

Early Palliative Care and Its Role in Oncology: A Qualitative Study

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ABSTRACT

Introduction. Early integration of palliative care alongside oncology is being increasingly recommended, although the strategies and models for integration remain poorly defined. We solicited the opinions of patients and caregivers who participated in a randomized trial of early palliative care versus standard oncology care, regarding the respective roles of their oncologist (both groups) and palliative care physician (early palliative care group).

Materials and Methods. The study was performed at a comprehensive cancer center. Forty-eight patients (26 intervention, 22 control) and 23 caregivers (14 intervention, 9 control) were recruited purposefully at trial end. One-on-one, semistructured qualitative interviews were conducted and analyzed using grounded theory.

Results. The themes resulting from the analysis fell into three categories: the focus of care, the model of care delivery, and the complementarity between teams. The focus of care in

oncology was perceived to be disease-centered, with emphasis on controlling disease, directing cancer treatment, and increasing survival; palliative care was perceived to be more holistic and person-focused, with an emphasis on symptom management. Oncology visits were seen as following a structured, physician-led, time-constrained model in contrast to the more fluid, patient-led, flexible model experienced in the palliative care clinic. No differences were found in the descriptions of oncology between participants in the intervention and control groups. Participants in the intervention group explicitly described the roles of their oncologist and their palliative care physician as distinct and complementary.

Conclusion. Participants perceived the respective roles of their oncologist and palliative care physician as discrete, important, and complementary for the provision of excellent cancer care. *The Oncologist* 2016;21:1387–1395

Implications for Practice: Patients and their caregivers who experienced early palliative care described the roles of their oncologists and palliative care physicians as being discrete and complementary, with both specialties contributing to excellent patient care. The findings of the present research support an integrated approach to care for patients with advanced cancer, which involves early collaborative care in the ambulatory setting by experts in both oncology and palliative medicine. This can be achieved by more widespread establishment of ambulatory palliative care clinics, encouragement of timely outpatient referral to palliative care, and education of oncologists in palliative care.

INTRODUCTION

Patients with advanced cancer have a complex array of physical and psychosocial needs [1] that can arise early in the course of illness [2]. Palliative care services are well-placed to address those needs; however, referrals to palliative care are typically made late in the illness trajectory [3, 4]. A substantial body of quantitative evidence now supports the merits of early palliative care (EPC) for patients with advanced cancer, including improvements in quality of life, mood, satisfaction with care, symptom burden, and, in some cases, survival [5–7]. Thus, early integration of palliative care into oncology care is recommended as the standard of care by an increasing

number of international cancer organizations [8–10], with a shift in focus to how EPC can best be achieved [11–13].

Several potential models of EPC have been described [12, 14]. Of these, the model that has received the greatest attention and endorsement, in particular, for cancer centers, is simultaneous care by specialized palliative care in an outpatient setting [13, 15, 16]. This model was used in two randomized controlled trials (RCTs) demonstrating the benefits of EPC and was also supported by the results of nonrandomized prospective and retrospective studies [17–19]. Although this model has been examined qualitatively by a review of

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the electronic medical records of patients receiving EPC [20] and by interviewing oncologists and palliative care physicians [21, 22], the opinions of patients and caregivers regarding this model of care have not been sought.

We completed a cluster RCT of an EPC intervention versus standard cancer care at a tertiary cancer center that demonstrated improved quality of life, satisfaction with care, and symptom control in the EPC group compared with standard care [7]. On completion of the trial, we invited patients and caregivers in the control and intervention groups to participate in qualitative interviews. The purpose of the present study was to investigate, from the perspective of the patients and caregivers, what the perceived role was of their oncologist (control and intervention groups) and of their palliative care physician (intervention group only). A secondary aim was to examine whether the perceived role of the oncologist differed between participants in the control and intervention groups.

MATERIALS AND METHODS

Participant Selection and Study Procedures

Details of the cluster RCT trial have been previously published [7] and are summarized below. Eligible patients were recruited from 24 medical oncology clinics at the Princess Margaret Cancer Centre, a comprehensive cancer center in Toronto, Ontario, Canada, from December 2006 to February 2011. Individual clinics were randomized either to the intervention group (early concurrent palliative care) or the control group (usual oncology care, with referral to palliative care at the discretion of the treating oncologist).

The eligibility criteria included a diagnosis of stage IV gastrointestinal, genitourinary, gynecological, or breast cancer, stage III or IV lung cancer, or locally advanced esophageal or pancreatic cancer; an estimated prognosis of 6 months to 2 years; and an Eastern Cooperative Oncology Group performance status score of 0–2 [23] (the latter two criteria were determined by the patient's medical oncologist). Patients were asked to identify their primary caregiver, who, in turn, was invited to participate in the study. Participants were excluded if they were younger than 18 years old, had scored poorly on a cognitive screening tool (patients only) [24], or lacked sufficient English proficiency to consent to the intervention or to complete the study questionnaires.

The intervention consisted of monthly visits to the ambulatory palliative care clinic for 4 months. The physical, psychosocial, and spiritual needs of the patient and any caregiver concerns were assessed at each visit. The participants received regular follow-up telephone calls from a palliative care nurse between visits and had access to the team both during the working week and out-of-hours, via the on-call physician [7].

Data Collection

After completion of the trial, the patients and caregivers were invited to participate in qualitative interviews. Purposive sampling was used with the aim of including a broad range of participants from the control and intervention groups with regard to age, gender, and responses to quality of life and satisfaction with care measures used in the trial [25–29]. Trained research personnel followed an interview guide to conduct semistructured, one-on-one interviews that ranged in length from 25 to 90 minutes. The interview guide included open-ended questions pertaining to

participants' perceptions of the respective roles played by their oncologist and their palliative care team. Field notes were recorded after each interview. The University Health Network Research Ethics Board approved the study.

Qualitative Analysis

The grounded theory method was used for data collection and analysis [30]. All interviews were audiotaped and transcribed using a professional transcription service, before being verified by a research assistant. The NVivo software program, version 8, 2009, was used to facilitate management and analysis of qualitative data (QSR International, Doncaster, Australia, <http://www.qsrinternational.com>).

Data analysis was a dynamic process that began at the inception of data collection. Data were coded using an inductive, constant comparison method [30], whereby themes were generated through line-by-line coding and comparison within and between interviews. As new themes were identified, the interview guide was amended to verify the emergent themes [31]. At weekly team meetings, the themes were discussed and refined; this included identifying and discussing negative or divergent cases within each theme and integrating thematic categories around a core category [30, 32]. This iterative approach continued until theoretical saturation was reached [33].

RESULTS

Of 85 patients and 50 caregivers who were approached, 48 patients (26 intervention; 22 control) and 23 caregivers (14 intervention; 9 control) consented to participate and completed interviews from July 2007 to March 2011. The main reasons for declining participation were feeling unwell or caring for an unwell patient (intervention group, 5 patients, 2 caregivers; control group, 1 patient, 3 caregivers); lack of time or interest (intervention group, 3 patients, 5 caregivers; control group, 14 patients, 5 caregivers); and palliative care content of the interview (control group, 4 patients, 3 caregivers). The demographic and clinical characteristics of participants are listed in Table 1.

The emerging themes fell into three main categories, which related to the focus of care, the model of care delivery, and the manner in which the care from oncology and palliative care complemented each other to improve the patient and caregiver experience. Although some overlap was present in the roles, oncology care was perceived to be more cancer-centered and structured and palliative care to be more patient-centered and flexible. The themes within these categories and illustrative quotations are presented in Panels 1–5. No differences were found in the perceived role of the oncologist among those who participated in the palliative care intervention versus those in the control group.

Focus of Care: Treating the Cancer and the Person

Participants recognized a difference between the focus of their oncologist and that of the palliative care physician (Panels 1 and 2). Controlling the cancer was seen as an important responsibility: "Take care of the tumor" (P-543i [uppercase letter indicates patient (P) or caregiver (C), lowercase letter indicates intervention group (i) or control group (c); number indicates study unique identifier]). Directing anticancer treatment through a tailored approach was perceived to be the

Table 1. Participant demographics ($n = 71$)

Baseline demographic and clinical/caregiving characteristics	Patients ($n = 48$)		Caregivers ($n = 23$)	
	Intervention ($n = 26$)	Control ($n = 22$)	Intervention ($n = 14$)	Control ($n = 9$)
Age (yr)				
Median	60.5	64.5	60.5	57
Range	51–83	41–82	38–71	40–80
Female sex	19 (73.1)	10 (45.5)	8 (57.1)	8 (88.9)
European ethnicity ^a	26 (100)	20 (90.9)	14 (100)	9 (100)
Married or common-law partner	15 (57.7)	14 (63.6)	14 (100)	8 (88.9)
Living alone (patient); living with patient (caregiver)	7 (26.9)	5 (22.7)	13 (92.9)	7 (77.8)
Education				
Postsecondary ^b	24 (92.3)	18 (81.8)	10 (71.4)	6 (66.7)
High school	2 (7.7)	3 (13.6)	3 (21.4)	1 (11.1)
Less than high school	0	1 (4.6)	1 (7.1)	1 (11.1)
Missing	0	0	0	1 (11.1)
Employment status				
Retired	14 (53.9)	12 (54.5)	7 (50.0)	4 (44.5)
Employed	7 (26.9)	4 (18.2)	6 (42.9)	3 (33.3)
Unemployed	3 (11.5)	0	1 (7.1)	2 (22.2)
Receiving disability	2 (7.7)	6 (27.3)	0	0
Patient tumor site				
Lung	4 (15.4)	5 (22.7)	3 (21.4)	1 (11.1)
Gastrointestinal	7 (26.9)	8 (36.3)	6 (42.9)	4 (44.5)
Genitourinary	3 (11.5)	4 (18.2)	1 (7.1)	2 (22.2)
Breast	6 (23.1)	1 (4.6)	3 (21.4)	2 (22.2)
Gynecological	6 (23.1)	4 (18.2)	1 (7.1)	0
Patient ECOG score at baseline				
0	10 (38.5)	7 (31.8)	5 (35.7)	3 (33.3)
1	16 (61.5)	13 (59.1)	9 (64.3)	6 (66.7)
2	0	2 (9.1)	0	0
Patient receiving active chemotherapy at baseline	22 (84.6)	20 (90.9)	10 (71.4)	8 (88.9)
Relationship to patient				
Spouse or partner	NA	NA	12 (85.7)	7 (77.8)
Son or daughter	NA	NA	1 (7.1)	2 (22.2)
Other family	NA	NA	1 (7.1)	0
Informal help caring for patient ^c	NA	NA	3 (21.4)	3 (33.3)
Visits to palliative care clinic (n) ^d				
Median	5	0	4	0
Range	4–5	0–0	0–8	0–0

Data presented as n (%).

^aTwo participants were of Southeast Asian and South Asian ethnicity

^bPostsecondary education included college, university, vocational/trade school, and other.

^cInformal help included help from family or friends.

^dThirteen caregivers attended a palliative care clinic visit with the patient at least twice; one caregiver did not attend any visit.

Abbreviations: ECOG, Eastern Cooperative Oncology Group performance status; NA, not applicable.

primary domain of the oncologist: “To get me the best possible care that’s out there. To keep me alive as long as possible” (P-341i). The oncologist was regarded as a “scientist” whose role was “to provide information about the cancer and its path” and “to give you the information about the option he feels is best, the path that’s best available to you” (C-325c). From the caregivers’ perspective, it was generally believed that attention to their particular needs was not the responsibility of the oncologist: “I don’t expect the doctor to waste time with me” (C-352i).

In contrast, most participants identified symptom control as the principal role of palliative care and, in particular, cited the palliative care physicians’ expertise in pain management: “Pain relief, real relief, great mental relief to know about it” (P-543i). They described the care in the palliative care clinic as “looking at a whole person” (P-334i), “being more supportive emotionally as well as physically” (P-376i), and providing support not only to the patient but also to the broader family. Visits to the clinic were described as “comforting,” with the palliative care physician being described as an “interpreter

Panel 1. Focus of care: Controlling cancer vs. addressing symptoms

Oncology themes	Quotations related to oncology care	Palliative care themes	Quotations related to palliative care
Cancer control, increasing survival	<p>I was going to say, “Keep me alive!” [Laughter] Her main role, and what I think they’re excellent at, is just making sure that I’m aware of and getting the best care for getting rid of the particular cancer. <i>P-506c</i></p> <p>What’s in their care? To lead, guide and direct me and keep me going as long as they can and just get rid of this... I don’t mean get rid of it, but we can control it.... <i>P-618c</i></p> <p>I think his job probably is trying to get rid of the cancer. Yeah. <i>P-325c</i></p> <p>Trying to keep it stable, I think, with all the knowledge they have. (...) It’s the best they can do and what’s available to treat it with. Can’t expect any more. <i>P-528c</i></p> <p>She’s supposed to make me well. That’s what I expect of her. <i>P-334i</i></p>	Symptom control	<p>First of all, there’s somebody to talk to about the pain. It’s being dealt with. If what she prescribes doesn’t work, then you just call and she says, “Well, we’ll do this and this.” You’re never panicked really about the pain, because you know you’ve got somebody there that’s going to help you deal with it, or try to deal with it. <i>C-230i</i></p> <p>And being able to discuss symptoms and possible treatment outcomes—like what you could do to deal with certain symptoms if you wanted to—that’s not something I would discuss with... I probably wouldn’t discuss with my oncologist because it just doesn’t seem... it didn’t seem the right forum, you know? <i>P-053i</i></p> <p>He also has a very wide knowledge of medications. There’s yet different ones, if I ask him about something that he didn’t know about or followed up on and told me what good or what it may not be capable of doing. I think he’s very knowledgeable in his field of... part of that is controlling pain. I trust him very much... <i>P-438i</i></p>
Directing cancer treatment	<p>Directing treatment. (...) Well, when they get information, it’s their job then to say, “This is what we can do about it or not do about it,” and then it’s up to me to make the decision whether I will do this or that but it’s up to them to figure out what’s available, let me know so that I can make a decision. <i>P-378c</i></p> <p>Oh, I think to advise me and give me the treatments that will do the best or most good for me and wherever I am at with the cancer, so I think that’s the main job and then to do follow-ups to make sure that things are working or not working and I think that’s what they’ve done. <i>P-379c</i></p> <p>Well, I think my oncologist’s role was to try to find the most appropriate treatment for me. I think that’s primarily what the role of my oncologist should be... <i>P-376i</i></p> <p>Well, the doctor, the oncologist, is a program of treatment... he’s chemo. <i>C-652i</i></p> <p>I mean, they’re giving me what I’m here for, you know, ongoing diagnosis and treatment. <i>P-309i</i></p>	Holistic care	<p>Well, he has a different manner (...) I think he was very open to just listening to the symptoms and that’s one of the things that he’s there for, and was interested in your overall well-being, more than just the symptoms, how you’re feeling kind of thing, in a general sense, not just physically, but emotionally as well. <i>P-400i</i></p> <p>I think the palliative care view is one or more about the whole person, more about the emotions that you have, the feelings you have as well as how you’re physically feeling and so I think that holistic view is a valuable one and it should be encouraged... <i>P-400i</i></p> <p>Yeah because those are the intangibles that go beyond just the actual pain relief and so to me that’s part of the whole picture, treating the whole patient, not just one symptom. <i>P-352i</i></p> <p>I guess now I see the palliative care doctor’s role as being more supportive emotionally as well as physically. They’re not into planning your treatment, that’s the big difference. (...) It’s more of a supportive role but also certainly to keep tabs on how I am doing physically so she can support me. <i>P-376i</i></p>

of care” or as a “doctor-therapist”: “He will speak frankly, yet he will speak with compassion, and that’s his specialty” (P-341i).

Care Delivery: Structure and Flexibility

Oncology clinics were described as following a predictable, structured pattern based on the particular management protocol or stage of treatment: “What do the blood tests show, what does the liver scan show, what do we have to do now and so on” (P-352i) (Panel 3). In contrast, participants described the palliative care clinic as being less formally structured and often directed by the individual concerns of the patient or their family member on the day of the visit, affording them a greater level of control: “I’m the one probably as much as anything that sets the tone for what is talked about and also how it’s talked about...” (P-267i).

Similarly, participants commented on a contrast in the dynamic of their relationship with the oncologist compared with

their relationship with the palliative care physician (Panel 3). With the oncologist, a more traditional “medical” physician-patient relationship was described, whereas the relationship between participants and their palliative care physician was seen as “more personal.” Some participants reported feeling less apprehensive attending their palliative care appointment than when they saw their oncologist, as they were unlikely to be confronted with upsetting information relating to their latest scan results or blood work: “It’s not like your oncologist because your oncologist could give you bad news” (P-341i).

Time constraints within oncology clinics were a recurrent theme: “They’re pretty busy people, so you got 10 or 15 minutes and they’ve got to go through a lot of stuff” (P-339c) (Panel 4). Many participants expressed the need for assertiveness and self-advocacy to maximize their interactions with their oncologist: “... just to make sure that if I have a question that especially is

Panel 2. Focus of care: Disease vs. person and family

Oncology themes	Quotations related to oncology care	Palliative Care themes	Quotations related to palliative care
Disease-focused care	<p>I realize this man is a scientist. He's examining my blood all the time and trying to figure out what's best to control the cancer. <i>P-587c</i></p> <p>The paradigm is needles in and pills in or guts out. So I've been doing the other on my own. <i>P-618c</i></p> <p>I think he is a mechanic (...) He has the encountered problem, he has to solve it and fix it the best way he knows, which is using the chemo or whatever. He gives the chemo and you fix it and that's it. You know how busy mechanics are today and he's one of them and so far, I think he's doing a good job. <i>C-352i</i></p> <p>I think the oncologist, they see the disease or at least... that's the impression we've been getting. It's not so much focused on her. <i>C-674i</i></p>	Person-focused care	<p>He's a very good interpreter of care and dealing with people who are ill. And you get a very nice sense of that there's calm, peace, pain-free and not pain free, but a great deal of attention and care is given to the patient. You get that impression very quickly and it's a safe thing. He's very good. <i>P-355i</i></p> <p>The talks I've had with [palliative care physician] actually have been very comforting. He will speak frankly, yet he will speak with compassion and that's his specialty. He's got to know what these patients are going through or understand when I tell him what my feelings are. <i>P-341i</i></p> <p>(...) she's like wonderful to talk to. You know what I mean? (...) So that has really made it more comfortable for me. You know, I look forward to these visits when I come down here. I can't always say I look forward to my doctor's visits, because I'm always nervous or whatever. But these visits, I have no problem coming down. I like to. <i>P-031i</i></p>
Caregiver needs not the responsibility of the oncologist	<p>And as I have said, it shouldn't be in their job to have to worry about me. I really don't feel that's a necessary or appropriate use of resources. I know they're very, very busy, and they are pushed to the limit. <i>C-071c</i></p> <p>...they tend to just "Let's nail that cancer. Let's knock down that PSA. Let's keep the old car on the road a little bit longer." We'll do what we have to. But in the meantime, I'm about to go on long term disability. [Patient] is extremely depressed. And I'm depressed too. I mean it has an effect on me. (...) And that's why I say I feel trapped. I feel stuck. <i>C-263c</i></p> <p>The oncologist I think definitely addresses my disease. They address my needs, my medical needs. There's nothing really about family. <i>P-341i</i></p> <p>The doctor? He knows me because I am sitting next to her. But that's it. I don't expect the doctor to waste time with me. He's busy. (...) I just go there, sit there and that's it and try to understand the sickness. That's it. <i>C-352i</i></p>	Treating the family	<p>And I'm thinking, "It might be something I may need; the support I may need later. Or her husband may need later." And that's important for us as well. <i>C-031i</i></p> <p>Everybody shed tears, but everybody got to speak and everybody got to listen. I think it... I think it's good to have that support because, like I say, it is a family going through the process. <i>C-465i</i></p> <p>I think it's important for my family as well because they are my caregivers. So they need to know how to sort of manage me. I think it also helps them emotionally to prepare for the different eventualities that may come to pass. It familiarizes them with the hospital routine and because they are my children, they've been able to avail themselves of some of the counseling services. <i>P-376i</i></p> <p>That somehow I'll get through it. There will be help for me and there will be help for my family. <i>P-303i</i></p> <p>I think that's very important because you're able to treat the family. It is the family that's going through it. <i>C-465i</i></p>

important to me at that particular visit to make sure that I do ask it and not just let it go" (P-376i). This contrasted with the longer, more flexible consultations in the palliative care clinic, where interactions were less rushed. Participants reported an environment in which their questions were encouraged and their concerns were heard: "I was listened to" (P-380i).

Palliative Care and Oncology: Discrete and Complementary Roles

Participants in the intervention group were able to articulate clearly the discrete and complementary roles of their oncologist and their palliative care physician (Panel 5). They described how having access to palliative care for symptom management and psychosocial support meant that their oncologist could focus on disease-specific issues and cancer treatment, with each specialty focusing on its area of expertise: "I guess that's where I see [oncologist] being in charge of the cancer and [palliative

care physician] assisting with the symptoms and the fallout" (C-400i). Rather than one being valued over the other, both were perceived to play a pivotal role in cancer care: "So I think they're both necessary and I think they're both really beneficial" (P-400i). Participants perceived that concurrent palliative care alongside oncology made their overall health care experiences more satisfactory and holistic:

Aside from all the things that I think the palliative care and symptom control team have done that made it a better experience for [patient] and me, I think just the simple fact that there's another specialty that's being brought to bear and to not only have the specialty of the oncology people and having confidence in them, you get added confidence in your total (...) in the way that [the hospital] is looking after the person as a whole, not just treating the cancer but the person as a whole, the patient as a whole. (C-371i)

Panel 3. Care delivery: Structure and patient-physician relationship

Oncology themes	Quotations related to oncology care	Palliative Care themes	Quotations related to palliative care
Structured, physician-led visits	<p>Her job is to tell me what my symptoms are, what treatments we're going to do, what the best treatments are and what she thinks the prognosis is (...). She says, "We can do this and we can do this." P-585c</p> <p>Because I think the oncology doctor is dealing kind of with a protocol, with a set protocol and this is how things are supposed to be on, let's see... we're on visit number six; this is what I'm going to do with this patient on visit number six ... I want to check this blood and I want to look at this and I want to look at that. P-376i</p> <p>The oncologist's role, I suppose, is that since that is a specialty, he knows by the various scans and tests, etc. etc. just exactly what stage the disease is at, that he relay that information to the patient exactly. P-438i</p>	Open-ended, patient-led visits	<p>I feel it isn't specifically about ovarian cancer, it's about how are you doing (...) He's not going to give me a protocol. P-580i</p> <p>It's different. (...) It's really more free (...)</p> <p>Unstructured. Yeah. There is no real... and actually, I feel as I think about it now, I'm the one probably as much as anything that sets the tone for what is talked about and also how it's talked about, that sort of thing. P-267i</p> <p>I sort of set the agenda. It's very open-ended... P-376i</p> <p>Also, I think [oncologist] is not one to encourage an out-of-a-box approach. I've had [palliative care physician] who knows what the box is about, but is not afraid to be outside. P-438i</p> <p>I think she's finding that she's able to talk and express herself and that people are interested in how she's thinking and feeling. C-580i</p>
Medical relationship	<p>I think it's important that they understand from a medical point of view what's going on in my life. On a personal level, I don't know how they would do that in such a limited contact situation. (...) it's just like there's just simply not enough time for them to really get to know an individual. I don't know how they could do that. P-339c</p> <p>I mean she does very professional things with me (...), she's very professional, but the personal area it's not approached at all. I don't think she knows me. P-502c</p> <p>I think (...) in some ways, yes;... [oncologist] and I, have a relationship. But whether it goes <i>beyond</i> my disease, I'm not so sure. We very rarely talk about personal kinds of things. P-263c</p> <p>[T]hey really are trying to connect. And they do. But they're only... I'm only with them for, what, 15 minutes, 20 minutes. Because it's not necessary to have anything longer. So I don't see how it can go beyond sort of the patient-doctor... P-267i</p> <p>I think he knows me well enough to say, "Hi... how are things going?" (...) But, I don't necessarily think we have a great rapport and all of that. He's got a specific duty there. P-191i</p>	Personal relationship	<p>Because of... okay our contact was different. One is more... with [palliative care physician] is more personal. With [oncologist] is more medical. P-285i</p> <p>Well I don't feel like I'm just another cancer patient. I feel that there's somebody there that is, "Oh yes, this is [patient] and this is what she's dealing with and we're aware of it and there's a team here to help you in any way that we can..." P-380i</p> <p>I come out of the meetings and go, "That was fun." It's great because it's in the morning and then I just go off to work and it's a bit of fun actually. Who would have thought? I'm going to a palliative care meeting and we're just going to chat actually and laugh. P-580i</p> <p>I looked forward to the appointments I had with him. I wasn't apprehensive. It's not like your oncologist because your oncologist could give you bad news. He doesn't give you bad news or he doesn't give me bad news. I give him all the bad stuff and then tell me okay, what could happen. I need to know. P-341i</p> <p>We practically love [palliative care physician]. He just... We like... We love him. He's just a great guy. He's soft-spoken, full of knowledge. Sorry, I've never had this happen. [Crying] (...) We knew we could call him any time and we have... not only him but also the support team. C-454i</p>

DISCUSSION

In the present qualitative study, patients and caregivers who participated in a trial of EPC provided consistent accounts of the roles of their oncologists and their palliative care physicians in their care. Participants in both trial groups described the role of their oncologists as being rooted in devising a tailored, protocolled, cancer treatment plan with structured follow-up and monitoring. Those in the intervention group described the role of palliative care physicians as providing more holistic, less structured, symptom-based assessments in an unrushed atmosphere that allowed a more detailed exploration of personal and family concerns. The roles of oncology and palliative care were perceived to be discrete and complementary, with both contributing to comprehensive care for the patient and family.

These accounts lend support to a model of integrating palliative care into oncology care by early intervention in a specialized clinic setting. Although research in this area is limited, this integrated care model is one that has been recommended for cancer centers in recent reviews [16]. Other potential models include the "solo practice model," in which oncologists assume all care from diagnosis to death, and the "congress practice model," referring to multiple consultants who specialize in various symptom and psychosocial concerns [15, 34]. The solo practice model is limited by time constraints, variable interest in and comfort with discussing palliative and end-of-life care [35–37], and the lack of specialized training in palliative medicine [16]. This model also risks higher rates of burnout among oncologists, especially those who identify their role as rooted mainly in the biomedical realm [35]. The congress model has the disadvantage of necessitating the coordination of a myriad of appointments

Panel 4. Care delivery: Time and listening

Oncology themes	Quotations related to oncology care	Palliative care themes	Quotations related to palliative care
Time constraints	<p>I have the finest doctors that you can see and find. I think they're over busy. They have so many minutes for you and then next, next, next. Like they're so good, you know, they're so busy because of it. Everybody wants them and a lot of people that are out there, they're very ill and I guess they can only do so many, that's my town anyway. <i>P-347c</i></p> <p>There is that sense of in, out, in, out that... if that could slow down, you might have a more chance to kind of express some of that. (...) Sometimes it's an exploratory thing that you want and kind of think aloud and there's no time to do that. <i>P-348c</i></p> <p>They're pretty busy people, so you got 10 or 15 minutes and they've got to go through a lot of stuff. They aren't going to spend a lot of time on that. <i>P-339c</i></p> <p>Sometimes her phone is beeping a lot. (...) They don't have a lot of time. <i>C-462i</i></p> <p>I get the sense of, "deal with the immediate problems and go on from there," and I don't get any sense of... "I have all the time in the world," which he doesn't, of course. (...) again I understand that, completely, and why it is. <i>P-355i</i></p>	Time flexible	<p>But [palliative care physician] will, she'll take the time to go into it and she's very knowledgeable about the cancer. (...) So [she] provides that. She provides the time and I guess time is a good word. She never seems rushed. I'm sure she has a schedule, but she never seems rushed. <i>P-334i</i></p> <p>For the oncologist, that was your feeling that they came in, they did what they did, and then they left. I don't know if [palliative care physician] was on a timeline or not, but you <i>never</i> feel it. You never feel it. <i>C-031i</i></p> <p>For me, I get more information about my disease. I have more questions and I ask them because I happen to be here. I get a lot of information and actually, [palliative care physician] seems to have more time to discuss these issues with me. <i>P-303i</i></p> <p>Yeah, [palliative care physician], I think she spends more time than expected. Sometimes I think I should not so long but... (...) well, it's a pretty pleasant place to be. It just feels like it's not just a hospital to come to. <i>P-274i</i></p> <p>I was very frustrated (...) because my doctor had very little time for answering— the oncologist had very little time for answering questions. So I feel I get more time from [palliative care physician]. <i>P-157i</i></p> <p>[Palliative care physician] was there to listen and [patient] characterized him as he really listened. That's what he did, he listened. <i>C-371i</i></p> <p>I think that's why the palliative care is important to me is because I'm being listened to. It's not just like okay you need to do this and take this and do this and go here, it's the listening part that you think "okay." <i>P-580i</i></p> <p>I think it was another person who'd listen from a different perspective, one who wasn't necessarily going to give you your next procedure, process or prognosis, but one who is just more or less there to listen with full understanding (...) and who could offer some suggestions about how to deal with some of the symptoms and some of the emotions that are very much part of this whole thing. <i>P-400i</i></p> <p>I think the palliative care doctor, she was very good about asking questions. And not really pushing me to answer, but if I would answer something then she would ask some more. She dealt with that very well. <i>P-221i</i></p>
"I need to be more assertive"	<p>[I]f I thought they weren't giving me the time I needed, I would bring them up on that and say, "Just a minute, I'm not finished." <i>P-378c</i></p> <p>I think all of my needs have met because I'm a person that ask questions... maybe sometime too many questions later. I'm a nuisance. <i>P-425c</i></p> <p>I was very satisfied with the care that I had, but I wouldn't have been satisfied if I hadn't done my homework and hadn't decided, if my wife and I hadn't decided that we would really be able to advocate like we did for ourselves. <i>P-009i</i></p> <p>They're very willing to talk to you, but I've always found that if you don't ask, they're not willing to share. And, we don't know what to ask. So, by the time you ask, it's probably a problem. <i>P-191i</i></p>	"I was listened to"	

for individual symptoms, psychosocial concerns, and existential issues [15, 34]. The integrated care model, described in the present study, allows timely, efficient, and coordinated management of multiple physical, psychosocial, and existential needs by an interdisciplinary team [16].

The endorsement of an integrated model of care by patients and caregivers is consistent with qualitative accounts of oncologists and palliative care physicians. In a qualitative study, oncologists who had been exposed to an EPC model described benefits of such a model similar to those described in the present study, including access to expertise in symptom management and the additional time that palliative care physicians could devote to complex psychosocial issues and advance care planning [21]. In addition, they identified personal benefits in terms of sharing the care of complex patients and assisting in challenging conversations

around transitions in care or prognosis. In another study, palliative care physicians described that they provided EPC by managing symptoms, engaging patients in emotional work, and assuming a mediating role between the oncologist and the patient [22]. Our study provides the crucial perspective of patients and their caregivers who did or did not receive an EPC intervention. Although participants in both trial arms were pleased with their care, the oncologist's role was described as providing excellent cancer treatment, while the palliative care physician addressed broader symptom, psychosocial, and family-related concerns. These concerns could not be addressed as readily within the time-pressured, biomedically centered model of the oncology clinic.

Barriers exist to implementing an integrated care model for delivery of EPC. Although access to palliative care services has increased markedly over the past decade, these tend to be focused



Panel 5. Palliative care and oncology: Discrete and complementary roles

Quotations From Intervention Group

I think [oncologist's] job is to explain the disease, explain what's happening to the disease, to my body and it's left to others to deal with the psychological side of it (...) And I think he sticks to that and I think that's good because he is the oncologist. That is, I don't think palliative care to any extent (...) should be dealt with by [oncologist], that's [palliative care physician's] job and he does it very well. *P-355i*

I do see them as different. I think [oncologist] is there... He's the guy who's mapping the way. He's saying, "Okay, these tests and based on my experience and my understanding of this disease indicates that we should go this way and there are side effects as a result of that". [Palliative care physician]'s role is understanding what the path is doing and saying, "Okay, if you're experiencing this, this is the way to counteract that." As well as being there just as another ear and looking at you from a more holistic perspective, as a whole person. So I think they're both necessary and I think they're both really beneficial. *P-400i*

I think from my perspective, the palliative care doctors have more of an understanding of, yes, there are more symptoms and there are more drugs. Whereas the oncology—if you're just dealing with oncology and you're just left with oncology, you're dealing with chemo or radiation or whatever their specialty is, period. *P-191i*

And that there was doctors that dealt with the technical parts of your body and your treatments and stuff. And then there was your other being that nobody usually looked after, and how you're feeling mentally, and how you're feeling socially, and...you know, whether you were scared in dealing with death coming, and how you were feeling inside. That's what I figured palliative care was. *P-031i*

Well, because the palliative care doctor sees the person who happens to have a disease; whereas the chemo doctor saw the disease and there happens to be a person attached to it. And I happen to have this disease but that is not who I am [...] and I mean again [oncologists] are scientists, they're doctors and that's the fascination is the disease and how to cure it [...] and that's great and that's their job and that's their training but especially with a disease that is going to end up killing you it's good to have honesty. It's good to have empathy. It's good to have compassion and that's what I felt and that's what I got from the palliative care. *P-380i*

I don't want to sound like oncology just is focusing on the lung or whatever, that's not what I mean. I think that that's what their expertise is to what's the treatment, what's the protocol for this patient at this stage of the cancer and how can we best deal with it. Whereas I think [palliative care physician] is more about what other things are bothering you.... *C-462i*

on providing care for inpatients, with variable access to outpatient palliative care clinics [3, 38, 39]. In a recent survey, palliative care clinics were available at 59% of National Cancer Institute (NCI) centers and 22% of non-NCI centers [38]. Even at centers with access to such clinics, referrals tend to occur late in the disease process [40], although oncologists with palliative care training tend to refer earlier in the course of illness [3]. One reason for late referrals is the faulty perception by those providing and receiving cancer care that palliative care is synonymous with "end-of-life" care [41–44]. This has led some services to change their name to "supportive care" [41] and has galvanized a broader interest in the education of both providers and the public about palliative care [45]. The lack of an adequate workforce of trained specialists in palliative care is also a limitation [42], although specialist training programs for palliative care are available in an increasing number of countries [46, 47].

Our study had a number of strengths. The study was nested in an RCT, allowing us to obtain the accounts and opinions of those who did or did not receive treatment from palliative care. Incorporating qualitative research methods into RCTs is rarely performed but increasingly recommended [48]. The relatively large qualitative sample, range of tumor sites and use of purposeful sampling methods allowed inclusion of a broad range of experiences. The limitations of the study included recruitment from a single tertiary cancer center with a well-established ambulatory palliative care program; this might not reflect the practices or experiences elsewhere. Also, only participants who had completed the trial were recruited into the qualitative study; those who had withdrawn early might have had differing views. Most participants were highly educated and of European backgrounds and might not reflect the experiences of other, more diverse demographic groups. The study was also limited to describing the perceived roles of oncologists and palliative care physicians; further research is needed to describe patient perceptions of the roles of other health care providers.

CONCLUSION

Patients and caregivers in the present study perceived distinct and complementary roles for oncology and palliative care, supporting an integrated care model for EPC. Further studies are needed to assess the role of family physicians in providing palliative care, to assess the effects of educational interventions for oncologists in palliative care, and to assess whether this integrated care model could be adapted to community hospitals and noncancer settings.

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