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## **Authors**

Palmer, Nynikka RA Kent, Erin E Forsythe, Laura P et al.

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# 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

#### A B S T R A C T

#### **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.

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#### nia, 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 Insti-

Nynikka R.A. Palmer, San Francisco General Hospital, University of Califor-

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

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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: palmern@medsfgh.ucsf.edu.

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#### INTRODUCTION

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

Effective PPC has also been shown to facilitate patient activation in health care. <sup>1,6,7</sup> 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." <sup>8(p216)</sup> Activated patients are more likely to be engaged in improving and maintaining their health <sup>9,10</sup> 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

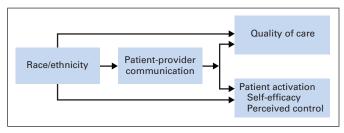


Fig 1. Conceptual framework for associations between race/ethnicity, patient-provider communication, quality-of-care rating, and patient activation.

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, <sup>7</sup> as well as higher perceived control. <sup>6</sup> High-quality care facilitating patient activation may promote survivors' psychosocial adjustment and optimal postcancer health. <sup>11-14</sup>

Studies of cancer survivors reveal racial/ethnic disparities in PPC<sup>15-18</sup> and perceived care quality.<sup>3,19-21</sup> 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 care<sup>22</sup> and their perceived control.<sup>23</sup> 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 treatment<sup>17</sup> and comparisons between whites and African Americans, <sup>15-17,22,23</sup> with few studies including Hispanics and Asian/Pacific Islanders.<sup>3,19-21</sup> 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%. <sup>25,26</sup> 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. <sup>25-27</sup> 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<sup>3,11,28</sup> (http://outcomes.cancer.gov/surveys/apecc/) 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 exchange<sup>3</sup>: "In the past 2 years, how often did 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  $\alpha$  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 questions<sup>28</sup>: "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  $\alpha$  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  $\nu$  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. <sup>22,30</sup> The five-item Decision-Making Participation Self-Efficacy Scale <sup>11</sup> 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  $\alpha$  exceed .95 for each race/ethnicity group.

The four-item Perceived Personal Control Scale <sup>11</sup> 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  $\alpha$  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 ≥ 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. Registryreported 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 ( $\leq$  2 visits or  $\geq$  3 visits), length of relationship with main follow-up care physician ( $\leq 2, 3$  to 4, or  $\geq 5$  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. 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  $\chi^2$  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 ( $\pm$  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, <sup>3,19,20,28,32</sup> 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

Age, years  Mean  Mean  Age, years  Mean  Age, years  Mean  Age, years  Mean  Age, years  Sox  Sox  Sox  Mean  Age, years  Mean  Age, years  Sox  Sox  Mean  Age, years  Mean  Age, years  Mean  Age, years  Sox  Sox  Sox  Sox  Sox  Sox  Sox  So		Tota (n = 1,1		African American (n = 294)		Asian/Pacific Islander (n = 272)		Hispanic (n = 161)		Non-Hispanic White (n = 469)			
Mean   Se.   Se	Characteristic		%		%		%		%		%	P*	
Sear	Age, years											.0	
Sex Male	Mean	68.9		68.8		67.6	6	70.3		69.4			
Male	<u> </u>	31-93	3	36-89	9	34-8	7	31-87	7	32-93	}		
Female Education												< .0	
Second college	Male	469	39.2	129	43.9	108	39.7	82	50.9	150	32.0		
Figh school   106   9.0   29   10.0   12   4.5   49   30.8   16   3.4   Figh school/GED   197   16.7   46   15.9   36   31.5   36   22.6   79   16.9   Figh school/GED   197   16.7   46   15.9   36   31.5   36   22.6   79   16.9   Figh school/GED   197   16.7   46   15.9   36   31.5   36   22.6   79   16.9   Figh school/GED   197   16.7   46   15.9   36   31.5   36   22.6   79   16.9   Figh school/GED   197   16.7   14.9   18.3   31.2   45   28.3   16.4   35.0   Figh school/GED   18.1   19.8   32.2   13.5   50.8   29   18.2   20.9   44.7   Figh school/GED   18.1   19.8   18.2   18.2   18.3   18.3   Figh school/GED   18.1   18.3   18.3   18.3   Figh school/GED   18.1   18.3   18.3   18.3   Figh school/GED   18.1   18.3   Figh school/GED   18.3   18.3   Figh school/GED   18.	Female	727	60.8	165	56.1	164	60.3	79	49.1	319	68.0		
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Scalege graduate   466   39.4   93   32.2   135   50.8   29   18.2   209   44.7     Insurance	High school/GED	197	16.7	46	15.9	36	13.5	36	22.6	79	16.9		
None   22   1,9   8   2,8   4   1,5   6   3,9   4   0,9   1,18   1,8	Some college	413	34.9	121	41.9	83	31.2	45	28.3	164	35.0		
None	≥ College graduate	466	39.4	93	32.2	135	50.8	29	18.2	209	44.7		
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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         In situ or stage I         493         40.6         119         40.5         110         40.4         58         36.0         201         42.9           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           Instaged Since diagnosis, years         4.9         4.6         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         264         56.3           10-14         512         42.8         126         42.9         107													
Endometrial         116         9.5         38         12.9         24         8.8         14         8.7         40         8.5           Stage at diagnosis           In situ or stage I         493         40.6         119         40.5         110         40.4         58         36.0         201         42.9           Stage II 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           1m-staged         684         57.2         168         57.1         165         60.7         30         18.6         41         8.7           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         26.3         26.3           10-14         512         42.8         126         42.9         107         39.3         74 </td <td></td>													
Stage at diagnosis           In situ or stage I         493         40.6         119         40.5         110         40.4         58         36.0         201         42.9           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           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           Chemotherapy         507         41.7         114         39.4         121         45.7         53         33.3         212         45.9													
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         14         11.9         42         14.3         26         9.6         30         18.6         41         8.7           Time since diagnosis, years           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         265         43.7           Treatment           Surgery         1,040         85.6         240         82.8         229         87.1         134         84.8         423         91.6           Chemotherapy         507         41.7         1		116	9.5	38	12.9	24	8.8	14	8.7	40	8.5		
Stage III or IV         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           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           Chemotherapy         507         41.7         114         39.4         121         45.7         53         33.3         212         45.9           Raidation         48.6         38.4	· · · · · · · · · · · · · · · · · · ·												
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           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         264         56.3           Treatment           Surgery         1,040         85.6         240         82.8         229         87.1         134         84.8         423         91.6           Chemotherapy         507         41.7         114         39.4         121         45.7         53         33.3         212         45.9           Radiation         466         38.4         120         41.2         98         36.8         54         33.5         185         40.1           Adjuvant         1,184         97.4	· · · · · · · · · · · · · · · · · · ·												
Unstaged         144         11.9         42         14.3         26         9.6         30         18.6         41         8.7           Time since diagnosis, years         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         Chemotherapy         507         41.7         114         39.4         121         45.7         53         33.3         212         45.9         82.8         229         87.1         134         84.8         423         91.6         Chemotherapy         50         41.7         114         39.4         121         45.7         53         33.3         212         45.9         82.0         82.0         82.8         28.9         87.1         134         84.8         423         91.6         40.1         190         42.1         40.1 <td< td=""><td>•</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></td<>	•												
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Surgery     1,040     85.6     240     82.8     229     87.1     134     84.8     423     91.6       Chemotherapy     507     41.7     114     39.4     121     45.7     53     33.3     212     45.9       Radiation     466     38.4     120     41.2     98     36.8     54     33.5     185     40.1       Adjuvant     1,184     97.4     82     28.6     72     27.2     34     21.8     128     28.0       No. of visits for follow-up care     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     ≤ 2     132     12.1     32     11.9     39     16.3     21     14.4     40     9.2       3-4     26     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 </td <td>10-14</td> <td>512</td> <td>42.8</td> <td>126</td> <td>42.9</td> <td>107</td> <td>39.3</td> <td>74</td> <td>45.0</td> <td>205</td> <td>43.7</td> <td></td>	10-14	512	42.8	126	42.9	107	39.3	74	45.0	205	43.7		
Chemotherapy       507       41.7       114       39.4       121       45.7       53       33.3       212       45.9         Radiation       466       38.4       120       41.2       98       36.8       54       33.5       185       40.1         Adjuvant       1,184       97.4       82       28.6       72       27.2       34       21.8       128       28.0         No. of visits for follow-up care       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       ≤ 2       132       12.1       32       11.9       39       16.3       21       14.4       40       9.2         3-4       26       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 <td>Treatment</td> <td></td>	Treatment												
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Adjuvant     1,184     97.4     82     28.6     72     27.2     34     21.8     128     28.0       No. of visits for follow-up care       ≤ 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     ≤ 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       No     459     43.5     117     45.5     85     37.3     64     46.0     193     44.8	Chemotherapy	507	41.7	114	39.4	121	45.7	53	33.3	212	45.9		
Adjuvant     1,184     97.4     82     28.6     72     27.2     34     21.8     128     28.0       No. of visits for follow-up care       ≤ 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     ≤ 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       No     459     43.5     117     45.5     85     37.3     64     46.0     193     44.8	Radiation	466	38.4	120	41.2	98	36.8	54	33.5	185	40.1		
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Length of relationship with follow-up care physician, years $\leq 2$ 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 $\geq 5$ 693 63.5 171 63.6 135 56.3 83 56.8 304 69.7 Same physician seen for cancer treatment No 459 43.5 117 45.5 85 37.3 64 46.0 193 44.8													
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	• •	ΛEO	\13 E	117	15 E	QE	27.2	6/	16 O	102	// O		
	Yes	596	56.5	140	54.5	143	62.7	75	54.0	238	55.2		

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

							Patient Activation				
	Patie Ove Commun	rall	Communicat Medical		Quality	of Care‡	Self-Effi Med Decisi	ical	Perceived Control		
Race/Ethnicity	Mean Score	SE	Mean Score	SE	Odds Ratio	95% CI	Mean Score	SE	Mean Score	SE	
Unadjusted											
Р	< .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											
P	< .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

||Perceived control score = 0 to 100 points.

Previous studies have reported Asian disparities in PPC and quality-of-care ratings among the general population<sup>24,33-35</sup> and newly diagnosed/treated survivors.<sup>20</sup> 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, <sup>36,37</sup> poorer continuity of care, <sup>36,38</sup> expectations, <sup>38-40</sup> sociocultural orientation, <sup>38,40,41</sup> and response style/measurement limita-

tions<sup>38,40,42</sup> 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.<sup>40</sup> 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).<sup>43</sup> 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.<sup>43</sup> In addition,

Table 3. Adjusted Models of Racial/Ethnic Differences in Quality-of-Care Ratings										
	Afric	can American	Asian	Pacific Islander		Hispanic				
Model (variables)	OR	95% CI	OR	95% CI	OR	95% CI	Likelihood Ratio Tests*			
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.

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

<sup>‡</sup>Excellent/very good overall rating of quality of care.

<sup>\$</sup>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,

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

<sup>\*</sup>Likelihood ratio test comparing models 1 and 2 and models 2 and 3.

<sup>†</sup>Statistically significant at P < .05.

<sup>‡</sup>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).

<sup>§</sup>Includes overall communication and communication about medical tests.

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

							African American		Asian/Pacific Islander		nic
Model (variables)	$R^2$	R <sup>2</sup> Change	P	F	P	β	Р	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;  $\beta$  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).

fincludes overall communication and communication about medical tests.

improving PPC is likely to improve survivors' perceived care quality and self-efficacy<sup>19,21,24</sup>; 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. <sup>32,44,45</sup> 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. <sup>46</sup> 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

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#### **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.

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#### **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

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Nynikka R.A. Palmer

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Erin E. Kent

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Laura P. Forsythe

No relationship to disclose

Neeraj K. Arora

No relationship to disclose

Julia H. Rowland

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Noreen M. Aziz

No relationship to disclose

Danielle Blanch-Hartigan

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Ingrid Oakley-Girvan

No relationship to disclose

Ann S. Hamilton

No relationship to disclose

Kathryn E. Weaver

No relationship to disclose

#### Palmer et al

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