

# Social support, self-efficacy for decision-making, and follow-up care use in long-term cancer survivors

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## Abstract

**Objective:** Cancer survivors play an important role in coordinating their follow-up care and making treatment-related decisions. Little is known about how modifiable factors such as social support are associated with active participation in follow-up care. This study tests associations between social support, cancer-related follow-up care use, and self-efficacy for participation in decision-making related to follow-up care (SEDM). We also identified sociodemographic and clinical factors associated with social support among long-term survivors.

**Methods:** The Follow-up Care Use among Survivors study is a cross-sectional, population-based survey of breast, prostate, colon, and gynecologic cancer survivors ( $n = 1522$ ) 4–14 years post-diagnosis. Multivariable regression models were used to test associations between perceived social support (tangible and emotional/informational support modeled separately), follow-up care use (past 2 years), and SEDM, as well as to identify factors associated with perceived support.

**Results:** Neither support type was associated with follow-up care use (all  $p > 0.05$ ), although marital status was uniquely, positively associated with follow-up care use ( $p < 0.05$ ). Both tangible support (B for a standard deviation increase (SE) = 9.75(3.15),  $p < 0.05$ ) and emotional/informational support (B(SE) = 12.61(3.05),  $p < 0.001$ ) were modestly associated with SEDM. Being married, having adequate financial resources, history of recurrence, and better perceived health status were associated with higher perceived tangible and emotional support (all  $p < 0.05$ ).

**Conclusions:** While perceived social support may facilitate survivor efficacy for participation in decision-making during cancer follow-up care, other factors, including marital satisfaction, appear to influence follow-up care use. Marital status and social support may be important factors to consider in survivorship care planning.

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## Introduction

Growth in the number of survivors who are living longer after cancer [1,2] has generated increased attention to optimizing cancer follow-up care [3]. Follow-up care encompasses prevention, detection, and treatment of recurrence, second cancers, and long-term and late physical and psychological effects of cancer or its treatment [3]. Patient-centered models of care recognize the key role that patients play in the receipt and coordination of cancer follow-up care, as well as in making decisions about the management of the adverse effects of cancer [4]. Yet, little is known about how modifiable factors such as social support may enable survivors to actively participate in

their cancer follow-up care. Perceived social support, a multidimensional construct including tangible aspects (i.e., perceived availability of practical resources such as transportation) and emotional or informational aspects (i.e., perceived acceptance, empathy, assistance with coping) [5,6], is widely acknowledged as beneficial for health after cancer, including psychological adaptation [7–10], quality of life [11–13], and, in some cases, survival [14,15]. However, associations between social support and participation in health care have received less attention in the literature.

Perceived social support may affect receipt of cancer follow-up care through the availability of practical assistance obtaining and attending appointments, or, as observed for other chronic health conditions, through creation of

an emotionally supportive environment, which facilitates healthy behavior and treatment adherence [16–19]. However, attendance at follow-up care appointments does not guarantee active participation in patient-centered care. Perceived social support may also increase *active involvement* in follow-up care; for example, through increasing self-efficacy for participating in decision-making [20], a core skill necessary for self-management of chronic illness [4]. Self-efficacy for decision-making (SEDM) has been positively associated with survivors' sense of control, asking questions of providers, actual participation in treatment-related decisions, and health-related quality of life [21–23]. Thus, perceived social support might affect health and adjustment in long-term cancer survivors via self-efficacy for, and ultimately participation in, treatment-related decision-making.

Most research on social support in cancer survivors is based on middle-aged, Caucasian, breast cancer survivors within 5 years of diagnosis. The Follow-up Care Use among Survivors (FOCUS) study offers a unique opportunity to examine the role of social support in cancer-related follow-up care using a population-based sample of long-term survivors that is diverse in terms of ethnicity, age, and cancer site. The current study tested associations between both tangible and emotional/informational support and the following: (a) receipt of recent follow-up care and (b) SEDM, hypothesizing positive associations between both support types and both outcomes. Additionally, because identification of those survivors most likely to report low social support may facilitate referral of such individuals to support-enhancing interventions, we also identified sociodemographic and clinical factors associated with social support.

## Methods

### Sample and data collection

This inquiry utilized data from the cross-sectional FOCUS study (<http://cancercontrol.cancer.gov/ocs/focus.html>). A detailed description of the methodology employed in FOCUS has been published elsewhere [24]. Briefly, FOCUS is a population-based, cross-sectional survey of adult survivors of breast, prostate, colorectal, endometrial, and ovarian cancer who were 4–14 years post-diagnosis ( $n=1666$ ). Survivors were recruited from two Surveillance, Epidemiology, and End Results cancer registries in California: the Los Angeles County Cancer Surveillance Program and the Greater Bay Area Cancer Registry at the Cancer Prevention Institute of California. The study was approved by the institutional review boards at the Northern California Cancer Center (now Cancer Prevention Institute of California) and the University of Southern California, in accord with assurances filed with and approved by the US Department of Health and Human

Services. Mailed surveys were fielded between March 2005 and July 2006. Survivors eligible for the FOCUS study were diagnosed with cancer at age 21 or older, able to read English, and had completed active treatment. A total of 4981 eligible cases were sampled by the registries. Of the eligible cases, 2977 were located and 1666 completed the survey (overall participation rate based on located cases = 56%). Among located cases, nonrespondents were more likely to be older, non-White, diagnosed with colorectal or gynecologic cancers, and diagnosed longer ago (all  $p < 0.05$ ). The current analytic sample ( $n = 1522$ ) excluded respondents who were not cancer free at the time of survey ( $n = 84$ ), who were missing >25% of social support items ( $n = 32$ ), or who reported American Indian/Alaska Native descent ( $n = 28$ , small sample would preclude comparisons by race/ethnicity). Male survivors and survivors of prostate or ovarian cancer (compared with breast cancer) were more likely to be excluded ( $p < 0.05$ ).

## Measures

### Social support

Perceived social support was measured using a short form of the Medical Outcomes Study Social Support Scale, which measures perceived instrumental, informational, and emotional support [6]. The full measure contains 19 items and is scored from 0 to 100, with higher scores indicating better social support. The instrument was shortened in consultation with the instrument's author [25] to a 12-item version scored similarly to the longer version. The shortened version has been used in large epidemiological surveys [19,25]. The measure does not specify a referent time frame over which support should be evaluated. Exploratory factor analysis using principle components analysis and promax (oblique) rotation provided a 2-factor solution accounting for 74.9% of the variance: tangible support (four items, Cronbach's  $\alpha = 0.92$ ) and emotional/informational support (eight items, Cronbach's  $\alpha = 0.94$ ). The interfactor correlation was 0.64. As part of the Medical Outcome Study Scale, survivors also identified the one person who is most likely to help them with day-to-day activities (spouse/significant other, sibling, parent, child, friend) and the number of close friends or relatives with whom they feel at ease and can talk about what is on their mind. We measured *perceived* support rather than *received* support or other definitions. Perceived support, which is moderately correlated with received support, is the conceptualization of social support most consistently linked to health [26].

### Follow-up care use

The FOCUS team developed questions to assess cancer follow-up care use. Specifically, survivors indicated whether or not they had seen any doctor for cancer-related follow-up care in the past 2 years, as well as when they

last saw any doctor for cancer-related follow-up care (>1 year ago, 7–12 months ago, 4–6 months ago, 1–3 months ago, <4 weeks ago). The National Comprehensive Cancer Network® Clinical Practice Guidelines in Oncology (NCCN Guidelines®) currently recommend annual follow-up including appropriate surveillance examination for survivors  $\geq 5$  years posttreatment of breast [27], prostate [28], ovarian,[29] and endometrial cancer [30]. However, because these guidelines were released between November 2003 and January 2004, only approximately 1 year before FOCUS was fielded, adequate time may not have elapsed for these guidelines to have become common practice. Additionally, survivors on an annual follow-up schedule may schedule appointments immediately after a full year has passed (i.e., in the 13 month), and guidelines for follow-up frequency do not extend beyond 5 years posttreatment for colon [31] and rectal cancer [32]. Given these limitations, we defined recent follow-up care as any cancer-related visit in the past 2 years (yes/no), and we replicated our analyses examining cancer-related follow-up care in the past 12 months as a sensitivity analysis.

#### Self-efficacy for decision-making

The Decision-making Participation Self-efficacy Scale [21] was used to measure survivors' confidence about participating in multiple aspects of medical decisions related to their cancer follow-up care (e.g., letting the physician know he/she has questions, telling the physician which option he/she prefers). Survivors respond to five items on a 5-point Likert scale ranging from 'not at all confident' to 'completely confident'. A SEDM score was computed by summing item scores and then linearly transformed on a 0–100 metric (higher scores reflect greater self-efficacy). This measure has demonstrated high internal consistency among cancer survivors (Cronbach's  $\alpha = 0.89$ ) and convergent validity such that SEDM is positively associated with perceived control and health-related quality of life [21].

#### Survivor characteristics

We collected self-report information on sociodemographic characteristics including age at survey, sex, marital status, race/ethnicity, and education. Additionally, participants indicated if they had adequate financial resources to meet their daily needs over the past 4 weeks (yes/no). Reports of having adequate financial resources were used as an economic indicator rather than annual household income because there was less missing data for adequate financial resources (2.5% vs. 10.2%, respectively); income is a limited predictor of health outcomes, particularly in an older adult population [33]; and perceived financial adequacy may be more predictive of follow-up care use than income [34].

Survivors rated their general health status on a 5-point Likert scale as assessed by the SF-12 [35]. We obtained

data on comorbidity burden using an index of 14 possible conditions (congestive heart failure, cardiomyopathy, heart attack, angina, hypertension, pericarditis, blood clots in the legs or lungs, stroke, chronic lung disease, lung fibrosis, liver disease, diabetes, arthritis, and depression/anxiety) adapted from previous studies of cancer survivors [19,36] and symptom burden using an index of 26 possible problems experienced in the last 6 months [19]. We obtained data on cancer site, stage at diagnosis, and date of diagnosis from the registry. Survivors self-reported history of cancer recurrence and cancer treatment history.

#### Statistical analysis

Analyses were conducted using the Statistical Analysis Software callable version of SUDAAN 10.0 (RTI International, Research Triangle Park, NC). All analyses incorporated population weights, which is necessary in order to account for the complex survey design (sampling based on cancer site, age group, race/ethnicity, gender, time since diagnosis, and registry site). Weighted analyses also allow for inferences intended to reflect the population of cancer survivors, rather than a convenience sample. Prior to analysis, the data were examined using frequencies and descriptive statistics. Multiple logistic or linear regression models tested the association between social support (tangible and emotional/information support modeled separately) and receipt of cancer-related follow-up care or SEDM. For these models, social support was rescaled by the standard deviation (regression coefficients reflect differences in the dependent variable per standard deviation increase in social support). Potential confounders (age, sex, marital status, race/ethnicity, education, insurance, adequate financial resources, cancer site, time since diagnosis, treatment history, history of recurrence, general health status, comorbidity burden, symptom burden) were modeled using backward elimination, with a >10% change in the coefficient for social support indicating confounding to appropriately control confounding and preserve statistical power [37,38]. For models of recent follow-up care use, we developed the fully adjusted models for follow-up care in the past 2 years and then tested models of follow-up care in the past year including the same confounders. To identify the unique predictors of social support, multiple linear regression models simultaneously tested associations between sociodemographic and cancer characteristics selected a priori because of previous or hypothesized associations with support (age, race, gender, marital status, education, adequate financial resources, cancer site, time since diagnosis, history of cancer recurrence, perceived health status) [7,39–42] and tangible and emotional/informational support (in separate models). Survivors in the analytic sample excluded from any multivariable regression models because of missing data on follow-up care use, decision-making self-efficacy,

and/or a covariates were older than those with complete data ( $p < 0.001$ ) but were otherwise similar on race, gender, cancer site, and time since diagnosis (all  $p > 0.05$ ).

## Results

### Sample characteristics

Approximately half of the sample was diagnosed with cancer >10 years ago and reported non-White race/ethnicity (Table 1). Most survivors were older than 65 years (67.0%), married (66.0%), reported at least some

**Table 1.** Descriptive characteristics of long-term cancer survivors in FOCUS ( $n = 1522$ )

	<i>n</i> (weighted %)
Age at survey (years)	
<50	3.9
50–64	29.1
65+	67.0
mean (SD)	69.4 (43.7)
Race/ethnicity <sup>a</sup>	
Non-Hispanic White	590 (51.6)
Hispanic White	217 (16.5)
African-American	367 (18.3)
Asian/Pacific Islander	347 (13.6)
Male	572 (49.8)
Marital status <sup>a</sup>	
Married/living as married	926 (66.0)
Single, widowed, separated, divorced	595 (34.0)
Education <sup>a</sup>	
High school or less	400 (23.9)
Some college	550 (35.9)
College graduate or more	558 (39.1)
Adequate financial resources <sup>a</sup>	
No	165 (10.0)
Insurance <sup>a</sup>	
None/public only	341 (23.0)
Other	1125 (73.8)
Cancer site	
Breast	379 (24.4)
Prostate	376 (38.2)
Colon/rectum	380 (21.5)
Ovary	194 (5.4)
Endometrial	193 (10.6)
Stage at diagnosis <sup>a</sup>	
Localized	708 (39.3)
Regional	334 (19.9)
Distant	95 (2.7)
Localized regional (prostate)	359 (36.5)
Years since cancer diagnosis	
4–9	798 (52.0)
10–15	724 (48.0)
Treatment history	
Chemotherapy	576 (31.1)
Radiation	515 (36.4)
Chemoprevention	324 (19.5)
Recurrence/second cancer	
Yes	218 (15.9)
Perceived health status (1 = excellent, 5 = poor), mean (SD)	2.7 (3.7)
Number of comorbid conditions	
0	275 (19.2)
1–2	756 (49.9)
3+	491 (31.0)
Number of symptoms	
0	128 (8.0)
1–2	241 (16.0)
3+	1153 (76.0)

<sup>a</sup>Variable also includes  $\leq 3\%$  missing data.

college education (75.0%), and reported adequate financial resources (88.3%).

### Perceived social support

Cancer survivors reported relatively high perceived tangible and emotional/informational social support (weighted mean(SD) = 75.2(105.9) and 75.1(90.7), respectively).<sup>1</sup> Most survivors indicated that the one person most likely to help with day-to-day activities was their spouse/significant other (59.5%), followed by child (19.4%), friend (6.5%), sibling (3.6%), or parent (1.0%). More than half (52.0%) of survivors reported at least five close relatives or friends, whereas more than a third (38.6%) indicated having two to four close relatives or friends and a small proportion of survivors reported none to one close friend or relative (9.2%). Survivors who were married/living as married reported higher tangible and emotional/informational support than those who were not married (B(SE) = 21.97(2.17),  $p < 0.001$  and B(SE) = 14.55(1.84),  $p < 0.001$ , respectively).

### Social support, cancer follow-up care use, and self-efficacy for decision-making

Approximately three-quarters of survivors (75.7%, 95% CI = 72.1–78.8) reported using cancer-related follow-up care in the past 2 years. The weighted mean SEDM score was 82.5 (SD = 74.0). Follow-up care use in the past 2 years was not associated with SEDM (B(SE) = 3.22 (1.82),  $p = 0.08$ ). Tangible support was positively associated with follow-up care use in the past 2 years in the unadjusted model ( $p = 0.04$ , Table 2), but this effect was attenuated and nonsignificant after adjustment for confounders. Emotional/information support was not significantly associated with follow-up care use in the past 2 years either before or after adjustment for confounders (all  $p > 0.05$ ). It is notable that survivors who were married/living as married were more likely than unmarried survivors to report follow-up care use in the past 2 years, over and above tangible support and emotional/informational support (OR, 95% CI = 1.48, 1.01–2.15,  $p = 0.04$  and OR, 95% CI = 1.53, 1.04–2.25,  $p = 0.03$ , respectively). Approximately two-thirds of survivors (67.3%, 95% CI = 63.5–70.8%) reported follow-up care in the past year. Repeating our final models using follow-up care in the past year also revealed nonsignificant associations in adjusted models for both tangible and emotional/informational support (Table 2); marital status was again a significant predictor beyond tangible support (OR, 95% CI = 1.70, 1.17–2.47,  $p = 0.01$ ) and emotional/informational support (OR, 95% CI = 1.63, 1.11–2.39,  $p = 0.01$ ).

Both tangible and emotional/informational social support were positively associated with SEDM before adjustment for confounders (all  $p < 0.001$ , Table 2) and after adjustment ( $p = 0.002$  and  $p < 0.001$ , respectively), although the

**Table 2.** Associations between social support, follow-up care use, and self-efficacy for decision-making among long-term cancer survivors

	Unadjusted models		Multivariable models	
	OR (95% CI)*	p	OR (95% CI)*	P
Follow-up care use (past 2 years)				
Tangible support <sup>d,h</sup>	<b>2.25 (1.05–4.84)</b>	<b>0.04</b>	1.52 (0.69–3.32)	0.30
Emotional/informational support <sup>a,d,e,g,h,i</sup>	1.81 (0.85–3.85)	0.12	1.20 (0.56–2.55)	0.64
Follow-up care use (past year)				
Tangible support <sup>d</sup>	1.73 (0.86–3.49)	0.13	1.07 (0.52–2.21)	0.86
Emotional/informational support <sup>a,d,e,g,h,i</sup>	1.89 (0.94–3.81)	0.07	1.27 (0.62–2.60)	0.51
	B (SE)*	p	B (SE)*	P
Self-efficacy for decision-making				
Tangible support <sup>d,o</sup>	<b>13.60 (2.77)</b>	<b>&lt;0.001</b>	<b>9.75 (3.15)</b>	<b>0.002</b>
Emotional support <sup>o</sup>	<b>15.61 (2.96)</b>	<b>&lt;0.001</b>	<b>12.61 (3.05)</b>	<b>&lt;0.001</b>

Bold indicates  $p < 0.05$ .

<sup>a–o</sup>Indicate confounders included in multivariable models:

<sup>a</sup>Race/ethnicity,

<sup>b</sup>Sex,

<sup>c</sup>Age,

<sup>d</sup>Marital status,

<sup>e</sup>Education,

<sup>f</sup>Adequate financial resources,

<sup>g</sup>Insurance,

<sup>h</sup>Time since diagnosis,

<sup>i</sup>Cancer site,

<sup>j</sup>Stage at diagnosis,

<sup>k</sup>History of chemotherapy,

<sup>l</sup>History of radiation,

<sup>m</sup>History of chemoprevention,

<sup>n</sup>Recurrence or second cancer (considered as confounder only for association between social support and self-efficacy for decision-making).

<sup>o</sup>Perceived health status.

<sup>p</sup>Comorbidities.

<sup>q</sup>Symptom burden. Confounders were modeled using backward elimination based on a 10–15% change in the coefficient for social support indicating significant confounding.

\*Per standard deviation increase in social support.

overall variance in SEDM accounted for by these models was modest ( $R^2 = 0.07$  and  $0.08$ , respectively).

### Factors associated with perceived social support

On the basis of multivariable models, survivors who were married, had adequate financial resources, had a history of cancer recurrence or multiple cancers, and perceived better health status reported higher tangible and emotional/informational support (all  $p < 0.05$ , Table 3). Furthermore, survivors with a college degree reported lower emotional/informational support than those with less education ( $p = 0.02$ ). Neither tangible nor emotional/informational support was associated with age, race/ethnicity, gender, cancer site, or time since cancer diagnosis (all  $p > 0.05$ ).

### Discussion

This study examined associations between perceived social support, receipt of recent cancer follow-up care, and self-efficacy for participation in decision-making related to follow-up care among long-term survivors. Contrary to expectations, neither tangible nor emotional/informational support was associated with use of recent cancer follow-up care. Although this finding is consistent with one previous study that failed to find an association

between social support and surveillance for recurrent cancer among breast cancer survivors [43], this null association was surprising because social support has been positively associated with receipt of health care in other circumstances, including receipt of cancer screening in the general population [44,45] and adherence to recommended care for other chronic conditions [17]. Ours and other studies that did not observe an association between social support and receipt of care were all conducted in cancer survivors. Particularly for this population, other factors (e.g., comorbid conditions or symptoms, survivorship care planning, provider recommendations) may play a stronger role in receipt of cancer care than social support. Although effects of marital status on health are often explained by perceived social support, in our study, there was an effect of marital status on recent follow-up care, over and above perceived social support. This finding suggests there is something unique about the resources (either practical or emotional) associated with the marital/partnered relationship as opposed to other relationships (e.g., relatives, friends) [46]. For example, spousal relationships, particularly those perceived as high quality [46], may foster a sense of obligation to manage one's health. Marriage may also facilitate access to medical care, including cancer-related follow-up care,

**Table 3.** Multivariable models examining factors associated with tangible and emotional/informational support among long-term cancer survivors

	Tangible support (n = 1469)		Emotional support (n = 1470)	
	B (SE)	p	B (SE)	p
Age at survey (years)	0.10 (0.09)	0.27	0.04 (0.08)	0.5767
Race/ethnicity	Wald F = 1.78, p = 0.15		Wald F = 1.54, p = 0.20	
Non-Hispanic White	Ref		Ref	
Hispanic White	0.36 (2.80)	0.90	-0.09 (2.72)	0.97
African-American	5.25 (2.42)	0.03	2.73 (2.43)	0.26
Asian/Pacific Islander	1.08 (2.05)	0.60	-2.37 (1.92)	0.22
Gender				
Female	Ref		Ref	
Male	4.40 (3.62)	0.22	3.89 (2.89)	0.18
Marital status				
Unmarried	Ref		Ref	
Married	<b>19.06 (2.53)</b>	<b>&lt;0.0001</b>	<b>12.33 (2.18)</b>	<b>&lt;0.0001</b>
Education	Wald F = 1.31, p = 0.27		Wald F = 4.09, p = 0.02	
College graduate or more	Ref		Ref	
Some college	1.93 (2.12)	0.36	<b>3.90 (1.94)</b>	<b>0.04</b>
High school or less	4.14 (2.58)	0.11	<b>6.36 (2.34)</b>	<b>0.007</b>
Adequate financial resources				
Yes	Ref		Ref	
No	<b>-12.14 (3.82)</b>	<b>0.002</b>	<b>-11.15 (3.24)</b>	<b>0.0006</b>
Cancer site	Wald F = 1.15, p = 0.33		Wald F = 0.71, p = 0.59	
Breast	Ref		Ref	
Prostate	-2.12 (4.13)	0.61	-5.23 (3.54)	0.14
Colon/rectum	2.64 (3.48)	0.45	-1.34 (2.63)	0.61
Ovary	1.53 (2.73)	0.58	-0.49 (2.32)	0.83
Endometrial	-1.16 (3.45)	0.74	-0.30 (2.56)	0.91
Time since cancer diagnosis (years)				
4-9	Ref		Ref	
10+	-2.09 (1.84)	0.26	-1.37 (1.62)	0.40
History of recurrence or second cancer				
No	Ref		Ref	
Yes	<b>5.03 (2.43)</b>	<b>0.04</b>	<b>5.17 (1.91)</b>	<b>0.007</b>
Perceived Health Status (1 = excellent, 5 = poor)	<b>-4.28 (1.05)</b>	<b>&lt;0.0001</b>	<b>-4.94 (1.06)</b>	<b>&lt;0.0001</b>

Bold indicates  $p < 0.05$ .

through increased financial resources, access to health insurance, transportation assistance, or reminders to keep medical appointments. More research is needed to explore whether and how support from spouses differ from other relationships. However, because marital status may be an important factor in identifying survivors at greatest risk for inadequate follow-up care, marital status may be an important factor to consider in survivorship care planning with the patient and the patients' other healthcare providers.

Both tangible and emotional/informational support were positively associated with SEDM among long-term survivors. Survivorship care can involve many complex medical decisions that affect long-term health; [47] thus, one way that family and friends of survivors may play an ongoing role in survivors' health long after cancer treatment ends is through facilitation of self-efficacy for participating in decisions. However, associations between social support and decision-making self-efficacy were modest. While other factors, such as survivorship care planning, patient-provider communication, and support for disease self-management, may play a stronger role in

facilitating decision-making self-efficacy than social support, social support may be more strongly related to self-efficacy for decision-making than receipt of follow-up care because of the more social nature of active participation in follow-up care.

Although the associations with social support tested in this study were modest, clinicians caring for survivors may foster numerous aspects of health and well-being in their patients, including mood, quality of life, management of physical symptoms [48,49], and, potentially, engagement in follow-up care, by making appropriate referrals to support-enhancing interventions. Additionally, healthcare providers can be an important source of emotional and informational support [50,51], for example, through active listening and empathic or empowering statements, that might potentially promote survivor self-efficacy for decision-making. Clinicians can use the characteristics identified in this study to understand that survivors are at risk of experiencing low levels of social support to facilitate referral to support-enhancing interventions. We found that survivors who were not married/

living as married, had inadequate financial resources, and reported poor health status perceived lower levels of tangible support and emotional/informational support. Additionally, in this study, education was inversely associated with emotional/informational support. In contrast, research on recently diagnosed survivors found that higher education was associated with greater perceived emotional support [50]. Perhaps long-term survivors with higher education have different priorities or demands (e.g., prioritizing career over relationships), evaluate their available support more critically, or perceive fewer emotional needs over time and therefore identify less available support to meet such needs compared with less educated survivors. Surprisingly, history of recurrence or second cancers was associated with greater social support, suggesting that perceived support systems may be galvanized, rather than 'burnt out', by multiple cancer treatment episodes. Further, although prior research has reported that support declines during the first year after cancer treatment [7,39,50], in our study, the level of support reported was similar among survivors diagnosed 4–9 versus 10–15 years ago suggesting that support may stabilize over time in the absence of new major cancer events.

To our knowledge, this study is the first to examine associations between social support and participation in cancer-related follow-up care. We utilized a large, population-based sample of long-term cancer survivors that was heterogeneous with respect to cancer site and race/ethnicity. However, the registries from which the FOCUS sample was selected cover California, including predominantly urban/suburban regions and our sample reported notable levels of higher education and adequate financial resources. One reason may be that eligible participants with lower socioeconomic status may be more difficult to locate using mail-based surveys. Thus, findings may not be applicable to survivors in other regions of the United States, those with fewer economic resources, or those living in rural areas. Also, these results may reflect respondent bias: Survivors who were younger and diagnosed more recently were more likely to participate in FOCUS, responding survivors may be more involved in cancer care and/or more socially connected, and nonlocatable survivors may differ from those who were located in unmeasured but perhaps important ways. In particular, nonrespondents were more likely to be older, perhaps because of age-associated limitations in health status or changes in residence, in which case these results may not reflect the experiences of older adults with the poorest health. However, our survey sample reflects the age distribution of cancer survivors [52]. Given that older adults tend to have fewer social relationships from which greater support is obtained relative to younger adults [53], our findings may have limited generalizability for young adults.

Follow-up care was assessed using one-item indicators, and survivors may misreport follow-up care, particularly

the timing of care. Furthermore, this survey was conducted at little over 1 year after follow-up care guidelines were released. Findings may have differed if this study were fielded after more time had passed for these guidelines to be adopted. The lack of clear guidelines for long-term follow-up care across the cancers surveyed make it difficult to define which survivors are 'current' on follow-up care. Consistent findings across analyses of multiple follow-up care intervals increase confidence in our results. Further, we measured perceived social support; results may have differed if we measured support differently (e.g., received support or social network size). Given the limitations of cross-sectional data, no causal inferences can be made regarding the association between social support and decision-making self-efficacy, or between SEDM and better health outcomes. Finally, although FOCUS data were collected several years ago (2005–2006); we see no indication that associations between social support and follow-up care have changed since that time, although financial resources and the ability of social networks to provide support may have decreased with recent economic declines.

Although factors other than social support determine recent follow-up care use, marital status was robustly associated with follow-up care use. Additionally, social support was modestly associated with self-efficacy to participate in follow-up care decision-making among long-term survivors. Recent research has found associations between social support and other aspects of patient centeredness; emotional/informational support was positively associated with satisfaction with providers and inversely associated with difficult interactions with providers [54]. Future research should examine the role of social support and marital status in additional aspects of patient-centered care (e.g., survivor adherence to treatment or behavior change recommendations, trust in physicians, and survivor attitudes towards survivorship care). Additionally, future research could investigate whether explicitly incorporating spouses/partners as key members of the survivorship care team might increase survivors' receipt of, and active participation in, follow-up care. Other factors not measured in this study, such as survivorship care planning, communication with and among members of the healthcare team, and provider or survivor attitudes and preferences also merit future research attention as these factors may play a stronger role than social support in determining receipt of cancer follow-up care. Also, longitudinal research is needed to fully understand how social support changes over time in long-term survivors. Finally, future work should determine whether associations between social support and improved health among cancer survivors can be partially explained by active participation in cancer follow-up care. Ultimately, a better understanding of the pathways through which social support affects health in cancer survivors will lead to more targeted, maximally effective interventions for empowering

survivors to manage their health and actively participate in their care.

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### Conflict of interest

Findings and conclusions in this report are those of the authors and do not necessarily represent the official posi-

tion of the Patient-Centered Outcomes Research Institute or the National Cancer Institute. The authors have no conflicts of interest to report.

### Note

- Standard deviations are large because of application of weights. For example, the unweighted mean (SD) for tangible and emotional/informational support was 75.2 (25.7) and 75.1 (22.2), respectively.

### References

- Jemal A, Clegg LX, Ward E, et al. Annual report to the nation on the status of cancer, 1975–2001, with a special feature regarding survival. *Cancer* 2004;**101**(1):3–27.
- Howlader N, Noone A, Krapcho M, et al. SEER Cancer Statistics Review, 1975–2009 (Vintage 2009 Populations), 2012. [http://seer.cancer.gov/csr/1975\\_2009\\_pops09/](http://seer.cancer.gov/csr/1975_2009_pops09/), based on November 2011 SEER data submission, posted to the SEER web site, April 2012].
- Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. National Academies Press: Washington DC, 2006.
- McCorkle R, Ercolano E, Lazenby M, et al. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011;**61**(1):50–62.
- Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;**98**(2):310–357.
- Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med* 1991;**32**(6):705–714.
- Bloom JR, Stewart SL, Chang S, Banks PJ. Then and now: quality of life of young breast cancer survivors. *Psycho-Oncology* 2004;**13**(3): 147–160.
- Helgeson VS, Snyder P, Seltman H. Psychological and Physical Adjustment to Breast Cancer Over 4 Years: Identifying Distinct Trajectories of Change. *Health Psychol* 2004;**23**(1):3–15.
- Clough-Gorr KM, Ganz PA, Silliman RA. Older breast cancer survivors: factors associated with change in emotional well-being. *J Clin Oncol* 2007;**25**(11):1334–1340.
- Pinto BM, Trunzo JJ, Reiss P, Shiu SY. Exercise participation after diagnosis of breast cancer: trends and effects on mood and quality of life. *Psycho-Oncology* 2002;**11**(5):389–400.
- Courtens AM, Stevens FC, Crebolder HF, Philipsen H. Longitudinal study on quality of life and social support in cancer patients. *Cancer Nurs* 1996;**19**(3):162–169.
- Lim JW, Zebrack B. Different pathways in social support and quality of life between Korean American and Korean breast and gynecological cancer survivors. *Qual Life Res* 2008;**17**(5):679–689.
- Sammarco A. Quality of life of breast cancer survivors: a comparative study of age cohorts. *Cancer Nurs* 2009;**32**(5):347–356.
- Lutendorf SK, De Geest K, Bender D, et al. Social Influences on Clinical Outcomes of Patients With Ovarian Cancer. *J Clin Oncol* 2012;**30**(23):2885–2890.
- Pinquart M, Duberstein PR. Associations of social networks with cancer mortality: a meta-analysis. *Crit Rev Oncol Hematol* 2010;**75**(2):122–137.
- Magai C, Consedine N, Neugut AI, Hershman DL. Common psychosocial factors underlying breast cancer screening and breast cancer treatment adherence: a conceptual review and synthesis. *J Womens Health (Larchmt)* 2007;**16**(1):11–23.
- DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol* 2004;**23**(2):207–218.
- Magai C, Consedine NS, Adjei BA, Hershman D, Neugut A. Psychosocial influences on suboptimal adjuvant breast cancer treatment adherence among African American women: implications for education and intervention. *Health Educ Behav* 2008;**35**(6):835–854.
- Arora NK, Hamilton AS, Potosky AL, et al. Population-based survivorship research using cancer registries: a study of non-Hodgkin's lymphoma survivors. *J Cancer Surviv* 2007;**1**(1):49–63.
- Qian H, Yuan C. Factors associated with self-care self-efficacy among gastric and colorectal cancer patients. *Cancer Nurs* 2012;**35**(3): E22–E31.
- Arora NK, Weaver KE, Clayman ML, Oakley-Girvan I, Potosky AL. Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient Educ Couns* 2009;**77**(3):404–412.
- Heckman JE, Chamie K, Maliski SL, et al. The role of self-efficacy in quality of life for disadvantaged men with prostate cancer. *J Urol* 2011;**186**(5):1855–1861.
- Maly RC, Umezawa Y, Leake B, Silliman RA. Determinants of participation in treatment decision-making by older breast cancer patients. *Breast Cancer Res Treat* 2004;**85**(3):201–209.
- Bellizzi KM, Aziz NM, Rowland JH, et al. Double Jeopardy? Age, Race, and HRQOL in Older Adults with Cancer. *J Cancer Epidemiol* 2012;**2012**:478642.
- Ganz PA, Desmond KA, Leedham B, et al. Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *J Natl Cancer Inst* 2002;**94**(1):39–49.
- Haber MG, Cohen JL, Lucas T, Baltes BB. The relationship between self-reported received and perceived social support: a meta-analytic review. *Am J Community Psychol* 2007;**39**(1–2):133–144.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Breast Cancer version 1.2012. Fort Washington, PA, 2012.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Prostate Cancer version 1.2012. Fort Washington, PA, 2012.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Ovarian Cancer version 2.2012. Fort Washington, PA, 2012.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Uterine neoplasms version 3.2012. Fort Washington, PA, 2012.
- National comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Colon Cancer version 3.2012. Fort Washington, PA, 2012.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Rectal Cancer version 3.2012. Fort Washington, PA, 2012.
- Robert S, House JS. SES differentials in health by age and alternative indicators of SES. *J Aging Health* 1996;**8**(3):359–388.
- Gage E. Examining the most relevant conceptualization of the socioeconomic status construct for cancer research. *Cancer Nurs* 2010;**33**(3):E1–E9.
- Ware JE, Snow KK, Kosinski M, Gandek B. SF-36 health survey. Manual and interpretation guide. Boston: The Health institute, New England Medical Center, 1993.



36. Potosky AL, Harlan LC, Stanford JL, et al. Prostate cancer practice patterns and quality of life: the Prostate Cancer Outcomes Study. *J Natl Cancer Inst* 1999;**91**(20): 1719–1724.
37. Mickey RM, Greenland S. The impact of confounder selection criteria on effect estimation. *Am J Epidemiol* 1989;**129**(1): 125–137.
38. Thompson WD. Statistical analysis of case-control studies. *Epidemiol Rev* 1994;**16**(1): 33–50.
39. Arora NK, Gustafson DH, Hawkins RP, et al. Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: a prospective study. *Cancer* 2001;**92**(5):1288–1298.
40. Ashida S, Palmquist AE, Basen-Engquist K, Singletary SE, Koehly LM. Changes in female support network systems and adaptation after breast cancer diagnosis: differences between older and younger patients. *Gerontologist* 2009;**49**(4):549–559.
41. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;**16**(3):413–428.
42. Schöllgen I, Huxhold O, Schüz B, Tesch-Römer C. Resources for health: Differential effects of optimistic self-beliefs and social support according to socioeconomic status. *Health Psychol* 2011;**30**(3):326–335.
43. Katz ML, Donohue KA, Alfano CM, et al. Cancer surveillance behaviors and psychosocial factors among long-term survivors of breast cancer. Cancer and Leukemia Group B 79804. *Cancer* 2009;**115**(3):480–488.
44. Farmer D, Reddick B, D'Agostino R, Jr., Jackson SA. Psychosocial correlates of mammography screening in older African American women. *Oncol Nurs Forum* 2007;**34**(1):117–123.
45. Katapodi MC, Facione NC, Miaskowski C, Dodd MJ, Waters C. The influence of social support on breast cancer screening in a multicultural community sample. *Oncol Nurs Forum* 2002;**29**(5):845–852.
46. Holt-Lunstad J, Birmingham W, Jones BQ. Is there something unique about marriage? The relative impact of marital status, relationship quality, and network social support on ambulatory blood pressure and mental health. *Ann Behav Med* 2008;**35**(2):239–244.
47. Arora NK. Importance of patient-centered care in enhancing patient well-being: a cancer survivor's perspective. *Qual Life Res* 2009;**18**(1):1–4.
48. Winzelberg AJ, Classen C, Alpers GW, et al. Evaluation of an internet support group for women with primary breast cancer. *Cancer* 2003;**97**(5):1164–1173.
49. Lutgendorf SK, Sood AK, Antoni MH. Host factors and cancer progression: biobehavioral signaling pathways and interventions. *J Clin Oncol* 2010;**28**(26): 4094–4099.
50. Arora NK, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-Oncology* 2007;**16**(5): 474–486.
51. Luszczynska A, Pawlowska I, Cieslak R, Knoll N, Scholz U. Social support and quality of life among lung cancer patients: a systematic review. *Psycho-Oncology* 2012;**22**(10): 2160–2168.
52. Carstensen LL. Social and emotional patterns in adulthood: support for socioemotional selectivity theory. *Psychology And Aging* 1992;**7**(3):331–338.
53. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. *Cancer Epidemiology Biomarkers Prevention* 2011;**20**(10):1996–2005.
54. Han WT, Collie K, Koopman C, et al. Breast cancer and problems with medical interactions: relationships with traumatic stress, emotional self-efficacy, and social support. *Psycho-Oncology* 2005;**14**(4): 318–330.