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O R I G I N A L   R E P O R T

Promoting End-of-Life Discussions in Advanced Cancer: Effects of Patient Coaching and Question Prompt Lists

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A B S T R A C T

Purpose
To build on results of a cluster randomized controlled trial (RCT) of a combined patient-oncologist intervention to improve communication in advanced cancer, we conducted a post hoc analysis of the patient intervention component, a previsit patient coaching session that used a question prompt list (QPL). We hypothesized that intervention-group participants would bring up more QPL-related topics, particularly prognosis-related topics, during the subsequent oncologist visit.

Patients and Methods
This cluster RCT with 170 patients who had advanced nonhematologic cancer (and their caregivers) recruited from practices of 24 participating oncologists in western New York. Intervention-group oncologists (n = 12) received individualized communication training; up to 10 of their patients (n = 84) received a previsit individualized communication coaching session that incorporated a QPL. Control-group oncologists (n = 12) and patients (n = 86) received no interventions. Topics of interest identified by patients during the coaching session were summarized from coaching notes; one office visit after the coaching session was audio recorded, transcribed, and analyzed by using linear regression modeling for group differences.

Results
Compared with controls, more than twice as many intervention-group participants brought up QPL-related topics during their office visits (70.2% v 32.6%; $P < .001$). Patients in the intervention group were nearly three times more likely to ask about prognosis (16.7% v 5.8%; $P = .03$). Of 262 topics of interest identified during coaching, 158 (60.3%) were QPL related; 20 (12.7%) addressed prognosis. Overall, patients in the intervention group brought up 82.4% of topics of interest during the office visit.

Conclusion
A combined coaching and QPL intervention was effective to help patients with advanced cancer and their caregivers identify and bring up topics of concern, including prognosis, during their subsequent oncologist visits. Considering that most patients are misinformed about prognosis, more intensive steps are needed to better promote such discussions.

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INTRODUCTION

Most patients with advanced cancer say they want honest, sensitive communication about end-of-life issues.[1,2] These conversations help patients and their families prepare, make informed decisions, and avoid potentially burdensome aggressive medical treatments near death.[3-6] Yet, patients are often misinformed about cancer survival and curability, and those with overoptimistic prognosis estimates are more likely to die in a hospital and receive burdensome aggressive care.[7,8] Patients often do not disclose their concerns and vary in the amount of information they want about the disease, prognosis, and treatment options,[9-11] whereas physicians often do not know or enact patient preferences about end-of-life issues.[12]

Interventions to promote communication in cancer settings have targeted patients and physicians. Randomized controlled trials in early cancer and palliative care[13-16] have shown that question prompt lists (QPLs) —structured lists of questions given to patients before consultations—help patients with cancer and their caregivers ask more questions, particularly if the physician also encourages and

endorses the QPL. In addition, a tailored previsit educational coaching intervention (that did not involve QPLs) helped patients with cancer communicate concerns about pain.[17] Meanwhile, an oncologist intervention that used audio recordings with tailored feedback positively influenced patient trust and oncologist responsiveness to patient emotions.[18] Yet, no randomized trials have evaluated interventions directed toward both oncologists and their patients with advanced cancer who are not yet receiving palliative or hospice care. This phase in the disease is a crucial time to initiate discussions about prognosis and end-of-life issues, because it is still early enough to influence the clinical course of the patient.[19,20]

Our group recently reported the results of a cluster randomized controlled trial that used brief, individualized, skill-based training for oncologists combined with individualized communication coaching for outpatients with advanced cancer and their caregivers, when available. The coaching incorporated a QPL with suggested topics that related to current and future cancer care and end-of-life issues. The combined intervention improved communication between patients and their oncologists, which resulted in greater patient active engagement, increased physician responsiveness to patient emotions, and more discussions of prognosis and treatment choices.[21,22]

This secondary analysis investigates how the intervention affected the number and nature of topics brought up during an oncology office visit. We hypothesized that the intervention would result in more topics related to QPL items and more topics about the future (eg, prognosis, curability, future quality of life) brought up and subsequently discussed during the office visit. Also, we reviewed field notes from the previsit coaching session to assess which topics were identified by patients as being of interest and which topics were brought up during the subsequent oncology visit.

PATIENTS AND METHODS

Data for this post hoc analysis are from the intervention phase of a National Cancer Institute–sponsored multisite cluster randomized controlled trial designed to test a combined intervention to facilitate communication and decision making among oncologists, patients with advanced cancer, and their caregivers. Details of this randomized controlled trial are described elsewhere.[22,23] All protocols were approved by the University of Rochester research subjects review board.

Participants

Medical oncologists caring for patients with nonhematologic cancers were recruited at practice meetings from outpatient oncology practices in western New York and Sacramento, CA. With clinic staff, research assistants reviewed clinic rosters of enrolled physicians to contact potentially eligible patients. Patients were eligible to participate if they were at least 21 years old, were able to understand spoken English and provide consent, had either stage IV nonhematologic cancer or stage III nonhematologic cancer, and had an oncologist who "would not be surprised" if the patient died within 12 months. During the intervention phase, up to a maximum of 10 patients per physician was recruited sequentially between August 2012 and June 2014 until the target sample size of 265 patients was reached. Patients were asked to identify a caregiver age 21 years or older. Patients were blinded to study arm assignment until completion of baseline measures. All participants had one audio-recorded office visit with their oncologist. Given that notes by the coaches were consistently retained only

in western New York, this analysis is restricted to that site, which included nine practices that encompassed urban, suburban, and rural settings. Informed consent was obtained from all participants (Fig 1).

Intervention Overview

Stratified random assignment occurred at the level of the oncologist to balance assignment by study site (western NY *v* Sacramento) and cancer focus (> 50% breast cancer patients *v* other). Within strata, physicians were randomly assigned 1:1 to intervention or control. Patient assignment to intervention or control was identical to that of their oncologist. Oncologists randomly assigned to the intervention arm participated in a tailored educational intervention that involved standardized patient instructors.[23] Their patients (and the informal family caregivers of each patient, if available) received individualized communication coaching with a QPL to help them identify questions and concerns to share during an upcoming oncologist visit. Both interventions were directed toward the same four key communication domains of patient-centered communication[23] that are based on six core communication functions identified by the National Cancer Institute.[6]

Coaching and QPL Intervention

Two social workers with health care backgrounds were trained to coach intervention patients. They participated in a 3-day intensive training; their subsequent coaching sessions were audio recorded and reviewed for fidelity. Patients and caregivers in the intervention arm met face to face with a coach during a 1-hour session, during which time they were each given a QPL booklet. After the patients were asked about their backgrounds and experiences with their oncologists, coaches reviewed the QPL and then helped patients and caregivers identify and prioritize their two to three most immediate topics of interest. They also coached patients about how to ask questions or express concerns during the next office visit. For 77.4% of patients, the office visit occurred the same day as the coaching session; for 90.5%, it occurred within 3 days. Coaches wrote notes that detailed each patient's topics of interest.

The QPL used in the study was adapted from a QPL developed in Australia for patients with cancer who were in palliative care.[24,25] The QPL was subsequently refined on the basis of a focus group (n = 8) and 11 individual semistructured interviews with demographically diverse patients who had advanced cancer (Table 1).

Coding

A coding manual was developed to categorize topics of interest identified during the coaching session and topics brought up during the office visit (Fig 2). These topics were coded as QPL related (either verbatim or carrying a similar intent and meaning to questions and statements contained in the QPL) or not QPL related (clearly not addressing any of the topics in the QPL).

Two researchers (R.A.R. and K.B.) each listened to five audio-recorded coaching sessions and read transcripts of five corresponding intervention oncology office visits and five control oncology office visits, from which a preliminary coding manual was developed. This coding manual was applied to data from an additional five intervention-group and five control-group patients. Differences were resolved by consensus. The coding manual was continually refined for application to both the coaching sessions and the office visit transcripts. Data from a total of 30 patients were double coded, and differences were resolved by consensus. Kappa was 0.85. The notes from coaches that concisely listed the topics of interest of each patient were validated by comparing them to audio-recorded data of the coaching session from 20 intervention-group patients; only the notes were used for final coding of the coaching sessions. The remaining data were singly coded by R.A.R. (n = 99 patients) and K.B. (n = 41 patients); questions that occurred during coding were discussed on a case-by-case basis with R.M.E.
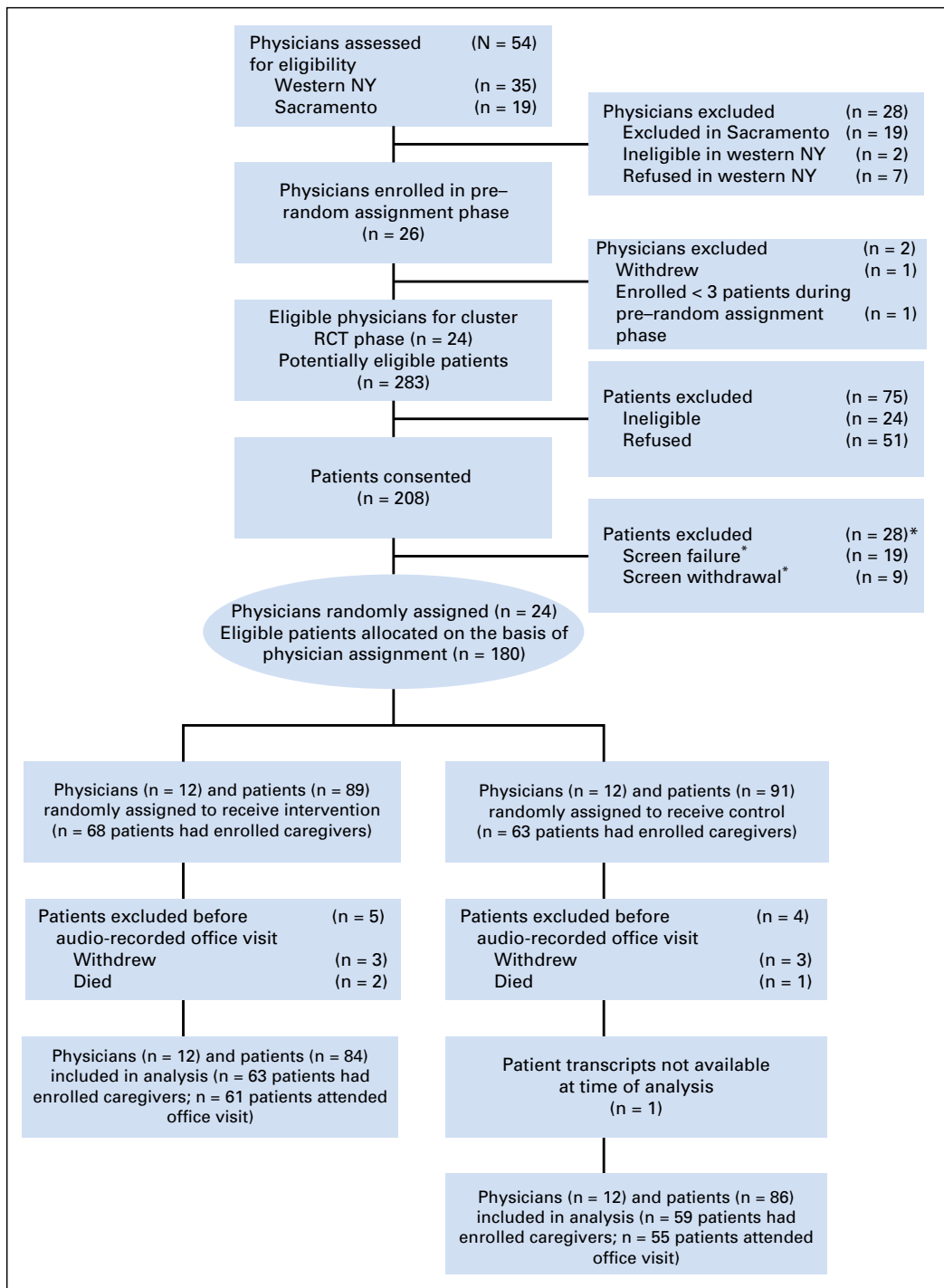
Fig 1. CONSORT diagram. *Screen failure is defined as a patient who becomes ineligible after consent but before completion of the baseline survey (eg, if the patient entered hospice care); screen withdrawal is defined as a patient who gave consent but withdrew before completion of the baseline survey.

Statistical Analysis

We compared intervention-group and control-group patients on the total number of questions asked during the office visit, the number of QPL-related topics brought up, the number of topics brought up about the future (including prognosis, likelihood of cure, end of life, and expressions of fear/avoidance), and symptoms/quality of life.

We performed descriptive analyses for the intervention group on the topics of interest identified during the coaching session and the topics subsequently brought up during the office visit. We coded them according to whether the topic was QPL related or not.

Statistical analyses were conducted with SAS (Version 9.4; SAS Institute, Cary, NC). Mixed-effects linear regression models were used to compare continuous outcomes between intervention and control groups, and generalized estimating equations were used for binary outcomes comparisons. The models were specified to account for the nesting of patients (the units of analysis) within physicians (the units of random assignment). Regression models included

Table 1. QPL Booklet Content and Non-QPL Categories

Category	Specific QPL Question or Non-QPL Example
QPL booklet	
My cancer I (current cancer state)	1.1 What is currently happening with my cancer?
My cancer II (goals of cancer treatment)	2.1 What are the main aims of my cancer treatment? Is it to help me live longer? Is it to slow down the cancer? Or is it to get rid of symptoms like pain?
	2.2 Is it still possible to cure my cancer?
Treating my cancer (cancer treatment)	3.1 What are the pros and cons of further treatment of my cancer?
	3.2 How will I know if the treatments are working?
	3.3 How likely is it that these treatments will control my cancer?
	3.4 Should I consider an experimental therapy or a second opinion?
Treating my symptoms (symptom management)	4.1 Will continued cancer treatments make me feel better or worse?
	4.2 What treatments can help me manage my symptoms, such as pain, nausea, fatigue, depression, and anxiety?
	4.3 Would it make sense for me to see a specialist in pain and symptom control?
What I can expect (expectations/prognosis)	5.1 What can I expect to be able to do in the future? (eg, working, driving, traveling, holidays)
	5.2 Is it possible to give me a time frame?
	5.3 What's the best-case scenario? What's the worst-case scenario?
What I can do (lifestyle, support, planning)	6.1 What can help me get the most out of my life? (eg, diet, exercise, meditation, massage, support groups)
	6.2 How can I help my family and children understand what is happening?
	6.3 Are there any organizations or services that would be useful for me or my caregivers? (eg, Web sites, support organizations, social services, disability parking)
	6.4 How can I be sure that my family and my physicians know my wishes in case I am unable to speak for myself? How can I document those wishes?
If cancer treatment does not work (hospice and end of life)	7.1 Should I consider stopping anticancer treatments and focus more on treatments to make me feel better?
	7.2 Who will be my doctor if I stop getting chemotherapy or radiation?
	7.3 How will I know when I might need to consider hospice?
	7.4 What is likely to happen at the very end?
Your family might like to ask (questions for caregivers)	8.1 What skills will I need to care for my family member with cancer?
	8.2 What can I do to cope and care for myself while caring for my loved one?
	8.3 Where can I get more help?
What I want to tell my doctor (concerns/preferences about care at the end of life)	9.1 I want to know the pros (benefits) and cons (adverse effects) of the treatments I'm getting.
	9.2 I can deal with the truth about my condition.
	9.3 I don't know what to tell my family.
	9.4 I worry that I'm going to suffer.
	9.5 I worry that if I stop treatment, you might not be my doctor anymore.
	9.6 I hate being dependent on others.
	9.7 I would rather not discuss how much longer I have left.
	9.8 When the time comes, I'd prefer to die at home.
	9.9 I am afraid of dying.
Commonly asked questions not in the QPL (with examples)	
Test results (not cancer specific)	Did my calcium return to normal?
	What was my white count?
Logistics (planning/organizing testing, medications, or treatments)	How long will the scan take?
	How many pills should I take each day?
Concerns about medication, treatment, or symptoms	What kinds of effects are there from getting a transfusion?
	Should I stay on the same dose of my medicine?
Vacation-planning logistics	So, one and then 2, 3, and then I skip this week… So then the end of April would be okay to be gone?
Financial/insurance concerns	Did she help get my insurance stuff done from last month?
Not relevant (Other logistics, clarifications, social talk, filler words)	But I haven't hardly itched, you know?
	How are you doing?
	What did you say?

Abbreviation: QPL, question prompt list.

a covariable to account for the stratified randomized design (an indicator for oncologist subspecialty: breast cancer *v* not) and a covariable to statistically adjust for aggressive cancer (aggressive *v* not) in a patient.[22]

RESULTS

Table 2 lists characteristics of the 24 oncologists (n = 12 each in the intervention and control groups) and 170 patients (n = 84 in the

intervention group; n = 86 in the control group). Caregivers were present in 72.6% and 64.0% of office visits with patients in the intervention and control groups, respectively. The transcript for one office visit of a control-group patient was not available at the time of analysis and the patient was excluded.

Effects of Intervention on Topics Brought Up

More than twice as many patients and caregivers in the intervention group as in the control group brought up QPL-related
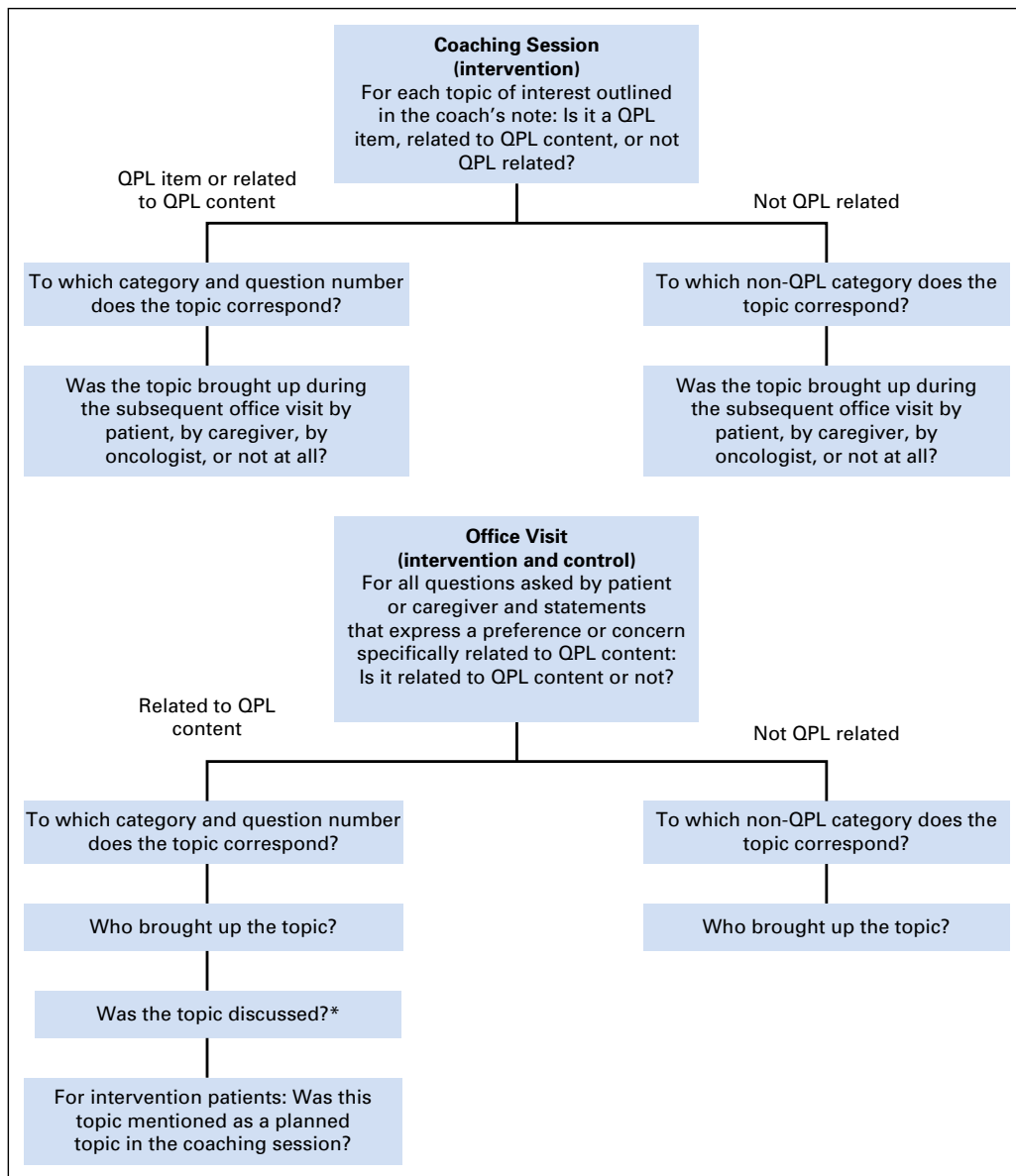
Fig 2. Coding algorithm to categorize topics of interest identified during the coaching session (intervention) and to categorize topics brought up during the office visit (intervention and control). *A topic was coded as discussed if the oncologist responded to the topic; the topic was coded as not discussed when the oncologist did not respond or changed the subject and did not return to the topic later in the visit.

topics during their audio-recorded oncology visit (70.2% *v* 32.6%; *P* < .001; Table 3). Intervention-group patients and caregivers brought up topics that spanned the entire QPL booklet, whereas approximately one third of QPL-related topics were never broached by control-group patients and caregivers (Appendix Table A1, online only). Topics related to expectations/prognosis, current cancer state, goals of treatment, cancer treatment, symptom management, and preferences/concerns about care at the end of life were more commonly brought up during the office visit of intervention-group patients. Overall, intervention-group patients brought up significantly more topics related to expectations/prognosis than control-group patients did (*P* = .02). Prognosis-related discussions brought up by patients or caregivers were more frequent in the intervention group than in the

control group (16.7% *v* 5.8%, *P* = .03). Of the 140 topics brought up by intervention-group patients and 55 topics brought up by control-group patients, 99.3% and 100%, respectively, were discussed with the oncologist. Representative quotations are listed in Table 4.

Topics of Interest Identified During Coaching Session

Overall, the 84 intervention-group patients and their caregivers identified 262 topics of interest during their coaching session (mean, 3.1; standard deviation [SD], 1.6; range, 0 to 8); 158 (60.3%) were QPL related (mean, 1.9; SD, 1.5; range, 0 to 5; Table 5). In aggregate, almost all items from the QPL booklet were selected by at least one patient (Appendix Table A2, online only).

	Intervention (n = 84)		Control (n = 86)		
Characteristic	No.	%	No.	%	P from t Test or χ² Test
Patients*					
Ethnicity					.499
Nonwhite	8	10	11	13	
White	76	90	75	87	
Sex					
Male	34	40	35	41	
Female	50	60	51	59	
Have enrolled caregiver?					.182
No	17	20	25	29	
Yes	67	80	61	71	
Patient education					.450
High school or less	32	38	28	33	
Some college or more	52	62	58	67	
Aggressive cancer†					.009
Aggressive	36	43	54	63	
Less aggressive	48	57	32	37	
Income, $					.620
Missing	9	11	9	10	
≤ 20,000	16	19	23	27	
20,001-50,000	30	36	25	29	
50,001-100,000	21	25	22	26	
> 100,000	8	10	7	8	
Marital status					.320
Committed/married	51	61	51	59	
Divorced/separated	16	19	23	27	
Never married	8	10	3	3	
Widowed	9	11	9	10	
Patient insurance					.623
Private	32	38	29	34	
Medicare	43	51	49	57	
Medicaid	9	11	7	8	
Other	0	0	1	1	
Patient religion					.107
Christianity	67	80	59	69	
Other	7	8	6	7	
No religion	10	12	21	24	
Oncologists‡					
Sex					.640
Male	8	67	10	83	
Female	4	33	2	17	
Breast cancer specialist					1.00
No	10	83	10	83	
Yes	2	17	2	17	
Ethnicity					.158
Asian	4	33	4	33	
White	5	42	8	67	
Other	3	25	0	0	

Table 2. Patient and Oncologist Characteristics

Abbreviation: SD, standard deviation.
*Mean (SD) age of patients, years: intervention, 64.4 (10.7); control, 64.7 (11.3); P = .857.
†Aggressive cancers were determined prospectively in consultation with two oncologists. They included lung, GI cancers (except colon), and genitourinary cancers (except prostate). Less aggressive cancers included breast, prostate, and colon cancers.
‡Mean (SD) age of oncologists, years: intervention, 43.2 (11.3); control, 45.8 (10.4); P = .577.

The most commonly-selected QPL-related topics were about cancer treatment, current cancer state, and concerns/preferences about care at the end of life. Expectations/prognosis topics were selected a total of 20 times, nine of which (5.7%) were explicit requests for a time frame or prognosis, and another 11 (7.0%) were indirect, such as questions about what to expect in the future and best-case/worst-case scenarios. In addition, six patients selected explicit questions about whether the cancer was curable (3.8%), and four patients (2.5%) selected "I would rather not discuss how much longer I have left."

Of the 104 topics of interest identified by patients and caregivers that were not QPL related, the most common topics were about medications, treatment logistics or symptoms (63.5%), and other logistics (26.9%; Appendix Table A3, online only).

Topics of Interest From Coaching Session Brought Up During Office Visit

During the subsequent office visit, 82.4% of all topics of interest and 78.5% of QPL-related topics of interest identified

Table 3. Effects of Intervention on Topics Brought Up During the Subsequent Office Visit

Variable or topic	Intervention (n = 84)	Control (n = 86)	P*
Total No. of questions asked			.11*
Mean (SD)	17.4 (11.1)	13.6 (9.6)	
Median (range)	14 (1-52)	10 (1-42)	
Total No. of QPL-related topics brought up			< .001*
Mean (SD)	1.7 (1.7)	0.6 (1.2)	
Median (range)	1 (0-6)	0 (0-6)	
No. (%) of patients (or their caregivers) who brought up at least one QPL-related topic during the office visit			
Any QPL booklet category	59 (70.2)	28 (32.6)	< .001
Current cancer state	19 (22.6)	10 (11.6)	.012
Goals of cancer treatment	14 (16.7)	8 (9.3)	.044
Cancer treatment	23 (27.4)	10 (11.6)	.0003
Symptom management	12 (14.3)	2 (2.3)	.014
Expectations/prognosis	14 (16.7)	5 (5.8)	.034
Lifestyle, support, planning	5 (6)	4 (4.7)	.51
Hospice and end of life	4 (4.8)	3 (3.5)	.68
Questions for caregivers	0 (0)	0 (0)	NA
Concerns/preferences about care at the end of life	23 (27.4)	6 (7.0)	< .001
Item by topic			
Prognosis (including QPL 5.1, 5.2, and 5.3)			.006*
Total No.	16	5	
No. per patient (SD)	0.19 (0.45)	0.06 (0.24)	
Likelihood of cure (including QPL 2.2 and 3.3)			.37*
Total No.	11	8	
No. per patient (SD)	0.13 (0.40)	0.09 (0.36)	
End of life (including QPL 7.1, 7.3, 7.4, and 9.8)			.76*
Total No.	8	6	
No. per patient (SD)	0.10 (0.33)	0.07 (0.34)	
Expressions of fear/avoidance (including QPL 9.7 and 9.9)			.0025*
Total No.	9	0	
No. per patient (SD)	0.11 (0.35)	0	
Symptoms and quality of life (including QPL 4.1, 4.2, 4.3, and 9.4)			.0025*
Total No.	20	4	
No. per patient (SD)	0.24 (0.51)	0.05 (0.21)	

Abbreviations: NA, not applicable; QPL, question prompt list; SD, standard deviation.
*For continuous outcomes, P values were two-sided generalized t tests from mixed-effects linear regression models that compared outcomes between intervention and control groups. For binary outcomes, P values were two-sided χ^2 tests from generalized estimating equation models. All models were specified to account for the nesting of patients within physicians. Models also included an indicator for oncologist subspecialty (breast cancer v not) to account for the stratified randomized study design and an indicator for patient cancer aggressiveness (aggressive v not) as covariables to statistically adjust for these effects.

during the coaching session were brought up. The patient brought up the topic most often (56.1%), followed by the physician (16.8%) or caregiver (9.5%; Table 5). For QPL-related topics, the results were similar (50.6%, 7.0%, and 20.9% initiated by patient, physician, or caregiver, respectively). Of the topics of interest related to prognosis, 80.0% were brought up during the office visit, most often by patients (Table 5; Appendix Table A2).

DISCUSSION

This cluster randomized clinical trial, which combined an oncologist communication training intervention with a previsit patient intervention that used communication coaching and a QPL, was effective to help patients with advanced cancer actively seek information and express preferences about their care. We found that patients and caregivers who received the QPL and were coached, and whose oncologists were trained to be receptive to patient questions and concerns, brought up more topics relevant to

their illness and more future-oriented topics compared with control-group patient and caregivers. In particular, intervention-group patients brought up topics about prognosis three times as frequently as control-group patients. In addition, most topics of interest that patients and caregivers identified during the coaching session were brought up during the subsequent oncologist visit, including those about prognosis. Taken together, the link observed in this study between patient intentions (as revealed by topics prioritized through use of a QPL and coaching) and actions (as demonstrated through what was brought up during their subsequent office visit) suggests a possible mechanism whereby the intervention was effective. The finding that most topics of interest were brought up by patients and caregivers (rather than clinicians), coupled with the finding that oncologists nearly always responded to topics raised by patients regardless of whether they received training, suggests that discussion of topics important to patients was more a result of the patient/caregiver-targeted component of the intervention than of oncologist communication training.

Table 4. Representative Quotations About QPL-Related Topics From Intervention Group During Office Visit

QPL-related topic	Representative Quotations From Intervention Group
Prognosis (including QPL 5.1, 5.2, and 5.3)	C: Can we plan for a little bit of a future vacation that she may want to go on? She may want to sit on a beach for a little bit. You know what I'm saying? Is that stuff that we can still plan for? (Pt 7065) P: So, someone with a cancer I have, what is the prognosis for someone like me? I mean do I–do you have like two years? Do you have like five years? (Pt 7036)
Likelihood of cure (including QPL 2.2 and 3.3)	C: And is her cancer a curable cancer? (Pt 7070) P: So, with the results of a follow-up CAT scan what are we… so last time it was good news. It was, you know, it shrunk the lung mass which is ultimately what we're trying to do. Do you foresee that it will continue to do that? (Pt 7065)
End of life (including QPL 7.1, 7.3, 7.4, and 9.8)	P: …when that time comes is there a way to make… more painless and comfortable? (Pt 7095) P: I thought, if this therapy is no good, I thought well, I'm gonna die. So then I've got to prepare something. I've got to arrange something or say something or do something about making arrangements for that. And I'm like everybody else. I want to die at home. (Pt 7181)
Expressions of fear/avoidance (including QPL 9.7 and 9.9)	P: And then they did have stuff here, a lot of questions about will this cure and how much time may I have left and that stuff that right now I don't want to think about. You know, I just want to concentrate on my treatment at the moment. So, you know, if you know any stuff you can, for right now (()) stop until I say. (Pt 7047) C: Does this add time? He doesn't want to hear this. He doesn't want to hear the time thing. So if it ever comes to a time thing, by the way, between you and I, he wants to step out of the room. (Pt 7054) P: That's where the fear also comes in. You know, it's like I don't want to walk on egg shells after chemo… after my last treatment I'll wonder, oh, God, what's gonna happen now? What if it… shows up and we won't be able to catch it in time. (Pt 7040)
Symptoms and quality of life (including QPL 4.1, 4.2, 4.3, and 9.4)	P: After the treatments will I have pain? How will it be controlled? (Pt 7138) P: But I don't know if I'm really worried about dying. I just don't want to suffer with pain. That's my biggest worry. (Pt 7086)

Abbreviations: C, caregiver; P, patient; Pt, patient identification number; QPL, question prompt list.

Patients in this study were at a more advanced illness phase than those in previous QPL studies in oncology settings, yet they still were not in palliative care or hospice.[13,26] This phase represents a time when information about disease status and prognosis is critical to decision making about future care and when it is particularly important for oncologists to understand their patients' desire for information as well as their care needs.[27] Because discussion of end-of-life topics has been associated with better quality of life, lower use of potentially burdensome aggressive treatments, and lower likelihood of a hospital death,[4,7] our results may be seen as a promising first step to help patients realize their treatment preferences and end-of-life goals.

Our intervention improved the likelihood of discussion of prognosis-related topics nearly threefold, from 5.8% to 16.7% of office visits. Although this finding represents an important advance in the promotion of discussions that have an effect on future treatment decisions, prognosis discussions remain infrequent. Most patients continue to have much more optimistic prognosis estimates and more unrealistic treatment expectations than their oncologists,[7,8,28,29] and our intervention had no effect on these discrepancies.[21] In addition, despite skilled previsit coaching that used a QPL that listed explicit and indirect ways of asking about prognosis, most patients with advanced cancer did not prioritize prognostic information, and a few expressed preferences not to discuss prognosis. The intervention also had no effect on discussions of hospice and end-of-life topics. Although one might assume that patients want prognostic information, and that oncologists represent a major stumbling block,[30,31] our findings support a more nuanced explanation: In addition to physician-based factors, patient factors, including avoidance of such discussions and lack of awareness that they remain misinformed, play a role.[8] Other

studies have suggested that many patients are not emotionally ready to hear bad news, consider physician prognostic estimates unreliable, believe they understand their prognosis on the basis of prior discussions or internet searches, wait for their doctors to make the first move, think their doctors are unwilling to provide an estimate, or view prognostic information as irrelevant because of their unique situation or coping style.[23,32] Taken altogether, a pattern in current research on communication in advanced cancer is emerging—that patients often say that they want to be well informed about their disease and prognosis[1,33,34] but frequently say (not now) when offered the opportunity,[28] as we observed here. This, combined with oncologists' reluctance to provide realistic prognosis estimates,[30] creates a tension throughout the course of the patient's illness. Our intervention, which comprised only a single face-to-face coaching session with a QPL in addition to oncologist training, likely was insufficiently intensive or tailored to alleviate the understandable reluctance of patients to receive prognostic information. Patients often chose to focus on smaller, immediate, or logistical issues, which possibly crowded out concerns of a bigger picture and plans for the future.[35] Although this might be psychologically adaptive in the short term and reflect a sometimes healthy attitude of "one day at a time" by patients, it can hamper end-of-life planning and deprive those who want to participate actively in their care of the opportunity of doing so. Perhaps the advantages and disadvantages of receiving prognostic information need to be more explicitly explored, so patients can make a truly informed decision about requesting such information. Alternatively, psychologically based approaches to prognosis-discussion readiness may be needed to address patient-level barriers.

This study has several limitations. The intentionally integrated intervention prevented us from distinguishing among the effects of

Table 5. QPL-Related Topics of Interest Identified During the Coaching Session and Subsequently Brought Up by Patient, Caregiver, or Oncologist During The Next Office Visit

QPL or overall topic	QPL-Related Topics of Interested				
	No.* (%†) Identified During Coaching Session	No. (%‡) Brought Up by Patient During Office Visit	No. (%‡) Brought Up by Caregiver During Office Visit	No. (%‡) Brought Up by Oncologist During Office Visit	Total No. (%‡) Brought Up During Office Visit
By QPL topic					
Current cancer state	31 (19.6)	9 (29)	3 (9.7)	16 (51.6)	28 (90.3)
Goals of cancer treatment	12 (7.6)	6 (50)	1 (8.3)	2 (16.7)	9 (75)
Cancer treatment	39 (24.7)	20 (51.3)	4 (10.3)	7 (17.9)	31 (79.5)
Symptom management	15 (9.5)	9 (60)	1 (6.7)	3 (20)	13 (86.7)
Expectations/prognosis	20 (12.7)	12 (60)	1 (5)	3 (15)	16 (80)
Lifestyle, support, planning	7 (4.4)	5 (71.4)	0 (0)	0 (0)	5 (71.4)
Hospice and end of life	6 (3.8)	2 (33.3)	1 (16.7)	1 (16.7)	4 (66.7)
Questions for caregivers	3 (1.9)	1 (33.3)	0 (0)	0 (0)	1 (33.3)
Concerns/preferences about care at the end of life	25 (15.8)	16 (64)	0 (0)	1 (4)	17 (68)
Overall					
Total QPL-related topics of interest	158 (60.3)	80 (50.6)	11 (7.0)	33 (20.9)	124 (78.5)
Total non-QPL topics of interest	104 (39.7)	67 (64.4)	14 (13.5)	11 (10.6)	92 (88.5)
All identified topics (QPL and non-QPL)	262 (100.0)	147 (56.1)	25 (9.5)	44 (16.8)	216 (82.4)

Abbreviation: QPL, question prompt list.
*No. of times the topic was identified in the sample.
†Percentage of all QPL-related topics of interest identified during the coaching session.
‡Percentage of topics brought up by each particular party or in total during the subsequent office visit.

the QPL alone, the QPL plus coaching, and the training of physicians, though past research supports greater effectiveness of QPLs when endorsed by clinicians.[13-16] Because we were actively looking for correspondences between the coaching session and the office visit, and because the coaching session was often referred to during the subsequent office visit by the patient and/or oncologist, it was impossible to blind coders to treatment assignments. It is also possible that topics of interest identified by intervention-group patients in the coaching session were asked in visits other than the one that we audio recorded, which potentially underestimates the effect of the study. Previous studies[36] suggest that patients with advanced cancer often defer prognosis questions until very close to the time of death. We do not know if patients in this study did so. In addition, we did not attempt to assess the quality of discussions, only whether a discussion occurred. Finally, we did not prospectively identify just those office visits most likely to involve treatment decisions and prognosis discussions, such as during initial consultation or when disease progression, treatment toxicity, or decline in quality of life occurred, for which the patient intervention may have had a more powerful effect.

In a context in which patients are known to have misconceptions about their illness and prognosis, we found that patients with advanced cancer who participated in a combined QPL and coaching intervention identified key topics of interest relevant to the status of their disease, including prognosis, and that they brought up topics relevant to disease status and prognosis more often than control-group patients did. In this sense, our intervention appears to have been effective in giving a voice to patients and their caregivers during office visits with their oncologists. These findings are critical, because many patients may choose to make different decisions about their care when they are fully informed.[7]

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at jco.org.

AUTHOR CONTRIBUTIONS

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Promoting End-of-Life Discussions in Advanced Cancer: Effects of Patient Coaching and Question Prompt Lists

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Appendix

Table A1. Effects of Intervention on Topics About the Future and Symptoms/Quality of Life Brought Up During the Subsequent Office Visit, Broken Down by Specific Question or Statement

Variable	Total No.		No. per Patient (SD)		P
	Intervention	Control	Intervention	Control	
Prognosis	16	5	0.19 (0.5)	0.06 (0.2)	.02
What can I expect to be able to do in the future? (eg, working, driving, traveling, holidays)	5	0	0.06	0.00	
Is it possible to give me a time frame?	4	5	0.05	0.06	
What's the best-case scenario? What's the worst-case scenario?	1	0	0.01	0.00	
Related but no corresponding question/statement	6	0	0.07	0.00	
Likelihood of cure	11	8	0.13 (0.4)	0.09 (0.4)	.40
Is it still possible to cure my cancer?	4	2	0.05	0.02	
How likely is it that these treatments will control my cancer?	4	1	0.05	0.01	
Related to goals of treatment but no corresponding question/statement	3	5	0.04	0.06	
End of life	8	6	0.10 (0.3)	0.07 (0.3)	.65
Should I consider stopping anticancer treatments and focus more on treatments to make me feel better?	0	0	0.00	0.00	
How will I know when I might need to consider hospice?	0	1	0.00	0.01	
What is likely to happen at the very end?	0	0	0.00	0.00	
Related to hospice and end of life but no corresponding question/statement	2	3	0.02	0.03	
When the time comes, I'd prefer to die at home	5	1	0.06	0.01	
Preferences at the end of life	1	1	0.01	0.01	
Expressions of fear/avoidance	16	0	0.19 (0.3)	0.00	.0019
I would rather not discuss how much longer I have left.	7	0	0.08	0.00	
I am afraid of dying.	1	0	0.01	0.00	
Other expressions of fear	1	0	0.01	0.00	
Symptoms and quality of life	20	4	0.24 (0.5)	0.05 (0.2)	.0038
Will continued cancer treatments make me feel better or worse?	3	0	0.04	0.00	
What treatments can help me manage my symptoms, such as pain, nausea, fatigue, depression, and anxiety?	9	2	0.11	0.02	
Would it make sense for me to see a specialist in pain and symptom control?	1	0	0.01	0.00	
I worry that I'm going to suffer.	4	2	0.05	0.02	
Quality-of-life statements	3	0	0.04	0	

Abbreviation: SD, standard deviation.

Table A2. QPL-Related Topics Identified During the Coaching Session and Subsequently Brought Up During the Next Office Visit, Broken Down by Specific Question or Statement

Question or Statement by Topic	QPL-Related Topics of Interested				
	No.* (%†) Identified During Coaching session	No. (%‡) Brought Up by Patient During Office Visit	No. (%‡) Brought Up by Caregiver During Office Visit	No. (%‡) Brought Up by Oncologist During Office Visit	Total No. (%‡) Brought Up During Office Visit
Current cancer state	31 (19.6)	9 (29)	3 (9.7)	16 (51.6)	28 (90.3)
What is currently happening with my cancer?	4 (2.5)	1 (25)	0 (0)	1 (25)	2 (50)
Implications of imaging results/cancer-specific test results	25 (15.8)	7 (28)	2 (8)	15 (60)	24 (96)
What will happen in the future with my cancer?	2 (1.3)	1 (50)	1 (50)	0 (0)	2 (100)
Goals of cancer treatment	12 (7.6)	6 (50)	1 (8.3)	2 (16.7)	9 (75)
What are the main aims of my cancer treatment?	4 (2.5)	4 (100)	0 (0)	0 (0)	4 (100)
Is it still possible to cure my cancer?	6 (3.8)	2 (33.3)	1 (16.7)	1 (16.7)	4 (66.7)
Related but no corresponding question/statement	2 (1.3)	0 (0)	0 (0)	1 (50)	1 (50)
Cancer treatment	39 (24.7)	20 (51.3)	4 (10.3)	7 (17.9)	31 (79.5)
What are the pros and cons of further treatment of my cancer?	5 (3.2)	3 (60)	0 (0)	0 (0)	3 (60)
How will I know if the treatments are working?	9 (5.7)	4 (44.4)	1 (11.1)	2 (22.2)	7 (77.8)
How likely is it that these treatments will control my cancer?	4 (2.5)	3 (75)	0 (0)	1 (25)	4 (100)
Should I consider an experimental therapy or a second opinion?	6 (3.8)	4 (66.7)	1 (16.7)	0 (0)	5 (83.3)
What treatment comes next?	11 (7)	3 (27.3)	2 (18.2)	3 (27.3)	8 (72.7)
Related but no corresponding question/statement	4 (2.5)	3 (75)	0 (0)	1 (25)	4 (100)
Symptom management	15 (9.5)	9 (60)	1 (6.7)	3 (20)	13 (86.7)
Will continued cancer treatments make me feel better or worse?	3 (1.9)	1 (33.3)	0 (0)	1 (33.3)	2 (66.7)
What treatments can help me manage my symptoms, such as pain, nausea, fatigue, depression, and anxiety?	11 (7)	8 (72.7)	0 (0)	2 (18.2)	10 (90.9)
Would it make sense for me to see a specialist in pain and symptom control?	1 (0.6)	0 (0)	1 (100)	0 (0)	1 (100)
Expectations/prognosis	20 (12.7)	12 (60)	1 (5)	3 (15)	16 (80)
What can I expect to be able to do in the future? (eg, working, driving, traveling, holidays)	6 (3.8)	4 (66.7)	1 (16.7)	0 (0)	5 (83.3)
Is it possible to give me a time frame?	9 (5.7)	5 (55.6)	0 (0)	1 (11.1)	6 (66.7)
What's the best-case scenario? What's the worst-case scenario?	2 (1.3)	2 (100)	0 (0)	0 (0)	2 (100)
Related but no corresponding question/statement	3 (1.9)	1 (33.3)	0 (0)	2 (66.7)	3 (100)
Lifestyle, support, planning	7 (4.4)	5 (71.4)	0 (0)	0 (0)	5 (71.4)
What can help me get the most out of my life? (eg, diet, exercise, meditation, massage, support groups)	3 (1.9)	2 (66.7)	0 (0)	0 (0)	2 (66.7)
How can I help my family and children understand what is happening?	1 (0.6)	1 (100)	0 (0)	0 (0)	1 (100)
Are there any organizations or services that would be useful for me or my caregivers? (eg, Web sites, support organizations, social services, disability parking)	2 (1.3)	2 (100)	0 (0)	0 (0)	2 (100)
How can I be sure that my family and my physicians know my wishes in case I am unable to speak for myself? How can I document those wishes?	1 (0.6)	0 (0)	0 (0)	0 (0)	0 (0)

(continued on following page)

Table A2. QPL-Related Topics Identified During the Coaching Session and Subsequently Brought Up During the Next Office Visit, Broken Down by Specific Question or Statement (continued)

Question or Statement by Topic	No.* (%†) Identified During Coaching session	No. (%‡) Brought Up by Patient During Office Visit	No. (%‡) Brought Up by Caregiver During Office Visit	No. (%‡) Brought Up by Oncologist During Office Visit	Total No. (%‡) Brought Up During Office Visit
			QPL-Related Topics of Interested		
Hospice and end of life	6 (3.8)	2 (33.3)	1 (16.7)	1 (16.7)	4 (66.7)
Should I consider stopping anticancer treatments and focus more on treatments to make me feel better?	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Who will be my doctor if I stop getting chemotherapy or radiation?	3 (1.9)	2 (66.7)	1 (33.3)	0 (0)	3 (100)
How will I know when I might need to consider hospice?	2 (1.3)	0 (0)	0 (0)	1 (50)	1 (50)
What is likely to happen at the very end?	1 (0.6)	0 (0)	0 (0)	0 (0)	0 (0)
Questions for caregivers	3 (1.9)	1 (33.3)	0 (0)	0 (0)	1 (33.3)
What skills will I need to care for my family member with cancer?	1 (0.6)	0 (0)	0 (0)	0 (0)	0 (0)
What can I do to cope and care for myself while caring for my loved one?	0 (0.0)	0 (0)	0 (0)	0 (0)	0 (0)
Where can I get more help?	2 (1.3)	1 (50)	0 (0)	0 (0)	1 (50)
Concerns/preferences about care at the end of life	25 (15.8)	16 (64)	0 (0)	1 (4)	17 (68)
I want to know the pros (benefits) and cons (adverse effects) of the treatments I'm getting.	2 (1.3)	1 (50)	0 (0)	0 (0)	1 (50)
I can deal with the truth about my condition.	12 (7.6)	8 (66.7)	0 (0)	1 (8.3)	9 (75)
I don't know what to tell my family.	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
I worry that I'm going to suffer.	1 (0.6)	0 (0)	0 (0)	0 (0)	0 (0)
I worry that if I stop treatment, you might not be my doctor anymore.	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
I hate being dependent on others.	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
I would rather not discuss how much longer I have left.	4 (2.5)	1 (25)	0 (0)	0 (0)	1 (25)
When the time comes, I'd prefer to die at home.	1 (0.6)	1 (100)	0 (0)	0 (0)	1 (100)
I am afraid of dying.	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Statements about preferences at the end of life	1 (0.6)	1 (100)	0 (0)	0 (0)	1 (100)
Value statements about quality of life	2 (1.3)	2 (100)	0 (0)	0 (0)	2 (100)
Statements about coping with cancer	2 (1.3)	2 (100)	0 (0)	0 (0)	2 (100)

Abbreviation: QPL, question prompt list.
*No. of times that topic was identified in the sample.
†Percentage of all QPL-related topics of interest identified during the coaching session.
‡Percentage brought up by each particular party or in total during the subsequent office visit.

Table A3. Non-QPL Topics Identified by Patients and Caregivers During the Coaching Session

Topic	Non-QPL Topics of Interest Identified	
	No.	%
Test results (not cancer specific)	5	4.8
Logistics (related to planning or organization of testing, medications, or treatments)	28	26.9
Concerns about medications, treatment logistics, or symptoms	66	63.5
Vacation-planning logistics	2	1.9
Financial/insurance concerns	1	1.0
Not relevant (other logistics, clarifications, social talk, rhetorical questions, filler words)	2	1.9

Abbreviation: QPL, question prompt list.