Racial and Ethnic Disparities in Patient-Provider Communication, Quality-of-Care Ratings, and Patient Activation Among Long-Term Cancer Survivors

Nynikka R.A. Palmer, Erin E. Kent, Laura P. Forsythe, Neeraj K. Arora, Julia H. Rowland, Noreen M. Aziz, Danielle Blanch-Hartigan, Ingrid Oakley-Girvan, Ann S. Hamilton, and Kathryn E. Weaver

Nynikka R.A. Palmer, San Francisco General Hospital, University of California, San Francisco, San Francisco; Ingrid Oakley-Girvan, Cancer Prevention Institute of California, Fremont; Ann S. Hamilton, Keck School of Medicine, University of Southern California, Los Angeles, CA; Erin E. Kent, Neeraj K. Arora, Julia H. Rowland, Danielle Blanch-Hartigan, National Cancer Institute, National Institutes of Health; Noreen M. Aziz, National Institute of Nursing Research, National Institutes of Health, Bethesda, MD; Laura P. Forsythe, Patient-Centered Outcomes Research Institute, Washington, DC; and Kathryn E. Weaver, Wake Forest School of Medicine, Winston-Salem, NC.

Published online ahead of print at www.jco.org on November 17, 2014.

Supported by National Cancer Institute Contracts and Grants No. N01-PC-35136, N01-PC-35139, HHSN 261201100189P, and R25-CA-122061.

Terms in blue are defined in the glossary, found at the end of this article and online at www.jco.org.

Findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Cancer Institute, National Institute of Nursing Research, or the Patient-Centered Outcomes Research Institute.

Authors' disclosures of potential conflicts of interest are found in the article online at www.jco.org. Author contributions are found at the end of this article.

Corresponding author: Nynikka R.A. Palmer, DrPH, MPH, Department of Medicine, Division of General Internal Medicine, University of California, San Francisco, Bldg 10, Ward 13, San Francisco, CA 94110; e-mail: palmer@medsfgh.ucsf.edu.

© 2014 by American Society of Clinical Oncology

0732-183X/14/3236w-4087w/\$20.00

DOI: 10.1200/JCO.2014.55.5060

ABSTRACT

Purpose

We examined racial and ethnic disparities in patient-provider communication (PPC), perceived care quality, and patient activation among long-term cancer survivors.

Methods

In 2005 to 2006, survivors of breast, prostate, colorectal, ovarian, and endometrial cancers completed a mailed survey on cancer follow-up care. African American, Asian/Pacific Islander (Asian), Hispanic, and non-Hispanic white (white) survivors who had seen a physician for follow-up care in the past 2 years ($n = 1,196$) composed the analytic sample. We conducted linear and logistic regression analyses to identify racial and ethnic differences in PPC (overall communication and medical test communication), perceived care quality, and patient activation in clinical care (self-efficacy in medical decisions and perceived control). We further examined the potential contribution of PPC to racial and ethnic differences in perceived care quality and patient activation.

Results

Compared with white survivors (mean score, 85.16), Hispanic (mean score, 79.95) and Asian (mean score, 76.55) survivors reported poorer overall communication ($P = .04$ and $P < .001$, respectively), and Asian survivors (mean score, 79.97) reported poorer medical test communication ($P = .001$). Asian survivors were less likely to report high care quality (odds ratio, 0.47; 95% CI, 0.30 to 0.72) and reported lower self-efficacy in medical decisions (mean score, 74.71; $P < .001$) compared with white survivors (mean score, 84.22). No disparity was found in perceived control. PPC was positively associated with care quality ($P < .001$) and self-efficacy ($P < .001$). After adjusting for PPC and other covariates, when compared with whites, Asian disparities remained significant.

Conclusion

Asian survivors report poorer follow-up care communication and care quality. More research is needed to identify contributing factors beyond PPC, such as cultural influences and medical system factors.

J Clin Oncol 32:4087-4094. © 2014 by American Society of Clinical Oncology

INTRODUCTION

Patient-provider communication (PPC) is a key factor affecting health care quality for post-treatment cancer survivors in the United States.¹ Key functions of PPC include exchanging information, fostering healing relationships, making medical decisions, and enabling patient self-management.^{1,2} Effective PPC helps survivors cope with their illness, comprehend health information, communicate with multiple providers, and engage in their own health care.¹ Studies of cancer survivors have found PPC to be positively associated with survivors' ratings of and satisfaction with care.³⁻⁵

Effective PPC has also been shown to facilitate patient activation in health care.^{1,6,7} Patient activation, defined by Hibbard et al, entails patients "understanding their role in their health care, and having the knowledge, skills, and confidence to take on that role."^{8(p216)} Activated patients are more likely to be engaged in improving and maintaining their health^{9,10} by confidently communicating with health care providers, making decisions, and using their knowledge, skills, and belief they have control over their life. Mechanisms to facilitate patient activation include improving survivors' confidence to manage their health (ie, self-efficacy) and enhancing the extent to which they feel their personal actions

Fig 1. Conceptual framework for associations between race/ethnicity, patient-provider communication, quality-of-care rating, and patient activation.

can affect their health (ie, perceived control). Previous cross-sectional studies of cancer survivors show a positive association between effective PPC and survivors' self-efficacy in interacting with providers,⁷ as well as higher perceived control.⁶ High-quality care facilitating patient activation may promote survivors' psychosocial adjustment and optimal postcancer health.¹¹⁻¹⁴

Studies of cancer survivors reveal racial/ethnic disparities in PPC¹⁵⁻¹⁸ and perceived care quality.^{3,19-21} Studies of the general population have also found racial/ethnic disparities in patient activation, specifically patients' ability and willingness to manage their health and health care²² and their perceived control.²³ To date, our understanding of these constructs among survivors is limited by a focus on newly diagnosed survivors^{15,16,18-21} or those who recently completed treatment¹⁷ and comparisons between whites and African Americans,^{15-17,22,23} with few studies including Hispanics and Asian/Pacific Islanders.^{3,19-21} To address this gap, this study used a diverse sample of long-term cancer survivors to examine racial/ethnic disparities in survivors' perceived PPC during follow-up care, their ratings of follow-up care quality, and their perceptions of activation in clinical care; assess whether PPC is associated with survivors' ratings of follow-up care quality and activation in their care; and determine whether racial/ethnic disparities in care quality and patient activation are independent of potential disparities in PPC (Fig 1). As consistent with prior studies,^{19,21,24} we hypothesized that nonwhite survivors would perceive poorer quality of care and that PPC would at least partially account for these differences.

METHODS

Data Source and Sample Population

We used cross-sectional survey data from the Follow-Up Care Use Among Survivors (FOCUS) study, a population-based study of 1,666 long-term cancer survivors conducted in March 2005 through July 2006, with a response rate of 56%.^{25,26} Eligible survivors were diagnosed with breast, prostate, colorectal, ovarian, or endometrial cancer; age 21 years or older at diagnosis; 4 to 14 years after diagnosis at survey completion; and able to read English. The survey was available in English only. Cancer survivors were randomly sampled from the Los Angeles and Greater San Francisco Bay Area Surveillance, Epidemiology, and End Results (SEER) cancer registries and stratified by cancer type, race/ethnicity, current age (≤ 64 and ≥ 65 years), and time since diagnosis (4 to 9 years and 10 to 14 years). African Americans, Hispanics, and Asian/Pacific Islanders (Asian) were oversampled.

Cancer survivors who reported visiting a physician for cancer-related follow-up care in the past 2 years ($n = 1,215$, 72.9%) composed our study sample. We excluded American Indian/Alaska natives ($n = 18$) because of the small cell sizes and one individual missing race/ethnicity, resulting in a final

analytic sample of 1,196 cancer survivors. Survivors excluded and ineligible as a result of missing information were more likely to be unmarried ($P < .001$), have less education ($P = .014$), and have no or public health insurance only ($P < .001$), and less likely to have had chemotherapy, radiation, and adjuvant therapy ($P < .001$).

Survey data were supplemented with SEER registry data if information was missing (eg, race/ethnicity, cancer stage and treatment). Previous publications provide additional methodologic details.²⁵⁻²⁷ Approval for the study was obtained from the institutional review boards at the University of Southern California (Los Angeles, CA) and the Cancer Prevention Institute of California (Fremont, CA).

Measures

Measures used in this analysis were adapted by the FOCUS team from previous studies of cancer survivors' follow-up care experiences^{3,11,28} (<http://outcomes.cancer.gov/surveys/apeccl/>) and are described in the following sections.

PPC. PPC consisted of measures for overall communication and communication about medical tests, both assessed on a 4-point scale (never to always). Instrument means were rescaled to a 0 to 100 score. Higher scores indicated better communication.

Overall communication consisted of the following eight questions adapted from a previous survey assessing physician-specific items on information exchange³: "In the past 2 years, how often did you your cancer-related follow-up care physician(s): (a) listen carefully to you, (b) explain things in a way you could understand, (c) show respect for what you had to say, (d) encourage you to ask all the cancer-related questions you had, (e) make sure that you understood all the information he or she gave you, (f) spend enough time with you, (g) give you as much cancer-related information as you wanted, and (h) involve you in decisions about your medical care as much as you wanted?" Cronbach's α was $\geq .98$ for each race/ethnicity group.

Survivors whose follow-up care physician ordered a test in the last 2 years ($n = 822$) were asked the following three questions²⁸: "In the past 2 years, when your cancer-related follow-up care physician(s) ordered any medical tests: (a) how often was the need for or purpose of these tests explained to you in a way you could understand, (b) how often did you get the test results in a timely manner, and (c) how often were the test results explained to you in a way you could understand?" Cronbach's α was $\geq .80$ for each race/ethnicity group, except Hispanics ($\alpha = .74$).

Perceived quality of care. We assessed survivors' ratings of the quality of follow-up care received in the last 2 years using a single overall rating of care item.^{3,19,29} Responses were assessed on a 5-point response scale (poor to excellent). We dichotomized responses because of the negatively skewed distribution of responses (poor/fair/good v very good/excellent).

Patient activation. We assessed patient activation using self-efficacy in medical decisions and perceived control, which have been used previously to measure aspects of patient activation.^{22,30} The five-item Decision-Making Participation Self-Efficacy Scale¹¹ assessed survivors' confidence in engaging in communication activities with the physician related to medical decision making, including taking part in discussing available options. Responses were assessed on a 5-point response scale (not at all confident to completely confident). Cronbach's α exceed .95 for each race/ethnicity group.

The four-item Perceived Personal Control Scale¹¹ assessed survivors' perception of their control over cancer-related care and outcomes, such as the kind of follow-up care they receive. Responses were assessed on a 5-point response scale (no control at all to complete control). Cronbach's α was $\geq .83$ for all groups except Hispanics ($\alpha = .71$). Mean scores for both scales were transformed to a 0 to 100 scale, where higher scores indicate more self-efficacy and control.

Sociodemographic, clinical, and follow-up care-related factors. Survivors self-reported their race as American Indian or Alaska native, Asian, black or African American, native Hawaiian/other Pacific Islander, or white. Separately, survivors indicated if they considered themselves to be Hispanic or Latino. Missing information on race/ethnicity was supplemented with SEER registry data ($n = 77$). We categorized race/ethnicity into non-Hispanic black (African American), non-Hispanic Asian or Pacific Islander (Asian), Hispanic/Latino, and non-Hispanic white (white).

We examined several other sociodemographic and clinical variables to adjust for potential confounding, including age, sex, education, and health insurance (none, public only, and private/with or without Medicare). We included self-reported comorbidities (none, one, two, or $\geq$ three comorbidities) of ever having been diagnosed with arthritis, diabetes, chronic lung disease, congestive heart failure, hypertension, myocardial infarction, angina, stroke, inflammatory bowel disease, liver disease, and deep venous thrombosis. Cancer treatment was also self-reported (yes or no for surgery, chemotherapy, radiation, and adjuvant hormonal therapy). We categorized time since diagnosis as 4 to 9 years and 10 to 14 years based on year of diagnosis from the cancer registry data and the timing of the completion of the survey. Registry-reported American Joint Committee on Cancer/Union for International Cancer Control TNM stage at diagnosis was categorized into four groups (in situ and I, II, III and IV, and unstaged). Unstaged primarily included patients with prostate cancer. Three additional follow-up care–related variables were also assessed, including the number of visits for cancer-related follow-up care in the last 2 years (≤ 2 visits or ≥ 3 visits), length of relationship with main follow-up care physician (≤ 2 , 3 to 4, or ≥ 5 years), and whether the main follow-up care physician was the same physician seen for cancer treatment (yes or no).

Statistical Analysis

Data were analyzed using SPSS 21 (SPSS, Chicago, IL), and all tests of statistical significance were two-sided with the $P = .05$. We conducted unweighted analyses, because our focus was on associations among variables rather than estimation of population parameters.³¹ The percentage of survivors with missing data ranged from 1.1% to 4.3% for each variable, and only survivors with complete data were included in analyses; therefore, unadjusted and adjusted models vary in sample size. We summarized sociodemographic, clinical, and follow-up care–related variables, stratified by racial/ethnic group, and tested differences between the racial/ethnic groups using the χ^2 statistic for categorical variables and analysis of variance for continuous variables (Table 1).

We conducted a series of linear regression analyses and logistic regression analyses, including Tukey post hoc and simple contrast tests, to examine racial/ethnic disparities in PPC (overall communication and communication about medical tests), quality-of-care rating, and patient activation (self-efficacy and perceived control), both unadjusted and adjusted for the sociodemographic, clinical, and follow-up care–related factors described earlier (Table 2). We then conducted a series of individual linear and logistic regression models to examine the association between PPC and ratings of follow-up care, self-efficacy in medical decisions, and perceived control. Finally, we used logistic and linear regression models to determine whether racial/ethnic differences in quality-of-care rating and patient activation were present after accounting for PPC, sociodemographic, clinical, and follow-up care factors (Tables 3 and 4). The sample sizes vary between the regression models (Table 2) and full models that include PPC as a covariate (Tables 3 and 4) as a result of missing data for all covariates. Therefore, respondents with missing data on PPC were excluded from the models presented in Tables 3 and 4.

RESULTS

Sample Characteristics

Study population characteristics, stratified by race/ethnicity, are listed in Table 1. The analytic sample ($n = 1,196$) consisted of 25% African American, 23% Asian, 13% Hispanic, and 39% white survivors. The average age of the overall sample was 68.9 years (± 11.0 years). A large proportion of survivors were college educated, privately insured, and had at least one noncancer comorbidity. Significant racial/ethnic differences were noted by sex, education, insurance, cancer site, surgery, chemotherapy, and length of relationship with follow-up care physician (Table 1). Hispanic survivors were more likely to be male and have less education, no

insurance, and prostate cancer and were less likely to have breast cancer or receive chemotherapy compared with white survivors. African American survivors were less likely to have private insurance and to have undergone surgery compared with white survivors. Asian and Hispanic survivors were less likely to have a relationship with their follow-up care physician for 5 or more years.

Racial/Ethnic Differences in PPC, Quality-of-Care Ratings, and Patient Activation

In adjusted analysis, racial/ethnic differences were identified in PPC (overall communication and medical test communication), follow-up care ratings, and one indicator of patient activation (self-efficacy in medical decisions; Table 2). Both Asian (mean score, 76.55) and Hispanic (mean score, 79.95) survivors reported significantly lower overall communication scores compared with white survivors (mean score, 85.16; $P < .001$ and $P = .040$, respectively). Asian survivors' overall communication scores were also significantly lower compared with African American survivors' scores (mean score, 83.63; $P = .002$). Only Asian survivors reported significantly lower scores in medical test communication compared with white survivors (mean score, 79.97 v 88.03, respectively; $P = .001$). Asian survivors were also less likely than white survivors to rate their follow-up care as very good/excellent (odds ratio, 0.47; 95% CI, 0.30 to 0.72). Compared with all racial/ethnic groups, Asian survivors reported significantly lower self-efficacy in medical decisions ($P < .001$). No racial/ethnic differences were identified in perceived control scores.

Racial/Ethnic Disparities in Quality-of-Care Ratings and Patient Activation, Accounting for PPC

Both indicators of PPC, overall communication and medical test communication, were significantly associated with quality-of-care ratings ($P < .001$ and $P = .001$, respectively) and self-efficacy in medical decisions ($P < .001$ and $P = .004$, respectively) in fully adjusted models. Racial/ethnic differences in quality-of-care ratings (Table 3) and self-efficacy in medical decisions (Table 4) were observed after adjusting for PPC and other covariates. Asian survivors remained less likely than white survivors to report high-quality care (odds ratio, 0.50; 95% CI, 0.27 to 0.91; Table 3). Similarly, Asian survivors reported significantly lower self-efficacy in medical decisions compared with white survivors (unstandardized regression coefficient, $\beta = -4.813$, $P = .006$), despite adjusting for PPC (Table 4). We did not model perceived control because there were no racial/ethnic disparities identified in unadjusted or adjusted analyses.

DISCUSSION

Building on prior work focused on survivors in treatment or early after treatment,^{3,19,20,28,32} this study examined racial/ethnic disparities in PPC, quality-of-care ratings, and patient activation among a racially and ethnically diverse sample of survivors 4 to 14 years after diagnosis. We observed that Asian and Hispanic survivors report worse PPC compared with white survivors and Asian survivors report worse PPC compared with African American survivors. Both African American and Asian survivors report poorer quality-of-care ratings compared with white survivors; however, this disparity attenuated for African American survivors after

Table 1. Sociodemographic, Clinical, and Follow-Up Care–Related Characteristics of Long-Term Cancer Survivors by Race/Ethnicity

Characteristic	Total (n = 1,196)		African American (n = 294)		Asian/Pacific Islander (n = 272)		Hispanic (n = 161)		Non-Hispanic White (n = 469)		P*
	No. of Survivors	%	No. of Survivors	%	No. of Survivors	%	No. of Survivors	%	No. of Survivors	%	
Age, years											.070
Mean	68.9		68.8		67.6		70.3		69.4		
Range	31-93		36-89		34-87		31-87		32-93		
Sex											< .001
Male	469	39.2	129	43.9	108	39.7	82	50.9	150	32.0	
Female	727	60.8	165	56.1	164	60.3	79	49.1	319	68.0	
Education											< .001
< High school	106	9.0	29	10.0	12	4.5	49	30.8	16	3.4	
High school/GED	197	16.7	46	15.9	36	13.5	36	22.6	79	16.9	
Some college	413	34.9	121	41.9	83	31.2	45	28.3	164	35.0	
≥ College graduate	466	39.4	93	32.2	135	50.8	29	18.2	209	44.7	
Insurance											< .001
None	22	1.9	8	2.8	4	1.5	6	3.9	4	0.9	
Public	213	18.5	76	26.9	53	20.0	31	20.0	53	11.8	
Private	916	79.6	199	70.3	208	78.5	118	76.1	391	87.3	
No. of comorbidities											.125
0	220	18.4	43	14.6	58	21.3	29	18.0	90	19.2	
1	321	26.8	66	22.4	74	27.2	45	28.0	136	29.0	
2	293	24.5	79	26.9	58	21.3	38	23.6	118	25.2	
≥ 3	362	30.3	106	36.1	82	30.1	49	30.4	125	26.7	
Cancer site											< .001
Breast	310	25.5	75	25.5	77	28.3	27	16.8	126	26.9	
Prostate	332	27.3	88	29.9	70	25.7	68	42.2	97	20.7	
Colon/rectal	291	24.0	79	26.9	70	25.7	34	21.1	107	22.8	
Ovarian	166	13.7	14	4.8	31	11.4	18	11.2	99	21.1	
Endometrial	116	9.5	38	12.9	24	8.8	14	8.7	40	8.5	
Stage at diagnosis											.073
In situ or stage I	493	40.6	119	40.5	110	40.4	58	36.0	201	42.9	
Stage II	306	25.2	70	23.8	70	25.7	41	25.5	122	26.0	
Stage III or IV	272	22.4	63	21.4	66	24.3	32	19.9	105	22.4	
Unstaged	144	11.9	42	14.3	26	9.6	30	18.6	41	8.7	
Time since diagnosis, years											.542
4-9	684	57.2	168	57.1	165	60.7	87	54.0	264	56.3	
10-14	512	42.8	126	42.9	107	39.3	74	45.0	205	43.7	
Treatment											
Surgery	1,040	85.6	240	82.8	229	87.1	134	84.8	423	91.6	.003
Chemotherapy	507	41.7	114	39.4	121	45.7	53	33.3	212	45.9	.020
Radiation	466	38.4	120	41.2	98	36.8	54	33.5	185	40.1	.337
Adjuvant	1,184	97.4	82	28.6	72	27.2	34	21.8	128	28.0	.436
No. of visits for follow-up care											.909
≤ 2	481	42.0	123	43.5	107	41.2	61	40.1	190	42.1	
≥ 3	665	58.0	160	56.5	153	58.5	91	59.9	261	57.9	
Length of relationship with follow-up care physician, years											.010
≤ 2	132	12.1	32	11.9	39	16.3	21	14.4	40	9.2	
3-4	266	24.4	66	27.5	66	27.5	42	28.8	92	21.1	
≥ 5	693	63.5	171	63.6	135	56.3	83	56.8	304	69.7	
Same physician seen for cancer treatment											.198
No	459	43.5	117	45.5	85	37.3	64	46.0	193	44.8	
Yes	596	56.5	140	54.5	143	62.7	75	54.0	238	55.2	

Abbreviation: GED, General Educational Development.

*Racial/ethnic differences were analyzed using χ^2 statistics for categorical variables and analysis of variance for continuous variables. Analyses are not weighted.

adjustments, whereas it persisted for Asian survivors. Asian survivors also report less confidence in engaging in medical decisions compared with all other racial/ethnic groups, and this disparity persisted after accounting for PPC.

Current findings provide some support for our hypothesis that nonwhite survivors would perceive poorer quality care and that PPC would at least partially account for these differences; however, questions remain regarding the persistent disparity among Asian survivors.

Table 2. Racial/Ethnic Differences in Patient-Provider Communication, Quality-of-Care Ratings, and Patient Activation

Race/Ethnicity	Patient-Provider Communication				Patient Activation					
	Overall Communication*		Medical Tests†		Quality of Care‡		Self-Efficacy in Medical Decisions§		Perceived Control	
	Mean Score	SE	Mean Score	SE	Odds Ratio	95% CI	Mean Score	SE	Mean Score	SE
Unadjusted										
<i>P</i>	< .001		.002		< .001		< .001		.288	
African American	82.53	1.49	82.67	1.92	0.55	0.38 to 0.79	82.08	1.11	60.30	1.25
Asian/Pacific Islander	75.16	1.67	79.91	1.87	0.43	0.30 to 0.62	73.14	1.35	60.44	1.40
Hispanic	77.50	2.21	83.13	2.31	0.69	0.44 to 1.09	80.03	1.66	64.02	1.76
Non-Hispanic white	85.42	0.97	87.65	1.09	Reference	—	83.23	0.84	61.33	0.90
Total	81.34	0.73	84.17	0.82	—	—	80.24	0.59	61.25	0.61
Adjusted										
<i>P</i>	< .001		.005		.004		< .001		.825	
African American	83.63	1.56	84.01	1.80	0.69	0.45 to 1.08	82.76	1.24	62.34	1.39
Asian/Pacific Islander	76.55	1.68	79.97	1.88	0.47	0.30 to 0.72	74.71	1.33	60.66	1.51
Hispanic	79.95	2.22	82.81	2.49	1.00	0.56 to 1.80	83.61	1.75	61.36	1.97
Non-Hispanic white	85.16	1.21	88.03	1.34	Reference	—	84.22	0.96	60.83	1.08
Total	81.32	0.83	83.70	0.94	—	—	81.34	0.66	61.30	0.74

NOTE. Adjusted analysis was adjusted for sociodemographics (age, sex, education, and health insurance), clinical characteristics (comorbidities, stage at diagnosis, time since diagnosis, and treatment), and follow-up care–related factors (number of visits for cancer-related follow-up care, length of relationship with main follow-up care physician, and whether main follow-up care physician was the same physician seen for cancer treatment). Sample sizes vary between unadjusted and adjusted analyses as a result of respondents having missing covariates and being excluded from the final models. Sample sizes for overall communication, quality of care, self-efficacy, and perceived control ranged from 1,124 to 1,174 survivors for unadjusted analysis and 905 to 920 survivors for adjusted analysis. Medical tests sample size was 812 survivors for unadjusted analysis and 690 survivors for adjusted analysis. Analyses are not weighted.

*Overall follow-up care communication score = 0 to 100 points. Adjusted model: Asian v white, $P < .001$; Hispanic v white, $P = .040$; Asian v African American, $P = .002$.

†Explanation of medical tests score = 0 to 100 points. Adjusted model: Asian v white, $P = .001$.

‡Excellent/very good overall rating of quality of care.

§Self-efficacy in medical decision making score = 0 to 100 points. Adjusted model: Asian v white, $P < .001$; Asian v Hispanic, $P < .001$; Asian v African American, $P < .001$.

||Perceived control score = 0 to 100 points.

Previous studies have reported Asian disparities in PPC and quality-of-care ratings among the general population^{24,33-35} and newly diagnosed/treated survivors.²⁰ However, to our knowledge, this is the first study to report this disparity among long-term cancer survivors and self-efficacy in medical decisions. These findings are important because Asians are one of the fastest growing ethnic minority groups in the United States.

For Asians, previous experiences across the health care system,^{36,37} poorer continuity of care,^{36,38} expectations,³⁸⁻⁴⁰ sociocultural orientation,^{38,40,41} and response style/measurement limita-

tions^{38,40,42} may contribute to the observed disparities. For example, Chinese patients trust and respect physicians as the authority and may not ask questions or question the physician, which can leave these patients with unmet needs and can ultimately have an impact on their perceived care quality.⁴⁰ A qualitative study observed quiet acceptance among South Asian survivors of breast cancer, manifested as appearance of being passive, uninvolved in their own care, and accepting of their fate (eg, karma).⁴³ This study also found that individualized follow-up care plans are salient and amendable to Asian women and may help them overcome barriers to quality care.⁴³ In addition,

Table 3. Adjusted Models of Racial/Ethnic Differences in Quality-of-Care Ratings

Model (variables)	African American		Asian/Pacific Islander		Hispanic		Likelihood Ratio Tests*
	OR	95% CI	OR	95% CI	OR	95% CI	
1 (race/ethnicity)	0.54	0.33 to 0.89†	0.39	0.24 to 0.64†	0.62	0.34 to 1.15	—
2 (race/ethnicity + covariates)‡	0.57	0.34 to 0.96†	0.37	0.22 to 0.62†	0.76	0.39 to 1.48	.024
3 (race/ethnicity + covariates + PPC)§	0.61	0.33 to 1.15	0.50	0.27 to 0.91†	1.09	0.49 to 2.43	< .001

NOTE. Comparisons were made to non-Hispanic white. Two hundred thirty-six respondents had missing data with the inclusion of PPC and were excluded from this analysis but were included in analyses presented in Table 2.

Abbreviations: OR, odds ratio; PPC, patient-provider communication.

*Likelihood ratio test comparing models 1 and 2 and models 2 and 3.

†Statistically significant at $P < .05$.

‡Covariates include sociodemographics (age, sex, education, and health insurance), clinical characteristics (comorbidities, stage at diagnosis, time since diagnosis, and treatment), and follow-up care–related factors (number of visits for cancer-related follow-up care, length of relationship with main follow-up care physician, and whether main follow-up care physician was the same physician seen for cancer treatment).

§Includes overall communication and communication about medical tests.

Table 4. Adjusted Models of Racial/Ethnic Differences in Self-Efficacy in Medical Decisions

Model (variables)	R^2	R^2 Change	P	F	P	African American		Asian/Pacific Islander		Hispanic	
						β	P	β	P	β	P
1 (race/ethnicity)	0.033	—	< .001	7.69	< .001	−0.785	.670	−8.834	< .001	−1.810	.426
2 (race/ethnicity + covariates)*	0.083	0.050	.001	3.54	< .001	−0.092	.961	−8.194	< .001	0.038	.987
3 (race/ethnicity + covariates + PPC)†	0.274	0.190	< .001	13.08	< .001	1.135	.499	−4.813	.006	2.075	.329

NOTE. Comparisons to non-Hispanic white. R^2 change refers to the comparison to the previous model; β refers to the unstandardized regression coefficient. Two hundred forty-one respondents had missing data with the inclusion of PPC and were excluded from this analysis but were included in analyses presented in Table 2.

Abbreviation: PPC, patient-provider communication.

*Covariates include sociodemographics (age, sex, education, and health insurance), clinical characteristics (comorbidities, stage at diagnosis, time since diagnosis, and treatment), and follow-up care–related factors (number of visits for cancer-related follow-up care, length of relationship with main follow-up care physician, and whether main follow-up care physician was the same physician seen for cancer treatment).

†Includes overall communication and communication about medical tests.

improving PPC is likely to improve survivors' perceived care quality and self-efficacy^{19,21,24}; yet, our findings suggest that addressing communication alone may be insufficient to bridge racial/ethnic disparities in perception of these factors.

Future studies should examine potential confounding factors beyond PPC, such as cultural beliefs, attitudes, and preferences for interacting with providers and the health care system.^{32,44,45} A qualitative approach inquiring about patients' care experiences; their approach to completing surveys; and social, cultural and organizational factors influencing care quality can elucidate reasons for persistent disparities among Asian survivors. For example, beliefs that physicians are the sole authority of medical knowledge tend to be stronger in Asian cultures with a hierarchical emphasis, which may facilitate a more paternalistic provider role.⁴⁶ In addition, multilevel studies may be needed to assess patient-, provider-, and health system–level factors contributing to care quality in diverse populations.

Notable limitations of this study include the following. First, the cross-sectional design precludes causal inference between PPC, quality care, and patient activation. Second, because of small subgroup sample sizes, we combined Asians and Pacific Islanders into one category. Similarly, we were unable to disaggregate both the Asian and Hispanic samples for more distinct analysis that could capture the divergent geographic, cultural, and linguistic backgrounds within one race/ethnicity category. The broad racial and ethnic categories used by US cancer registries may not reflect the considerable subgroup diversity.⁴⁷ Third, we did not assess language preference or provide the option to complete the survey in another language beyond English. Fourth, consistent with a patient-centered care model, we relied on patients' reports on their care quality. Thus, racial/ethnic differences in quality ratings may also reflect differences in survey response tendencies; some evidence suggests that Asians tend to choose response options toward the middle of Likert scales.⁴⁸ Fifth, results from this study may not be generalizable, because our study population was sampled from long-term survivors from California, excluded those who could not read English, and was limited to survivors seen for recent follow-up care. Sixth, although we adjusted for multiple covariates, it is possible that racial/ethnic differences observed are a result of residual confounding by known and unknown factors. Finally, the racial/ethnic distribution of this study is from a survey in 2005 to 2006 and may not reflect the current US population.

In conclusion, Asian survivors report worse communication, quality care, and self-efficacy compared with white survivors. Providers working with racial/ethnic minority patients should be aware that these survivors may view communication with their providers and their health care quality as less than ideal. Potential strategies to improve care for these patients could include periodically checking in about communication and care ("How are things going from your perspective?"), encouraging patients to participate in agenda setting, and paying increased attention to nonverbal communication from both the patient and provider.^{49,50} Providers are also encouraged to enhance their cultural competence through training and consultations as needed.⁵¹ Finally, survivor-focused interventions may need to be geared toward educating survivors on the importance of follow-up care, active involvement in their health care, and promoting health and health care self-management.^{1,52} Because factors beyond PPC may impact patient-reported outcomes, more research is needed among racially/ethnically diverse cancer survivors to better identify the diverse biologic, socioeconomic, social, and cultural factors that contribute to disparities in health outcomes and patient experiences.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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

AUTHOR CONTRIBUTIONS

Conception and design: Nynikka R.A. Palmer, Erin E. Kent, Laura P. Forsythe, Neeraj K. Arora, Julia H. Rowland, Noreen M. Aziz, Kathryn E. Weaver
Administrative support: Erin E. Kent, Neeraj K. Arora, Julia H. Rowland
Provision of study materials or patients: Neeraj K. Arora, Ingrid Oakley-Girvan, Ann S. Hamilton
Collection and assembly of data: Neeraj K. Arora, Julia H. Rowland, Ingrid Oakley-Girvan, Ann S. Hamilton
Data analysis and interpretation: Nynikka R.A. Palmer, Erin E. Kent, Laura P. Forsythe, Neeraj K. Arora, Julia H. Rowland, Danielle Blanch-Hartigan, Kathryn E. Weaver
Manuscript writing: All authors
Final approval of manuscript: All authors

REFERENCES

1. Epstein RM, Street RL: Patient-Centered Communication in Cancer Care: Promoting Health and Reducing Suffering. Bethesda, MD, National Cancer Institute, NIH publication 07-6225, 2007
2. Ong LM, de Haes JC, Hoos AM, et al: Doctor-patient communication: A review of the literature. *Soc Sci Med* 40:903-918, 1995
3. Arora NK, Reeve BB, Hays RD, et al: Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *J Clin Oncol* 29:1280-1289, 2011
4. Thorne SE, Bultz BD, Baile WF, et al: Is there a cost to poor communication in cancer care?: A critical review of the literature. *Psychooncology* 14:875-884, 2005
5. Song L, Bensen JT, Zimmer C, et al: Patient-health care provider communication among patients with newly diagnosed prostate cancer: Findings from a population-based survey. *Patient Educ Couns* 91:79-84, 2013
6. Donovan HS, Hartenbach EM, Method MW: Patient-provider communication and perceived control for women experiencing multiple symptoms associated with ovarian cancer. *Gynecol Oncol* 99:404-411, 2005
7. Maly RC, Stein JA, Umezawa Y, et al: Racial/ethnic differences in breast cancer outcomes among older patients: Effects of physician communication and patient empowerment. *Health Psychol* 27:728-736, 2008
8. Hibbard JH, Greene J, Overton V: Patients with lower activation associated with higher costs: Delivery systems should know their patients' "scores." *Health Aff* 32:216-222, 2013
9. Harvey L, Fowles JB, Xi M, et al: When activation changes, what else changes? The relationship between change in patient activation measure (PAM) and employees' health status and behaviors. *Patient Educ Couns* 88:338-343, 2012
10. Greene J, Hibbard JH: Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* 27:520-526, 2012
11. Arora NK, Weaver KE, Clayman ML, et al: Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient Educ Couns* 77:404-412, 2009
12. Magnezi R, Glasser S, Shalev H, et al: Patient activation, depression and quality of life. *Patient Educ Couns* 94:432-437, 2014
13. Jarden M, Møller T, Kjeldsen L, et al: Patient Activation through Counseling and Exercise—Acute Leukemia (PACE-AL): A randomized controlled trial. *BMC Cancer* 13:446-459, 2013
14. Jerofke T, Weiss M, Yakusheva O: Patient perceptions of patient-empowering nurse behaviours, patient activation and functional health status in postsurgical patients with life-threatening long-term illnesses. *J Adv Nurs* 70:1310-1322, 2014
15. Gordon HS, Street RL Jr, Sharf BF, et al: Racial differences in doctors' information-giving and patients' participation. *Cancer* 107:1313-1320, 2006
16. Gordon HS, Street RL Jr, Sharf BF, et al: Racial differences in trust and lung cancer patients' perceptions of physician communication. *J Clin Oncol* 24:904-909, 2006
17. Manfredi C, Kaiser K, Matthews AK, et al: Are racial differences in patient-physician cancer communication and information explained by background, predisposing, and enabling factors? *J Health Commun* 15:272-292, 2010
18. Siminoff LA, Graham GC, Gordon NH: Cancer communication patterns and the influence of patient characteristics: Disparities in information-giving and affective behaviors. *Patient Educ Couns* 62:355-360, 2006
19. Ayanian JZ, Zaslavsky AM, Arora NK, et al: Patients' experiences with care for lung cancer and colorectal cancer: Findings from the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 28:4154-4161, 2010
20. 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
21. Bickell NA, Neuman J, Fei K, et al: Quality of breast cancer care: Perception versus practice. *J Clin Oncol* 30:1791-1795, 2012
22. Hibbard JH, Greene J, Becker ER, et al: Racial/ethnic disparities and consumer activation in health. *Health Aff* 27:1442-1453, 2008
23. Shaw BA, Krause N: Exploring race variations in aging and personal control. *J Gerontol B Psychol Sci Soc Sci* 56:S119-S124, 2001
24. Saha S, Arbelaez JJ, Cooper LA: Patient-physician relationships and racial disparities in the quality of health care. *Am J Public Health* 93:1713-1719, 2003
25. National Cancer Institute: Follow-Up Care Use Among Survivors (FOCUS) Survey. <http://cancercontrol.cancer.gov/ocs/focus.html>
26. Bellizzi KM, Aziz NM, Rowland JH, et al: Double jeopardy? Age, race, and HRQOL in older adults with cancer. *J Cancer Epidemiol* 2012:478642, 2012
27. Kent EE, Arora NK, Rowland JH, et al: Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Educ Couns* 89:345-352, 2012
28. 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:S472-S479, 2009 (suppl 2)
29. Nielsen SS, He Y, Ayanian JZ, et al: Quality of cancer care among foreign-born and US-born patients with lung or colorectal cancer. *Cancer* 116:5497-5506, 2010
30. Hibbard JH, Stockard J, Mahoney ER, et al: Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 39:1005-1026, 2004
31. Graubard BI, Korn EL: Analyzing health surveys for cancer-related objectives. *J Natl Cancer Inst* 91:1005-1016, 1999
32. Wang JH, Adams I, Huang E, et al: Physical distress and cancer care experiences among Chinese-American and non-Hispanic White breast cancer survivors. *Gynecol Oncol* 124:383-388, 2012
33. Agency for Healthcare Research and Quality: National Healthcare Disparities Report. Rockville, MD, US Department of Health and Human Services, AHRQ publication 13-0003, 2013. www.ahrq.gov/research/findings/nhqrdr/index.html
34. Ngo-Metzger Q, Legedza AT, Phillips RS: Asian Americans' reports of their health care experiences: Results of a national survey. *J Gen Intern Med* 19:111-119, 2004
35. Lurie N, Zhan C, Sangl J, et al: Variation in racial and ethnic differences in consumer assessments of health care. *Am J Manag Care* 9:502-509, 2003
36. Taira DA, Safran DG, Seto TB, et al: Asian-American patient ratings of physician primary care performance. *J Gen Intern Med* 12:237-242, 1997
37. Quach T, Nuru-Jeter A, Morris P, et al: Experiences and perceptions of medical discrimination among a multiethnic sample of breast cancer patients in the Greater San Francisco Bay Area, California. *Am J Public Health* 102:1027-1034, 2012
38. Mead N, Roland M: Understanding why some ethnic minority patients evaluate medical care more negatively than white patients: A cross sectional analysis of a routine patient survey in English general practices. *BMJ* 339:b3450, 2009
39. Sitzia J, Wood N: Patient satisfaction: A review of issues and concepts. *Soc Sci Med* 45:1829-1843, 1997
40. Wang JH, Adams IF, Pasick RJ, et al: Perceptions, expectations, and attitudes about communication with physicians among Chinese American and non-Hispanic white women with early stage breast cancer. *Support Care Cancer* 21:3315-3325, 2013
41. Kagawa-Singer M, Dadia AV, Yu MC, et al: Cancer, culture, and health disparities: Time to chart a new course? *CA Cancer J Clin* 60:12-39, 2010
42. Pasick RJ, Stewart SL, Bird JA, et al: Quality of data in multiethnic health surveys. *Public Health Rep* 116:223-243, 2001 (suppl 1)
43. Singh-Carlson S, Wong F, Martin L, et al: Breast cancer survivorship and South Asian women: Understanding about the follow-up care plan and perspectives and preferences for information post treatment. *Curr Oncol* 20:e67-e79, 2013
44. Nápoles-Springer AM, Santoyo J, Houston K, et al: Patients' perceptions of cultural factors affecting the quality of their medical encounters. *Health Expect* 8:4-17, 2005
45. Wang J, Matthews JT: Chronic disease self-management: Views among older adults of Chinese descent. *Geriatr Nurs* 31:86-94, 2010
46. Claramita M, Utarini A, Soebono H, et al: Doctor-patient communication in a Southeast Asian setting: The conflict between ideal and reality. *Adv Health Sci Educ Theory Pract* 16:69-80, 2010
47. Ida D, SooHoo J, Chapa T: Integrated care for Asian American, Native Hawaiian and Pacific Islander communities: A blueprint for action. Rockville, MD, US Department of Health and Human Services, Office of Minority Health, 2012. http://www.integration.samhsa.gov/workforce/Integrated_Care_for_AANHPI_Communities_1_23_12_Blue_II.pdf
48. Murray-Garcia JL, Selby JV, Schmittiel J, et al: Racial and ethnic differences in a patient survey: Patients' values, ratings, and reports regarding physician primary care performance in a large health maintenance organization. *Med Care* 38:300-310, 2000
49. Rao JK, Anderson LA, Inui TS, et al: Communication interventions making a difference in conversations between physicians and patients: A systematic review of the evidence. *Med Care* 45:340-349, 2007
50. Patak L, Wilson-Stronks A, Costello J, et al: Improving patient-provider communication: A call to action. *J Nurs Adm* 39:372-376, 2009
51. Taylor SL, Lurie N: The role of culturally competent communication in reducing ethnic and racial healthcare disparities. *Am J Manag Care* 10:SP1-SP4, 2004
52. McCorkle R, Ercolano E, Lazenby M, et al: Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 61:50-62, 2011

GLOSSARY TERMS

**American Joint Committee on Cancer (AJCC)/
Union for International Cancer Control (UICC)**

TNM staging: a cancer staging system that describes the extent of cancer in a patient's body. "T" describes the size of the tumor and whether it has invaded nearby tissue; "N" describes regional lymph nodes that are involved; "M" describes distant metastasis (spread of cancer from one body part to another). The TNM Classification of Malignant Tumours was developed and maintained by the UICC to achieve consensus on one globally recognized standard for classifying the extent of spread of cancer. The TNM classification was also used by the AJCC. In 1987, the UICC and AJCC staging systems were unified into a single staging system. Prognosis of a patient is defined by TNM classification.

linear regression analysis: the estimation of the slopes for each of the explanatory variables in a linear regression model. That is, finding the best fit line.

linear regression model: a mathematical equation in which a continuous outcome variable is a linear combination of one or more explanatory variables, plus random noise.

logistic regression analysis: a multivariable regression model in which the log of the odds of a time-fixed outcome event (eg, 30-day mortality) or other binary outcome is related to a linear equation.

logistic regression model: a multivariable prediction model in which the log of the odds of a time-fixed outcome event or other binary outcome is related to a linear equation.

Surveillance, Epidemiology, and End Results (SEER): a national cancer registry that collects information from all incident malignancies in multiple geographic areas of the United States.

Simplify Your Search With JCO Subject Collections

Subject Collections are topic-specific archives of articles published on jco.org that make it easy for you to find the research you need. Instead of random, time-consuming keyword searches, JCO Subject Collections allow you to quickly browse your interest areas for articles on specific diseases and treatments. Best of all, by signing up for Collection Alerts, you'll receive e-mail notification whenever JCO publishes an article in your interest area.

Sign up today at jco.org/collections.

American Society of Clinical Oncology

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Racial and Ethnic Disparities in Patient-Provider Communication, Quality-of-Care Ratings, and Patient Activation Among Long-Term Cancer Survivors

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Nynikka R.A. Palmer

No relationship to disclose

Erin E. Kent

No relationship to disclose

Laura P. Forsythe

No relationship to disclose

Neeraj K. Arora

No relationship to disclose

Julia H. Rowland

No relationship to disclose

Noreen M. Aziz

No relationship to disclose

Danielle Blanch-Hartigan

No relationship to disclose

Ingrid Oakley-Girvan

No relationship to disclose

Ann S. Hamilton

No relationship to disclose

Kathryn E. Weaver

No relationship to disclose

Acknowledgment

We thank the entire Follow-Up Care Use Among Survivors (FOCUS) study research team for making this research possible and their contributions to this article.

Presented in part at the Fifth American Association for Cancer Research Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, October 27-30, 2012, San Diego, CA.