Patient Preferences for Primary Care Provider Roles in Breast Cancer Survivorship Care

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Abstract

Purpose—Prior studies suggest a need for greater clarity about provider roles in team-based cancer care. However, little is known about patient's preferences for which providers handle their care needs after primary cancer treatment.

Methods—We surveyed women newly diagnosed with stages 0-II breast cancer who were treated in 2014–15 as reported to the Georgia and Los Angeles SEER registries (N=2,372, 68% response rate). Patient preferences for which provider handles the following care needs after treatment were ascertained: follow-up mammograms, screening for other cancers, general preventive care, and comorbidity management. The associations between patient demographic factors with preferences for provider roles (Oncology-directed care vs. primary care provider (PCP)-directed) were assessed using multivariable logistic regression.

Results—The majority of women preferred that their PCPs handle their general preventive care (79%) and comorbidity care (84%), but a notable minority of women preferred their oncologists direct this care (21% and 16%). Minority women (black and Asian vs. white) and women with a high school education or less (vs. college grad or more) had a greater odds of preferring oncology-directed care (vs. PCP-directed) for their general preventive care (black OR: 2.01, 95%CI: 1.43,

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2.82; Asian OR: 1.74, 95%CI: 1.13, 2.69;   high school OR: 1.51, 95%CI: 1.10, 2.08). Similar variation existed for comorbidity care.

Conclusion—In this sample, minority women and those with less education more often preferred oncologists direct aspects of their care after breast cancer treatment that are normally delivered by a PCP. Efforts to clarify provider roles in survivorship care to patients may be effective in improving team-based cancer care.

INTRODUCTION

The exponential growth in the aging adult cancer survivor population[1] necessitates the delivery of comprehensive, coordinated continuing care after the initial course of treatment. Indeed, the National Academy of Medicine recommends team-based continuing care that promotes cross-specialty provider collaboration, particularly between primary care physicians (PCPs) and oncologists.[2] However, coordination and communication between primary care and oncology care teams remains challenging, in part due to the lack of clarity around provider roles in delivering survivorship care.[3] Current survivorship guidelines suggest that patients with favorable long-term prognosis can be transitioned back to primary care after completion of initial curative treatment and the PCPs role in survivorship care can be enhanced.[4–6] Though, the guidelines do not explicitly state which provider should handle the numerous aspects of survivorship care.

Prior research has largely focused on identifying provider-level barriers to providing team-based cancer care, including knowledge deficits about survivorship care and differences in practices and attitudes about provider roles in this care among both PCPs and oncologists.[7–11] However, very little is known about patient preferences and expectations regarding which providers deliver the various aspects of survivorship care after primary treatment. In order to deliver continuing care that is patient-centered, it is critical to understand how patients perceive provider roles in delivering continuing cancer care and whether these preferences vary across patients. Understanding these patient preferences, particularly early in the transition to survivorship, is important as this is a critical time to discuss the goals of survivorship care and coordinate this care going forward. This may be particularly important in underserved populations who have historically had difficulty in access to care.[12,13] While team-based care models offer promise for improving continuing care, our ability to design interventions to promote patient-centered, comprehensive, team-based cancer care will be limited without a better understanding of the preferences and expectations of patients themselves.

The objectives of this study were to examine patient preferences for provider roles in follow-up care after primary breast cancer treatment and whether preferences vary by patient demographics in a large, contemporary, diverse, population-based sample of women with favorable prognosis breast cancer.

METHODS

Study Population

As described previously,[14] the Individualized Cancer Care (iCanCare) Study is a large, diverse, population-based survey study of women with early-stage breast cancer and their providers. We identified and accrued 3930 women, ages 20–79 with newly diagnosed, early-stage breast cancer (stages 0-II) as reported to the SEER registries of Georgia and Los Angeles County in 2014–15. Patients were ineligible if they had tumors larger than 5cm, had 4 or more positive nodes, or could not complete a questionnaire in English or Spanish (N= 258). Of the remaining 3,672 eligible women who were mailed surveys, 2,502 completed the survey (68% response rate) and those who identified having a PCP at the time of survey (N=2,372) were included in this analysis.

Patients were identified via rapid case ascertainment of their initial surgical pathology reports, derived from a list of "definitive" surgical procedures (performed with the intent of removing the entire tumor and obtaining clear margins, including excisional biopsy). They were then surveyed after definitive surgery (average 8 months after diagnosis) about their treatment experiences, knowledge and attitudes, appraisal of communication and decision-making, and quality of life. To encourage response, we provided a $20 cash incentive and used a modified Dillman approach to patient recruitment,[15] including reminders to non-respondents. All materials were sent in English and Spanish to those with Spanish surnames. Responses to the survey were then merged with clinical data by the SEER registries and a de-identified analytic dataset was created. The study was approved by the University of Michigan Institutional Review Board.

Measures

As described previously,[14] questionnaire content was developed based on a conceptual framework, research questions, hypotheses, prior literature and our prior work. We utilized standard techniques to assess content validity, including systematic review by design experts, cognitive pretesting with patients, and pilot studies in selected clinic populations.

Patient preferences for Provider Roles in Follow-up Care

We asked respondents to indicate their preferences regarding the role of oncologists and PCPs in delivering four aspects of their survivorship care: follow-up for breast cancer (mammograms), screening for other cancers, general preventive care (vaccinations, check-ups) and treatment for ongoing or future medical conditions (such as diabetes, heart disease). Specifically, we asked, "After your initial cancer treatment is finished, which doctor would you prefer to see for each of the following?", with possible response categories that included "Prefer primary care provider", "Prefer cancer doctor" (i.e., oncologist), "Either one is fine", or "Prefer to see both" for each of the four aspects of care. These responses were mutually exclusive and categorized as PCP-directed vs. Oncology-directed (Oncology/Both/Either) for analysis. We performed multiple sensitivity analyses to confirm the robustness of the findings across different specifications of the outcome variable. These included defining the outcome as the original four-level response variable categorized as PCP (referent), Oncologist, Both and Either and re-categorizing the outcome as PCP vs. Oncology/Both,

with Either excluded. All of the sensitivity analyses performed using these outcome definitions yielded comparable results.

Demographics

Demographic factors were collected via survey and included age at diagnosis and race, categorized as white, black, Latina, Asian, and other/unknown. We also collected information on educational attainment (>high school, high school graduate or some college or more) and insurance status (Private, Medicare, Medicaid, Other Public, None).

Covariates

The covariates in this analysis included clinical and breast cancer treatment factors, measures of PCP continuity and frequency, and patient-reported worry about recurrence. Clinical factors included the number of comorbid conditions (COPD, heart disease, diabetes or stroke), breast cancer treatment characteristics, including primary surgical treatment modality (lumpectomy, unilateral mastectomy, bilateral mastectomy), use of chemotherapy (yes/no) and endocrine therapy (yes/no). To ascertain primary care continuity, respondents were asked, "How long have you been seeing your primary care provider?" with response categories of < 6 months, 6–11 months, 1–2 years and more than 2 years, which were collapsed into < 1 year, 1–2 years and > 2 years for analyses. Patients were also asked ""How many times have you seen your PCP since your cancer diagnosis?", which was categorized as 0, 1, 2 or 3+. Frequency of worry about recurrence was defined by asking women to indicate on a 5 point scale how often they worried about their cancer coming back in the past month (not at all to always) and was then dichotomized as frequent worry (sometimes/often/almost always) vs. less worry (almost never/rarely).

Statistical Analysis

The overall distribution (weighted %) of patient preferences for PCP-directed vs. Oncology-directed care for each of the four aspects of care (mammograms, screening for other cancers, comorbidity, preventive services) were estimated. The bivariate distributions of patient preferences for PCP-directed vs. Oncology-directed care were then compared across age, race, and education for each of the four aspects of follow-up care using Rao-Scott Chi-Square tests.

The covariate-adjusted associations between patient-level demographics (age, race, education, insurance) and patient preferences for Oncology-directed care were then estimated using logistic regression for each individual aspect of follow-up care, adjusting for time from diagnosis to survey completion, study site, comorbidity, surgical treatment, chemotherapy, radiation therapy, endocrine therapy, worry about recurrence and PCP frequency and continuity. PCP-directed was treated as the consistent referent category across models, as this is an early-stage population where fully transitioning back to primary care is likely appropriate.

All statistical analyses incorporated weights to allow our statistical inference more representative of the target population and reduce potential bias due to non-response. This included the use of design weights to account for differential probability of sample selection

and non-response weights to account for disproportionate non-response rates across different patient subgroups.[14,16,17] All analyses were performed using SAS 9.4 (Cary, NC), used two-sided tests, and p-values <0.05 were considered statistically significant.

RESULTS

Table 1 shows the demographic and clinical characteristics of the sample of 2,372 women included in this analysis. The majority of women were over the age of 60 (63%) and were White (54%), followed by Black (18%), Latina (15%), and Asian (10%). Forty-five percent had private insurance and 39% had a college education or more. Over a quarter had at least one other comorbid condition (30%). The majority of women received a lumpectomy (63%), 26% received chemotherapy, 60% received radiation therapy, and 68% had initiated endocrine therapy at the time of survey. Over a third of women (36%) reported frequently worrying about breast cancer recurrence. The majority of women (67%) reported seeing their PCP for more than 2 years and 73% having at least 1 visit with their PCP on average since their diagnosis. (Table 1)

Patient preferences for provider roles for general preventive care, comorbidity care, mammography, and screening for other cancers are displayed in Figure 1. For general preventive and comorbidity care, the majority of women preferred their PCPs handle these services (79% and 84%), but notable percentages of women preferred their oncologists handle these services (21% and 16%). The vast majority of women reported they prefer their oncologists handle their mammography (93%) and second cancer screening (91%) rather than their PCP. (Figure 1)

For general preventive care and comorbidity care, while the majority of women preferred PCP-directed care, variation existed across race and education as displayed in Table 2. For both service types, there was significant variation in provider preference across race: Asian women were most likely to report this preference for both preventive care (29%) and comorbidity care (23%), followed by Latina women (28% and 23%), black women (28% and 21%) and white women (15% and 11%) (p<0.001). A greater proportion of women with high school degree or less preferred their oncologists handle these services when compared to women with a college degree or more education (p<0.001). (Table 2)

For mammography and second cancer screenings, the majority of women preferred their oncologists direct this care rather than their PCPs, but there was less variation across age, race and education as also displayed in Table 2. For mammography, the proportion of women who preferred their oncologists handle this care decreased slightly with age (p=0.06), with 96% of those less than 50 years old reporting this preference compared to 92% of those over age 70. A greater proportion of women with a college degree or more preferred their oncologists direct this care when compared to women with a high school degree or less (95% vs. 92%) (p=0.002). For second cancer screenings, no significant variation existed across age, race, education or insurance. (Table 2)

Figure 2 A–D displays the covariate-adjusted associations between patient sociodemographic characteristics (age, race, education, insurance) and patient-reported

preferences for provider roles in follow-up care, comparing a preference for oncology-directed vs. PCP-directed care for each of the four aspects of follow-up care. For general preventive care (Figure 2A), the odds of black and Asian women reporting a preference that their oncologists handle this care rather than their PCPs were significantly greater than the odds of white women reporting this preference (Black OR: 2.00, 95%CI: 1.43, 2.82, Asian OR: 1.95, 95%CI: 1.28, 2.97). The odds of women with a high school education or less preferring their oncologists handle their preventive care rather than their PCPs were 1.53 times the odds of women with a college degree or more reporting this preference (Adjusted OR: 1.53, 95%CI: 1.12, 2.11). (Figure 2A) For comorbidity care (Figure 2B), black women were again more likely to prefer their oncologists handle this care rather than their PCPs when compared to white women (black OR: 1.93, 95%CI: 1.34, 2.79). (Figure 2B) Women with less than a high school education were more likely to prefer their oncologists handle their comorbidity care when compared to women with a college degree or more (OR: 1.50, 95%CI: 1.06, 2.12). (Figure 2B) Women with private or other insurance were less likely to prefer their oncologists handle their comorbidity care when compared to women with Medicaid insurance (OR: 0.56, 95%CI: 0.36–0.85). The full multivariable-adjusted results for all covariates are shown in the Supplemental Online Table.

For mammography (Figure 2C), there were no significant differences in the odds of women preferring their oncologists vs. their PCPs across levels of race or age. (Figure 2C) However, lower educational attainment was associated with a greater odds of reporting preferences for PCP-directed care (vs. oncology-directed) when compared to women with a college education or more (Some college OR: 0.49, 95%CI: 0.31, 0.77; <High school graduate OR: 0.63, 95%CI: 0.39,1.02). For screening for other cancers (Figure 2D), the odds that black women preferred their oncologists handle this service rather than their PCPs were nearly twice the odds among white women (black OR: 1.96, 95%CI: 1.15, 3.36). No significant differences in preferences for second cancer screenings were seen across age, education or insurance. (Figure 2D)

DISCUSSION

Results from this population-based study of early-stage breast cancer patients suggest that women have clear preferences for which providers they want to handle their survivorship care after primary treatment. Of note, a substantial minority of women in this study preferred that their oncologists handle aspects of survivorship care that are typically delivered in a primary care setting. These results suggest that patients may benefit from better education about provider roles and specifically, the potential benefits of greater involvement of the PCP, in delivering care after primary breast cancer treatment. Differences by race and education in preferences suggest additional challenges for those seeking to extend the model of PCP-led care to diverse populations of breast cancer survivors.

Our findings that the majority of women preferred to see their oncologists for services typically considered related to the cancer - mammography and second cancer screenings - are not surprising, but suggest there is an opportunity to educate patients about PCPs' ability to manage these care needs. Additionally, the findings that some women, particularly minority women and those with less education, prefer to see their oncologists for their

general preventive and comorbidity care, are notable, as PCPs typically direct this care. If women are reluctant to go to their PCPs for these services, they may be at greater risk of receiving fragmented survivorship care or not receiving the preventive care they need as they age. In addition, as survivorship care is complex, protracted, and often includes competing care priorities with other conditions, the involvement of PCPs is important as they are often the providers most attuned to patients' preferences and may be best able to prioritize competing care needs.[10] PCPs are often already involved throughout the cancer care continuum,[2] and, interestingly, our prior work in this cohort suggests that their involvement during treatment may be greatest among minority women and those with less education.[14] As such, it is important that clinicians discuss provider roles with patients and encourage them to continue their relationship with their PCP throughout the continuum of their cancer. These discussions are particularly critical to have with patients early in the transition from primary treatment to survivorship when the goals of survivorship care are typically first discussed. Also, targeting these sub-populations of women to understand their concerns and clarify provider roles and the potential benefits of PCP leadership may be particularly effective for interventions focused on improving the delivery and quality of team-based cancer care.

Adult cancer patients with favorable prognoses, like those included in this study, most will now live long after their diagnosis and are more likely to die of causes other than their cancer.[18–21] This also argues for the increased involvement of PCPs, to ensure that comprehensive care focusing on more than just the cancer is delivered. However, prior studies which are mostly qualitative, suggest that some cancer patients may be hesitant and uncertain about the role of the PCP in delivering this care.[22–25] As a result, many survivors report that they continue to receive care and reassurance from their cancer specialists rather than their PCPs.[22] Further compounding this issue, current survivorship guidelines do not specify how roles should be shared among primary care and oncology care teams.[5,6] Therefore, uncertainty remains among PCPs and oncologists as well about who should be handling the different aspects of survivorship care.[7,26] Future versions of survivorship guidelines and care plans should therefore consider including additional clarification around provider roles in delivering the various aspects of survivorship care. Additionally, ensuring that PCPs have the training and resources they need to effectively care for cancer patients is increasingly important.

While this study has a number of strengths, including the use of a large, diverse, population-based sample of women and being one of the first to provide insight into patients preferences for which provider manages the specific aspects of their follow-up care, there are potential limitations. The ascertainment of preferences for follow-up care occurred on average 8 months after diagnosis when many women have not yet fully started focusing on their survivorship care. Therefore, it is possible that the timing relative to completing treatment may have influenced womens' preferences for provider roles and it remains unknown whether these preferences change as time from diagnosis increases. We did, however, adjust for the timing of survey completion in our models to account for the influence of any variation in time from diagnosis to survey completion on our results, and found the results did not change. As our population only includes breast cancer patients in Los Angeles County and Georgia, generalizability to other populations may be limited. Finally, we did

not have information on which provider ultimately handled each aspect of care, and therefore future research should assess how these preferences align with the actual utilization of these services in survivorship.

CONCLUSIONS

Most women with early-stage breast cancer reported clear preferences regarding which providers handle the various aspects of their continuing care after breast cancer treatment. While many women preferred PCPs handle their general preventive care, many did not identify PCPs as their preferred providers for cancer screening and surveillance, suggesting a need for both patient and provider education about the ability of PCPs to deliver this care. Efforts to clarify provider roles to patients, and in particular, the roles of PCPs in cancer survivorship care, may improve team-based cancer care, satisfaction, and outcomes.

Acknowledgments

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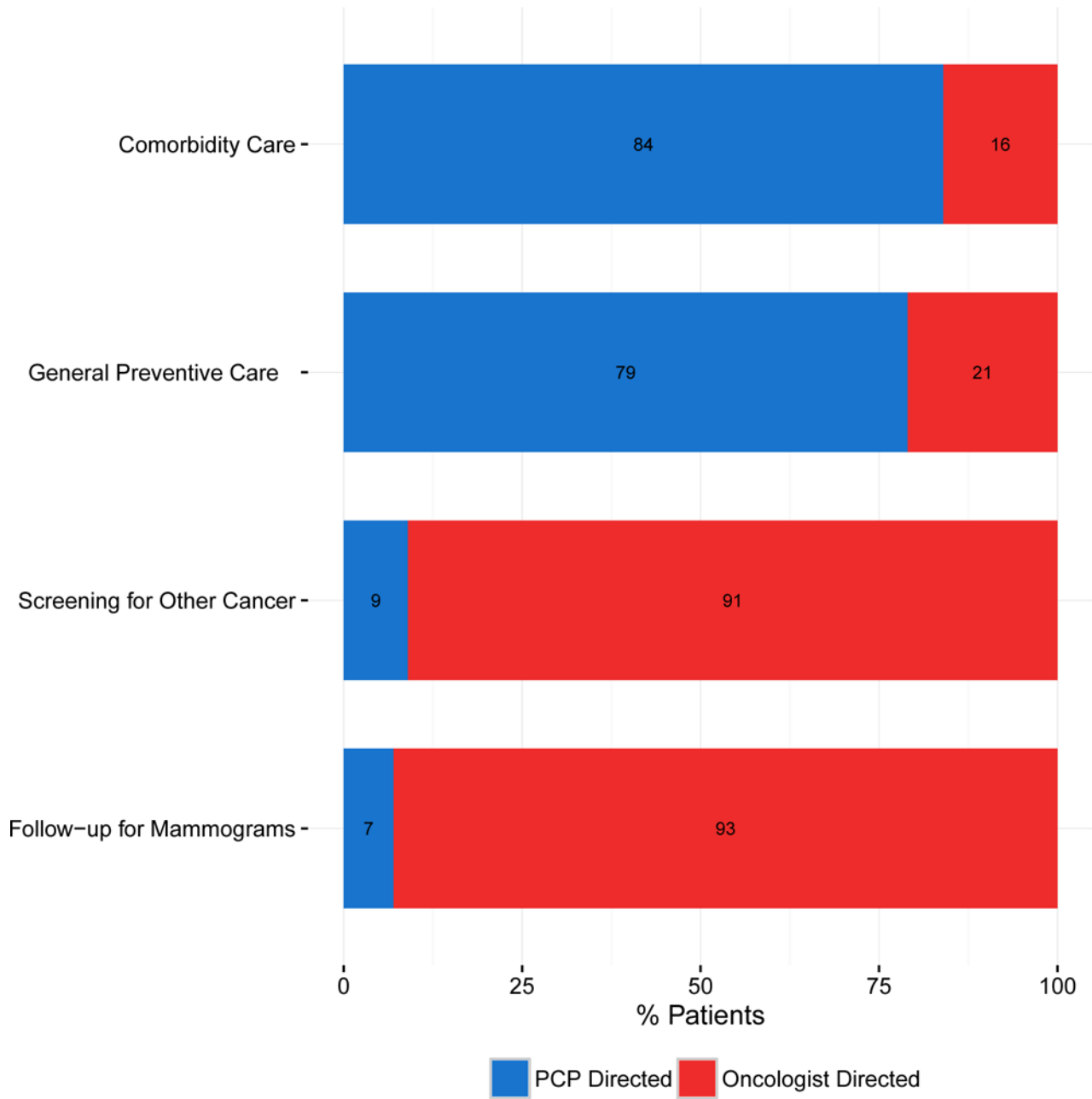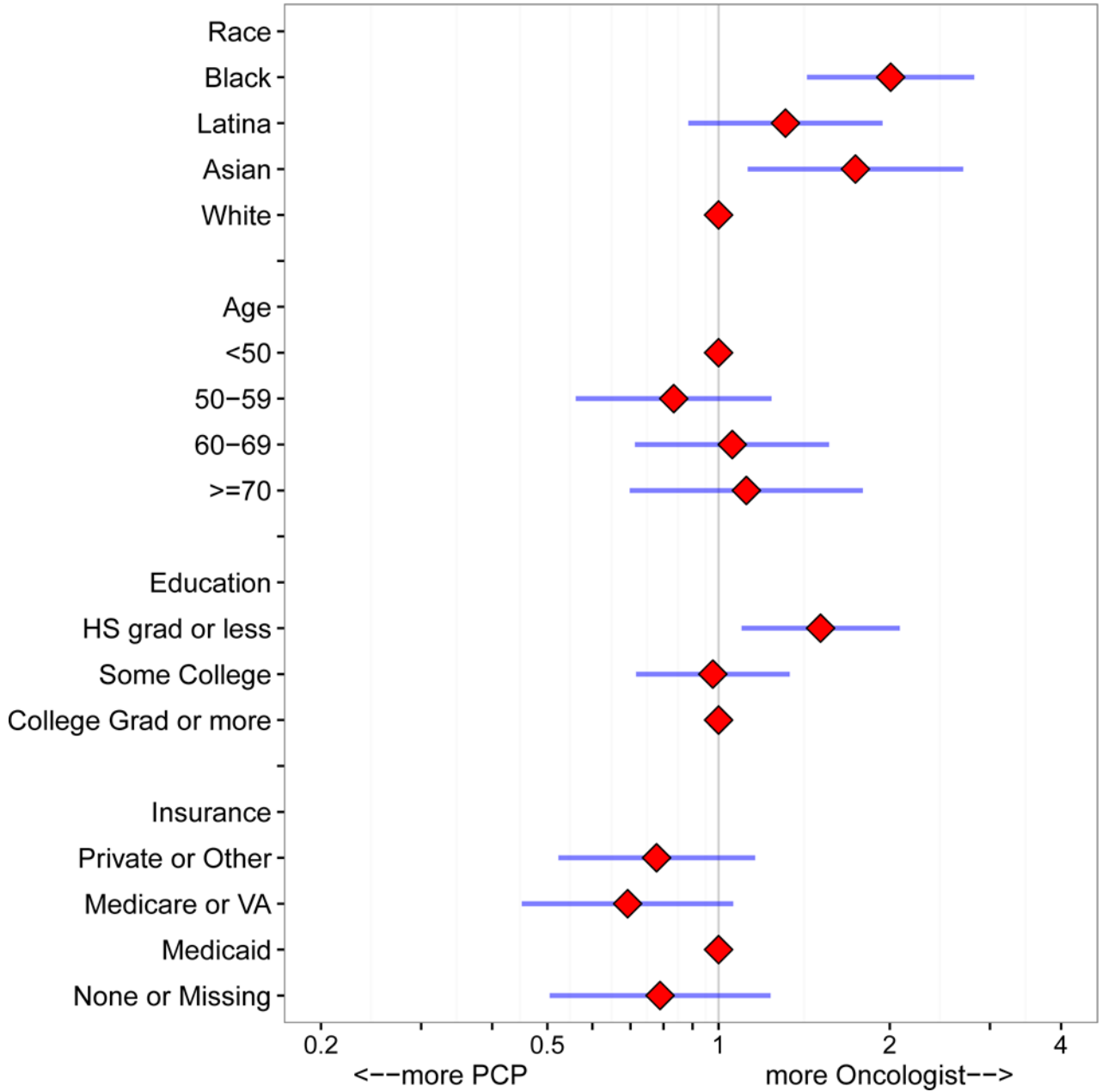
Figure 1.
Patient Preferences for Provider Roles in Survivorship Care (weighted %). *Of the 2372 women, 79 were missing preferences for mammography, 89 were missing second cancer screening, 82 were missing preventive care and 85 were missing comorbidity preferences. **For mammography, 12.6% responded "Either" and 18.6% responded "Both". For second cancer screenings, 12.0% responded "Either" and 14.5% responded "Both". For preventive care, 8.0% and 7.0% responded "Either" or "Both" and for comorbidity care, 5.4% and 6.8% responded "Either" or "Both". "Either" and "Both" were combined with those who responded "Oncologist" into the "Oncologist-directed" category for analyses.

General Preventative Care
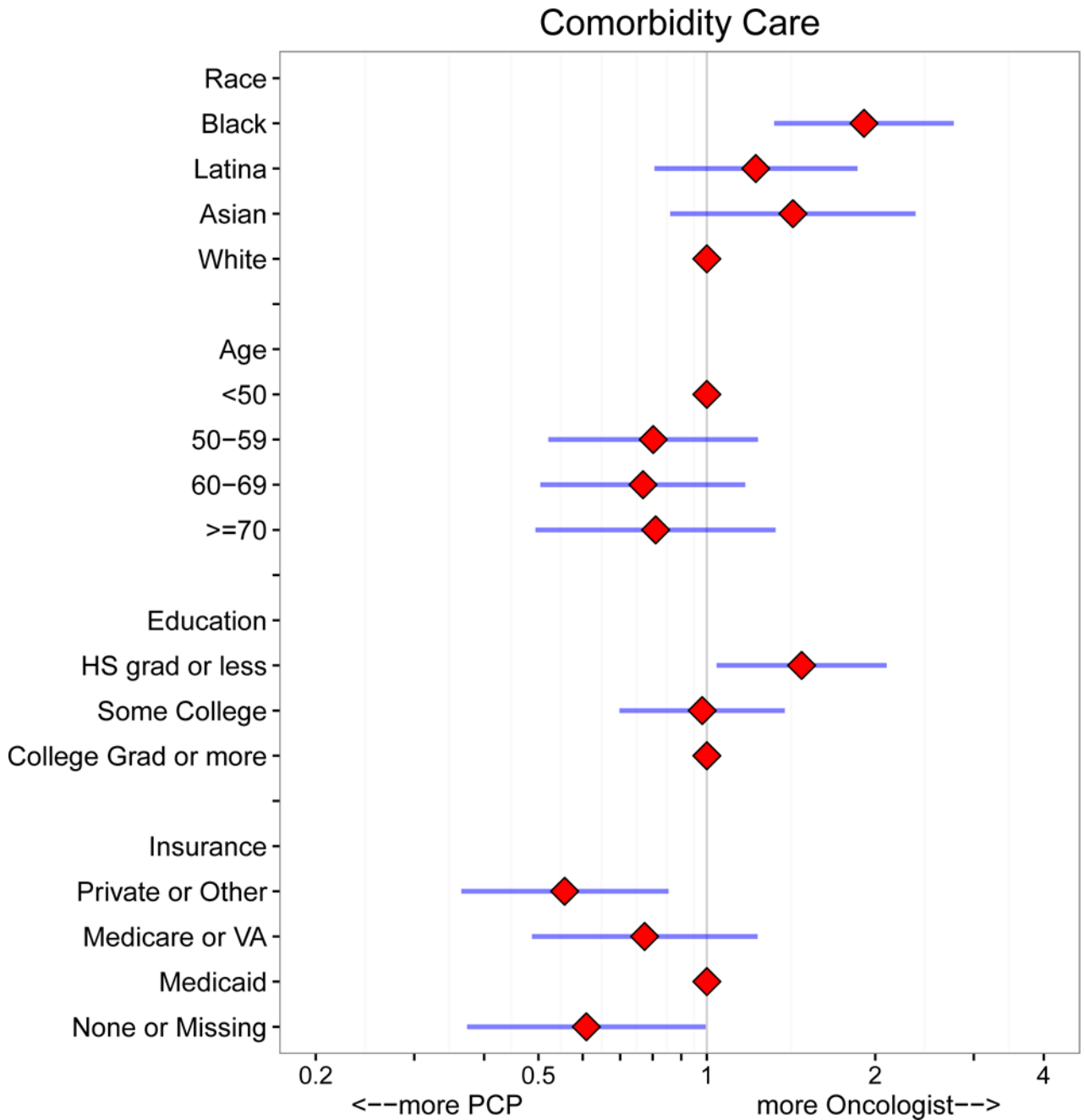
Comorbidity Care

Figure 2.

A–B: Covariate-adjusted ORs and 95% CIs Comparing Patient Preferences for Provider Roles in General Preventive Care (A) and Comorbidity Care (B). ORs were obtained from the logistic regression, which include the following covariates: age, race, education, insurance, comorbidities, treatment, time from diagnosis to survey, radiation treatment, chemotherapy treatment, endocrine therapy, PCP frequency, PCP continuity, and worry about recurrence, and site.

Figure 2A footnote: 286 women out of 2,372 were excluded from the model due to missing values.

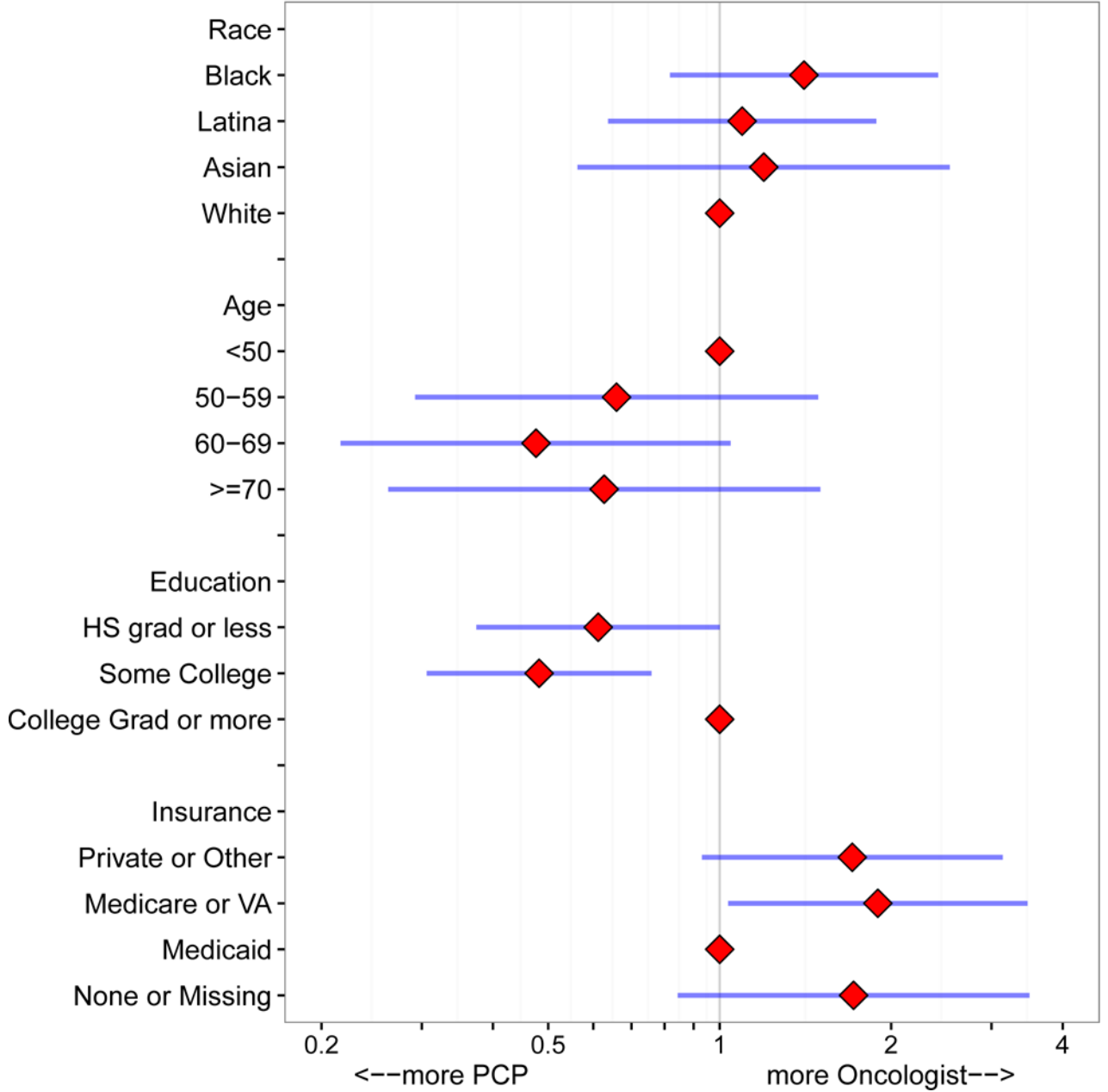Figure 2B footnote: 290 women out of 2372 were excluded from the model due to missing values.
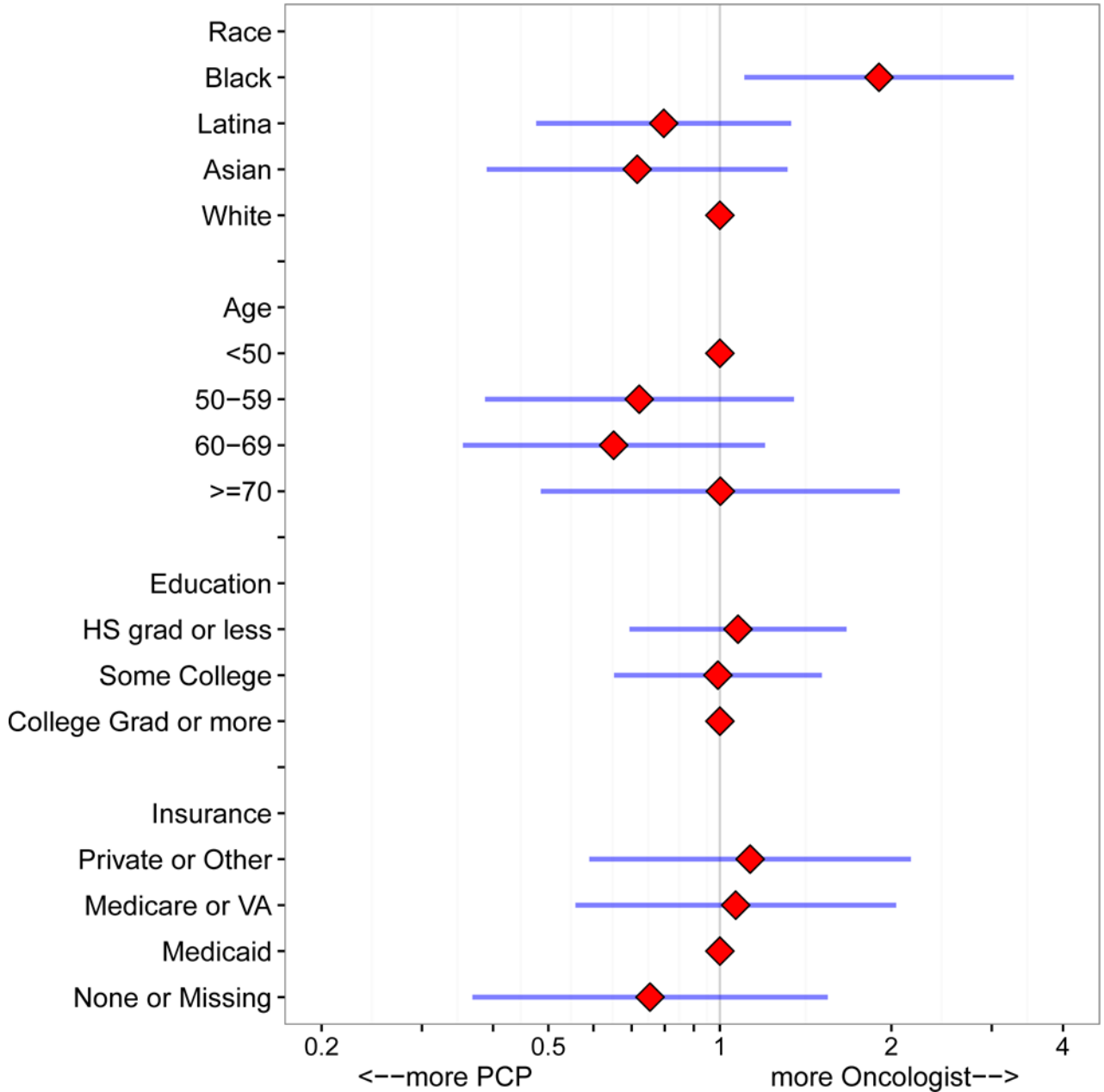
Mammography

Figure 3.

A–B: Covariate-adjusted ORs and 95% CIs Comparing Patient Preferences for Provider Roles in Mammography (A) and Second Cancer Screenings (B). ORs were obtained from the logistic regression, which include the following covariates: age, race, education, insurance, comorbidities, treatment, time from diagnosis to survey, radiation treatment, chemotherapy treatment, endocrine therapy, PCP frequency, PCP continuity, and worry about recurrence, and site.

Figure 3A footnote: 290 of the 2372 women were excluded from the model due to missing values.

Figure 3B footnote: 290 of the 2372 women were excluded from the model due to missing values.

Table 1

Patient demographic and clinical characteristics (n=2,372)

Demographic Characteristics	Weighted %
Age at survey	
<50	13
50–59	24
60–69	35
70+	28
Race	
White	54
Black	18
Latina	15
Asian	10
Other/Unknown/Missing	2
Insurance	
Medicaid	11
Medicare or VA	27
Private or other	46
None/missing	16
Education	
High School Degree	29
Some College	29
College Degree or more	39
Missing	3
Clinical Characteristics	
Comorbid Conditions	
None	70
At least 1 condition	23
>1 condition	6
Surgical Management	
Lumpectomy	63
Unilateral Mastectomy	17
Bilateral Mastectomy	17
Missing	3
Received Chemotherapy	
No	71
Yes	26
Started Endocrine Therapy	

Demographic Characteristics	Weighted %
No	29
Yes	68
Received Radiation Treatment	
No	37
Yes	60
Worry about Recurrence	
Less worry	64
Frequent worry	36
PCP Frequency	
Haven't seen PCP since diagnosis	25
1 visit	25
2 visits	21
3 or more visits	27
PCP Continuity	
< 6 months	9
6–11 months	9
1–2 years	13
> 2 years	67
Site	
Los Angeles	47
Georgia	53
Time from diagnosis to survey (in months) – Mean (SD)	8.30 (3.54)

Table 2

Distribution (weighted %) of Patient Preferences for Provider Roles by Patient Demographic Characteristics

	Mammograms		2nd cancer screening		Preventive Care		Comorbidity Care	
	PCP (%)	Oncology (%)	PCP (%)	Oncology (%)	PCP (%)	Oncology (%)	PCP (%)	Oncology (%)
Age								
<50	4	96	6	94	78	22	81	19
50–59	5	95	9	91	80	20	83	17
60–69	8	92	10	90	80	20	85	15
70+	8	92	8	92	79	21	84	16
p-values	0.056		0.294		0.892		0.479	
Race								
White	7	93	9	91	85	15	89	11
Black	6	94	6	94	72	28	79	21
Latina	7	93	9	91	72	28	77	23
Asian	6	94	11	89	71	29	77	23
Other/missing	11	89	14	86	81	19	84	16
p-values	0.786		0.1418		<0.0001		<0.0001	
Education								
HS Graduate	8	92	9	91	73	27	78	22
Some College	9	91	8	92	82	18	86	14
College Graduate	5	95	9	91	83	17	87	13
p-values	0.002		0.809		<0.0001		<0.0001	
Insurance								
None or Missing	7	93	11	89	75	25	81	19
Medicaid	10	90	9	91	68	32	72	28
Medicare or VA	7	93	8	92	82	18	85	15
Private or Other	6	94	8	92	81	19	87	13
p-values	0.160		0.456		<0.0001		<0.0001	