Encouraging Patients to Speak up About Problems In Cancer Care

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Abstract

Objectives—Many patients with cancer believe something has gone wrong in their care, but are reluctant to speak up. This pilot study sought to evaluate the impact of an intervention of active outreach to patients undergoing cancer treatment, wherein patients were encouraged to speak up if they had concerns about their care, and to describe the types of concerns patients reported.

Methods—Patients receiving cancer care at two sites were randomly assigned to an intervention or control group. Intervention patients received a brochure encouraging them to speak up about any concerns, and an outreach telephone call during which the interviewer explicitly asked about concerns. Participants in both groups received baseline and follow-up questionnaires assessing their perceptions of their care and whether anything had "gone wrong", and provided ratings of health care providers' communication and responsiveness. Qualitative content coding was used to categorize patient-reported concerns collected through the baseline and follow-up questionnaires (both groups) and during telephone outreach (intervention patients only). The primary outcome was the number of patients reporting a concern about their care. Communication and responsiveness ratings for intervention and control group patients were compared using *t*-tests.

Results—Of the 60 patients in the intervention group, 34 (56.7%) reported at least one problem or concern, compared to 16 (29.1%) of the 55 patients in the control group (p=.003). The telephone outreach in particular resulted in over half of those reached reporting a new concern (55.3%). We detected no impact of the intervention on patients' ratings of communication or support for speaking up.

Conclusions—Patients in this study reported a variety of concerns in response to active outreach, demonstrating that active outreach to patients can provide healthcare teams and systems

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the opportunity to offer a real-time response to the patient, identify where system improvements are needed, and implement policies, procedures, or programs to prevent recurrences.

Introduction

Cancer care is complex, typically involving multiple providers and increasingly nuanced therapies. Such complexity results in many opportunities for things to go wrong, or for patients to perceive a problem in care. Some breakdowns in care can be obvious to all involved, but others – such as miscommunication between patients and providers– may be apparent only to the patient. Studies of patients with cancer have found that up to 1 in 4 cancer patients believed that something had gone wrong in their care[1,2], and patients frequently report difficult and distressing communication experiences during cancer diagnosis and treatment.[3–5]

Importantly, many patients hesitate to speak up about their concerns. There are a variety of reasons for this, including feeling poorly, uncertainty about how to raise concerns and whom to contact, the belief that speaking up will not lead to change, and fear that speaking up might damage their relationship with their treatment team.[2,6] When patients suffer in silence, health care providers and organizations miss opportunities to address these concerns, and to prevent similar breakdowns from recurring.[7]

Encouraging patients to speak up if they perceive a breakdown in care has the potential to improve healthcare quality by both identifying and reducing medical errors and improving patient experiences. Passive reporting systems to encourage patients to report concerns about safety, including hotlines and web-based portals, have produced disappointing results, with very few patients taking advantage of such systems.[8] Such findings suggest a need to **actively** reach out to patients in a way that is distinct from existing patient experience surveys, with the goal of learning about and responding to patients' concerns in real-time in order to remediate the experience for the individual patient, as well as to provide feedback to the organization and improve future care.[7] Active outreach should convey caring and a desire to understand and improve the patient's experience, and thus potentially strengthen the provider-patient relationship and patient engagement in their care. Active outreach should also make it easy for the patient to raise concerns. Finally, actively reaching out to patients to ask about breakdowns in care could lead to more activated, satisfied patients and better cancer care outcomes. This paper describes a pilot intervention involving active outreach to patients undergoing cancer treatment, wherein patients were encouraged to speak up if they had concerns about their care. The study sought to evaluate the impact of the intervention with respect to the number and types of concerns that patients raised in response to repeated, active outreach. The primary outcome of interest was the number of patients reporting a concern; we also examined patients' perceptions of communication and responsiveness.

Methods

Setting

The study was conducted in the context of the Cancer Communication Research Center (CCRC) of the Cancer Research Network (CRN), a National Cancer Institute-funded initiative to support and facilitate cancer research based in integrated healthcare delivery systems. The focus of the CCRC is on discovering and disseminating promising practice-based approaches to cancer communication and care coordination. Two CRN settings, referred to as Site A and Site B, participated in this pilot. The study flow for each site is depicted in Figure 1, and described below.

Eligibility

Participant eligibility criteria at each of the study sites included receiving cancer care, age 21–80 years at the time of recruitment, and ability to speak English. Additional criteria varied, and were determined by the participating sites. At Site A, eligibility to participate was determined by infusion clinic nurses using these broad criteria. At Site B, potentially eligible patients were identified from administrative and electronic medical record data, and then medical histories were reviewed by an oncologist to determine whether the patient was well enough to participate.

Recruitment

Recruitment procedures varied slightly across the two sites. At Site A, infusion clinic staff at four clinics approached eligible patients in person to invite participation; interested patients were given a study packet containing a cover letter explaining the study, and a baseline questionnaire. Patients who accepted a study packet were considered enrolled, even if they did not return the baseline questionnaire. At Site B, eligible patients were mailed a study packet containing a cover letter describing the study, the baseline questionnaire, and a HIPAA fact sheet; only those who returned the baseline questionnaire were considered to be study participants. Patients who did not respond, but did not actively decline participation were sent a reminder approximately two weeks after the initial mailing.

Randomization

At Site A, randomization to the intervention or control groups occurred as the baseline questionnaires were distributed. That is, half of the study packets also included a study intervention brochure; patients receiving a study packet with an intervention brochure were assigned to the intervention group. Infusion clinic staff members were blinded to assignment of patients to the intervention or control group. At Site B, patients who returned completed baseline questionnaires were randomized by the study programmer to either the intervention or control group.

Intervention Protocol

Questionnaires were provided to both intervention and control group participants at baseline; and, depending on site and when the baseline questionnaire was returned, participants were mailed a follow-up questionnaire 5 to 12 weeks later. The questionnaires included both

closed- and open-ended items (below). Problems discovered through participant responses to questionnaires which appeared to require immediate attention were flagged for attention. At Site A, an additional abbreviated phone script was deployed to allow for rapid follow-up with patients experiencing problems needing immediate attention, and issues were triaged to the appropriate clinical personnel. At Site B, the study team reviewed and triaged problems needing immediate attention to the appropriate clinical personnel.

Intervention group participants received a brochure (Appendix 1) and an outreach telephone call (Appendix 2). The brochure was included with the initial packet for Site A patients, and was mailed upon receipt of the completed questionnaire for Site B. The brochure was headed with the text "We Want to Know", and encouraged patients to talk to their providers about any concerns or questions they had, and included a telephone number to facilitate contact.

Outreach telephone calls were attempted two to nine weeks after the baseline questionnaire was distributed, and study interviewers made up to 8 attempts to reach participants. All study interviewers were trained by experienced research staff at the site. The outreach call was a critical component of the intervention. The script was designed to express interest in the patient's experience and to elicit the patient's views. At both sites, the interviewer opened the telephone call by asking an open-ended question about the patient's perception of care (e.g., "Overall, how would you describe your care at (site name here)?". Depending on the patient's response, the interviewer followed with a series of probes to elicit further details. If the patient reported any problems in care, the interviewer also asked whether the patient had spoken to anyone within the care system about the problem, and whether it had been resolved. The interviewer made note of any unresolved problems, and asked the patient's permission to take steps to resolve the problem (e.g., by contacting an oncology clinic nurse).

Control group participants received neither the brochure nor outreach calls. At Site A, posters with the "We Want To Know" message and contact information were displayed in the participating infusion clinics, and were therefore visible to all participants (both intervention and control) and non-participants.

Data Collection

Questionnaires—The baseline questionnaire focused primarily on patients' experiences with communication during cancer care. These items were developed by the study team, informed primarily by prior interviews with patients about problems in their care experiences and interviews with patients and family members about their views on assessing communication during cancer care.[9] Two questions were included to elicit patients' reports of their experiences. The first asked whether anything in their care had "gone especially well"; the second asked whether anything had "gone wrong that could have been prevented". Each of these questions was followed by an open-ended request for a description of what had occurred. A small number of demographic questions were included. The follow-up questionnaire repeated the questions about communication and care from the baseline questionnaire, supplemented by five new questions developed for this study to assess comfort with expressing concerns about care.

Outreach Telephone Call—The outreach telephone call, which was an essential part of the intervention as described above, also generated qualitative data (i.e., patients' responses to interviewer's questions and probes). The interviewer took detailed notes, capturing patients' responses as completely as possible during the interview.

All questionnaire data and responses to the outreach telephone call were entered into a REDCap electronic data capture system.[10]

Data analysis

Qualitative Analyses of Questionnaires and Outreach Telephone Interview Data—Three sources of qualitative data were reviewed: patients' written descriptions of something they believed had gone wrong on both the baseline and follow-up questionnaire, and (for intervention patients only) patients' responses to the interviewer's question about what had gone wrong during the outreach telephone interview as captured by the interviewer. We used a combination of deductive and inductive content analysis methods to code responses. An initial set of coding categories was generated based on our prior work.[2] These categories were modified iteratively based on reading of patients' responses to the questionnaires, and review of interviewer notes. Two readers (KMM and CS) reviewed all comments, and developed the final coding categories. If a patient identified a problem that did not fit into one of the initial categories, that response was reviewed by both authors participating in coding, and additional categories were established if needed. One author conducted initial coding of all text (CS); a second round of review was conducted by another author (KMM). A third author was available to resolve discrepancies, but was not required.

Quantitative Analysis—Summary scores were computed reflecting patients' ratings of their communication experiences at baseline and follow-up by taking the mean across the 9 "core" communication items, and the mean of the 5 items assessing comfort expressing concerns and perceived responsiveness to concerns (follow-up only). Coefficient alpha was computed to assess score reliability for the 9 core items and the 5 items assessing comfort expressing concerns. *T*-tests were used to compare core communication and comfort speaking up scores of intervention and control participants on the follow-up questionnaire.

Results

At Site A, a total of 63 patients returned completed baseline questionnaires. An additional 2 patients returned follow-up questionnaires but did not return baseline questionnaires, and an additional two patients completed outreach telephone interviews but did not respond to either questionnaire, resulting in a total sample size of 67 for Site A. Of the 67 patients, 38 were assigned to the intervention, and 29 were controls. Outreach telephone interviews were completed with 20 of the 38 intervention patients -- 2 patients declined, and 16 were not reached. A total of 65 follow-up questionnaires were mailed (36 to intervention patients, and 29 to control patients). Follow-up questionnaires were returned by 13 patients, including 7 from intervention patients and 6 from controls.

At Site B, a total of 118 patients were invited to participate (i.e., received a baseline questionnaire), and 48 completed baseline questionnaires. Respondents were randomized

with 22 assigned to the intervention group and 26 assigned to the control group. Two patients from the intervention group declined participation prior to receiving any intervention materials, but the remaining 20 were reviewed and approved for participation by an oncologist, and were sent the intervention brochure. Outreach telephone interviews were attempted with 18 completed while 2 patients were not reachable. A total of 48 follow-up questionnaires were mailed (22 to intervention patients and 26 to controls). Follow-up questionnaires were returned by 31 patients with 16 from the intervention group and 15 from controls. Patient characteristics are summarized in Table 1; chi-square tests detected no statistically significant differences between the intervention and control groups.

Only two patient-initiated telephone calls were received, one from a patient in the intervention group at Site B and the second from a family member of a non-participating patient who had viewed the clinic poster at Site A.

Qualitative Analysis Results

Overall, a total of 115 patients responded to one or more forms of active outreach; of these, 50 patients (43.4%) reported at least one problem or concern. Table 2 presents the number of patients reporting a concern according to intervention or control group and by mode of reporting. Chi-square tests for differences in reporting at baseline and follow up were not statistically significant (p >.10). However, overall more patients in the intervention group reported concerns compared to those in the control group (56.7% vs 29.1%; p=.003). This is due in large part to the number of patients reporting new events in response to the telephone outreach. Of the 38 intervention patients who were contacted via telephone, 55.3% reported a concern that had not been reported on the baseline questionnaire.

Results of the qualitative coding of patients' responses to the open-ended questionnaire item about events where something had gone wrong (baseline and follow-up) and the outreach telephone interviews are summarized in Table 3. The most common concerns related to experiences with tests, treatments or procedures, including beliefs that treatment had been delayed, overly aggressive, or that complications had occurred. The three next most common concerns were all related to communication. More than 1 in 10 respondents reported that something had gone wrong with information exchange (e.g., patient perceiving that he or she had not received sufficient, timely information), with the provider's manner (e.g., insensitive or uncaring manner), or with communication between providers (e.g., the patient received conflicting information or perceived that team members were not communicating with each other).

Quantitative Analysis Results

Patients' ratings of communication and responsiveness are presented in Table 4. Ratings of communication with the cancer care team were generally positive at baseline. We did not detect a statistically significant difference between intervention and control patients on their communication ratings at baseline. We also found no difference by age or sex (data not shown).

At follow-up, *t*-tests comparing mean communication ratings revealed no statistically significant differences between intervention and control groups (p >.10). Similarly, *t*-tests of

patients' ratings on the 5 responsiveness items which assessed comfort expressing concerns revealed no statistically significant difference between the two groups.

Discussion

This pilot study was intended to evaluate an intervention involving active outreach to patients with the message "we want to know" if patients believed they had experienced any problems in their care. Patients' responses to the open-ended questionnaire items and to the telephone outreach interviews revealed that many patients had concerns about some aspect of their care. Almost one third of the patients with cancer who completed a baseline questionnaire for this study believed that something had gone wrong in their care. Subsequent active outreach to patients (questionnaires to all participants, and telephone outreach to those in the intervention group) revealed new concerns. These findings contribute to a growing body of evidence that: 1) patient-perceived breakdowns in care are common; 2) many patients do not spontaneously express their concerns to their providers or utilize existing reporting systems; 3) without explicit encouragement to voice their concerns, many patients will *not* speak up; and 4) when asked, patients *will* speak up about their concerns.

Of note is the finding that each round of active outreach to patients revealed additional concerns not reported on the prior round(s), and the telephone outreach in particular resulted in over half of those reached reporting a new concern. There are a number of possible explanations. It may be that repeated messaging helped to persuade patients of the sincerity of the request, and created trust in researcher team, the healthcare team and/or the healthcare organization. It is also possible that repeated messaging caused patients to consider their care experiences more closely. This could have a retrospective effect causing patients to re-evaluate their past experiences and possibly weigh the cumulative or ultimate effects of what might have initially been considered minor issues or a prospective effect causing patients to be more sensitive and alert to care breakdowns. The finding that telephone outreach was particularly effective in eliciting concerns may be attributable to interviewers' ability to establish rapport and trust, or patients may simply prefer the person-to-person contact over surveys for reporting concerns. These results are consistent with a recent pilot study comparing three strategies for encouraging hospitalized patients to report safety concerns. This study found that patients identified significantly more concerns when approached in-person compared to the paper form or a telephone hotline (requiring the patient to initiate the call).[11] While further research to understand the underlying mechanisms may be warranted, the current findings highlight the need to repeat and reinforce the message encouraging patients to speak up if they have concerns.

In a service industry, it is understood that customer-initiated complaints represent only the "tip of the iceberg", and that unexpressed concerns are problematic as they result in missed opportunities for service recovery.[12] Historically, the active solicitation of patient complaints has not been a priority in healthcare. Our results in general, and our finding that approximately half of the patients in this study had not previously expressed their concern to their providers or others within the health care system, underscore that this lack of active patient engagement still exists today. This is consistent with a growing body of evidence

suggesting that typical satisfaction measures lead to underestimation of the prevalence of patient-perceived breakdowns in care, as such measures are generally insensitive to episodes of discrete care breakdowns, and are therefore likely to miss the root causes of poor patient experiences. For instance, Jenkinson and colleagues reported that over half of patients rated their healthcare experience as "excellent" on a patient experience survey, but still indicated that a "problem" or "issue" had occurred.[13] Similarly, Solberg and colleagues found that two-thirds of patients who had "agreed" that they were satisfied with their visit perceived an error during that same visit.[14] More recently, Kemp and colleagues reported that patients who identified at least one complaint in response to an open-ended question incorporated into the Hospital Consumer Assessment of Providers and Systems survey provided lower overall experience ratings than those who did not identify a complaint, and that those who did not notify the organization of their concern gave lower experience ratings than those who did.[15] Ultimately, patients who experience breakdowns may continue to have unmet needs, and future patients may suffer similar breakdowns that could have been prevented had earlier patients spoken up.

The literature on patient safety and patient experience reveals a growing recognition that: 1) patients have knowledge and insights which could inform care improvements, 2) patients face significant challenges in sharing these insights, and 3) processes are needed to make it easy for patients to speak up about their care experiences.[7,16–22] Our findings provide further evidence of the need to actively encourage patients to voice their concerns, and suggest that relatively simple outreach to patients, repeated over time, can be an effective means of eliciting patients' concerns. Telephone outreach was more effective than paper questionnaires in terms of eliciting concerns, as 55% of those interviewed via telephone identified a concern. The brochures and posters (the latter were present at one site only) resulted in very few patient-initiated calls, though it is possible that the brochures encouraged patients to be more forthcoming on the questionnaires and outreach telephone calls. However, success in getting patients to speak up is only part of the story – once patients speak up, the care team and institutional leaders must "listen up" and provide an appropriate response.[7,23] Depending on the details, an appropriate response may be a conversation, an apology, a change in staffing, a change in the plan of care, or some other action. One recent qualitative study of providers' views on patient complaints found a tendency to marginalize complaints by characterizing those who complain as inexpert, distressed or advantage-seeking.[24] Effective strategies are needed to encourage and support providers in responding to patients who do speak up, as an inadequate response to a patient's concern may damage the provider-patient relationship and reduce trust.[25]

A limitation of our study was the very small number of patients who responded to the follow-up questionnaire. This limited our analytic power to detect an effect of the intervention to improve patients' perceptions of communication and care experiences and may be the reason that we did not detect an impact of the intervention on patients' ratings of communication or support for speaking up. As this was a pilot study, there are important questions related to the intervention that we were not able to address; for example we did not collect data on actions that were taken to address individual patient's reports of concerns, and we did not evaluate the cost of the intervention, the reactions of providers, and whether any system-level changes were made in response to patients' concerns. Future research

should include these and other data related to implementation outcomes for this or similar interventions. Future research efforts should investigate of the impact of patient characteristics on likelihood of speaking up. One recent systematic review of studies of patients' reports of adverse events suggests that certain clinical and demographic characteristics – such as income, education, and health burden - are associated with increased reporting of adverse events. Findings with respect to the effects of age and gender were mixed, and no findings with respect to race or ethnicity were reported.[18]

Conclusion

Patients frequently perceive that significant breakdowns have occurred in their care, yet may be reluctant to formally report their concerns to the institution or to their care providers. The findings reported here add to a growing body of evidence that when asked, patients are willing to voice their concerns. When patients speak up, healthcare teams and systems have the opportunity to not only provide a real-time response to the patient, but also identify where care or system improvements are needed, and implement policies, procedures, or programs to prevent care breakdowns.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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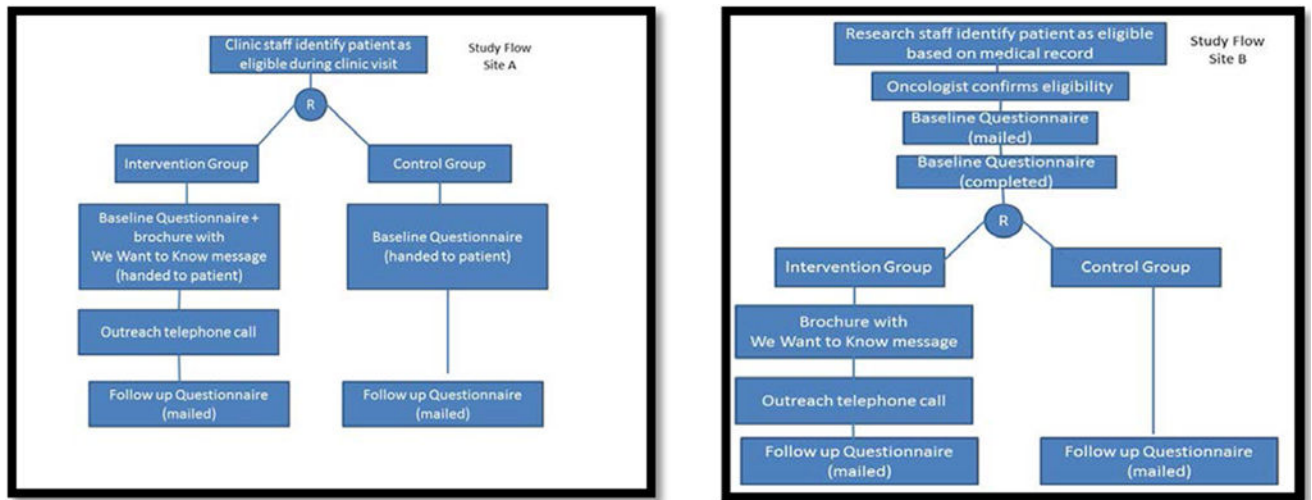
Figure 1.
Study flow for each site

Table 1

Patient Characteristics by Randomization Group

	Intervention N (%)	Control N (%)	Total N (%)
Number of Patients	60 (52.2)	55 (47.8)	115 (100)
Sex			
Female	38 (63.3)	29 (52.7)	67 (58.3)
Male	22 (36.7)	25 (45.5)	47 (40.9)
Missing	0	1 (1.8)	1 (0.9)
Age mean, (SD)	59.03 (11.81) (range: 24–80)	60.43 (10.3) (range: 32–80)	59.69 (11.09) (range: 24–80)
Race			
Asian	3 (5.0)	4 (7.3)	7 (6.1)
African-American/Black	21 (35.0)	14 (25.5)	35 (30.4)
White	33 (55.0)	33 (60.0)	66 (57.4)
Unknown/Missing	3 (5.0)	4 (7.3)	7 (6.1)
Ethnicity			
Hispanic	1 (1.7)	4 (7.3)	5 (4.3)
Educational Achievement			
Less than high school	3 (5.0)	3 (5.5)	6 (5.2)
High school graduate or GED	12 (20.0)	7 (12.7)	19 (16.5)
Some college or technical degree	21 (35.0)	24 (43.6)	45 (39.1)
College graduate	10 (16.7)	9 (16.4)	19 (16.5)
Some graduate school or advanced degree	12 (20.0)	8 (14.5)	20 (17.4)
Missing	2 (3.3)	4 (7.3)	6 (5.2)
Marital status			
Never married	2 (3.3)	1 (1.8)	3 (2.6)
Married or living with partner	39 (65.0)	35 (63.6)	74 (64.4)
Married but separated or divorced	14 (23.3)	12 (21.8)	26 (22.6)
Widowed	2 (3.3)	4 (7.3)	6 (5.2)
Missing	3 (5.0)	3 (5.5)	6 (5.2)
Annual household income			
15, 000 or less	4 (6.7)	3 (5.5)	7 (6.1)
15,001 to $25,000	3 (5.0)	1 (1.8)	4 (3.5)
25,001 to $35,000	7 (11.7)	3 (5.5)	10 (8.7)
35,001 to $50,000	9 (15.0)	11 (20.0)	20 (17.4)
50,001 to $75,000	9 (15.0)	9 (16.4)	18 (15.7)
75,001 to $99,999	8 (13.3)	3 (5.5)	11 (9.6)
100,000 or more	9 (15.0)	7 (12.7)	16 (13.9)
Missing/Prefer not to answer	11 (18.3)	18 (32.7)	29 (25.2)
Type of Cancer			

	Intervention N (%)	Control N (%)	Total N (%)
Breast	21 (35.0)	17 (30.9)	38 (33.0)
Colorectal	12 (20.0)	14 (25.5)	26 (22.6)
Lung	6 (10.0)	4 (7.3)	10 (8.7)
Hematologic	9 (15.0)	10 (18.2)	19 (16.5)
Other Solid	10 (16.7)	9 (16.4)	19 (16.5)
Missing	2 (3.3)	1 (1.8)	3 (2.6)

Table 2

Distribution of Patients Reporting Problems by Randomization Group

Timing and Mode of Reporting	Randomization Group		
	Intervention	Control	p value
Baseline Questionnaire	21/58 (36.2%)	13/53 (24.5%)	p=.18
Telephone Outreach	21/38 (55.3%)		NA
Follow-up Questionnaire	5/23 (21.7%)	6/21 (28.6%)	p=.60
Total	34/60 (56.7%)	16/55 (29.1%)	p =.003

Table note: Counts represent the number of patients reporting problems (i.e., not the number of problems identified). Counts for the follow-up questionnaire and via telephone are based on newly reported issues only; i.e., a problem reported on the baseline questionnaire which was also described on the follow-up questionnaire was not included in the count of problems reported on follow-up because it had already been identified on baseline. Total represents the total number of patients reporting a problem at *any* contact point, i.e., on the baseline questionnaire, on the telephone outreach call, or on the follow-up questionnaire. Each patient is counted only once in the total regardless of the number of unique problems reported.

Table 3

Distribution of Types of Patient-Perceived Problems with Care by Randomization Group and by Timing and Mode of Reporting

Problem Category	Intervention Group				Control Group		
	Baseline N=58	Telephone N=38	Follow-up N=23	Total N=60	Baseline N=53	Follow-up N=21	Total N=55
Problems with tests, treatments, or procedures, including delays, denial of desired tests, overly aggressive or not sufficiently aggressive treatment, general disagreement with treatment; and unexpected complications.	11	1	1	13	5	1	6
Insufficient, inaccurate information, poor explanations, delays in providing information	3	6	0	9	6	0	6
Poor team communication including team members not communicating with each other, disagreements between team members, contradictory or conflicting information from different providers, and poor communication between teams or facilities.	2	5	0	7	4	2	6
Poor manner, including cold, uncaring or insensitive demeanor	4	2	4	10	1	2	3
Problems with diagnosis, including delayed diagnosis and misdiagnosis	4	3	0	7	3	0	3
Lack of responsiveness, including provider or other team members not returning phone calls and lack of follow-up.	2	1	0	3	1	2	3
Difficulty accessing providers including difficulty knowing how to contact a provider, not knowing who to contact, providers cancelling appointments or not available when promised.	2	2	1	5	0	0	0
Other poor experience, including long wait time, absence of support resources.	2	3	0	5	0	0	0
Administrative issues, including paperwork and insurance.	1	1	0	2	1	1	2
Not enough time with provider, including feeling rushed or hurried.	0	3	0	3	0	0	0
Complaints related to the facility, or equipment, includes quality, cleanliness, comfort, and atmosphere (e.g., of chemotherapy suite).	1	1	0	2	1	0	1
Financial costs, including co-payments.	3	0	0	3	0	0	0
Poor continuity of care, including undesired changes in providers	0	2	0	2	1	0	1
Location or distance to the facility.	0	1	0	1	1	0	1
Poor or insensitive delivery of diagnosis, including problems with manner, setting, persons involved, and timeliness.	0	2	0	2	0	0	0

Table note: Categories are not mutually exclusive; that is, a single event could be coded in multiple categories. Counts for at follow-up and via telephone are based on newly reported issues only; i.e., a problem reported on the baseline questionnaire which was also described on the follow-up questionnaire was not included in the count of problems reported on follow-up because it had already been identified on baseline.

Table 4

Communication and Responsive Ratings by Randomization Group

Item Set: Timing	Intervention		Control		
	N	Mean (SD)	N	Mean (SD)	p-value
Communication Rating: Baseline	58	3.63 (.48)	53	3.77 (.40)	p=.11
Communication Rating: Follow-up	23	3.59 (.52)	21	3.68 (.48)	p=.53
Responsiveness Rating: Follow-up	22	3.38 (.86)	21	3.36 (.84)	p=.93

Table note: Higher values indicate more positive ratings [possible score range 1–4]. Cronbach's alpha for the communication items (calculated on the baseline data) = .95; Cronbach's alpha for the responsiveness items = .97. Independent *t*-tests.