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# Understanding cancer patients' experience and outcomes: development and pilot study of the Cancer Care Outcomes Research and Surveillance patient survey

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**Abstract** *Goals of work:* The National Cancer Institute's Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium is conducting a population-based study of newly diagnosed patients with lung and colorectal cancer to describe the experience of persons living with cancer and to understand which barriers present the most significant obstacles to their receipt of appropriate care. The keystone to this effort is the baseline patient survey administered approximately 4 months after diagnosis. *Patients and methods:* We developed a survey to obtain information from patients newly diagnosed with lung and colorectal cancer about their personal characteristics, decision making, experience of care, and outcomes. We conducted a pilot study to evaluate the feasibility of a lengthy and clinically detailed interview in a convenience sample of patients within 8 months of diagnosis ($n$=71). *Main results:* The median length of the interviews was 75 min for patients with lung cancer (range 43–130) and 82 min for patients with colorectal cancer (range 46–119). Most patients had received some form of treatment for their cancer: 66.1% had undergone surgery, 28.2% had received radiation therapy, and 54.9% were treated with chemotherapy. In addition, 26.7% reported their overall health was less than 70 on a 0–100 scale, demonstrating that patients with

substantial health impairment were able to complete the survey. *Conclusions:* A clinically detailed survey of newly diagnosed lung and colorectal cancer patients is feasible. A modified version of this survey is being fielded by the CanCORS Consortium and should provide much needed population-based data regarding patients' experiences across the continuum of cancer care and their outcomes.

**Keywords** Quality of health care · Patterns of care · Outcome assessment · Process assessment · Patient satisfaction · Decision making · Health disparities

## Introduction

In 2001, almost 10 million people in the United States were living with a history of cancer, up from three million people in 1971 [1]. The increasing number of cancer survivors over the past 25 years has stimulated interest in understanding the quality of life of persons living with cancer [1–5]. Further, improved survival following a diagnosis of cancer reinforces the importance of survivors experience [6–11], across the continuum of the illness from diagnosis and staging through remission, recurrence, and end of life. Reports by the Institute of Medicine (IOM) [12] and from the President's Cancer Panel [10, 11] suggest that many patients suffer a myriad of debilitating symptoms while receiving active treatment, as well as for years thereafter [13]. Patient-reported outcomes are particularly critical to understanding the trade-offs between treatment toxicity and survival benefit, especially when cure is not anticipated [3].

Patient outcomes are influenced by the disease (type of cancer and stage) and its treatment (extent of surgery, chemotherapy, radiotherapy), as well as comorbid conditions. The IOM and others have raised concerns that many patients are experiencing worse outcomes because they do not receive state-of-the-art care [10, 11]. Striking variations in the treatment of lung and colorectal cancer suggest disparities in the care of patients of different racial/ethnic background and those of advanced age [14–23]. Although less well studied, disparities in the palliation of patients with advanced cancer with chemotherapy and radiation therapy, as well as hospice care, also exist [16, 24, 25]. For many cancer patients, unsatisfactory interactions with the health care system can pose an additional burden at a time when they are debilitated and vulnerable. Anecdotally, for many patients, medical care is so disorganized that they must be the primary repository of information about their illness, requiring them to communicate the technical details of their disease to their physicians and to coordinate their own treatment plan. Data are needed to describe the experience of persons living with cancer and to understand which barriers most significantly impede appropriate care. Such data are a prerequisite for the development of policies to foster positive change.

To respond to this change, the National Cancer Institute (NCI) established the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium, a collaboration of eight teams of investigators, to conduct a population-based study of newly diagnosed patients with lung and colorectal cancer in multiple regions of the country, including a variety of health care delivery systems. The specific aims of the CanCORS Consortium are to determine how patients, providers, and health-care organizations influence treatments and outcomes, spanning the continuum of cancer care from diagnosis to recovery or death [26]. In addition, CanCORS will evaluate the effects of specific therapies on patients' survival, quality of life, and satisfaction with care.

CanCORS is a centerpiece of the ongoing initiative of the NCI to improve the quality of cancer care [27]. Using rigorous approaches to population-based sampling and rapid case ascertainment, the CanCORS Consortium is enrolling approximately 5000 patients with lung cancer and 5000 patients with colorectal cancer 3–4 months after their diagnosis. Data collection for this effort includes a detailed patient survey at enrollment and again 12 months after diagnosis, abstraction of patients' medical records, a survey of informal caregivers, and a survey of the treating physicians, as well as linkages to other existing databases such as Medicare and U.S. Census data.

The keystone to the CanCORS effort is the baseline patient survey administered approximately 4 months after diagnosis, which initiates a patient's enrollment in the study and provides information critical to the diverse aims of the study. However, many patients with lung and colorectal cancer have advanced disease at diagnosis, and prior studies have not always found it feasible to obtain self-report data in this patient population [28, 29]. In this article, we describe the development and feasibility of a clinically detailed patient survey in patients newly diagnosed with lung and colorectal cancer.

## Methods

### Survey design

The objective of the patient survey was to obtain information about personal characteristics, decision making, processes of care (i.e., types of therapies received), experience of care, and outcomes (i.e., symptoms, quality of life) that can only be obtained reliably from patients [26]. In addition, the survey elicited information required for

other components of the research, such as identifying patients' physicians to access their medical records and naming of a surrogate in the event that the respondent was deceased or too ill to participate in the planned follow-up survey. To capture information about the initial treatment decision-making process, the survey was designed to be administered approximately 4 months post-diagnosis, after most treatment decisions were likely to have been made.

Working groups of CanCORS investigators identified the important research questions and drafted reports that detailed the relevant variables and potential data sources (patient self-report, medical records, physician survey, and administrative data). Using the working group reports, we identified domains to be included in the survey and mapped these back to relevant research questions (Table 1). To capture the details of decision making and therapy across the spectrum of lung and colorectal cancer, from patients with early-stage disease potentially cured by surgery alone to those at the end of life receiving hospice care, we planned to use computer-assisted telephone interviewing (CATI) technology to administer the survey because it does not depend on participants' literacy. CATI is an established survey methodology in social sciences and is increasingly being used in health research [30]. With CATI, trained interviewers conduct surveys by telephone, reading questions from a computer screen and directly entering subjects' responses during the course of the interview. In comparison with face-to-face interviews and mailed questionnaires, CATI generally yields higher participation rates [31]. In addition, CATI allows for complex skip patterns, which can minimize respondent burden by tailoring survey questions to each patient's unique situation.

## Sources of items and scales

To enhance the comparability of CanCORS data with other studies, we used previously validated items and scales whenever possible. Items from the California Health Interview Survey (CHIS) [32, 33] were used to ascertain patients' demographic characteristics and insurance coverage, supplemented by several items from the State of Michigan Study [34]. Questions regarding symptoms leading to the diagnosis of the cancer, decision making regarding initial treatments, clinical trial participation, supportive care and symptom management, and provider identification were adapted from the Los Angeles Women's Health Care Study Baseline Survey [35], with some additional items regarding beliefs about clinical trials from the Harris Poll sponsored by the Coalition of National Cancer Cooperative Groups [36].

To be able to compare patient reported outcomes from CanCORS with a variety of other patient populations and also have the sensitivity to identify problems that were specific to lung and colorectal cancer patients, we incorporated a generic quality-of-life instrument, a cancer-specific instrument, and targeted instruments for pain, fatigue, and depression (domains that were not well addressed in the generic or cancer-specific instruments). The Medical Outcomes Study (MOS) 12-item short form (SF-12) was chosen to measure quality of life because of its widespread application in many conditions [37]. To describe the symptoms of this cohort, we included the cancer-specific European Organization for Research and Treatment of Cancer (EORTC) QLQ C30 [38], EORTC Lung and Colon quality-of-life modular questionnaires [39, 40], the Center for Epidemiologic Studies Depression Scale 8-item short form (CESD-8) [41, 42], the Brief Pain Inventory [43, 44], and the MOS 36-item short form (SF-36) vitality scale [45, 46].

We adapted items from the 1999–2002 National Health and Nutrition Examination Survey (NHANES), the Prostate Cancer Outcomes Study (PCOS) patient survey, and a patient self-report version of the Charlson Index to collect information regarding comorbid conditions [47–49]. For conditions that could have also occurred as complications of cancer treatments (e.g., renal failure), we added items to ascertain whether they were present before the cancer diagnosis. In addition, items were included to ascertain patients' health behaviors, including smoking (adapted from the Coronary Artery Risk Development in Young Adults study) [50] and use of vitamins (adapted from the National Cancer Institute Diet History Questionnaire) [51] and complementary and alternative medicine.

CanCORS provided a unique opportunity to estimate utility measures for different phases of illness and treatment for patients with lung and colorectal cancer in a population-based sample. We considered the available instruments for generating holistic utilities by direct elicitation methods (e.g., standard gamble, time trade-off, rating scale) as well as health indexes for generating community preferences from patient self-reported health status. Since these two general approaches yield distinct but complementary information, we selected the EQ5D [52], a health-state classification matrix for which results can be converted to time trade-off-based preference weights using a publicly available algorithm.

Questions about patients' experiences of their care were adapted from several existing surveys, including Consumer Assessment of Health Plans Study (CAHPS) adult core survey [53], a survey of cancer patients developed by the Picker Institute [54], the Northern California Colorectal Cancer Study Patient Survey [55], and the NCI's Assessment of Patients' Experience of Cancer Care (APECC) study survey (Neeraj Arora, personal communication). New items were developed to ascertain patients' prior beliefs about the efficacy and toxicity of each of the cancer therapy modalities. Degner et al.'s Control Preferences Scale regarding decision making was adapted to be administered over the telephone to ascertain patients' actual and preferred role in decision making regarding cancer treatment vis-à-vis both their physicians and their families [56, 57]. The final version of the survey is available at http://www.cancors.org/public.

**Table 1** CanCORS baseline patient survey content, rationale, and relevant research questions

| Domain | Content | Rationale | Relevant research questions |
|---|---|---|---|
| Demographic characteristics | Age | Important predictors of health care access, process, and outcomes of care | To what extent are racial disparities in the processes and outcomes explained or mediated by patients' sociodemographic characteristics? |
| | Gender | | Why are elderly patients much less likely to receive effective treatments? |
| | Race and ethnicity | | Do nonwhite or low SES patients report worse symptom control? |
| | Languages spoken and English fluency | | |
| | Education | | |
| | Literacy | | |
| | Marital status | | |
| | Country of origin | | |
| | Year of immigration to United States | | |
| Problem recognition | Confirm cancer diagnosis | Confirm eligibility | |
| | Identify patient's term for illness if not "cancer" | Establish rapport with patient and conduct survey in a way that is sensitive to their perception of their diagnosis | |
| | Identify symptom that led to diagnosis | | |
| Initial treatments: surgery, radiation, chemotherapy | Determine if patient received or scheduled to receive each treatment, had consult with relevant specialist, and recommendation provided | Describe treatments received, recommended for and against, and discussed for patients newly diagnosed with lung and colorectal cancer | To what extent are racial disparities in the processes and outcomes explained or mediated by referral to a cancer specialist? Recommendation by a physician? |
| | Reasons for not having treatment, if relevant | Describe patient beliefs about efficacy and side effects of treatment and their role in decision making | |
| | Patient's beliefs about efficacy and side effects of treatment | | Patients' beliefs about the efficacy and side effects of treatments? |
| | Patient's role in treatment decision making | | Patients' role in decision making? |
| Clinical trials | Determine if patient participated in or discussed a clinical trial | Describe the rates of participation and reasons for not participating in clinical trials among newly diagnosed lung and colorectal cancer patients | Why is participation in clinical trials so low for colorectal and lung cancer? |
| | Reasons for not participating in clinical trial | | What determines whether patients are offered participation and accept it? |
| Identification of surrogate | Identify a surrogate respondent and obtain permission to contact, if needed | Obtain data on patients who are deceased at the time of the follow-up survey | |

**Table 1** (continued)

| Domain | Content | Rationale | Relevant research questions |
|---|---|---|---|
| Patients' assessments of care | Overall rating of cancer care<br>Reports of specific aspects of care: coordination of care, information provided, access to specialists, perceived discrimination | Determine whether interpersonal aspects of care are associated with receipt of treatment for lung and colorectal cancer | What patient, provider, and organizational factors are associated with patients' interpersonal experiences with cancer care, including their perceptions of coordination of care, provision of desired information, respect for their preferences, and emotional support from health-care providers? |
| Quality of life | General health status | Important treatment outcomes | To what extent are racial disparities in the processes and *outcomes* explained or mediated by patients' clinical characteristics (e.g., comorbidity, lifestyle factors)? |
| | Symptoms, including pain and depression | Describe the burden of illness and treatment on quality of life of patients 4 months out from diagnosis with colorectal and lung cancer | |
| | Health utility index | Obtain population-based health utilities | |
| | Social support | Describe patients social support | |
| Symptom management and supportive care | Provider's awareness of symptom | Describe supportive services used and unmet need | Are patients receiving effective symptom control at the end of life? |
| | Patient's desire for and receipt of help with symptom | Understand the relationship between the frequency and severity of symptoms and providers' awareness and responsiveness to symptoms | What are the barriers to effective symptom control? |
| | Need for and use of hospice and other supportive services | Determine what patient factors are associated with provider's being aware of and responsive to symptoms | Are certain processes of care (e.g., use of hospice services) or organizational structures associated with better symptom control and/or reduced disparities in symptom control during end-of-life care? |
| Goals of treatment and prognosis | Family's role in decision making | Understand the relationship between patient beliefs on choice of treatment | What are the patient, provider, and organizational factors associated with variation in cancer treatments (e.g., the use of chemotherapy for metastatic non-small-cell lung cancer)? |
| | Preferred decision-making role | Understand the relationship between patients' preferred and actual decision-making role | Does this variation reflect the preferences of well-informed patients or are other factors responsible? |
| | Perceived life expectancy | Understand patients view of prognosis | |
| | Preferences for extending life vs palliation | Obtain patient preferences regarding treatment | |
| | Resuscitation preferences | | |

**Table 1** (continued)

| Domain | Content | Rationale | Relevant research questions |
|---|---|---|---|
| Health history and behaviors | Comorbid illness<br>Prior cancer and radiation therapy<br>Functional status<br>Smoking and alcohol use<br>Vitamin and complementary/alternative medicine use<br>Height and weight | Understand the role of comorbid illness and health behaviors as determinants of process of care | To what extent are racial disparities in the processes and outcomes listed above explained or mediated by patients' clinical characteristics (e.g., comorbidity, lifestyle factors)? |
| Insurance coverage and income | Characteristics of coverage, including gaps and coverage for prescription drugs<br>Tests or treatments forgone because of insurance problems<br>Household income and wealth | Understand the ways in which income, wealth, and insurance coverage facilitate or act as a barrier to cancer care | To what extent are racial disparities in the processes and outcomes explained or mediated by patients' having health insurance and the characteristics of their insurance coverage? |
| Provider identification | Identification of doctors and hospitals who provided care | Understand effect of provider characteristics (e.g., specialty) on receipt or recommendation for treatment<br>Contact information necessary to obtain medical records | What are the patient, provider, and organizational factors associated with variation in cancer treatments (e.g., the use of chemotherapy for metastatic non-small-cell lung cancer)? |

## Readability

Although the survey was developed for CATI, we assessed the readability of the survey to assess the complexity of its wording and to evaluate the feasibility of developing a self-administered version. We used both the Simple Measure Of Gobbledygook (SMOG) and Fry methods for evaluating readability. The SMOG formula estimates reading difficulty based on the number of polysyllabic words (words with three or more syllables) [58], while the Fry method estimates reading grade level based upon both the average number of sentences and average number of syllables [59, 60]. Both methods estimated the reading level at grade 10. These results affirmed our decision to develop an interviewer-assisted survey so that the reading level would not be a barrier to some respondents.

## Pilot study

We conducted a pilot study to evaluate the feasibility of a lengthy and clinically detailed interview with ill patients undergoing treatment for lung or colorectal cancer in a convenience sample of recently diagnosed patients. The primary goals of the pilot were to estimate the time needed to complete the interview and to evaluate the acceptability of newly developed questions.

To be eligible for the pilot study, patients had to be at least 21 years of age, have a histologically confirmed diagnosis of primary invasive lung, colon, or rectal cancer within the prior 8 months, and able to participate in an interview in English. Eligible patients were identified by their physicians at six sites (Alabama, Northern California, Hawaii, Iowa, Los Angeles County, and North Carolina). Participant enrollment occurred between August 30, 2002 and January 9, 2003. The Institutional Review Boards at all of the participating institutions approved the pilot study. All patients provided informed consent.

Although we designed the survey to be administered with CATI, because of the cost associated with programming CATI before the instrument was finalized, for this pilot study, interviews were conducted in person ($n$=18) or by telephone ($n$=53) using a paper questionnaire. In addition, after completing administration of each survey, the interviewer responded to a series of open-ended questions addressing the flow of the instrument, language that the respondent did not appear to understand or items that required additional probing, items that elicited an emotional or negative reaction, responses that were not among the listed options, and the respondent's attitude toward the length of the survey.

All patient questionnaire responses were entered into an Ingres relational database at the study's Statistical Coordinating Center, and analyses were conducted using SAS statistical software version 8.2 for Unix.

## Results

Across the six sites, 33 patients with colorectal cancer and 38 patients with lung cancer participated in the pilot study ($n$=71). On average, patients completed the interview 4.2 months after diagnosis (SD 2.3). Patients' mean ages were 68 (SD 10) and 64 (SD 12) years, respectively, with an even distribution of gender (Table 2). Although the patients in this pilot study were highly educated, 11.3% had less than 4 years of high school and 33.8% had a high school diploma or equivalent or had completed vocational training. Most patients had experienced some form of treatment for their cancer: 66.1% had had surgery, 28.2% had received radiation therapy, and 54.9% were treated with chemotherapy. Seventy-three percent of patients had at least one comorbid illness, and 22% reported a hospitalization during the prior year unrelated to their cancer diagnosis.

On the mental health component scale of the SF-12, patients scored only slightly below the population-based mean of 50. However, on the physical health component scale of the SF-12, colorectal cancer patients scored approximately 5 points below the general population mean (0.5 standard deviation), and lung cancer patients were

**Table 2** Characteristics of pilot participants ($n$=71)

| | | All cases ($n$=71) $n$ (%) | Lung cancer ($n$=38) $n$ (%) | Colorectal cancer ($n$=33) $n$ (%) |
|---|---|---|---|---|
| Site | Alabama | 19 (29) | 12 (32) | 7 (21) |
| | Los Angeles | 7 (10) | 4 (11) | 3 (9) |
| | Northern California | 21 (30) | 12 (32) | 9 (27) |
| | Hawaii | 4 (6) | 1 (3) | 3 (9) |
| | Iowa | 10 (14) | 10 (26) | 0 |
| | North Carolina | 10 (14) | 0 | 10 (30) |
| Age | Mean±SD | 66±11 years | 68±10 years | 64±12 years |
| Gender | Male | 36 (51) | 17 (45) | 19 (58) |
| Race/ethnicity | Latino | 2 (3) | 1 (3) | 1 (3) |
| | White | 57 (80) | 33 (87) | 24 (73) |
| | Black | 4 (6) | 1 (3) | 3 (9) |
| | Asian | 8 (11) | 3 (8) | 5 (15) |
| Education | HS not completed | 8 (11) | 6 (16) | 2 (6) |
| | HS/GED or vocational | 24 (34) | 13 (34) | 13 (39) |
| | At least some college | 38 (54) | 18 (47) | 18 (55) |
| Treatment | Surgery | 47 (66) | 19 (50) | 28 (85) |
| | Radiation | 20 (28) | 13 (34) | 7 (21) |
| | Chemotherapy | 39 (55) | 22 (58) | 17 (52) |
| Comorbid illness | Any | 52 (73) | 28 (72) | 24 (75) |
| | Asthma | 9 (13) | 7 (18) | 2 (6) |
| | Chronic lung disease | 11 (16) | 9 (24) | 2 (6) |
| | MI | 13 (18) | 10 (26) | 3 (9) |
| | CABG or stent | 11 (16) | 8 (21) | 3 (9) |
| | Stroke | 9 (13) | 4 (11) | 5 (15) |
| | Diabetes | 13 (18) | 8 (21) | 5 (15) |
| Hospitalizations in prior year | | 15 (21) | 7 (18) | 8 (24) |
| SF-12 | PCS±SD | 43.1±10.0 | 41.3±9.9 | 45.0±10.0 |
| | MCS±SD | 50.8±10.5 | 48.2±11.7 | 53.4±8.5 |
| EQ5D Thermometer Rating Scale of overall health [0–100] | 100 | 4 (6) | 1 (3) | 3 (9) |
| | 90–99 | 15 (21) | 8 (21) | 7 (21) |
| | 80–89 | 18 (25) | 6 (16) | 12 (36) |
| | 70–79 | 15 (21) | 6 (18) | 8 (24) |
| | 60–69 | 10 (14) | 8 (24) | 1 (3) |
| | 50–59 | 4 (6) | 2 (5) | 2 (6) |
| | 40–49 | 3 (4) | 3 (8) | 0 |
| | 30–39 | 2 (3) | 2 (5) | 0 |

*MI* Myocardial infarction, *CABG* coronary artery bypass grafting, *PCS* physical component summary, *MCS* mental component summary

approximately 10 points below the general population mean (1 standard deviation). This difference is consistent with clinical expectations since newly diagnosed lung cancer patients are more likely to have advanced disease and poor performance status. In addition, 26.7% reported their overall health on the EQ5D Thermometer Rating Scale was less than 70 on a 0–100 scale, demonstrating that patients with substantial burdens of illness were able to complete the survey.

Item nonresponse was minimal (mean 7.5% and median 3.0%) and appeared to be a consequence of implementing complicated skip patterns using a paper instrument. Review of the results from the standardized instruments (e.g., EORTC QLQ colorectal and lung cancer symptom checklists, CES-D, SF-12) in each type of cancer showed good variability in response and appropriate convergence in relevant domains (e.g., CES-D and the MCS of the SF-12). Respondents were able to answer questions about the major treatment modalities and their decision-making process without any difficulty. However, some respondents were not able to answer questions asking for technical details of care, for example, the type of surgery they received. In addition, although most patients were able to provide information about their health care coverage in general and the name of their insurance carrier, when applicable, few could report the specific insurance product or group code.

Most patients were willing to respond to questions regarding their beliefs about their disease and their experiences. Selected items are presented in Table 3. Although many patients had advanced disease, very few believed their cancer was incurable. Sixty percent of lung cancer patients and 85% of colorectal cancer patients said that they would have agreed or strongly agreed with the statement "Lung/colorectal cancer is curable" prior to their diagnosis with cancer. Only 10% of patients estimated their expected survival was less than 5 years. Interestingly, although some of the nonresponse to this item (more than one third of surveys) was because patients said that they did not know their expected survival (which was not a response option on the pilot survey), much of the nonresponse reflected the interviewers' reluctance to ask the question. In this pilot cohort, patients had favorable comments about their interactions with the health care system. However, a few patients reported problems with coordination of care and access to specialists. Similarly, among patients who rated the quality of their health care, most rated it very good or excellent.

Field testing of some of our newly developed questions, especially those that dealt with the sensitive issues of the goals of treatment and prognosis, was approached with some concern by our interviewers. In particular, many interviewers were quite uncomfortable asking patients to estimate their expected survival; however, most patients did so without any difficulty. Although these questions were more likely to evoke emotional reactions in the patients, many respondents commented that they appreciated the opportunity to discuss their experiences with cancer. With training and increasing confidence that patients would benefit from the opportunity to discuss these concerns, the interviewers found that these more sensitive questions were a valuable part of the interview. The resistance we experienced among the interviewers is not unlike what was first noted when quality-of-life questionnaires were introduced into cancer clinical trials—doctors and nurses were afraid that asking about experiences would distress patients, when in fact patients appreciated the opportunity to share their own evaluation of their circumstances [61].

The median time to complete the interviews was 75 min for patients with lung cancer (range 43–130) and 82 min for patients with colorectal cancer (range 46–119). All respondents completed the interview. Since our goal was to develop a baseline survey for the CanCORS cohort that could be administered in approximately 60 min, we used the results of this pilot study to determine which items to exclude. Questions that asked for information that many patients did not know (e.g., insurance group code) were dropped. Items were excluded if medical records would be a more valid data source (e.g., "What type of surgery did you have?"). Questions that had been repeated for each treatment modality in the pilot survey were modified to allow them to be asked only once. For example, instead of asking patients to evaluate the interpersonal aspects of care with each treatment, we now ask them to rate the interpersonal aspects of their care overall and provide a single global rating of the quality of care for each treatment. Finally, questions that pertained to a secondary research topic such as screening services (e.g., "What medical tests did you have that made a doctor think you might have cancer?") were dropped.

The revised CanCORS baseline patient survey has been programmed into CATI and is currently being fielded in the seven CanCORS study sites. Because of the heavy burden of illness and significant mortality associated with both lung and colorectal cancer, two alternate versions of the survey were developed: an abbreviated instrument for patients who are not able to complete the full survey and a version that can be administered to a surrogate when a patient is deceased or too ill to participate. As two of the sites have substantial Hispanic and Chinese populations, all versions of the survey have undergone forward and backward translations into Spanish, Mandarin, and Cantonese. A very brief self-administered paper version has subsequently been produced to obtain data from patients who are unwilling or unable to do an interview over the telephone or for whom we are unable to locate a phone number. In addition, CanCORS investigators have developed a follow-up survey to be administered 12 months after diagnosis. As of January 2006, approximately 10,000 patients with newly diagnosed lung and colorectal cancer, recruited from seven population-based cohorts, have completed the baseline patient survey with a median time of 58 min (available at http://www.cancors.org/public).

**Table 3** Patient beliefs and experience: selected items from the CanCORS patient survey

| | | Lung cancer (*n*=38) *n* (%) | Colorectal cancer (*n*=33) *n* (%) |
|---|---|---|---|
| Prior to your diagnosis with cancer, how much did you agree or disagree with the following statement: lung or colorectal cancer is curable | Strongly agree | 5 (13) | 12 (36) |
| | Agree | 18 (47) | 16 (49) |
| | Disagree | 3 (8) | 1 (3) |
| | Strongly disagree | 2 (5) | 0 |
| | Don't know | 6 (21) | 2 (9) |
| | Missing | 6 (5) | 1 (3) |
| Based upon your understanding about what your doctors have told you about your lung/colorectal cancer, your health in general, and the treatments that you are receiving, how long do you think you have to live? *Responses are not read to patient* | >5 years | 14 (37) | 16 (49) |
| | 1–5 years | 3 (8) | 1 (3) |
| | <1 year | 1 (3) | 2 (6) |
| | In God's hands | 8 (18) | 1 (3) |
| | Missing | 13 (34) | 13 (39) |
| If you had to make a choice now, would you prefer treatment that extends life as much as possible even if it means having more pain and discomfort, or would you want treatment that focuses on relieving pain and discomfort as much as possible, even if it means not living as long? | Extend life as much as possible | 21 (55) | 15 (46) |
| | Relieve pain as much as possible | 14 (37) | 15 (46) |
| | Don't know | 1 (3) | 3 (9) |
| | Skip | 2 (5) | 0 |
| | Missing | 1 (3) | 1 (3) |
| How often did you know who to ask when you had questions about your heath problems? | Never | 0 | 0 |
| | Sometimes | 1 (3) | 4 (12) |
| | Usually | 4 (11) | 4 (12) |
| | Always | 32 (84) | 24 (73) |
| How often were you able to see the specialists such as cancer doctors you wanted to see for your lung/colorectal cancer? | Never | 0 | 1 (3) |
| | Sometimes | 0 | 5 (15) |
| | Usually | 1 (3) | 3 (9) |
| | Always | 7 (18) | 21 (64) |
| | N/A | 30 (79) | 2 (6) |
| | Missing | 0 | 1 (3) |
| How would you rate the quality of your care for cancer? | Excellent | 25 (66) | 24 (73) |
| | Very good | 7 (18) | 6 (18) |
| | Good | 4 (11) | 3 (9) |
| | Fair | 1 (3) | 0 |
| | Poor | 0 | 0 |
| | Missing | 1 (3) | 0 |

## Discussion

This pilot study demonstrated the feasibility of performing a detailed interview with very ill patients to obtain information about their personal characteristics, processes of care, experience of care, and outcomes. The performance of established instruments was excellent in this clinically ill patient population. New items were developed to address the patient experience and satisfaction with care, as well as to ascertain patients' prior beliefs about the efficacy and toxicity of each of the cancer therapy modalities. We plan to examine the psychometric properties of these items (e.g., internal consistency reliability, correlations with other constructs) to determine whether or not they are scalable.

Patient self-report data are necessary to understand the experience of persons living with cancer. Our results provide encouragement that studies of patients' experience of care across the cancer continuum can and should include patients with advanced disease.

Despite much speculation, the reasons for underuse of effective therapies for lung and colorectal cancer and disparities in care are not fully understood [10–12]. Most research to date has relied upon data from cancer registries and insurance claims, which are limited in clinical detail

and contain no information about patient beliefs, information provided to patients regarding treatment options, or their decision-making process. By combining medical record data with patient self-report, CanCORS aims to elucidate the reasons for under use of care and disparities of care in patients with lung and colorectal cancer. The patient survey includes items that pertain to a number of hypotheses: patient sociodemographic characteristics, such as insurance, income, education, and literacy; patient beliefs regarding the efficacy and side effects of treatment; referral to a cancer specialist; and physician recommendations for (or against) treatment. Few of these relevant data elements are available in administrative sources.

Data from the CanCORS patient surveys will be supplemented with information from medical record regarding patients' comorbid conditions, diagnostic tests, staging evaluation, treatments recommended, the technical details of cancer treatments received, the reasons treatment was not received (when documented), and treatment toxicity, symptom recognition, and clinical outcomes. Although some of these topics are within the purview of clinicians, the patient's perspective will provide important additional information. For example, some discussions of treatment options may not be documented in the medical record, and patients may be better able to describe what treatments they were offered. In addition, for patients who do not receive recommended therapy, their reports of the reasons for not receiving treatment will help to shed light on disparities of care reported by other studies. In addition, symptoms experienced by patients as a result of their cancer and treatment may not be accurately captured using medical record data. A recent study found that the sensitivity and specificity of physicians' reporting of patients' symptoms on an adverse event log relative to patients' self-report using a validated questionnaire were 47 and 68%, respectively, although they varied considerably across symptoms [62]. While physicians may have different criteria for reporting a symptom on an adverse event log than documenting it in the medical record, the concordance between patient self-report and medical-record-documented symptoms is not known. By collecting data regarding patients' symptoms using the patient survey, we will describe patient-reported symptoms in population-based cohorts of patients with lung and colorectal cancer and use these data to validate the use of medical records as a source of data on patient symptoms.

Finally, little is known about many important outcomes of lung and colorectal cancer, such as quality of life and patient satisfaction. Using previously validated instruments, the CanCORS patient survey will provide population-based data on the quality of life reported by patients with lung and colorectal cancer, as well as data regarding differences in quality of life across patient groups. In addition, survey items that address patients' perceptions of coordination of care, provision of desired information, respect for their preferences, and emotional support from health-care providers will provide much needed data regarding patients' experiences with the health care system across the continuum of cancer care.

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