Follow-Up Care Experiences and Perceived Quality of Care Among Long-Term Survivors of Breast, Prostate, Colorectal, and Gynecologic Cancers

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Abstract

Introduction: Post-treatment follow-up represents a crucial aspect of quality cancer care; however, data are lacking regarding follow-up care experiences, perception of provider involvement in care, and perceived quality of care from diverse samples of long-term survivors diagnosed as adults.

Methods: Questionnaires were mailed in 2005 to 2006 to breast, prostate, colorectal, endometrial, and ovarian cancer survivors (4 to 14 years after diagnosis), sampled from California SEER cancer registries.

Results: Most survivors ($n = 1,490$) reported recent follow-up care (68.7%), generally from oncology specialists only (47.4%) or shared between oncology and primary care providers (PCPs; 27.6%). Most survivors reported follow-up care advice (79.9%); fewer reported late-effects advice or receipt of a treatment sum-

mary (41.7% and 19.9%, respectively). Survivors who identified a PCP as their main follow-up care physician were as likely as those identifying an oncology specialist to rate their care as high quality (odds ratio [OR], 2.56; 95% CI, 0.98 to 6.74); however, survivors who could not identify a main follow-up care provider were less likely to report high-quality care (OR, 0.20; 95% CI, 0.08 to 0.50). Compared with follow-up care by an oncology specialist only, care by a PCP only was associated with a lower quality-of-care rating (OR, 0.34; 95% CI, 0.13 to 0.91), but there was no significant difference in quality rating by survivors when care was shared by an oncology specialist and PCP compared with an oncology specialist only.

Conclusion: Long-term survivors commonly report follow-up care years after their diagnosis; however, many patients' follow-up lacks important components. Care is more likely to be rated as high quality when one main provider is identified and an oncology specialist is involved.

Introduction

With continued advances in early detection, improved treatments, and an aging population, the number of cancer survivors living ≥ 5 years after their diagnosis, commonly called long-term survivors, is now almost 8.7 million.¹ Continued follow-up after cancer treatment is a crucial component of cancer care for shorter- and longer-term survivors, with goals of preventing, detecting, and addressing cancer recurrence, second cancers, late and long-term effects of treatment, and psychosocial sequelae.²⁻⁴

Prior follow-up care studies have used administrative data such as SEER-Medicare linkage⁵⁻¹¹ to provide important data on types of providers seen and billable services provided to cancer survivors. However, studies focused on patients' perspective may provide a more comprehensive picture of follow-up care among adult survivors. Knowing survivors' perception of who is in charge of and/or involved in their follow-up care and of the reasons for care, as well as their recollection of follow-up care information and advice, is important for evaluating potential models of follow-up care and potential correlates of perceived care quality.

Limitations of prior follow-up care studies involving the patient perspective include focus on survivors relatively early in the trajectory or a single cancer type^{12,13} and limited racial and

ethnic diversity.^{13,14} To better understand the experiences of diverse long-term survivors of breast, prostate, colorectal, and gynecologic cancers, the National Cancer Institute sponsored the Follow-Up Care Use Among Survivors (FOCUS) study. Goals of the present analysis were to describe survivors': one, recalled information about follow-up care; two, perception of which providers are involved in follow-up care and who is the main follow-up care provider; and three, reasons for seeking follow-up care. Additionally, we identified correlates of follow-up care information and perceived follow-up care quality.

Methods

Participants and Procedures

FOCUS^{15,16} was a population-based, cross-sectional study of adult survivors of breast, prostate, colorectal, and gynecologic (endometrial and ovarian) cancers with oversampling of ethnic minority participants. Institutional review boards at participating sites approved study procedures.

Patient cases were sampled from the Los Angeles County Cancer Surveillance Program and the Greater Bay Area Cancer Registry (National Cancer Institute SEER programs), stratified

by time since diagnosis (4 to 9 and 10 to 14 years). Provisionally eligible survivors were mailed a survey between March 2005 and July 2006. Participants had to read English and have completed active treatment. Survivor addresses were traced using multiple services, and trained telephone interviewers encouraged participants to complete the survey if it was not returned. Voluntary return of the questionnaire after the provision of study information was considered informed consent.

Measures

Sociodemographic and clinical variables were assessed via self-report (age, sex, race/ethnicity, education, and health insurance coverage) and registry data (cancer site, date of diagnosis, and American Joint Commission on Cancer and SEER summary stage at diagnosis). Cancer treatment was assessed via self-report (all modalities) and from the registry (for surgery and radiation therapy); report in either source was considered receipt of modality. We summed self-reported major medical comorbidities other than cancer, including heart attack, chest pain, heart failure, stroke, hypertension, chronic lung disease, diabetes, liver disease, osteoporosis, depression or anxiety, arthritis, inflammatory bowel disease, and blood clots (range, zero to 13). This list was adapted from comorbidity measures used in prior survivor studies.^{17,18}

Follow-Up Care Variables

FOCUS information and survey items are available online.¹⁹ The questionnaire provided a general description and examples of follow-up care before the specific questions about use of follow-up care to help respondents distinguish between general medical care and cancer-specific follow-up care.

Recalled information about follow-up care. Survivors reported: one, if they were ever told by any treating physician that they needed regular follow-up care and monitoring after cancer treatment was over; two, if a physician or health professional ever discussed what late or long-term adverse effects they may experience; and three, if they received a written summary mentioning details of their treatment and other important cancer care information when they completed treatment. These items were adapted from a previous study of non-Hodgkin lymphoma survivors.¹⁸ Eight additional questions assessed reasons for seeking follow-up care in the past 2 years.

Follow-up care providers. Survivors reported if they had ever seen a physician for cancer-related follow-up care and the frequency of follow-up care in the past 2 years. Questions regarding follow-up care providers seen in the past 2 years included: one, specialties of physicians seen (defined as oncology or cancer-related specialist only, primary care only, oncologist/specialist and primary care, or other/unknown), and two, specialty of a physician considered to be the main physician for cancer-related follow-up care (none identified, primary care, oncology or cancer-related specialist, or other). Following methodology used by Pollack et al,¹¹ cancer-related specialists included oncologists as well as obstetricians/gynecologists for endometrial and ovarian cancers, urologists for prostate cancer, and gastro-

enterologists for colorectal cancer. Additional questions were asked regarding use of other medical care in the past 2 years.

Perceived quality of follow-up care. Survivors who received cancer-related follow-up care in the past 2 years rated the overall quality of their care on a poor, fair, good, very good, and excellent response scale.¹¹

Analytic Plan

Follow-up care variable frequencies were examined for the total sample and by cancer site. Next, multivariable logistic regression models were conducted for three outcome variables (advice about follow-up care, information about late effects, and receipt of a treatment summary), with time since diagnosis, cancer site, age at diagnosis, race/ethnicity, education, number of treatments received, and number of comorbidities as covariates. Finally, we used multivariable logistic regression to examine likelihood of rating follow-up care quality as excellent or very good versus good, fair, or poor. This model included only those survivors who reported receiving follow-up care in the past 2 years and had nonmissing data for the outcome and covariates ($n = 806$). The model included the same sociodemographic and cancer-related variables as the other models, as well as follow-up care characteristics (three recalled information variables, number of follow-up care visits in the past 2 years, specialty of the main follow-up care provider, and follow-up care modalities (oncology only, primary care only, or both). All analyses incorporated sampling weights based on cancer site, age group, race/ethnicity, sex, time since diagnosis, and registry site using SUDAAN statistical software (<http://www.rti.org/sudaan/>).

Results

Of the 4,981 eligible survivors, 2,004 were lost to follow-up; 1,667 of the remaining provided survey data (participation rate, 56%). After excluding survivors who reported a recurrence or second cancer diagnosis within 2 years of survey completion or reported that they were not cancer free, the analytic sample was 1,490 survivors. Among all eligible survivors, those age ≥ 65 years; of minority race; with colorectal, ovarian, or endometrial cancer; and those diagnosed 10 to 14 years ago were less likely to participate (data not shown). Among eligible located patients, the only factors associated significantly with nonresponse were older age, colorectal cancer history, and diagnosis 10 to 14 years ago.

Sample Characteristics

A majority of survivors were age ≥ 65 years (66.5%), well educated (76.2% reported at least some college education), and insured (97.2%; Table 1). Ethnic minorities comprised 50.6% of the sample. Most participants had early-stage cancer (American Joint Commission on Cancer stages 0/I/II, 64.0%).

Survivors' Recalled Information About Follow-Up Care

Most survivors (79.9%) reported being told that they needed cancer-related follow-up care (Table 2). However, only 41.7%

Table 1. Weighted Percent Distribution or Means of Selected Characteristics of Long-Term Survivors of Breast, Prostate, Endometrial, Ovarian, and Colorectal Cancers Recruited From California SEER Cancer Registries (N = 1,490)

Characteristic	All Patients (%)	Breast Cancer (%)	Prostate Cancer (%)	Endometrial Cancer (%)	Ovarian Cancer (%)	Colorectal Cancer (%)
Total No. of patients*	1,490	374	369	192	191	364
Current age, years						
29-64	33.5	43.1	27.7	31.7	59.9	26.8
65-79	46.9	34.4	55.8	43.0	31.6	54.1
≥ 80	19.6	22.5	16.6	25.3	8.5	21.8
Race/ethnicity						
Non-Hispanic white	49.4	60.4	38.0	59.6	56.7	49.8
Hispanic white	16.8	11.1	22.8	15.6	13.9	13.9
African American	18.6	12.7	27.9	8.5	5.1	17.5
Asian/Pacific Islander	13.9	15.1	9.6	15.9	19.4	17.6
American Indian/Alaska Native	1.3	0.6	1.7	0.3	4.7	1.1
Sex						
Male	49.4	0.0	100.0	0.0	0.0	53.7
Female	50.6	100.0	0.0	100.0	100.0	46.3
Education						
≤ High school	23.8	22.5	25.5	21.4	21.1	24.0
Some college	37.8	36.1	35.7	41.1	38.5	41.6
College graduate	38.4	41.4	38.8	37.5	40.4	34.4
Health insurance						
None	2.8	2.3	2.0	4.4	4.9	3.6
Public only	20.8	12.1	29.8	16.8	8.8	19.4
Private (± Medicare)	76.3	85.6	68.2	78.8	86.3	77.0
Mean No. of comorbidities*†	2.1	2.3	2.0	2.3	1.8	2.2
Time since diagnosis, years						
4-9	52.1	23.1	65.6	54.0	61.7	57.7
10-14	47.9	76.9	34.4	46.0	38.3	42.3
AJCC stage‡						
0/I	41.1	56.3	21.9	79.6	61.4	32.6
II	22.9	32.1	15.4	10.9	14.0	34.5
III	15.2	4.6	15.3	4.2	19.9	31.9
IV	1.6	0.3	2.0	4.1	4.4	0.3
Unknown/unstaged	19.2	6.7	45.3	1.2	0.3	0.7
Treatment						
Surgery	84.7	96.5	68.6	95.6	96.2	90.9
Chemotherapy	30.5	47.3	2.8	11.9	72.3	59.9
Radiation therapy	34.7	51.7	35.6	35.7	5.3	20.7
Maintenance/hormonal therapy	19.0	54.3	8.9	9.0	4.7	5.1
Mean No. of treatments received*	1.7	2.5	1.2	1.5	1.8	1.8

Abbreviation: AJCC, American Joint Commission on Cancer.

* Value given is number rather than percent.

† Comorbidities were counted from 13 possible major medical conditions.

‡ SEER-modified AJCC staging (third edition; 1988 to 2003).

reported that a physician had discussed late and long-term effects of cancer treatment; 19.9% received written treatment summaries. Endometrial cancer survivors reported the lowest rates of advice regarding follow-up care and late and long-term effects. Prostate cancer survivors had the highest reports of long-term effects advice and treatment summaries.

In adjusted models (Appendix Table A1, online only), 4- to 9-year survivors were 1.5 to 1.8× as likely as those in the 10- to

14-year group to report advice regarding follow-up care or late effects of treatment and to receive a treatment summary (all $P < .05$). Compared with breast cancer survivors, prostate cancer survivors were more likely to report advice about late effects and receive treatment summaries (odds ratio [OR], 5.83; 95% CI, 3.23 to 10.53 and OR, 2.72; 95% CI, 1.30 to 7.72, respectively). Colorectal cancer survivors were also more likely than breast cancer survivors to report receiving a treatment

Table 2. Weighted Percent Distribution of Cancer-Related Follow-Up Care Characteristics Reported by Long-Term Survivors of Breast, Prostate, Endometrial, Ovarian, and Colorectal Cancers: FOCUS Study (N = 1,490)

Characteristic	All Patients (%)	Breast Cancer (%)	Prostate Cancer (%)	Endometrial Cancer (%)	Ovarian Cancer (%)	Colorectal Cancer (%)	P
Total No. of patients*	1,490	374	369	192	191	364	
Ever received follow-up care	82.9†	85.7	81.5	70.5	91.6	86.6	.002
Follow-up visits in past 2 years							.002
0	31.3	32.0	30.0	45.7	20.5	28.4	
1-2	31.3	33.3	28.5	28.4	29.1	36.1	
3-4	25.1	22.3	30.8	19.2	25.1	21.0	
≥ 5	12.3	12.4	10.6	6.7	25.2	14.5	
Specialty of main follow-up care physician‡§							< .001
No primary follow-up physician	13.7	10.6	11.3	14.2	10.9	20.1.7	
Primary care	17.1	22.4	18.5	9.3	6.7	14.6	
Oncology or cancer-related specialty	67.2	64.4	69.5	76.3	82.4	59.0	
Other	2.0	2.7	0.7	0.2	0.0	4.8	
Physician type seen for follow-up care in past 2 years§							< .001
Oncology or cancer specialty only	47.4	35.9	52.6	58.8	58.1	43.3	
Primary care only	15.8	21.7	13.7	13.4	5.9	16.7	
Oncology or specialty plus primary care	27.6	29.5	27.7	19.0	30.1	28.2	
Other/unknown	9.2	13.0	6.1	8.8	6.0	11.8	
> One provider seen for follow-up care in past 2 years§	40.8	38.4	39.1	32.0	51.2	46.5	.20
PCP involvement in past 2 years‡§							
Has PCP	96.5	96.6	97.8	96.9	93.1	94.9	.004
Primary care visit	73.5	72.8	72.8	77.6	69.0	74.7	.747
Cancer-related care by PCP	43.4	51.2	41.4	32.4	35.9	45.0	.094
Reasons for follow-up care§							
Check for recurrence	71.1	74.4	70.7	46.1	79.9	76.1	.002
Screening for other cancer	66.1	76.8	58.5	69.5	69.9	65.2	.023
Routine physical examination	54.2	59.5	48.5	55.8	65.7	54.4	.163
Noncancer screening tests	27.0	35.5	23.3	19.6	23.6	28.0	.109
Check for resulting health problems	27.8	31.7	23.5	33.7	32.4	27.3	.494
Receive additional cancer treatment	13.9	15.3	17.0	10.7	11.9	8.5	.269
Adverse effect or symptom treatment	12.3	18.1	13.0	7.1	9.1	7.7	.057
Obtain referral	9.3	11.5	7.6	9.2	11.4	9.1	.835
Recalled information about follow-up care							
Received follow-up care advice	79.9	84.0	76.2	68.2	90.7	85.2	.001
Advised about late effects	41.7	34.6	54.7	31.0	34.1	33.8	< .001
Received treatment summary	19.9	11.5	27.0	13.6	10.9	22.6	.023
Perceived quality of cancer-related follow-up care in past 2 years§							.67
Excellent or very good	77.3	73.6	80.6	78.1	76.3	74.8	
Good, fair, or poor	22.7	26.4	19.4	21.9	23.7	25.2	

Abbreviations: FOCUS, Follow-Up Care Use Among Survivors; PCP, primary care provider.

* Value given is number rather than percent.

† All percentages incorporate weights based on cancer site, age group, race/ethnicity, sex, time since diagnosis, and registry site to reflect sampling design.

‡ Primary care included internal medicine, family medicine, and obstetrics/gynecology (for female survivors). Cancer specialists included urology for prostate cancer, gastroenterology for colorectal cancer, and obstetrics/gynecology for endometrial and ovarian cancers.

§ A total of 230 participants reported that they had never received follow-up care and were not asked additional questions about their follow-up care experiences. Additional 204 participants had not received follow-up care in past 2 years and did not answer questions about physicians seen for follow-up care or reasons for follow-up care.

summary (OR, 2.02; 95% CI, 1.02 to 3.97). African American survivors were less likely to recall follow-up care advice compared with non-Hispanic white survivors (OR, 0.44; 95% CI, 0.24 to 0.80). Survivors who were younger at diagnosis were more likely than older survivors to receive ad-

vice about late treatment effects (*P* value for linear trend < .01), but not general follow-up care advice or treatment summaries. Education and comorbidities were not significantly associated with any of these outcomes, whereas number of cancer treatments was positively associated with advice

regarding both follow-up care and late and long-term effects, but not treatment summaries.

Characteristics of Follow-Up Care

A majority of survivors (82.9%) reported receiving cancer-related follow-up care (Table 2). Although 31.3% of the total sample did not receive any follow-up care in the past 2 years, almost 40% had $\geq$ three follow-up care visits during this time period. Follow-up care frequency was significantly different between survivors 4 to 9 and 10 to 14 years after diagnosis ($\chi^2 = 9.31$; $P < .05$); no follow-up care visits were reported by 24.9% and 38.6% of 4- to 9-year and 10- to 14-year survivors, respectively, with 48.0% and 25.5% reporting $\geq$ three visits in the past 2 years, respectively. Follow-up care was most common among ovarian cancer survivors and least common among endometrial cancer survivors (Table 2).

Reported reasons for recent follow-up care were similar across cancer sites (Table 2). Checking for recurrence of primary cancer and being screened for other cancers were the most common reasons for follow-up care (reported by 71.1% and 66.1% of total sample, respectively). Activities associated with preventive care were also commonly reported: routine physical examination (54.2%) and noncancer screening tests (27.0%). Checking for resulting health problems (ie, late effects) was reported by $<$ one third of survivors (27.8%). Additional cancer treatment (13.9%) and treatment for adverse effects or symptoms (12.3%) were less commonly reported by survivors as reasons for care.

Follow-Up Care Providers

An oncology or cancer-related specialist was most commonly identified as the main follow-up care physician across cancer types (67.2%; Table 2), with 44.8% reporting that the main follow-up care physician also provided initial cancer treatment. A majority of survivors (59.2%) saw a single provider for follow-up care, but 13.7% reported no main physician responsible for cancer-related follow-up care. Most survivors reported use of primary care in the past 2 years (73.5%); however, only 43.4% reported that they received cancer-related follow-up care from their primary care provider (PCP), and only 17.1% identified a PCP as their main follow-up physician (Table 2).

Perceived Quality of Follow-Up Care

Most survivors perceived their recent follow-up care as high quality (excellent or very good, 77.3%). In multivariable models examining associations with perceived follow-up care quality (Table 3), there was no significant difference in likelihood of rating care as high quality between survivors who identified an oncology specialist or a PCP as their main follow-up care physician. In contrast, not having an identified main follow-up care physician compared with having a cancer specialist in charge of care was associated with lower rating of care (OR, 0.20; 95% CI, 0.08 to 0.50). Although the overall effect of follow-up care modalities (oncology only, PCP only, or both) was not statistically significant ($P = .09$), lower care ratings were reported by

survivors receiving follow-up care from a PCP only (OR, 0.34; 95% CI, 0.13 to 0.91), but not those receiving follow-up care from both an oncology specialist and PCP (OR, 0.61; 95% CI, 0.31 to 1.19). Reports of discussions of long-term adverse effects were associated with higher-quality care (OR, 2.09; 95% CI, 1.16 to 3.76), but treatment summary receipt and advice about follow-up care were not. Number of cancer treatments was positively associated with perceived care quality, but number of follow-up care visits was not.

Discussion

Most long-term survivors in our sample reported being advised about follow-up care (79.9%) and continued to receive it 4 to 14 years after their cancer diagnosis (68.7%). However, $<$ half of survivors reported receiving advice about late effects of cancer and its treatment (41.7%) or a cancer treatment summary (19.9%). We did not observe differences in perceived quality or follow-up care advice by cancer site; however, prostate and colorectal cancer survivors were more likely to report receipt of a treatment summary. Use of treatment summaries has been recommended to facilitate patient-physician communication and the transition from active treatment to survivorship.^{2,20} Survivors in this study were diagnosed and treated before the 2006 Institute of Medicine report highlighting the importance of cancer-related follow-up care and implementation of formal survivorship care programs at many cancer centers. Thus, the rates in our study are lower than those from a 2006 to 2010 national study reporting that 38% of survivors received treatment summaries,²¹ and we expect future cohorts to report higher levels.

The majority of survivors continued to receive follow-up care from an oncologist or cancer-related specialist (75%). This finding has implications for health care systems looking to constrain cost and meet a growing demand for oncology services.²² Shared care models have emerged as a way to meet survivors' complex care needs.^{20,23-25} A substantial number of our long-term survivors did see multiple physicians for follow-up care (40.8%); however, few reported receiving care by both an oncology specialist and a PCP (27.6%), which is typically proposed as the preferred model of shared care. Most survivors reported having a PCP (96.5%), but $<$ half reported PCP participation in follow-up care (43.4%). The high rates of oncology and specialist care in this study seem consistent with SEER-Medicare data from 6- to 12-year breast, prostate, colorectal, bladder, and uterine cancer survivors showing that 32.9% of long-term survivors had a billed visit for a cancer specialist and 48.4% for a cancer-related specialist.¹¹ Practice guidelines are not clear regarding optimal duration of follow-up care. Neither American Society of Clinical Oncology guidelines for breast²⁶ and colorectal²⁷ cancers nor 2013 National Comprehensive Cancer Network (NCCN) guidelines for breast, ovarian, prostate, and uterine cancers²⁸ specify an end date for yearly surveillance or follow-up. NCCN colon cancer guideline recommends targeted colon cancer surveillance for 5 years, after which it is recommended that long-term surveillance be managed with "routine good medical care, and monitoring, includ-

Table 3. Adjusted ORs for Excellent and Very Good Perceived Quality of Cancer-Related Follow-Up Care Among Long-Term Cancer Survivors Who Received Follow-Up Care in Past Two Years: FOCUS Study (n = 806)

Predictor	Adjusted OR	95% CI	P*
Current age, years			
< 65	1.00	Ref	
65-79	0.86	0.47 to 1.57	
≥ 80	1.51	0.67 to 3.42	
Race/ethnicity			
Non-Hispanic white	1.00	Ref	
Hispanic white	0.92	0.37 to 2.30	
African American	0.38	0.20 to 0.74	
Asian/Pacific Islander	0.32	0.17 to 0.59	
Cancer type			
Breast	1.00	Ref	
Prostate	0.94	0.20 to 4.50	
Endometrial	1.45	0.47 to 4.46	
Ovarian	1.42	0.57 to 3.58	
Colon/rectum	2.07	0.75 to 5.68	
Education			.37
≤ High school	0.70	0.32 to 1.53	
Some college	0.51	0.28 to 0.91	
College graduate	1.00	Ref	
Sex			
Male	1.00	Ref	
Female	0.29	0.08 to 1.05	
No. of comorbidities (per additional comorbidity)†	1.05	0.89 to 1.24	
Health insurance			
Private	1.00	Ref	
Public only	0.73	0.37 to 1.43	
None	1.79	0.17 to 19.25	
Time since diagnosis, years			
4-9	1.00	Ref	
10-14	0.59	0.35 to 1.01	
No. of treatment modalities (per additional modality)‡	1.47	1.00 to 2.17	
Main follow-up care specialty§			
Oncology or cancer specialty	1.00	Ref	
Primary care	2.56	0.98 to 6.74	
No main follow-up provider identified	0.20	0.08 to 0.50	
Follow-up care modality§			
Oncology or cancer specialty only	1.00	Ref	
Primary care only	0.34	0.13 to 1.91	
Oncology or specialty plus primary care	0.61	0.31 to 1.19	
No. of follow-up care visits in past 2 years			.17
1-2	1.00	Ref	
3-4	1.33	0.68 to 2.61	
≥ 5	1.60	0.81 to 3.15	
Recalled follow-up care (yes v no)			
Received follow-up care advice	0.79	0.32 to 1.99	
Advised about late effects of treatment	2.09	1.16 to 3.76	
Received treatment summary	0.98	0.49 to 1.95	

NOTE. Bold font indicates statistically significant parameters ($P < .05$).

Abbreviations: FOCUS, Follow-Up Care Use Among Survivors; OR, odds ratio.

* Linear trend.

† Comorbidities were counted from 13 possible major medical conditions.

‡ Cancer treatments included radiation therapy, chemotherapy, surgery, and hormonal therapies.

§ Primary care included internal medicine, family medicine, and obstetrics/gynecology (for female survivors). Cancer specialists included urology for prostate cancer, gastroenterology for colorectal cancer, and obstetrics/gynecology for endometrial and ovarian cancers.

ing cancer screening." The NCCN colon cancer guideline is also the only guideline to mention transferring care to primary care.

The inclusion of multiple providers in follow-up care suggests challenges for care coordination.^{2,24,25} Importantly, 14% of survivors could not identify a main follow-up care provider, and these survivors were significantly less likely to report high-quality care. We could not ascertain whether care received from multiple providers was complementary or duplicative, but this will be a crucial topic for future studies, as will health-related outcomes achieved by different care models. Although survivors who identified a PCP as their main follow-up care physician were as likely as those who identified a cancer specialist to perceive their follow-up care as high quality, those who received follow-up care by only a PCP were less likely than those seeing only an oncologist to rate this care as high quality. This suggests that survivors are comfortable with a PCP as their main follow-up care physician as long as an oncology specialist is also involved. This adds to the literature suggesting that shared care models, led by either PCPs or oncology providers, may be acceptable to survivors.^{23,29}

Our study focused on follow-up care provided by physicians, but increasingly, survivorship care models are focusing on the role of nurse practitioners and physician assistants. Future studies should examine their role in care. It will also be important to monitor how ongoing changes in oncology and primary care associated with the Patient Protection and Affordable Care Act and the rise of accountable care organizations will affect follow-up care among survivors, particularly among the underinsured.

Survivors seem to believe that follow-up care is largely for cancer surveillance (ie, checking for recurrence or new cancer development). Only 27.8% reported that screening for late effects was a reason for recent care; however, survivors who reported advice about late effects also rated that care as higher quality. Given the critical importance of late effects among long-term survivors, better survivor and provider education regarding the reasons for and content of survivorship care should be a focus of future research and practice. As the growing literature provides a stronger evidence base for the role of screening for late and long-term effects in long-term patient outcomes,³⁰ it will be important to incorporate screening modalities that offer early detection and better management of late effects.

An important strength of our population-based study is our diverse sample of long-term survivors, nearly half of whom belonged to racial/ethnic minorities and 20% of whom were age $\geq$ 80 years. Nevertheless, there are limitations to this study. First, this sample was recruited from two registries in California and may not be reflective of survivors from other regions. Second, we relied on survivors' recall of providers seen, frequency of care, and follow-up care discussions. Recollection may be challenging, especially for more

distal visits; however, much of the information gathered from survivors in this study (eg, perception of responsibility for follow-up care) is not available in billing or medical records. It is also possible that providers may have different perceptions of topics covered during survivorship care encounters. Third, we used a single-item general assessment of perceived quality. Although these types of items have been used in prior studies,¹⁴ we could not examine differences among aspects of care quality, such as patient-provider communication or accessibility. Fourth, follow-up care experiences of our sample may differ from those of shorter-term survivors, including survivors diagnosed with more lethal cancers, but are relevant to other long-term survivors. Finally, our modest participation rate is similar to response rates of other long-term survivor survey studies^{31,32} and was primarily driven by difficulty locating survivors many years after treatment.

As the number of US cancer survivors approaches 14 million,¹ extended medical care is emerging as a public health concern. Our study provides valuable information regarding types of providers seen and perceived quality of care during the extended survivorship years. Continued research should inform survivorship care models that are efficient, equitable, and affordable and that reduce morbidity and premature mortality resulting from cancer.

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Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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Appendix

Table A1. Correlates of Recalled Information About Cancer-Related Follow-Up Care Among Long-Term Survivors of Breast, Prostate, Endometrial, Ovarian, and Colorectal Cancers

Predictor	Received Follow-Up Care Advice (n = 1,396)			Advised About Late Effects of Treatment (n = 1,337)			Received Treatment Summary (n = 1,236)		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Time since diagnosis, years			.04*			< .01*			.01*
4-9	1.59	1.01 to 2.50		1.80	1.27 to 2.57		1.78	1.15 to 2.76	
10-14	1.00	Ref		1.00	Ref		1.00	Ref	
Cancer site			.01*			< .01*			< .01*
Breast	1.00	Ref		1.00	Ref		1.00	Ref	
Prostate	1.29	0.63 to 2.64		5.83	3.23 to 10.53		2.72	1.30 to 7.72	
Endometrial	0.61	0.29 to 1.30		1.51	0.81 to 2.79		1.15	0.46 to 2.89	
Ovary	2.10	0.91 to 4.89		1.16	0.66 to 2.04		0.76	0.34 to 1.70	
Colon/rectum	1.88	0.96 to 3.67		1.44	0.86 to 2.43		2.02	1.02 to 3.97	
Race/ethnicity			.05*			.20*			.53*
Non-Hispanic white	1.00	Ref		1.00	Ref		1.00	Ref	
Hispanic white	0.70	0.36 to 1.34		0.70	0.40 to 1.24		0.80	0.39 to 1.62	
African American	0.44	0.24 to 0.80		0.98	0.59 to 1.61		1.25	0.70 to 2.25	
Asian/Pacific Islander	0.59	0.37 to 1.07		1.25	0.85 to 1.82		0.83	0.48 to 1.45	
Education			.14†			.06†			.17†
≤ High school	0.64	0.36 to 1.16		0.61	0.36 to 1.02		0.63	0.33 to 1.22	
Some college	0.85	−0.50 to 1.45		0.91	0.61 to 1.37		1.03	0.62 to 1.72	
College graduate	1.00	Ref		1.00	Ref		1.00	Ref	
Age at diagnosis, years			.08†			< .01†			.35†
< 50	1.90	0.93 to 3.89		2.28	1.38 to 3.78		1.40	0.69 to 2.83	
50-64	1.56	0.95 to 2.57		1.32	0.89 to 1.97		1.42	0.87 to 2.33	
≥ 65	1.00	Ref		1.00	Ref		1.00	Ref	
No. of comorbidities‡	0.95	0.82 to 1.10		0.97	0.86 to 1.09		0.95	0.82 to 1.10	
No. of cancer treatments§	2.02	1.46 to 2.79		1.89	1.49 to 2.39		1.17	0.87 to 1.58	

NOTE. Bold font indicates statistically significant parameters ($P < .05$).

Abbreviation: OR, odds ratio.

* Overall P .

† Linear trend.

‡ Comorbidities were a count from 13 possible major medical conditions.

§ Cancer treatments included radiation, chemotherapy, surgery, and hormonal therapies.