

Assessment of Quality of Cancer-Related Follow-Up Care From the Cancer Survivor's Perspective

Neeraj K. Arora, Bryce B. Reeve, Ron D. Hays, Steven B. Clauser, and Ingrid Oakley-Girvan

From the National Cancer Institute, Bethesda, MD; Lineberger Cancer Center, University of North Carolina at Chapel Hill, Chapel Hill, NC; University of California, Los Angeles, Los Angeles; and Cancer Prevention Institute of California, Fremont, CA.

Submitted August 11, 2010; accepted January 14, 2011; published online ahead of print at www.jco.org on February 28, 2011.

Support for data collection was provided by the National Cancer Institute (Contract No. N01-PC-35136) as a contract to the Cancer Prevention Institute of California (formerly known as the Northern California Cancer Center). R.D.H. was also supported in part by the University of California, Los Angeles (UCLA) Resource Center for Minority Aging Research/Center for Health Improvement in Minority Elderly, National Institutes of Health (NIH)/National Institute on Aging (NIA) Grant No. P30-AG021684, the UCLA/Drew Project Centers of Excellence in Partnerships for Community Outreach and Research on Disparities in Health and Training, National Center on Minority Health and Health Disparities Grant No. 2P20MD000182, and the UCLA Older Americans Independence Center (NIH/NIA Grant No. P30-AG028748).

This article reflects the personal opinions of N.K.A. and S.B.C. and does not convey any official position of the National Cancer Institute.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Neeraj K. Arora, PhD, Outcomes Research Branch, Applied Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, 6130 Executive Blvd, MSC 7344, EPN 4092, Bethesda, MD 20892-7344; e-mail: aroran@mail.nih.gov.

© 2011 by American Society of Clinical Oncology

0732-183X/11/2910-1280/\$20.00

DOI: 10.1200/JCO.2010.32.1554

ABSTRACT

Purpose

We assessed cancer survivors' perceptions of the quality of their follow-up care.

Methods

We surveyed a population-based cohort of leukemia, bladder, and colorectal cancer survivors diagnosed 2 to 5 years previously in northern California (N = 623; participation rate, 69.2%; overall response rate, 49.2%). Data were collected between April 2003 and November 2004. Ten scales assessed survivors' perceptions of different aspects of care in the last 12 months, and an eleventh scale measured their overall ratings of care.

Results

On nine of the 11 scales, mean scores ranged from 88 to 97 on a 0 to 100 response format, indicating very positive experiences. The two areas where quality perceptions were lower were discussions about health promotion and the physician's knowledge of the whole patient. In adjusted analyses, those without private health insurance ($P = .02$) and Hispanic and Asian survivors compared with whites ($P < .001$) reported worse timeliness of care. Survivors who had multiple comorbidities reported better scores on timeliness of care ($P < .01$) and physicians' knowledge ($P = .05$) than survivors without any comorbidity. Length of the patient-physician relationship was the variable most consistently found to be significantly associated with survivors' quality assessments. Physicians' information exchange had the strongest relationship with overall ratings of care, followed by physicians' affective behavior, their knowledge of the survivor, and survivors' perceptions of coordination of care ($P < .001$ for all).

Conclusion

Delivery of quality follow-up care to cancer survivors may require efforts to improve patient-centered communication and coordination. Special emphasis may need to be placed on health promotion discussions and adoption of a whole-person orientation.

J Clin Oncol 29:1280-1289. © 2011 by American Society of Clinical Oncology

INTRODUCTION

Cancer survivors require substantial follow-up care to monitor for disease recurrence, to check for late effects of treatment, and to manage ongoing symptoms and adverse effects.¹ Other goals of follow-up care include facilitating survivors' psychosocial adjustment to their illness and promoting healthy lifestyles.^{2,3} Although the importance of follow-up care has been recognized by clinicians, researchers, and policy makers,^{4,5} systematic assessments of the quality of care delivered to cancer survivors are limited.⁶

Existing studies have typically focused on understanding optimal models for delivering follow-up care and on developing and evaluating evidence-based guidelines for surveillance of cancer survivors.⁷⁻¹² More recently, attention has been given to evaluating the role of care plans in facilitating the delivery of high-quality follow-up care.¹³

However, evaluation of the patient-centered aspects of care such as survivors' perspectives on access, communication with health care professionals, and perceptions of care coordination is virtually nonexistent.¹⁴ The few studies in oncology that have assessed patient perspectives have typically focused on the diagnosis and treatment phases of care.¹⁵⁻¹⁹ To provide a more comprehensive picture of the quality of follow-up care delivered to cancer survivors, systematic evaluations of the perspectives of survivors are needed to complement efforts that focus on more technical aspects of quality such as evaluation of the concordance of follow-up care practices with evidence-based guidelines.²⁰⁻²³

To better understand cancer survivors' experiences of receiving follow-up care, the National Cancer Institute sponsored the Assessment of Patient Experiences of Cancer Care (APECC) study, a population-based study of cancer survivors in

northern California. This study had the following objectives: develop and test a comprehensive survey to assess cancer survivors' perceptions of the quality of their follow-up care; identify the sociodemographic, clinical, and follow-up care-related factors associated with survivors' quality-of-care assessments; and evaluate the association between survivors' assessments of the quality of individual aspects of care with their overall ratings of care.

cancer between their initial diagnosis and the start of the study; and have no objections from their physician of record to their participation. We focused on leukemia and bladder and colorectal cancer because we wanted to test the survey measures across multiple cancers that were applicable to both sexes and individuals with a broad age range.

Figure 1 presents the study's recruitment flowchart. On the basis of information from the registry and physician consent, we identified 2,983 survivors to be potentially eligible for the study. We mailed them an initial letter describing the study, informing them about a \$25 participation incentive, and indicating that an interviewer would call to screen them for eligibility. Of the 2,492 survivors who were located and screened, 1,572 (63.1%) were deemed eligible. Of these, 1,118 survivors agreed to participate and were mailed a self-reported survey. Surveys were returned by 774 survivors; the overall participation rate was 69.2% (774 of 1,118 survivors), and the overall response rate was 49.2% (774 of 1,572 survivors). Of the 774 survivors who provided data, 623 had received follow-up care in the last 12 months and responded to items assessing patients' care experiences. These 623 survivors form our analytic sample. All data collection procedures took place between April 2003 and November 2004. Study procedures were approved by the Institutional Review Board of the Cancer Prevention Institute of California.

METHODS

Study Design

We recruited cancer survivors from the Cancer Prevention Institute of California's cancer registry, a member of National Cancer Institute's Surveillance, Epidemiology, and End Results program. To be eligible, survivors had to read English; be diagnosed with leukemia or bladder or colorectal cancer between June 1, 1999, and May 31, 2001 (ie, 2 to 5 years before enrolling onto APECC); be at least 20 years old at diagnosis; have received cancer treatment; have the cancer of interest as their first cancer diagnosis; not have any other

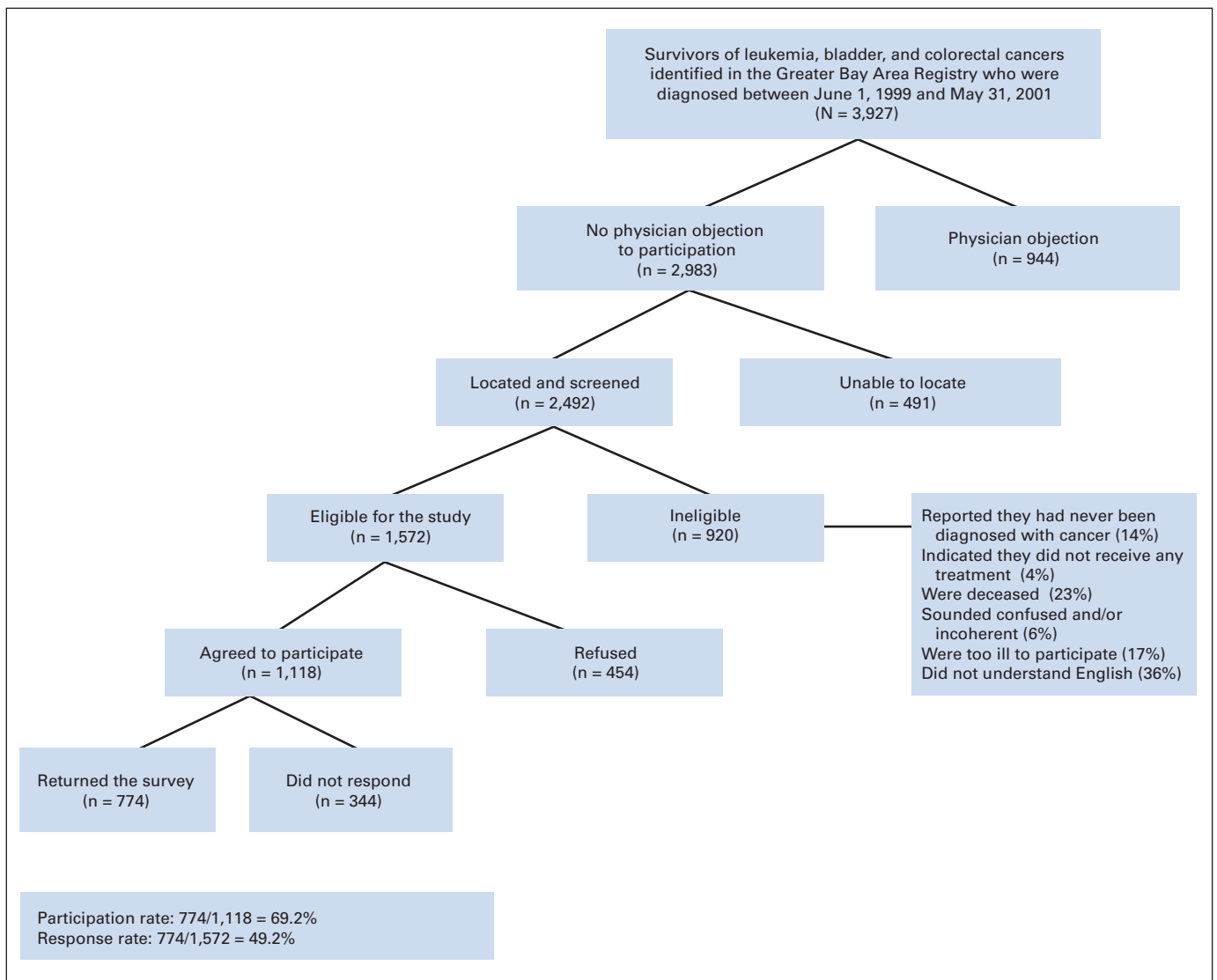


Fig 1. Recruitment flowchart for the Assessment of Patient Experiences of Cancer Care study. Six hundred twenty-three of 774 survivors received follow-up care in the prior 12 months and formed the analytic sample for the study.

Measures

We collected self-reported data on survivors' sociodemographic characteristics (age, sex, race/ethnicity, education, marital status, insurance status, and residence in a medically underserved area), their clinical characteristics (cancer type, perceived health status, number of comorbidities, years since diagnosis, type of treatments received, and whether or not their cancer was in remission), and several follow-up care-related variables (length of relationship with physician, number of visits in the last 12 months, physician's sex, survivor-physician sex match, physician specialty, and setting of care).

The APECC survey included 33 items assessing survivors' perceptions of the quality of their follow-up care in the last 12 months. Of these 33 items, 30 were divided into 10 conceptually distinct scales measuring survivors' experiences in the following five broad areas: access to care (six items, three scales: getting needed care, timeliness of care, and waiting time in physicians' office); interaction with physicians (17 items, three scales: information exchange, affective behavior, and physicians' knowledge); interaction with other members of the health care team (four items, two scales: interaction with nurses and interaction with office staff); discussion of health promotion (two items, one scale); and perceptions of coordination of care (one item). The remaining three items (one scale) assessed survivors' overall ratings of their care (Table 2 provides the exact wording of all items).

Where possible, items were adapted from existing surveys including the Consumer Assessment of Healthcare Providers and Systems surveys²⁴⁻²⁷ (11 items), the Primary Care Assessment Survey²⁸⁻³⁰ (four items), and the Ambulatory Care Experiences Survey^{31,32} (five items). Another two items were adapted from a study of experiences of patients with colorectal cancer.¹⁵ In addition, 11 new items were developed by the APECC investigators (noted in Table 2). Although the wording of existing items was modified for relevance to the context of follow-up care, we preserved their original response formats. A majority of the items had one of the following four response options: not a problem, a small problem, or a big problem; never, sometimes, usually, or always; yes definitely, yes somewhat, or no; or poor, fair, good, very good, or excellent. As suggested in other studies of patient experiences of care,^{15,16} for descriptive purposes only, for each item, we considered a response of less than the most positive option (ie, a response other than not a problem, always, yes definitely, or excellent) to be an indicator of suboptimal quality. All items underwent cognitive testing with nine cancer survivors (with diversity in age, race, sex, and cancer type) to ensure that the questions and response options were understandable and related to the concept being measured.

Data Analyses

To confirm the 10-factor/scale structure of the APECC items assessing patient perspectives on individual aspects of follow-up care, we conducted a confirmatory factor analysis using Mplus version 4.21 (Muthen & Muthen, Los Angeles, CA). We evaluated the statistical fit of the 10-factor model to the data using multiple fit indices, as follows: comparative fit index (CFI), the root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). Generally, CFI values greater than 0.95, RMSEA values less than 0.06, and SRMR values less than 0.09 are considered to indicate good model fit.³³ The confirmatory factor analysis indicated a reasonably good fit for the 10-factor model (CFI = 0.93, RMSEA = 0.04, and SRMR = 0.04). Scores for all of these 10 variables and the overall ratings of care variable were created by computing the mean of the scores on the individual items comprising each variable. All scores were then linearly transformed to a 0 to 100 range, with a higher score representing more positive quality assessments. All but two of the 10 multi-item scales had acceptable internal consistency reliability (Cronbach's $\alpha > .75$; details on score distribution are presented in Table 3 and discussed later).

We examined the associations of various sociodemographic, clinical, and follow-up care-related variables with survivors' quality assessments by estimating analysis of covariance models. Patient sex, residence in a medically underserved area, remission status, and time since diagnosis were not associated in bivariate analyses with any of the variables assessing survivors' quality perceptions ($P > .1$) and were not considered for adjusted analyses. We did not include physician specialty and treatment in our models because they were highly correlated with cancer type ($P < .001$). Among the bladder cancer survivors, 91% saw a urologist; all but two leukemia survivors saw a hemato-

logist/oncologist; and only colorectal cancer survivors saw physicians of different specialties (primary care physician, 15%; oncologist, 62%; other specialist, 23%). Similarly, a majority of bladder cancer survivors had surgery only (74%), 89% of leukemia survivors had chemotherapy with or without radiation, and 66% of colorectal cancer survivors had surgery and adjuvant therapy (chemotherapy, radiation, or both). We conducted linear regression analysis to examine the associations between the 10 variables assessing cancer survivors' perceptions of quality of individual aspects of care and their overall care ratings. We controlled for all the sociodemographic, clinical, and follow-up care-related variables analyzed in the analysis of covariance models. All models were estimated using SPSS version 14.0 (SPSS, Chicago, IL). $P \leq .05$ was considered to be statistically significant.

RESULTS

Sample Description

Table 1 lists the various characteristics of our sample. Twenty-six percent of participants were bladder cancer survivors, 60% were colorectal cancer survivors, and 14% were leukemia survivors. Approximately half of survivors had more than one comorbidity, and 80% received care from the same physician for more than 2 years. Compared with the eligible nonrespondents, respondents were relatively younger ($P < .001$) and were less likely to be bladder cancer survivors and more likely to be survivors of colorectal cancer or leukemia ($P < .001$). There were no differences between respondents and nonrespondents regarding sex, race/ethnicity, or year of diagnosis (data not shown).

Survivors' Perceptions of Quality of Care

Table 2 lists the percentage of survivors who reported less than optimal quality in response to the 33 APECC items. Reports of suboptimal quality ranged from 4% to 77%. Although only 4% of survivors reported problems with access to specialists, 33% reported that their physician did not always encourage them to ask questions, 59% reported limited or no discussion on health promotion and prevention topics, and 77% indicated that their physician had less than excellent knowledge of them as a person.

Table 3 lists the score distribution for the 10 variables assessing survivors' perceptions of quality of individual aspects of care as well as their overall care ratings. With the exception of the health promotion and physicians' knowledge scales, all scores indicated very positive care experiences.

Correlates of Survivors' Quality Assessments

As shown in Table 4, older survivors, survivors who were married or living as married, survivors who perceived themselves to be in better health, and survivors who had been seeing the same physician for more than 2 years had significantly more positive perceptions of quality on multiple aspects of care. Survivors belonging to minority racial/ethnic subgroups ($P < .001$) and those without private health insurance ($P = .02$) reported worse experiences on timeliness of care. Survivors who received care in a health maintenance organization clinic reported less problems with timeliness of care ($P < .05$) and waiting time ($P < .001$). With the exception of health promotion, survivors' perceptions of quality of care did not vary with type of cancer. Survivors who had multiple comorbidities reported better timeliness of care ($P < .01$) and greater physicians' knowledge ($P = .05$) than those who did not have any comorbidity.

Table 1. Demographics, Clinical Characteristics, and Follow-Up Care–Related Variables of Cancer Survivors

Demographic, Clinical Characteristic, or Follow-Up Care–Related Variable	% of Patients (N = 623)
Age, years	
< 50	15.9
50-64	37.7
65-74	25.8
≥ 75	20.5
Sex	
Male	56.7
Female	43.3
Education	
High school or less	20.9
Some college	31.4
College degree	20.3
Some graduate school/graduate degree	27.5
Race/ethnicity	
Non-Hispanic white	73.8
Hispanic	8.2
Non-Hispanic Asian	10.8
Non-Hispanic other*	7.2
Marital status	
Married/living as married	71.5
Other	28.5
Living in a medically underserved area	
Yes	33.1
No	66.9
Health insurance coverage	
Private insurance	83.6
Government insurance only/none	16.4
Years since diagnosis	
Mean	3.5
Standard deviation	0.7
Type of cancer	
Bladder cancer	26.2
Colorectal cancer	59.6
Leukemia	14.3
No. of comorbidities	
0	22.8
1	27.5
2	22.7
≥ 3	27.0
Remission status	
Yes	84.4
No	15.6
Perceived health status	
Poor	2.9
Fair	13.6
Good	35.9
Very good	35.6
Excellent	11.9
Treatment received	
Surgery only	38.7
Surgery plus chemotherapy or radiation	35.1
Surgery plus chemotherapy and radiation	12.3
Chemotherapy with or without radiation but no surgery	13.9
Length of relationship with physician, years	
< 1	9.2
1-2	10.5
≥ 2	80.4

(continued in next column)

Table 1. Demographics, Clinical Characteristics, and Follow-Up Care–Related Variables of Cancer Survivors (continued)

Demographic, Clinical Characteristic, or Follow-Up Care–Related Variable	% of Patients (N = 623)
No. of physician visits in last 12 months	
1	23.2
2-3	43.4
≥ 4	33.4
Physician specialty	
Primary care	9.3
Oncologist/hematologist	52.6
Other specialists	38.0
Physician sex	
Male	84.1
Female	15.9
Patient-physician sex match	
Yes	58.0
No	42.0
Setting of care	
Doctor's office	47.8
Hospital clinic	29.7
HMO clinic	22.5

Abbreviation: HMO, health maintenance organization.
 *The other category in race/ethnicity consists of non-Hispanic blacks (n = 32), non-Hispanic American Indians or Alaskan natives (n = 12), and non-Hispanic Pacific Islanders (n = 1), who were all grouped together because of small numbers.

Association Between Assessments of Individual Aspects of Care and Overall Ratings

As shown in Table 5, survivors' assessments of the quality of interactions with their physician ($P < .001$), nurses ($P = .05$), and office staff ($P = .001$), as well their perceptions of care coordination ($P < .001$), were significantly associated with their overall ratings of care. The strongest association with overall ratings was observed for information exchange. With the exception of getting needed care, access-related variables were not significantly associated with overall ratings; discussion of health promotion was also not significantly associated with overall ratings.

DISCUSSION

Cancer survivors in our study had positive quality perceptions for many aspects of their follow-up care. However, multiple areas for improvement were also identified. The top five items where survivors reported suboptimal quality were related to physician knowledge and health promotion. More than 60% of survivors reported that their physician lacked complete knowledge of how their quality of life had been affected by their cancer and its treatment, and more than 75% of survivors perceived their physician to have a less than ideal understanding of them as a person. To facilitate optimal patient outcomes, the Institute of Medicine's *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* report³⁴ calls for clinicians to adopt a whole-person orientation while interacting with patients. Survivors in our study perceived this to be an area for improvement. More than 50% of survivors also reported suboptimal discussion of things they could do to maintain healthy lifestyles and prevent future illnesses. Although

Table 2. Survey Items, Response Options, and Survivors Reporting Less Than Optimal Quality of Care

Construct and Item Content*	Response Format	% of Survivors Reporting Suboptimal Quality (N = 623)
Access-related items		
Getting needed care		
How much of a problem, if any, was it to get the follow-up cancer care that you or a doctor believed was necessary?	<i>Not a problem, † a small problem, a big problem</i>	5.3
How much of a problem, if any, was it to see a specialist that you needed to see to get follow-up cancer care?	<i>Not a problem, a small problem, a big problem</i>	4.3
Timeliness of care		
How often did you get an appointment for follow-up cancer care with your doctor as soon as you wanted?	Never, sometimes, usually, <i>always</i>	21.0
When you called your doctor's office or clinic during regular office hours with cancer-related questions, how often did you get the help or advice you needed?	Never, sometimes, usually, <i>always</i>	20.4
Waiting time in physician's office		
How many minutes late did your appointments with your doctor for follow-up cancer care usually begin?	<i>On time, < 15 minutes, 16-30 minutes, 31-45 minutes, > 45 minutes</i>	26.4
When you went to see your doctor for follow-up cancer care, how much of a problem was the wait before you got to see the doctor?‡	<i>Not a problem, a small problem, a big problem</i>	12.9
Physician-specific items		
Information exchange		
How often did your follow-up care doctor listen carefully to you?	Never, sometimes, usually, <i>always</i>	15.5
How often did your follow-up care doctor explain things in a way you could understand?	Never, sometimes, usually, <i>always</i>	19.1
How often did your follow-up care doctor show respect for what you had to say?	Never, sometimes, usually, <i>always</i>	13.3
How often did your follow-up care doctor encourage you to ask all the cancer-related questions you had?‡	Never, sometimes, usually, <i>always</i>	32.5
How often did your follow-up care doctor answer your cancer-related questions to your satisfaction?‡	Never, sometimes, usually, <i>always</i>	22.9
How often did your follow-up care doctor make sure that you understood all the information he or she gave you?‡	Never, sometimes, usually, <i>always</i>	25.7
How often did your follow-up care doctor spend enough time with you?	Never, sometimes, usually, <i>always</i>	26.0
How often did you feel rushed by your follow-up care doctor?‡	Never, sometimes, usually, <i>always</i>	17.3
How often did your follow-up care doctor give you as much cancer-related information as you wanted?‡	Never, sometimes, usually, <i>always</i>	28.2
How often did you leave your follow-up care doctor's office or clinic with unanswered questions related to your cancer?	Never, sometimes, usually, <i>always</i>	17.5
Physicians' affective behavior		
How often did your follow-up care doctor treat you with respect?	Never, sometimes, usually, <i>always</i>	9.6
How often was your follow-up care doctor caring and kind?	Never, sometimes, usually, <i>always</i>	13.0
How often did your follow-up care doctor show a genuine interest in you as a person?‡	Never, sometimes, usually, <i>always</i>	20.5
How often was your follow-up care doctor sensitive to your feelings and emotions?‡	Never, sometimes, usually, <i>always</i>	23.3
Physicians' knowledge		
How would you rate your follow-up care doctor's knowledge of your medical history?	Poor, fair, good, very good, <i>excellent</i>	43.5
How would you rate your follow-up care doctor's knowledge of your responsibilities at home, work, or school?	Poor, fair, good, very good, <i>excellent</i>	76.5
How would you rate your follow-up care doctor's knowledge of how cancer and the medical treatments you received for cancer have affected the quality of your life?‡	Poor, fair, good, very good, <i>excellent</i>	60.8
Health care team items		
Interaction with nurses		
How often did nurses at your follow-up care doctor's office or clinic treat you with courtesy and respect?‡	Never, sometimes, usually, <i>always</i>	17.4
How often were the nurses at your follow-up care doctor's office or clinic as helpful as you thought they should be?‡	Never, sometimes, usually, <i>always</i>	25.9
Interactions with office staff		
How often did office staff at your follow-up care doctor's office or clinic treat you with courtesy and respect?	Never, sometimes, usually, <i>always</i>	23.7
How often was office staff at your follow-up care doctor's office or clinic as helpful as you thought they should be?	Never, sometimes, usually, <i>always</i>	31.7

(continued on following page)

Table 2. Survey Items, Response Options, and Survivors Reporting Less Than Optimal Quality of Care (continued)

Construct and Item Content*	Response Format	% of Survivors Reporting Suboptimal Quality (N = 623)
Health promotion		
Did your follow-up care doctor or someone from your doctor's office or clinic talk with you about specific things you could do to improve your health or prevent illness?	<i>Yes, definitely</i> ; yes, somewhat; no	59.2
Did your follow-up care doctor or someone from your doctor's office or clinic give you the help you wanted to make changes in habits or lifestyle that would improve your health or prevent illness?	<i>Yes, definitely</i> ; yes, somewhat; no	61.2
Coordination of care		
In your opinion, how often did your follow-up care doctor, the nurses, and other staff at your follow-up care doctor's office or clinic seem to work well together as a team?	Never, sometimes, usually, <i>always</i>	28.4
Overall rating of care		
Overall, how would you rate your follow-up care doctor?	0 (worst doctor possible), 2-9, 10 (<i>best doctor possible</i>)	44.4
Based on your interactions with your doctor, nurses, and other staff, how would you rate the quality of care you received from your follow-up care doctor's office or clinic?	Poor, fair, good, very good, <i>excellent</i>	39.5
Would you recommend your follow-up care doctor's office or clinic to your family members and friends if they needed cancer-related care?	<i>Definitely yes</i> , probably yes, not sure, probably not, <i>definitely not</i>	17.0

*All items have a reference period of the last 12 months.

†Any response other than the response in italics was considered suboptimal.

‡Item developed by the Assessment of Patient Experiences of Cancer Care study team.

disease prevention and enhancement of well-being have been identified as essential components of survivorship care,⁴ our data suggest that communication about health promotion during follow-up care visits is limited.

There were several other areas of follow-up care where at least one in four survivors reported suboptimal quality that could be targets for improvement. These included delays in start of appointments, perceived lack of care coordination among the care team, less than ideal help provided by the office staff, and experiences of suboptimal information exchange with the physician. These reports suggest that to deliver optimal follow-up care, quality improvement efforts would need to focus not only on behaviors of individual physicians and health care team members, but also on redesigning

workflow in the office practice to improve efficiency, communication, and coordination.

Consistent with existing studies, older survivors reported more positive experiences, whereas survivors who perceived their health to be poorer reported worse experiences.³⁵ Contrary to our expectations, survivors with more comorbidities reported better timeliness of care and physician knowledge. It is possible that cancer survivors who live with multiple comorbidities have more intense interactions with the health care system, making them more experienced consumers. Support for this assertion is also obtained from our finding that survivors who had more contact with their providers in terms of number of visits also reported more positive experiences on timeliness of care and physician knowledge. It is also possible that given busy practices,

Table 3. Score Distribution of Cancer Survivors' Reports and Rating Scales

Scale	Score		Cronbach's α	% Floor	% Ceiling	Skewness	Kurtosis
	Mean	SD					
Getting needed care	96.9	13.4	.76	1.0	93.2	-5.2	29.2
Timeliness of care	89.2	22.3	.62	2.4	74.4	-2.4	5.3
Waiting time in physician's office	88.2	21.1	.65	0.8	70.4	-1.9	3.2
Information exchange	90.0	15.8	.92	0.0	47.8	-2.2	5.1
Physicians' affective behavior	92.2	17.1	.92	0.3	71.4	-2.9	8.8
Physicians' knowledge	72.1	24.9	.86	0.6	20.1	-0.9	0.1
Interaction with nurses	91.2	16.7	.82	0.0	72.2	-2.1	4.3
Interaction with office staff	88.1	20.5	.90	1.0	66.7	-2.0	3.8
Health promotion	50.7	42.1	.88	33.9	33.4	-0.1	-1.6
Coordination of care*	89.0	19.0	—	0.6	71.6	-1.7	3.1
Overall rating of care	90.4	15.1	.87	0.0	46.8	-2.3	6.0

NOTE: All scores were linearly transformed to a 0 to 100 scale.

Abbreviation: SD, standard deviation.

*Coordination of care was measured by a single item.

Table 4. Adjusted Mean Scores of Survivors' Quality Assessments by Sociodemographic, Clinical, and Follow-Up Care-Related Variables

Variable	Mean Score										Overall Rating of Care
	Getting Needed Care	Timely Care	Waiting Time	Information Exchange	Affective Behavior	Physician Knowledge	Nurses	Office Staff	Health Promotion	Coordination	
Age, years											
< 50	89.7	72.6	78.8	80.7	84.2	62.9	80.8	78.1	48.8	77.6	80.7
50-64	88.1	75.6	86.7	82.8	86.6	59.4	85.0	80.6	49.4	81.7	81.7
65-74	90.1	75.6	92.1	83.0	86.5	62.9	88.4	86.9	46.4	86.0	84.3
≥ 75	91.8	79.5	90.5	87.0	91.4	71.4	91.1	87.8	52.0	89.0	87.1
<i>P</i>	.11	.16	< .001	< .05	< .05	.001	.001	.001	.78	.001	< .01
Education											
High school or less	90.4	75.1	89.0	85.2	87.9	64.1	87.3	83.8	49.7	85.1	83.7
Some college	91.0	76.7	88.2	85.1	89.0	65.9	86.9	84.2	53.9	84.9	84.9
College degree	89.4	75.8	87.4	80.2	83.8	60.4	84.6	83.3	44.9	80.6	81.8
Graduate school	88.9	75.7	83.4	83.0	88.0	66.3	86.5	82.2	48.1	83.7	83.5
<i>P</i>	.47	.93	.10	.04	.07	.20	.65	.85	.36	.25	.41
Race/ethnicity*											
NH white	91.3	81.3	86.5	85.3	88.3	65.2	87.2	84.1	45.9	83.9	85.3
Hispanic	89.7	74.4	85.2	83.4	86.8	65.0	84.7	80.8	53.7	81.9	82.9
NH Asian	91.2	66.4	89.1	81.2	85.2	59.5	84.4	80.4	47.2	82.5	80.6
NH other	87.5	81.2	87.3	83.6	88.5	67.0	89.0	88.1	49.8	86.0	85.1
<i>P</i>	.37	< .001	.77	.24	.57	.35	.45	.22	.71	.74	.10
Marital status											
Married/living as married	91.7	77.8	89.6	85.0	87.2	64.9	87.2	84.7	48.9	84.8	83.5
Other	88.2	73.8	84.4	81.7	87.2	63.5	85.5	82.0	49.4	82.4	83.4
<i>P</i>	< .01	< .05	.01	< .05	.98	.56	.32	.17	.90	.20	.92
Insurance											
Private	91.3	78.8	88.5	83.4	88.3	65.3	86.2	84.6	48.5	83.5	84.1
Government only/none	88.5	72.8	85.5	83.3	86.0	63.0	86.4	82.1	49.8	83.6	82.9
<i>P</i>	.08	.02	.22	.96	.26	.44	.92	.30	.80	.96	.50
Health status											
Poor	93.4	68.6	90.0	73.5	84.5	50.8	82.6	81.0	37.3	77.0	78.6
Fair	87.2	73.9	86.0	82.8	85.1	61.6	84.6	82.1	49.0	81.5	81.8
Good	89.9	75.9	86.0	83.0	85.9	61.5	85.0	84.2	52.2	84.0	82.1
Very good	91.7	81.3	86.5	88.4	89.2	69.6	89.0	83.1	51.8	86.2	87.0
Excellent	87.5	79.5	86.6	89.2	91.2	77.3	90.3	86.6	55.5	89.1	87.9
<i>P</i>	< .05	< .05	.97	< .001	.09	< .001	.07	.67	.68	.08	< .01
Cancer type											
Bladder	89.8	76.4	88.4	83.6	86.8	61.2	85.1	80.7	39.0	82.0	82.8
Colorectal	91.3	74.7	87.1	83.8	87.2	64.1	85.9	83.4	55.4	82.7	83.0
Leukemia	88.7	76.3	85.5	82.6	87.5	67.2	87.9	85.9	53.1	86.1	84.5
<i>P</i>	.24	.65	.62	.84	.96	.21	.52	.17	.001	.30	.70
No. of comorbidities											
0	88.1	71.4	85.9	81.7	85.5	60.7	85.2	81.9	44.2	80.9	81.2
1	89.8	74.2	86.8	83.1	86.0	64.7	86.9	82.8	45.8	85.2	84.5
2	90.7	76.7	88.7	83.0	88.4	62.4	86.0	83.8	52.1	82.9	83.1
≥ 3	91.0	81.0	86.7	85.6	88.8	68.9	87.2	84.9	54.5	85.2	85.2
<i>P</i>	.36	< .01	.76	.27	.33	.05	.78	.71	.22	.22	.15
Length of relationship, years											
< 1	84.7	69.1	81.2	79.0	81.5	60.5	82.6	79.8	42.7	79.6	78.9
1-2	90.4	77.5	91.9	85.5	88.6	65.1	85.6	84.2	58.0	84.2	84.4
≥ 2	94.7	80.8	87.9	85.6	91.2	67.0	90.7	86.9	46.8	86.9	87.1
<i>P</i>	< .001	.001	< .05	< .05	.001	.21	< .01	.05	.14	< .05	.001
No. of visits in last year											
1	89.6	71.6	88.4	82.4	86.7	59.2	85.7	83.7	49.5	84.0	82.1
2-3	90.4	77.8	88.2	82.8	86.4	63.3	85.6	84.5	46.8	82.7	83.4
≥ 4	89.7	78.0	84.4	84.8	88.4	70.0	87.7	81.9	51.2	84.1	85.0
<i>P</i>	.80	.01	.12	.33	.48	.001	.42	.40	.58	.69	.22

(continued on following page)

Table 4. Adjusted Mean Scores of Survivors' Quality Assessments by Sociodemographic, Clinical, and Follow-Up Care-Related Variables (continued)

Variable	Mean Score										Overall Rating of Care
	Getting Needed Care	Timely Care	Waiting Time	Information Exchange	Affective Behavior	Physician Knowledge	Nurses	Office Staff	Health Promotion	Coordination	
Physician sex											
Male	90.6	77.6	86.2	84.1	87.9	67.4	86.5	83.5	52.8	85.4	86.4
Female	89.2	74.0	87.8	82.6	86.5	61.0	86.1	83.2	45.5	81.7	80.6
<i>P</i>	.38	.13	.51	.42	.47	< .05	.86	.90	.16	.10	.001
Patient-physician sex match											
Match	90.5	75.8	86.7	83.7	87.4	66.7	86.5	83.6	52.3	83.6	83.7
No match	89.4	75.8	87.2	83.1	87.0	61.6	86.1	83.2	46.0	83.6	83.3
<i>P</i>	.32	1.00	.77	.66	.79	.02	.77	.84	.10	.97	.74
Setting of care											
Doctor's office	89.5	76.9	86.7	83.0	86.7	64.6	86.1	85.9	43.4	84.3	83.3
Hospital clinic	89.1	72.3	81.6	83.4	88.3	65.1	87.6	82.8	52.0	84.4	83.9
HMO clinic	91.2	78.3	92.7	83.7	86.6	62.8	85.2	81.4	52.0	82.0	83.2
<i>P</i>	.37	< .05	< .001	.91	.58	.72	.50	.08	.07	.50	.90
Model R ²	0.13	0.21	0.14	0.12	0.10	0.16	0.09	0.08	0.07	0.10	0.14

NOTE. Patient sex, residence in a medically underserved area, remission status, and time since diagnosis were not significant in bivariate analyses (*P* > .1) and were not considered for adjusted analyses in the analysis of covariance models. A higher score indicates more positive quality assessments.

Abbreviations: NH, non-Hispanic; HMO, health maintenance organization.

*Race/ethnicity was coded such that any respondent who indicated to be Hispanic was coded as such; whites, Asians, and others represent NH whites, NH Asians, and NH others, respectively. The other group consists of blacks, American Indians, Pacific Islanders, and those who indicated multiple races; they were all grouped together as a result of small numbers.

clinicians tend to selectively pay more attention to their patients who have a greater cumulative disease burden. More studies are needed to disentangle the reasons for the intriguing association between disease burden and patient perceptions of quality.

Consistent with existing studies, Hispanic and non-Hispanic Asian survivors reported worse scores on timeliness of care than non-Hispanic white survivors.^{15,36-38} Given that survivors who did not have private health insurance also reported worse experiences with obtaining timely care suggests the potential for disparities in access to follow-up care between potentially underserved populations of survivors, such as minorities, the uninsured, and the underinsured, and the rest of survivors. Post hoc analysis exploring the interaction effect of

race/ethnicity and insurance status on timeliness of care revealed a nonsignificant interaction, suggesting that being of a minority race/ethnicity and being uninsured or underinsured may be independent risk factors for not receiving timely care. The impact of not receiving timely follow-up care on patient outcomes needs to be explored.

Survivors who had been receiving care from the same physician for more than 2 years reported more positive experiences on all but two quality indicators compared with survivors who knew their physician for less than a year. A longer tenure of the patient-physician relationship may result in better understanding of patient needs by the physician, thus resulting in more positive experiences.³⁹ It is also possible that more positive evaluations among survivors who knew their physician for a longer time are a reflection of a halo effect where survivors are more likely to ignore lapses in quality from a physician with whom they have established a long-term relationship than from one who they do not know well. Length of the patient-physician relationship and quality-of-care perceptions are likely to mutually influence each other, and their relationship can be better teased out within the context of longitudinal study designs.

Perceived quality of information exchange between physicians and survivors had the strongest relationship with overall ratings of care, followed by physicians' affective behavior, physicians' knowledge of the survivor, and survivors' perceptions of coordination of care. These associations further highlight the importance of optimizing the various functions of patient-physician communication as well as communication among the various members of the health care team.⁴⁰ Interestingly, although survivors reported limited communication related to health promotion, such lack of communication did not have any impact on their overall ratings. These findings suggest that although clinicians may not be devoting adequate time during follow-up care visits to facilitating healthy lifestyles among survivors, cancer survivors themselves may not be expecting such discussions.

Table 5. Association of Survivors' Quality Assessment of Individual Aspects of Follow-Up Care With Overall Ratings of Care

Independent Variable	B	SE	95% CI	<i>P</i>
Getting needed care	0.08	0.03	0.02 to 0.14	< .01
Timeliness of care	0.03	0.02	-0.01 to 0.07	.17
Waiting time	0.03	0.02	-0.07 to 0.07	.11
Information exchange	0.25	0.04	0.16 to 0.34	< .001
Affective behavior	0.14	0.04	0.06 to 0.21	< .001
Physician knowledge	0.14	0.02	0.10 to 0.18	< .001
Interaction with nurses	0.06	0.03	0.00 to 0.12	.05
Interaction with office staff	0.09	0.03	0.04 to 0.14	.001
Health promotion	0.00	0.01	-0.02 to 0.02	.98
Coordination of care	0.10	0.03	0.06 to 0.15	< .001

NOTE. Linear regression model controlled for survivors' age, education, race/ethnicity, marital status, insurance status, health status, type of cancer, number of comorbid conditions, length of relationship with physician, number of visits in past year, physician sex, sex match between survivor and physician, and setting of care. Model R² = 0.70.

Abbreviation: B, unstandardized regression coefficient.

Whether survivors' lack of expectation about health promotion discussions might be driven by a lack of awareness of the importance of healthy behaviors to their overall health or is a result of their health promotion needs being met by sources other than their follow-up care physician is not clear and needs further exploration.

Our findings should be interpreted in the light of potential limitations. The most important limitation is the cross-sectional nature of the study. Causal implications cannot be inferred from the significant associations reported in this study; findings need to be replicated within the context of longitudinal study designs. We recruited participants from a population-based sample of leukemia, bladder, and colorectal cancer survivors in Northern California. Our findings may not be generalizable to survivors of other common cancers such as breast and prostate cancer or to survivors in other parts of the United States. Further validation of the APECC measures in other cancer survivor populations is needed. Although we were able to compare the experiences of Hispanic and non-Hispanic Asian survivors with those of non-Hispanic white survivors, we could not do the same for non-Hispanic African American survivors because of the small size of the African American subgroup in our sample.

Despite potential limitations, the APECC study provides unique data on the follow-up care experiences of cancer survivors. With the aging of the population and the dissemination of effective therapeutic interventions in oncology, the ranks of cancer survivors are likely to

increase substantially in the future. Efforts at optimizing quality of care delivered to these survivors in the future should focus not only on the technical aspects but also on the patient-centered aspects of care. The APECC study lays the foundation for systematic evaluations of patient-centeredness of follow-up care provided to cancer survivors in the United States.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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

AUTHOR CONTRIBUTIONS

Conception and design: Neeraj K. Arora, Bryce B. Reeve, Ingrid Oakley-Girvan

Financial support: Steven B. Clauser

Provision of study materials or patients: Ingrid Oakley-Girvan

Collection and assembly of data: Ingrid Oakley-Girvan

Data analysis and interpretation: Neeraj K. Arora, Bryce B. Reeve, Ron D. Hays, Steven B. Clauser

Manuscript writing: Neeraj K. Arora, Bryce B. Reeve, Ron D. Hays, Steven B. Clauser, Ingrid Oakley-Girvan

Final approval of manuscript: Neeraj K. Arora, Bryce B. Reeve, Ron D. Hays, Steven B. Clauser, Ingrid Oakley-Girvan

REFERENCES

- Rowland JH, Hewitt M, Ganz PA: Cancer survivorship: A new challenge in delivering quality cancer care. *J Clin Oncol* 24:5101-5104, 2006
- Stanton AL: Psychosocial concerns and interventions for cancer survivors. *J Clin Oncol* 24:5132-5137, 2006
- Demark-Wahnefried W, Pinto BM, Gritz ER: Promoting health and physical function among cancer survivors: Potential for prevention and questions that remain. *J Clin Oncol* 24:5125-5131, 2006
- Hewitt M, Greenfield S, Stovall E (eds): *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC, The National Academies Press, 2006
- President's Cancer Panel: *Living Beyond Cancer: Finding a New Balance*. Bethesda, MD, National Cancer Institute, 2004
- Ayanian JZ, Jacobsen PB: Enhancing research on cancer survivors. *J Clin Oncol* 24:5149-5153, 2006
- Oeffinger KC, McCabe MS: Models for delivering survivorship care. *J Clin Oncol* 24:5117-5124, 2006
- Grunfeld E, Mant D, Yudkin P, et al: Routine follow up of breast cancer in primary care: Randomised trial. *BMJ* 313:665-669, 1996
- Grunfeld E, Levine MN, Julian JA, et al: Randomized trial of long-term follow-up for early-stage breast cancer: A comparison of family physician versus specialist care. *J Clin Oncol* 24:848-855, 2006
- Haggstrom DA, Arora NK, Helft P, et al: Follow-up care delivery among colorectal cancer survivors most often seen by primary and subspecialty care physicians. *J Gen Intern Med* 24:472-479, 2009 (suppl 2)
- Smith TJ, Davidson NE, Schapira DV, et al: American Society of Clinical Oncology 1998 update

of recommended breast cancer surveillance guidelines. *J Clin Oncol* 17:1080-1082, 1999

12. Desch CE, Benson AB 3rd, Somerfield MR, et al: Colorectal cancer surveillance: 2005 update of an American Society of Clinical Oncology practice guideline. *J Clin Oncol* 23:8512-8519, 2005

13. Earle CC: Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *J Clin Oncol* 24:5112-5116, 2006

14. Arora NK: Importance of patient-centered care in enhancing patient well-being: A cancer survivor's perspective. *Qual Life Res* 18:1-4, 2009

15. Ayanian JZ, Zaslavsky AM, Guadagnoli E, et al: Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *J Clin Oncol* 23:6576-6586, 2005

16. Teno JM, Lima JC, Lyons KD: Cancer patient assessment and reports of excellence: Reliability and validity of advanced cancer patient perceptions of the quality of care. *J Clin Oncol* 27:1621-1626, 2009

17. Brédart A, Razavi D, Robertson C, et al: A comprehensive assessment of satisfaction with care: Preliminary psychometric analysis in French, Polish, Swedish and Italian oncology patients. *Patient Educ Couns* 43:243-252, 2001

18. Brédart A, Coens C, Aaronson N, et al: Determinants of patient satisfaction in oncology settings from European and Asian countries: Preliminary results based on the EORTC IN-PATSAT32 questionnaire. *Eur J Cancer* 43:323-330, 2007

19. Wiggers JH, Donovan KO, Redman S, et al: Cancer patient satisfaction with care. *Cancer* 66:610-616, 1990

20. Snyder CF, Earle CC, Herbert RJ, et al: Preventive care for colorectal cancer survivors: A 5-year longitudinal study. *J Clin Oncol* 26:1073-1079, 2008

21. Snyder CF, Earle CC, Herbert RJ, et al: Trends in follow-up and preventive care for colorectal cancer survivors. *J Gen Intern Med* 23:254-259, 2008

22. Earle CC, Neville BA: Under use of necessary care among cancer survivors. *Cancer* 101:1712-1719, 2004

23. Earle CC, Burstein HJ, Winer EP, et al: Quality of non-breast cancer health maintenance among elderly breast cancer survivors. *J Clin Oncol* 21:1447-1451, 2003

24. Hays RD, Shaul JA, Williams VS, et al: Psychometric properties of the CAHPS 1.0 survey measures: Consumer Assessment of Health Plans Study. *Med Care* 37:MS22-MS31, 1999 (suppl 3)

25. Solomon LS, Hays RD, Zaslavsky AM, et al: Psychometric properties of a group-level Consumer Assessment of Health Plans Study (CAHPS) instrument. *Med Care* 43:53-60, 2005

26. Hargraves JL, Hays RD, Cleary PD: Psychometric properties of the Consumer Assessment of Health Plans Study (CAHPS) 2.0 adult core survey. *Health Serv Res* 38:1509-1527, 2003

27. Hays RD, Chong K, Brown J, et al: Patient reports and ratings of individual physicians: An evaluation of the DoctorGuide and Consumer Assessment of Health Plans provider-level surveys. *Am J Med Qual* 18:190-196, 2003

28. Safran DG, Kosinski M, Tarlov AR, et al: The Primary Care Assessment Survey: Tests of data quality and measurement performance. *Med Care* 36:728-739, 1998

29. Murphy J, Chang H, Montgomery JE, et al: The quality of physician-patient relationships: Patients' experiences 1996-1999. *J Fam Pract* 50:123-129, 2001

30. Montgomery JE, Irish JT, Wilson IB, et al: Primary care experiences of Medicare beneficiaries, 1998 to 2000. *J Gen Intern Med* 19:991-998, 2004

31. Safran DG, Karp M, Coltin K, et al: Measuring patients' experiences with individual primary care physicians: Results of a statewide demonstration project. *J Gen Intern Med* 21:13-21, 2006

32. Sequist TD, Schneider EC, Anastario M, et al: Quality monitoring of physicians: Linking patients'

experiences of care to clinical quality and outcomes. *J Gen Intern Med* 23:1784-1790, 2008

33. Hu L, Bentler PM: Cutoff criteria for fit indices in covariance structure analysis: Conventional criteria versus new alternatives. *Struct Equ Modeling* 6:1-55, 1999

34. Adler NE, Page AEK (eds): *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC, The National Academies Press, 2008

35. Hargraves JL, Wilson IB, Zaslavsky A: Adjusting for patient characteristics when analyzing re-

ports from patients about hospital care. *Med Care* 39:635-641, 2001

36. Ngo-Metzger Q, Legeza AT, Phillips RS: Asian Americans' reports of their health care experiences: Results of a national survey. *J Gen Intern Med* 19:111-119, 2004

37. Weech-Maldonado R, Morales LS, Elliott M, et al: Race/ethnicity, language, and patients' assessments of care in Medicaid managed care. *Health Serv Res* 38:789-808, 2003

38. Morales LS, Elliott MN, Weech-Maldonado R, et al: Differences in CAHPS adult survey reports and

ratings by race and ethnicity: An analysis of the National CAHPS benchmarking data 1.0. *Health Serv Res* 36:595-617, 2001

39. van Walraven C, Oake N, Jennings A, et al: The association between continuity of care and outcomes: A systematic and critical review. *J Eval Clin Pract* 16:947-956, 2010

40. Epstein RM, Street RL Jr: *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD, National Cancer Institute, NIH publication 07-6225, 2007



Journal of Oncology Practice Now Available on PubMed Central

Beginning with the January 2010 issue, full text for all *JOP* articles will be available on the NIH PubMed Central archive 4 months after publication. Once available, content is then delivered to PubMed, a metadata repository overseen by the National Library of Medicine and used by many scientific, technical, and medical researchers, making *JOP* material discoverable in PubMed for the first time.

Find yourself in PubMed. Submit your manuscript to *JOP* at jop.msubmit.net.



American Society of Clinical Oncology