

Kathryn E. Post, PhD, RN, ANP-BC
Donna L. Berry, PhD, RN, AOCN, FAAN
Judith Shindul-Rothschild, PhD, RN
Jane Flanagan, PhD, RN, ANP-BC, AHN-BC,
FNAP, FNI, FAAN

Patient Engagement in Breast Cancer Survivorship Care

KEY WORDS

Breast cancer
Health-related quality of life
Knowing participation
in change
Patient activation
Patient engagement
Self-management
Social support
Survivorship

Background: Patient engagement (PE) is a key factor for early-stage breast cancer survivors during survivorship, yet little is known about what factors may contribute to PE. **Objectives:** The aims of this study were to describe the relationship between sociodemographic factors, survivorship variables, and PE and explore how variations in these variables might contribute to PE in breast cancer survivors. **Methods:** A cross-sectional, web-based self-report national survey was conducted to assess sociodemographic factors and survivorship variables: health-related quality of life (HRQOL) as measured by 7-item Functional Assessment of Cancer Therapy—General, fear of cancer recurrence, cancer health literacy, and 2 measures of PE (Patient Activation and Knowing Participation in Change) in breast cancer survivors. One open-ended question assessed additional survivorship concerns. Data were analyzed via bivariate associations and backward linear regression modeling in SPSS. **Results:** The sample (N = 303), equally dispersed across the United States, was predominantly middle-aged (mean, 50.70 [SD, 14.01]), white, non-Hispanic women. Knowing Participation in Change and Patient Activation regression models indicate HRQOL was significantly associated with PE ($P \leq .001$), whereas findings related to fear of cancer recurrence lacked significance. In the Knowing Participation in Change regression model, HRQOL, social support, and level of education were all significantly associated with PE ($P \leq .001$). **Conclusions:** Breast cancer survivors with higher HRQOL, greater social support, and higher levels of education were more likely to have higher levels of PE. **Implications for Practice:** Findings may provide insight as to which survivors may be ready to engage in SC and those who may need more specific tailoring of resources and support.

Author Affiliations: Cancer Center, Massachusetts General Hospital (Dr Post); and Phyllis F. Cantor Center for Research in Nursing and Patient Care Services, Dana-Farber Cancer Institute, Boston (Dr Berry); and William F. Connell School of Nursing, Boston College, Chestnut Hill (Drs Shindul-Rothschild and Flanagan), Massachusetts.

The authors have no conflicts of interest to disclose.

This study was funded by a Doctoral Degree Scholarship in Cancer Nursing Award from the American Cancer Society (130716-DSCN-17-075-01-SCN; to K.E.P.), a scholarship from the Oncology Nursing Society, and a scholarship from the Society of Rogerian Scholars.

Correspondence: Kathryn E. Post, PhD, RN, ANP-BC, Massachusetts General Hospital, 86 Lowden Ave, Somerville, MA 02144 (kepost@partners.org).

Author Contributions: All authors contributed to the study conception and design. Material preparation and data collection were performed by K.E.P. Data analysis was conducted by K.E.P. and J.S.-R. The first draft of the manuscript was written by K.E.P., with all authors providing input on previous versions of the manuscript. All authors read and approved the final manuscript.

Accepted for publication April 28, 2020.

DOI: 10.1097/NCC.0000000000000853

Of the more than 3.8 million breast cancer survivors currently living in the United States,¹ many struggle with disease- and treatment-related adverse effects, psychosocial concerns, fear of cancer recurrence (FCR), and family and financial issues.²⁻⁵ Yet early-stage breast cancer survivors, like all cancer survivors, are increasingly expected to self-manage their care as they transition to survivorship,^{6,7} and they may be more or less able to do so independently.

The Institute of Medicine's report *From Cancer Patient to Cancer Survivor: Lost in Transition*⁸ was released in 2005 and mandated that all cancer survivors receive survivorship care (SC), or treatment and follow-up after primary cancer treatment is complete, and an SC plan (SCP). Despite this, more than a decade later, survivorship research and existing SC still largely struggle to determine the appropriate timing, dose, provider, and model for SC. Caring for all survivors in a "one size fits all" fashion has not been effective and is challenged as value-based care and cost-efficient care models are increasingly put forward. Limited data suggest that patient engagement (PE) could be a valuable link to a survivor's ability to benefit from SC and SC interventions.^{9,10} Research examining PE indicates that highly activated patients are more likely to exercise, eat a healthy diet, be involved in treatment planning, take medications as directed, and report that treatment plans reflect their values than less activated patients.⁹ Little is known about which factors may contribute to PE in people with cancer and how individual variation in terms of sociodemographic factors, symptom burden, or unknown factors among survivors may influence PE. This is a critical gap in the era of self-management for cancer survivors and their families.

The number of cancer survivors is expected to hit 26.1 million by 2040.¹¹ It is not feasible for all cancer survivors to continue to be followed by their oncology team. Self-management is increasingly recommended by the American Society of Clinical Oncology¹² and the Oncology Nursing Society¹³ as an important area to understand and prioritize for cancer survivors and their families as they transition to survivorship and beyond. Yet self-management has a requisite skill set, knowledge, and attributes, and some patients may be better equipped for this than others. Approaches to recognizing highly engaged patients versus those who are less engaged and how providers can identify these variations are not well documented. Understanding these factors can help providers to tailor resources to best support PE in SC.

■ Conceptual Framework

This study was guided by Rogers'¹⁴ Science of Unitary Human Beings (SUHB) and informed by Barrett's¹⁵ Knowing Participation in Change (KPC). Rogers' SUHB suggests that people are greater than the sum of their parts and that no one experience (such as breast cancer) can define them. Breast cancer, from a Rogerian perspective, is a disruptive experience, but the person is free to define the experience for themselves; it is the opposite of a one-size-fits-all linear approach to SC. Rogerian SUHB rather encourages individuation in care planning and supports a tailored approach to breast cancer SC, recognizing the varied ways that patients will react to a diagnosis of breast cancer and the varying needs

each individual may have. Barrett describes power as KPC as "being aware of what one is choosing to do, feeling free to do it, and doing it intentionally."^{15(p49)} Power as KPC has 4 inseparable dimensions: awareness, choice, freedom to act intentionally, and involvement in creating change. Barrett¹⁵ encourages her clients to find authority and clarity in their lives when they are facing a health crisis (such as a breast cancer diagnosis) through power as KPC. In this study, power as KPC represents an approach to viewing PE through a more inclusive lens of the whole survivor, more than simply the sum of their parts.

■ Objectives

The purposes of this cross-sectional, descriptive study were to describe the relationship between sociodemographic factors, survivorship variables, and PE in breast cancer survivors and to explore how variations in these variables might contribute to PE in breast cancer survivors.

■ Methods

Sample and Setting

In June to July 2018, early-stage breast cancer survivors were recruited from 2 sources using convenience sampling. Breast cancer survivors were recruited from the Army of Women (AOW) web site¹⁶ and Craigslist. The AOW web site connects researchers to both breast cancer survivors and those at high risk of breast cancer. At the time the study was conducted, there were more than 110 000 subscribers. Craigslist was selected as a way to extend the reach of the web-based survey to breast cancer survivor populations who may not be actively participating in breast cancer research activities and is increasingly being utilized in research as a way to increase community-based recruitment and sampling diversity.^{17,18} Craigslist postings were placed in major metropolitan areas across the United States including Boston, New York City, San Francisco, Detroit, and Atlanta. Eligible participants were individuals with self-reported stages 0 to 3 breast cancer, 18 years or older, and able to read English; had completed adjuvant breast cancer treatment within approximately the last 2 years; had access to an internet-enabled device such as a smart phone, laptop, or tablet; and were willing and able to give consent. Long-term breast cancer survivors or those living with metastatic disease were not included in this study as their experiences may differ.¹⁹⁻²¹

A power analysis using G*Power²² resulted in a target sample size of 246 participants to yield 85% power and an α of .05. Although no intervention/change was being measured, the effect size was set for 0.06. Response rate was not estimated because of the online recruitment methods and the inability to know the number of survivors versus at-risk or noncancer adults viewing the postings.

Procedures

The study was approved by the principal investigator's university institutional review board and also underwent scientific review by AOW Research Foundation. The survey link was sent out via an

AOW email blast and a Craigslist posting. Interested participants clicked “yes” and then were directed to the study inclusion criteria and consent form, prior to being directed to the survey questions. Each participant was provided with a \$10 Amazon gift card upon completion of the survey via email, not linked to their survey responses.

Measures

Data were collected via the REDCap (Research Electronic Data Capture) system, a secure, Health Insurance Portability and Accountability Act–compliant, online survey platform. A pilot of the survey was tested with 5 oncology experts on a range of internet browsers for validity, functionality, and ease of use prior to the study launch.

HEALTH-RELATED QUALITY OF LIFE

Health-related quality of life (HRQOL) was measured using the 7-item Functional Assessment of Cancer Therapy–General (FACT-G7).²³ The FACT-G7 is a brief, oncology-specific tool that measures HRQOL using a 7-item self-report Likert scale in which a higher score indicates greater HRQOL. The tool is psychometrically strong reporting Cronbach’s α ’s of .74 and .80, strong validity, and good internal consistency.²³

FEAR OF CANCER RECURRENCE

Fear of cancer recurrence was measured utilizing the Fear of Cancer Recurrence Inventory (FCRI)–Short Form.^{24,25} This 9-item self-report Likert scale briefly assesses a cancer survivor’s FCR by asking participants to read 9 statements regarding FCR and respond to what degree it applies to them within the last month. The tool is psychometrically strong, reporting a 90.5% interrater agreement on the presence of FCR and a 97% specificity and a 67% sensitivity. The recommended cutoff score of 16 for clinically significant FCR was used for this study.²⁶

CANCER HEALTH LITERACY

Cancer health literacy (CHL) was measured with the Cancer Health Literacy Tool-6 (CHLT-6).²⁷ The CHLT-6 is a 6-item multiple-choice tool in which participant’s CHL is assessed as either “adequate” or “limited,” depending on how they answers the multiple-choice questions. Participants must answer 4 of 6 questions correctly to be considered to have “adequate” CHL. The CHLT-6 was reported in the validation study to have an excellent Cronbach’s α of .88 and high reliability with a 2-week test-retest reliability of 0.90 and a 6-month test-retest reliability of 0.92.²⁷

KNOWING PARTICIPATION IN CHANGE

Knowing participation in change was evaluated by the KPC–Short Form (KPC-SF).^{15,28} The KPC-SF is a 4-factor visual analog scale Barrett developed to assess her clients’ power as KPC or “being aware of what one is choosing to do, feeling free to do it and doing it intentionally.”^{15(p49)} The KPC-SF was adapted from the long form, which reports excellent Cronbach’s α ’s ranging from .92 to .99²⁹ and has been used previously in breast cancer

survivors,³⁰ where it reported a Cronbach’s α of .96. The tool has also established content and construct validity in earlier studies.^{31,32}

PATIENT ACTIVATION

The Patient Activation Measure (PAM-10) is a 10-item, self-report Likert scale that groups participants into 1 of 4 activation levels: level 1 is disengaged and overwhelmed, level 2 is becoming aware but still struggling, level 3 is taking action and gaining control, and level 4 is maintaining behaviors and pushing further.^{33–35}

The PAM measures have been rigorously psychometrically tested using Rasch analysis and have reported infit and outfit statistics in the acceptable range of 0.5 to 1.5. The PAM-10 is increasingly being utilized in oncology populations^{10,36–39} for studies examining patient self-management, activation, and engagement.

SOCIODEMOGRAPHIC FACTORS

A sociodemographic worksheet was developed by the investigator and expert oncology providers and researchers. The demographic portion included items such as gender, race and ethnicity, income, education, and employment status. The health history section included items such as breast cancer treatment history, comorbid conditions, social support, receipt of an SCP, concomitant medications, alcohol intake, smoking status, and physical activity.

OPEN-ENDED QUESTION

The one open-ended question asked participants if there were any additional breast cancer survivorship concerns that they would like to share with the study team not previously addressed in the survey items.

Statistical Analyses

Data were entered into REDCap and were analyzed using SPSS version 24.0 (IBM Corp, Armonk, New York; 2016). Data were examined for normality of distribution. Descriptive statistics were conducted to provide information about the sample. Cronbach’s α ’s were calculated for all multi-item scales (FCRI, FACT-G7, FCRI, KPC-SF, PAM-10). This was the first time the CHLT-6 tool was used outside of the validation study.²⁷ Because of a low Cronbach’s α of .279, CHLT-6 was excluded from the regression analysis, and its association with PE could not be tested. To describe the relationship among sociodemographic factors, survivorship variables, and PE, bivariate analyses were calculated using Pearson r and/or χ^2 . To determine how sociodemographic factors and survivorship variables might contribute to PE measures, general linear regression modeling was conducted using backward elimination.⁴⁰ Variables that had significant analysis of variance relationships with both outcome variables or had Pearson r values of 0.4 or greater were included in the regression models. The final variables included were education, income, social support, FCR, and SCP receipt. All analyses were 2-tailed, and $P = .05$ was considered significant.

For the open-ended question, a classic content analysis as suggested by Miles et al⁴¹ was used. The open-ended responses were individually coded by J.F. and K.E.P. They were then categorized into broad areas of concern such as physical concerns,

mental health concerns, and social support concerns. The authors met to review the categories for consistency. All responses were then tallied to determine highest to lowest frequency.


■ Results

Sample Characteristics

The sample included 303 participants (203 from AOW and 100 from Craigslist); 5 cases were excluded via list-wise deletion because of having little or no data for a final sample of 298 participants. The sample was equally dispersed across the 4 regions of the United States (Northeast, South, Midwest, West), with a mean age of 50.70 years. Participants were mostly female (99.3%), white (87.5%), and non-Hispanic or Latino (86.7%); employed full or part time (64.2%); and were highly educated, and 68% of the sample reported an income of greater than \$75 000 per year. More detail about the sample is provided in Table 1.

Associations Between Sociodemographic Factors, Survivorship Variables, and PE

Preliminary analyses included bivariate associations between socio-demographic factors, survivorship variables (HRQOL, FCR, and CHL), and the variables measuring PE (KPC and Patient Activation). Mean scores and Cronbach's α 's were calculated for all multi-item scales as illustrated in Table 2. The data demonstrated that there was a positive correlation with CHL (KPC: $r = 0.631$, $P \leq .001$; Patient Activation: $r = 0.270$, $P \leq .001$), HRQOL (KPC $r = 0.426$ $P \leq .001$; Patient Activation: $r = 0.314$ $P \leq .001$), social support (KPC: $r = 0.413$, $P \leq .001$; Patient Activation: $r = 0.310$, $P \leq .001$), and smoking status (KPC: $r = 0.269$, $P \leq .001$ and Patient Activation $r = 0.142$, $P = .017$), for both PE variables. There were inverse relationships between the PE variables and FCR (KPC: $r = -.106$, $P = .108$; Patient Activation: $r = -.181$, $P = .002$), illustrating that as FCR increased, PE decreased. There was a significant relationship between KPC and survivorship plan receipt ($r = 0.259$, $P \leq .001$), suggesting survivors who were given an SCP were more likely to have higher levels of KPC. There was also a significant relationship between KPC and comorbidity sum score ($r = 0.256$, $P \leq .001$) in that survivors with higher numbers of comorbidities were more likely to have higher levels of KPC. All other bivariate correlations had non-significant relationships to PE. There were significant analysis of variance relationships between education (KPC: $F_{4,73.71} = 26.43$, $P \leq .001$; Patient Activation: $F_{7,274} = 2.61$, $P = .013$), employment status (KPC: $F_{5,31.52} = 9.90$, $P \leq .001$; Patient Activation: $F_{8,269} = 2.14$, $P = .033$), and income (KPC: $F_{4,237} = 4.90$, $P \leq .001$; Patient Activation: $F_{4,241} = 3.08$, $P = .017$) and both of the PE variables, suggesting that with higher levels of these variables there were higher levels of PE.

 **Table 1 • Sociodemographic Participant Characteristics (n = 298)^a**

Variable	Mean	SD
Age, y	50.70	14.01
	n	%
Race		
White	251	87.45
Black/African American	16	5.57
Asian	12	4.18
Other	6	2.10
Native American/Alaskan Native	1	.35
Prefer not to answer	1	.35
Ethnicity		
Not Hispanic or Latino	248	86.71
Hispanic or Latino	34	11.89
Prefer not to answer	4	1.40
Sex		
Female	285	99.30
Male	2	0.70
Employment status		
Employed full or part time	181	64.18
Retired	62	21.98
Other	24	8.51
Unemployed	15	5.32
Education		
Bachelor's degree or greater	115	40.21
Master's degree or greater	96	33.57
High school, tech graduate/GED or less	75	26.22
Income		
\$75 001-\$100 000	68	27.20
\$100 001-\$150 000	59	23.60
>\$150 001	43	17.20
0-\$50 000	40	16.00
\$50 001-\$75 000	40	16.00
US region		
West	72	29.38
South	61	24.90
Northeast	57	23.27
Midwest	55	22.45
Social support		
Yes	218	76.49
No	67	23.51
Survivorship care plan receipt		
Yes	125	44.64
No	115	41.07
Do not know	40	14.28

Abbreviation: GED, general education diploma.

^aThe total number of breast cancer survivors does not add up to 298 for some variables due to missing data.

Contribution of Selected Variables to PE in Breast Cancer Survivors

For the main analysis, backward linear regression modeling was conducted including HRQOL, FCR, education, income, social support, and receipt of an SCP in the models. Backward linear regression resulted in 2 models: one for KPC and one for Patient Activation.

Table 2 • Results for Study Measures

Item	n (%)	Mean (SD)	Range	95% Confidence Interval	Cronbach's α
FACT-G7 sum	295	17.57 (4.96)	0–28	17.01–18.14	.770
FCRI sum	293	11.77 (5.59)	0–36	11.13–12.41	.784
PAM level	294	3.03 (0.82)	1–4	2.94–3.12	.718
KPC sum	278	62.47 (11.00)	12–84	61.18–63.77	.866
CHL	290		Adequate or limited		.279
Adequate	199 (68.60)				
Limited	91 (31.38)				

Abbreviations: CHL, Cancer Health Literacy; FACT-G7, 7-item Functional Assessment of Cancer Therapy–General; FCRI, Fear of Cancer Recurrence Inventory; KPC, Knowing Participation in Change; PAM, Patient Activation Measure.

In the Patient Activation model as illustrated in Table 3, HRQOL was significantly associated with Patient Activation level ($R^2 = 0.14$; adjusted $R^2 = 0.13$; standard error of estimate = 0.70; sum of squares = 131.96; $n = 237$). Thus, as survivors' HRQOL scores increased, they were more likely to have higher levels of Patient Activation. In the KPC model illustrated in Table 3, HRQOL, increased social support, and higher level of education were all significantly associated with the level of KPC ($R^2 = 0.32$; adjusted $R^2 = 0.31$; standard error of estimate = 9.20; sum of squares = 28,521.16; $n = 234$). In this model, consistent with earlier findings, if they received an SCP, they were more likely to have higher KPC.

Open-Ended Question Results

The following 7 categories were derived from the 146 responses received: no additional concerns or none ($n = 48$), physical concerns ($n = 34$), social support ($n = 20$), mental health concerns ($n = 17$), other concerns ($n = 15$), financial toxicity ($n = 6$), and body image concerns ($n = 6$).

Discussion

Findings from this study indicate that PE is poorly understood in the setting of SC for breast cancer survivors. The findings of this study suggest that survivor's HRQOL, social support, and level of education may influence ability to engage in SC and ability to self-manage.

This study provides insight to the complexity of the whole person and what it brings to the survivorship experience before, during, and after treatment. This begins to inform what needs to be known in order to best care for breast cancer survivors and their families. These factors would be important for providers to consider when developing programs aimed at assisting breast cancer survivors and their families during the transition to survivorship.

Results related to FCR replicate prior research findings in breast cancer survivors, which also report clinically significant levels of FCR using the FCRI.^{42–44} In this sample, 25% of the participants reported clinically significant FCR using the recommended cut-off score of 16.²⁶ Living with clinically significant FCR is distressing, and there is some evidence to suggest that cancer survivors with FCR have detrimental health behaviors such as decreased physical activity and smoking⁴⁵ and decreased cancer screening.⁴⁶ There are few studies reporting FACT-G7 scores to compare the findings in this study. Pearman et al⁴⁷ used the FACT-G7 in both adult cancer patients and adults from the general US population and found the scores to be slightly higher for both the general US population (20.1) and the cancer patients (19.1) as compared with the mean score in this sample of early-stage breast cancer survivors (17.57).

Findings suggest that 31.4% of participants had "limited" CHL. Having adequate CHL may be an important piece of self-management during the transition to survivorship. Given the reported higher levels of education in this sample, it is concerning that CHL was limited, suggesting this would be of even greater concern had the sample been more diverse in terms of education level and other sociodemographic factors. Future research could further examine how CHL may impact survivorship. The KPC-SF

Table 3 • Backward Regression Models

Variables	B	β	SE (B)	t	95% Confidence Interval	P
PAM regression model						
FACT-G7	0.044	.304	0.010	4.505	0.03 to 0.06	.001
Social support	0.057	.117	0.033	1.730	–0.01 to 0.12	.085
KPC Regression Model						
FACT-G7	0.500	.227	0.140	3.566	0.22 to 0.78	.001
Education	2.445	.250	0.579	4.219	1.30 to 3.59	.001
Social support	1.556	.215	0.468	3.325	0.63 to 2.48	.001
SCP receipt	1.547	.098	0.930	1.664	–0.29 to 3.38	.098

Abbreviations: FACT-G7, 7-item Functional Assessment of Cancer Therapy–General; KPC, Knowing Participation in Change; PAM, Patient Activation Measure; SCP, Survivorship Care Plan.

PAM model: $R^2 = 0.14$; adjusted $R^2 = 0.13$; standard error of estimate = 0.70; SS = 131.96; $n = 237$. KPC model: $R^2 = 0.32$; adjusted $R^2 = 0.31$; standard error of estimate = 9.20; SS = 28521.16; $n = 234$.

data demonstrated that KPC-SF scores were higher when participants also reported social support, had higher levels of HRQOL and higher levels of education, or reported receiving an SCP. This is congruent with the description of power as KPC by Barrett^{15,28} in that when people are feeling better, have the necessary knowledge, and are supported, they can move forward and feel empowered to make decisions on their own behalf and self-manage their care.

The mean Patient Activation level of 3.03 is aligned with other studies examining PAM levels in cancer survivors. Mazanec et al³⁷ reported an average PAM level of 3 in a study of colorectal cancer survivors 4 months into survivorship. Another study by O'Malley et al⁴⁸ reported a mean PAM level of 3 for the breast cancer survivors in a study of breast and prostate cancer survivors. Future research is needed to elucidate the impact of survivorship interventions on Patient Activation level over time and how this may impact PE. The data also suggested that survivors who were given an SCP were more likely to have higher levels of KPC. Finally, those survivors who had greater comorbidities also were more likely to have higher KPC. This is the first study to look at such an association to this author's knowledge, but it may be that, with increased comorbidities to manage, survivors become more aware, involved, and intentional in their healthcare decisions.

Future nurse-led interventions designed to maximize PE and self-management can build off this work to improve outcomes for breast cancer survivors and their families. Because this national web-based survey was conducted on US-only breast cancer survivors, future studies need to be done across settings and cultures to replicate these results and determine its generalizability to breast cancer survivors.

Limitations

The findings from this study should be viewed in light of several limitations including the cross-sectional survey design and that the study used convenience sampling. The sample was predominately white, non-Hispanic, and well educated, limiting the generalizability to other breast cancer survivor experiences. Additionally, survey responses were dependent on participant self-report, and as with any survey, there is concern that participants may have overreported or underreported on certain survey measures. Although the PEW Research Center indicates 90% of US adults use the internet,⁴⁹ the web-based nature of this study may have led to a sampling bias.

Conclusions

In this study of breast cancer survivors, 32% of the variance in KPC was explained by social support and HRQOL. Specifically, the greater the breast cancer survivors' social support, level of education, and HRQOL, and if they received an SCP, the more likely they were to have higher levels of PE. Similarly, 14% of the variance in Patient Activation was explained by HRQOL. Fear of cancer recurrence, CHL, and other sociodemographic factors did not explain the variance in the 2 PE models.

This national survey reports factors that may contribute to PE, a poorly understood phenomenon in breast cancer survivors, and

in an era where many one-size-fits-all approaches to SC have failed to meet the needs of survivors, it is critical to risk stratify SC and scale SC interventions appropriately. This study provides early evidence to document the varying needs of breast cancer survivors and that the variation among survivors may contribute to their ability to engage. Findings suggest that, in breast cancer survivors, social support, HRQOL, and education level must be assessed and considered in order to provide person-centered care and tailor interventions with the goal of improving critical survivorship outcomes.

Implications for Practice

Increased self-management and PE have been recommended for cancer survivors,^{13,50} yet there is currently little evidence guiding nurses on how to enhance PE and self-management or discern those survivors who may need more resources and support from those who are faring well. This study demonstrated that breast cancer survivors with greater HRQOL and social support were more likely to have greater PE and are thus may be more equipped to self-manage during survivorship. Health-related quality of life, social support, and level of education are important factors for providers to consider when developing programs aimed at assisting breast cancer survivors and their families during the transition to survivorship. Oncology nurses should be alert for survivors who may be struggling with poor HRQOL, who lack social support, or whose level of education may make navigating the survivorship experience challenging. Doing so will allow them to seek out those survivors who may require more resources and support and tailor SC in a more needs-based fashion. Nurses can apply the findings from this study to better support those survivors who may be struggling with HRQOL issues and/or may be lacking social support. This approach is in line with a more patient-centered, self-management approach to SC.

ACKNOWLEDGMENT

The authors thank the study patients for their participation in this research study.

References

1. American Cancer Society. *Breast Cancer Facts & Figures 2019-2020*. Atlanta, GA: American Cancer Society; 2019. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2019-2020.pdf>. Accessed January 27, 2020.
2. Runowicz CD, Leach CR, Henry NL, et al. American Cancer Society/American Society of Clinical Oncology breast cancer survivorship care guideline. *J Clin Oncol*. 2016;34(6):611–635.
3. Ness S, Kokal J, Fee-Schroeder K, Novotny P, Satele D, Barton D. Concerns across the survivorship trajectory: results from a survey of cancer survivors. *Oncol Nurs Forum*. 2013;40(1):35–42.
4. Brennan ME, Butow P, Spillane AJ, Boyle F. Patient-reported quality of life, unmet needs and care coordination outcomes: moving toward targeted breast cancer survivorship care planning. *Asia Pac J Clin Oncol*. 2016;12(2):e323–e331.
5. Dunn LB, Langford DJ, Paul SM, et al. Trajectories of fear of recurrence in women with breast cancer. *Support Care Cancer*. 2015;23(7):2033–2043.
6. Leopold C, Park ER, Nekhlyudov L. The impact of the affordable care act on cancer survivorship. *Cancer J*. 2017;23(3):181–189.

7. 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.
8. The Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: National Academies Press; 2006: doi:10.17226/11468.
9. Hibbard JH, Mahoney E, Soner E. Does patient activation level affect the cancer patient journey? *Patient Educ Couns*. 2017;100(7):1276–1279.
10. Mayer DK, Deal AM, Crane JM, et al. Using survivorship care plans to enhance communication and cancer care coordination: results of a pilot study. *Oncol Nurs Forum*. 2016;43(5):636–645.
11. National Cancer Institute. Office of Cancer Survivorship Statistics. <https://cancercontrol.cancer.gov/ocs/statistics/statistics.html>. Published 2019. Accessed January 10, 2019.
12. American Society of Clinical Oncology. ASCO in Action Brief: ASCO's Survivorship Initiatives. <https://www.asco.org/advocacy-policy/asco-in-action/asco-action-brief-asco-survivorship-initiatives>. Accessed January 27, 2020.
13. Knobf MT, Cooley ME, Duffy S, et al. The 2014–2018 Oncology Nursing Society research agenda. *Oncol Nurs Forum*. 2015;42(5):450–465.
14. Rogers ME. Nursing science and the space age. *Nurs Sci Q*. 1992;5(1):27–34.
15. Barrett EA. Power as Knowing Participation in Change: what's new and what's next. *Nurs Sci Q*. 2010;23(1):47–54.
16. Dr Susan Love Army of Women Research Foundation. <https://www.armyofwomen.org/>. Published 2018. Accessed January 1, 2018.
17. Worthen MGF. An invitation to use craigslist ads to recruit respondents from stigmatized groups for qualitative interviews. *Qual Res*. 2014;14(3):371–383.
18. Dalessandro C. Recruitment tools for reaching millennials: the digital difference. *Int J Qual Methods*. 2018;17(1):1–7.
19. Mayer DK, Green M, Check DK, et al. Is there a role for survivorship care plans in advanced cancer? *Support Care Cancer*. 2015;23(8):2225–2230.
20. Lester J, Crosthwaite K, Stout R, et al. Women with breast cancer: self-reported distress in early survivorship. *Oncol Nurs Forum*. 2015;42(1):E17–E23.
21. Arndt V, Koch-Gallenkamp L, Jansen L, et al. Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. *Acta Oncol (Madr)*. 2017;56(2):190–197.
22. Faul F, Erdfelder E, Lang AG, Buchner A. G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behav Res Methods*. 2007;39(2):175–191.
23. Yanez B, Pearman T, Lis CG, Beaumont JL, Cella D. The FACT-G7: a rapid version of the Functional Assessment of Cancer Therapy–General (FACT-G) for monitoring symptoms and concerns in oncology practice and research. *Ann Oncol*. 2013;24(4):1073–1078.
24. Simard S, Savard J. Screening and comorbidity of clinical levels of fear of cancer recurrence. *J Cancer Surviv*. 2015;9(3):481–491.
25. Lebel S, Simard S, Harris C, et al. Empirical validation of the English version of the fear of cancer recurrence inventory. *Qual Life Res*. 2016;25(2):311–321.
26. Fardell JE, Jones G, Smith AB, et al. Exploring the screening capacity of the Fear of Cancer Recurrence Inventory–Short Form for clinical levels of fear of cancer recurrence. *Psychooncology*. 2018;27(2):492–499.
27. Dumenci L, Matsuyama R, Riddle DL, et al. Measurement of cancer health literacy and identification of patients with limited cancer health literacy. *J Health Commun*. 2014;19:205–224.
28. Barrett E, Farren AT, Kim TS, Larkin D, Mahoney J. A study of the PKPCT instructions. *Visions J Rogerian Nurs Sci*. 2001;9(1):61–66.
29. Kim TS. The theory of power as Knowing Participation in Change: a literature review. *Visions J Rogerian Nurs Sci*. 2009;16(1):19–40.
30. Farren AT. Power, uncertainty, self-transcendence, and quality of life in breast cancer survivors. *Nurs Sci Q*. 2010;23(1):63–71.
31. Caroselli C, Barrett EA. A review of the power as Knowing Participation in Change literature. *Nurs Sci Q*. 1998;11(1):9–16.
32. Barrett EAM, Caroselli C. Methodological ponderings related to the power as Knowing Participation in Change tool. *Nurs Sci Q*. 1998;11(1):17–22.
33. Insignia Health. Patient Activation Measure. <http://www.insigniahealth.com/products/pam-survey>. Published 2018.
34. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004;39(4 Pt 1):1005–1026.
35. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the Patient Activation Measure. *Health Serv Res*. 2005;40(6p1):1918–1930.
36. Krouse RS, Grant M, McCorkle R, et al. A chronic care ostomy self-management program for cancer survivors. *Psychooncology*. 2016;25(5):574–581.
37. Mazanec SR, Sattar A, Delaney CP, Daly BJ. Activation for health management in colorectal cancer survivors and their family caregivers. *West J Nurs Res*. 2016;38(3):325–344.
38. Rocque GB, Halilova KI, Varley AL, et al. Feasibility of a telehealth educational program on self-management of pain and fatigue in adult cancer patients. *J Pain Symptom Manage*. 2017;53(6):1071–1078.
39. van Maarschalkerweerd P, Rademakers J, Rijken M. Cancer survivors' activation to self-management and its relationship with participation in paid work and work-related problems. *Psychooncology*. 2017;26(11):1881–1887.
40. Pedhazur EL. *Multiple Regression in Behavioral Research Explanation and Prediction. Version Details—Trove*. 3rd ed. Orlando, FL: Holt, Rinehard and Winston, Inc; 1997.
41. Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed. Thousand Oaks, CA: Sage; 2014.
42. Burm R, Thewes B, Rodwell L, et al. Long-term efficacy and cost-effectiveness of blended cognitive behavior therapy for high fear of recurrence in breast, prostate and colorectal cancer survivors: follow-up of the SWORD randomized controlled trial. *BMC Cancer*. 2019;19(1):462.
43. Merckaert I, Lewis F, Delevallez F, et al. Improving anxiety regulation in patients with breast cancer at the beginning of the survivorship period: a randomized clinical trial comparing the benefits of single-component and multiple-component group interventions. *Psychooncology*. 2017;26(8):1147–1154.
44. Gonzalez-hernandez E, Romero R, Campos D, et al. Cognitively-based compassion training (CBCT[®]) in breast cancer survivors: a randomized clinical trial study. *Integr Cancer Ther*. 2018;17(3):684–696.
45. Fisher A, Beeken RJ, Heinrich M, Williams K, Wardle J. Health behaviours and fear of cancer recurrence in 10 969 colorectal cancer (CRC) patients. *Psychooncology*. 2016;25(12):1434–1440.
46. Thewes B, Butow P, Bell ML, et al. Fear of cancer recurrence in young women with a history of early-stage breast cancer: a cross-sectional study of prevalence and association with health behaviours. *Support Care Cancer*. 2012;20(11):2651–2659.
47. Pearman T, Yanez B, Peipert J, Wortman K, Beaumont J, Cella D. Ambulatory cancer and US general population reference values and cutoff scores for the Functional Assessment of Cancer Therapy. *Cancer*. 2014;120(18):2902–2909.
48. O'Malley D, Dewan AA, Ohman-Strickland PA, Gundersen DA, Miller SM, Hudson SV. Determinants of patient activation in a community sample of breast and prostate cancer survivors. *Psychooncology*. 2018;27(1):132–140.
49. Pew Research Center: Internet and Technology. Internet use. <https://www.pewresearch.org/internet/chart/internet-use/>. Published 2020. Accessed March 10, 2020.
50. American Society of Clinical Oncology. *ASCO Key Components of Survivorship Care*. American Society of Clinical Oncology. 2018. <https://www.asco.org/practice-policy/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship>. Accessed January 27, 2020.