I'm not expecting it to happen. But it would certainly be neat if it could.</p>
Embedding palliative care in oncology practices	<p>So, in a perfect world, I would say that the palliative care services . . . or the palliative care clinic would be back-to-back, in my mind, to the oncology clinic. It would be together . . . Physically, that it would be a multidimensional clinic: where a patient comes in and they have whatever kind of cancer. They see their cancer doc, their palliative care doc, they see maybe the radiation oncologist, they see their surgeon if they need any surgery stuff, and then they leave. It should be multidisciplinary like that. I think that would be the best scenario.</p> <p>It'd be probably better if . . . they shared office space in our practice, rather than in a separate practice. Or like someone who could come over and introduce themselves; I think that would make a huge difference for many patients.</p>