



Published in final edited form as:

*J Cancer Educ.* 2022 December ; 37(6): 1702–1710. doi:10.1007/s13187-021-02015-0.

## Reported concerns and acceptance of information or referrals among breast cancer survivors seen for care planning visits: results from the University of Wisconsin Carbone Cancer Center Survivorship Program

Leah Cha, BA<sup>1</sup>, Amye J. Tevaarwerk, MD<sup>1,2,3</sup>, Elena M. Smith, MS<sup>4</sup>, Thevaa Chandereng, PhD<sup>5</sup>, Karol J. Huenerberg, MSN, FNP-BC, APNP, AOCNP<sup>4</sup>, Lori A. Seaborne, MPAS, PA-C<sup>4</sup>, Cibele B. Carroll, MD, MPH<sup>2</sup>, Mary E. Sesto, PT, PhD<sup>1,2,3</sup>

<sup>1</sup>University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

<sup>2</sup>University of Wisconsin Carbone Cancer Center, Madison, WI, USA

<sup>3</sup>Department of Medicine, Division of Hematology/Oncology University of Wisconsin, 6037 Wisconsin Institutes for Medical Research, University of Wisconsin, 1111 Highland Ave, Madison, WI 53705 USA

<sup>4</sup>UW Health, Madison, WI, USA

<sup>5</sup>Department of Biostatistics, Columbia University, New York, NY, USA

### Abstract

**Purpose:** Breast cancer survivors experience physical and psychosocial concerns following active curative-intent treatment. Survivors' complex needs are often reviewed at survivorship

**Corresponding Author:** Amye J. Tevaarwerk, Associate Professor, Department of Medicine, Division of Hematology/Oncology, University of Wisconsin, 6037 Wisconsin Institutes for Medical Research, 1111 Highland Ave, Madison, WI 53705 United States of America, Phone: 608-262-2837 Fax: 608-265-6905.

Author contributions

Conceptualization: Leah Cha, Amye J. Tevaarwerk, Mary E. Sesto; Methodology: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto; Formal analysis and investigation: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto; Writing - original draft preparation: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto; Writing - review and editing: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto; Funding acquisition: Amye J. Tevaarwerk, Mary E. Sesto; Resources: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto; Supervision: Leah Cha, Amye J. Tevaarwerk, Elena M. Smith, Thevaa Chandereng, Karol J. Huenerberg, Lori A. Seaborne, Cibele B. Carroll, Mary E. Sesto.

Conflicts/Disclosures:

- Amye J. Tevaarwerk—Epic Systems (family member)
- Elena M. Smith—None
- Thevaa Chandereng—None
- Karol J. Huenerberg—None
- Lori A. Seaborne—None
- Cibele B. Carroll—None
- Mary E. Sesto—None

Availability of Data and Material

Data was extracted from the UW Health Healthy Planet Cancer Registry, an Electronic Health Records - based cancer registry. Data elements will be available upon direct request to the corresponding author (AJT) to ensure that we protect subject's privacy.

Ethics approval

This study was exempted from review by the University of Wisconsin IRB.

care planning visits (SCP visits). However, little is known about the post-treatment concerns and resource needs addressed within the context of SCP visits.

**Methods:** Using discretely collected electronic health record data, we examined characteristics, concerns, and acceptance of education materials and/or referrals among Stage 0–3 breast cancer survivors seen for SCP visits.

**Results:** Most survivors reported concerns related to activity ( $n = 739$ ; 72.7%) and nutrition ( $n = 677$ ; 66.6%). Survivors of color were more likely to report concerns related to pain/swelling (odds ratio [OR], 4.4; 95% CI, 1.7–11.4) and employment/insurance (2.8; 1.4–5.7) compared to Whites. More than half accepted materials or referrals for concerns related to nutrition, activity/pain, substance use, sexual health, mood, and sleep ( $p_{\text{adj-value}} < 0.05$ ). However, not all reported concerns led to acceptance of materials or referrals.

**Conclusion:** Survivors seen for SCP visits report a wide range of concerns at the end of active curative-intent treatment but may not necessarily accept materials or referrals for their concerns within the context of these visits. Our findings highlight the importance of exercise, physical rehabilitation, and nutrition interventions for survivors following active curative-intent treatment. Further study is needed to elucidate the reasons for acceptance vs. non-acceptance of resources addressing reported concerns.

### Keywords

Breast cancer survivor; symptoms; concern; resource need; survivorship care planning; EHR-based care planning

---

## INTRODUCTION

Over 3.5 million Americans are breast cancer survivors—the largest group of survivors in the U.S. [1]. The 5-year survival rate is nearly 90% after curative-intent treatment and continues to rise steadily. With improved long-term survival in this population, the management of physical and psychosocial side effects as a result of cancer and cancer therapies (e.g. chemotherapy, endocrine therapy, radiation, surgery) remains a challenge [2]. Post-treatment symptoms include, but are not limited to, fatigue, pain, lymphedema, hot flashes, sexual dysfunction, infertility, body image concerns, sleep disorders, cognitive impairment, and depression [2]. Additional concerns, such as loss of employment, under- or uninsurance, and financial toxicity are mediated by demographics and treatment factors [3–5]. Management of these sequelae requires comprehensive, coordinated follow-up care across multiple providers [2].

This complex mix of health and social needs are addressed in the context of survivorship care planning visits (SCP visits) following active curative-intent treatment [6]. SCP visits are intended to facilitate each survivor's transition from active- to post-treatment care by assessing specific concerns and providing resources, such as information or referrals for services, to address reported concerns. SCP visits may serve a vital role in the survivorship care pathway, as they have the potential to provide personalized continuity of care beyond treatment and improve quality of long-term survival. A study of early-stage breast cancer survivors found that survivors who attended SCP visits perceived their concerns in various

categories, including long-term side effects and practical concerns (e.g. work, finances, household activities), to be addressed more adequately than non-attendees [7]. However, the impacts of SCP visits on adequately identifying and addressing specific concerns, such as those related to activity, pain, sexual health, or employment/insurance, following curative-intent treatment are not well understood [8, 9]. Previous studies suggest gaps in post-treatment follow-up care, with breast cancer survivors reporting unmet needs for resources on persistent treatment side effects, emotional distress, and lifestyle changes [10–18].

Overall, breast cancer survivors at the end of or following curative-intent treatment may be unprepared for lingering effects of treatment [10, 14–17]. Survivors have reported that they did not receive information to fully understand the physical effects of therapy [10–12, 15, 17, 19]. A survey-based study of women several months after a breast cancer diagnosis found that nearly one-third reported not being provided with adequate information on available sources of support following diagnosis and treatment [13]. Information related to changes in body image, nutrition, risk for other malignancies, physical impairment, activity limitations, and hormonal treatment effects may be widely requested by survivors [10, 11, 18, 19]. Paradoxically, rates of referrals to and utilization of resources are low despite high symptom burden [13, 20]. Such findings might be explained by lack of desire for supportive services, limited knowledge about availability of services, and/or financial barriers to specialty care. A descriptive interview survey of breast cancer survivors who completed active treatment found that follow-up care tended to overlook survivors' physical and psychosocial concerns [21]. Thirty-eight percent of survivors did not feel comfortable discussing informational needs with their providers and 46% reported unmet informational needs and unanswered questions pertaining to a variety of topics, including management of treatment-induced side effects, cancer risk to children, and dietary habits.

Little is known about breast cancer survivors' need for and acceptance of resources—whether information (e.g. education materials) or referrals for services—at the end of treatment, particularly in the context of SCP visits [9, 11]. Using electronic health record (EHR) data collected discretely at standardized SCP visits, we conducted a retrospective analysis to examine the frequency and patterns of concerns reported by curatively treated survivors diagnosed with breast cancer, as well as their acceptance of survivorship materials and/or referrals.

## METHODS

### Setting and Population.

A retrospective study was conducted at the University of Wisconsin Carbone Cancer Center (UWCCC). The UWCCC's EHR vendor is Epic (Epic Systems; Verona, WI, USA). We identified 4,180 breast cancer survivors, irrespective of stage, from our EHR-based cancer registry who were seen for at least one visit at the UWCCC between January 2016 to January 2020 (Supplement 1). Only Stage 0–3 survivors who were seen for a SCP visit as standard-of-care were included in the analysis ( $n = 1,132$ , 27.1%). We excluded survivors who had a survivorship care plan provided by treating providers within the context of routine follow-up visits ( $n = 562$ , 13.4%) or had SCP visits at the end of treatments other than

radiation therapy (n = 116, 2.8%), such as surgery only, given differing workflows that did not include routine referral. This study was exempted from review by the University of Wisconsin Institutional Review Board.

### SCP visit Workflow.

Roughly 4 weeks after completing active treatment, survivors are seen for standardized SCP visits. Each visit focuses on assessing and managing post-treatment concerns and outlining follow-up care [6]. On arrival for the visit, each survivor completes a two-page, 10-item questionnaire. This questionnaire was developed at the UWCCC, based on recommended survivorship topics to assess for survivors' post-treatment concerns and resource needs (Supplement 2) [6]. At the visit, an advanced practice provider (APP) reviews the questionnaire and an individualized survivorship care plan with each survivor. The APP documents each survivor's concerns and acceptance of education materials or referral into an EHR templated documentation form to capture data about the concern and the action taken regarding that concern discretely. Data capture is guided by a survivor's response to the questionnaire informed by discussion between the survivor and APP. For each concern (e.g. "I have swelling"), the APP documents regarding the concern whether: 1) discussion was held, 2) the survivorship care plan section was reviewed, 3) materials in the form of survivorship patient education booklet was provided, and/or 4) a referral (e.g. lymphedema specialist) was accepted. While the APPs address other concerns raised by survivors in the context of this visit, *only* the concerns/actions represented by the questionnaire/flowsheets can be discretely captured. All materials and referrals were standardized over time, and the same APPs have provided care planning visits since 2015; regular (2–4/yr) meetings are conducted with the APPs and the Survivorship Program Director. Our survivorship care plan preparation and delivery processes are described elsewhere [6].

### Variables.

Discrete data regarding demographics, clinical characteristics, concerns, and acceptance of materials or referrals were extracted from our EHR (Supplement 1). Rural-Urban Continuum codes were generated using zip codes [22]. Survivor-specific concerns reported at the SCP visit were also extracted from the EHR, including activity, employment/insurance, endocrine therapy, genetics, memory/concentration, mood, nutrition, pain/swelling, pregnancy, primary care, sexual health, sleep, and substance use. Acceptance of materials or referrals to services related to activity/pain/swelling, employment/insurance, endocrine therapy, genetics, memory/concentration, mood, nutrition, pregnancy, primary care, sexual health, sleep, and substance use were likewise extracted (data captured as an aggregate by the flowsheet is indicated as follows "concern/concern"). Discrete data for acceptance of materials for employment/insurance, endocrine therapy, genetics, pregnancy, and primary care, as well as acceptance of referrals for memory/concentration, sleep, and substance use were not available options for survivors during the 2016–2020 study period, as other pathways were standard-of-care (e.g. endocrine therapy concerns were messaged to the treating oncologist). Acceptance of materials and referrals are defined by selection on the flowsheet. For example, the survivor might indicate "I want to lose weight" and "I want information" and "I want a referral" with regards to nutrition on the questionnaire; APP selects "lose weight," "written materials" and "referred to dietician" on the flowsheet (see

also Supplement 2). All variables describe the survivor, cancer diagnosis, concerns and/or materials/referrals *at the time of initial SCP visit*.

### Data Analysis.

Descriptive statistics were conducted to examine survivor characteristics, concerns, and acceptance of materials and/or referrals. We assessed for the likelihood of reporting a concern given a survivor's characteristics, including age, stage, race, type of health insurance, and receipt of chemotherapy, using a logistic regression model. A one-sided z-test was also performed to evaluate whether at least half of the patients who reported a concern accepted materials only, referral only, and materials or referral. A  $p_{adj}$ -value (p-value corrected for false discovery rate) of 0.05 was considered statistically significant. These analyses were conducted using R Software 4.0.1 (R Foundation for Statistical Computing; Vienna, AUT).

## RESULTS

### Characteristics.

Stage 0–3 breast cancer survivors (n = 1,016) were seen for at least one SCP visit. Most survivors were middle-aged (mean, 58 years; range, 22–88), female (n = 1,014; 99.8%), Non-Hispanic (n = 985; 96.9%), White (n = 962; 94.7%) and resided in urban areas (n = 826; 81.3%). All survivors received surgery and radiation (n = 1,016; 100%), more than a third received chemotherapy (n = 354; 34.8%), and nearly three-quarters received endocrine therapy (n = 718; 70.7%) (Table 1).

### Reported Concerns.

Nearly all survivors reported at least one concern (n = 975; 96.0%). Most commonly reported concerns were related to activity (n = 739; 72.7%), such as fatigue (n = 519; 51.1%) and desire to increase physical activity (n = 473; 46.6%) (Table 2). About two-thirds reported concerns related to nutrition (n = 677; 66.6%), with most reporting a desire to lose weight (n = 601; 59.2%). Other common concerns included pain (n = 492; 48.4%) and numbness/tingling (n = 222; 21.9%). Pregnancy- or primary care-related concerns were the least common (n = 31; 3.1% and n = 13; 1.3%). Stage was a significant predictor for the likelihood of reporting a concern related to endocrine therapy, pain/swelling, mood, sleep, sexual health, and memory/concentration. Survivors with Stage I, Stage II, and Stage III breast cancer were 5.1 (95% CI, 1.6–17.0), 5.6 (1.6–19.4), and 12.3 times (3.2–47.8), more likely to report an endocrine therapy-related concern, respectively, than Stage 0 survivors. A year decrease in age at diagnosis was also associated with increased odds of reporting a concern related to endocrine therapy (odds ratio [OR], 1.02; 95% CI, 1.01–1.03), nutrition (1.02; 1.01–1.03), mood (1.02; 1.01–1.03), sleep (1.02; 1.01–1.03), sexual health (1.04; 1.03–1.06), memory/concentration (1.03; 1.02–1.04), and employment/insurance (1.02; 1.00–1.05). Survivors who received chemotherapy were more likely to report a concern related to activity (1.5; 1.1–2.0), pain/swelling (2.5; 1.8–3.3), nutrition (1.4; 1.1–1.9), and employment/insurance (2.3; 1.5–3.4). Survivors of color were also more likely to report a concern related to pain/swelling (4.4; 1.7–11.4) and employment/insurance (2.8; 1.4–5.7) than Whites.

### Acceptance of Resources.

Overall, more than half accepted materials or referrals for concerns related to nutrition (n = 669/677; 98.8%), activity/pain (n = 842/854; 98.6%), substance use (n = 50/54; 92.6%), sexual health (n = 255/366; 69.7%), mood (n = 211/324; 65.1%), and sleep (n = 240/426; 56.3%) ( $p_{\text{adj-value}} < 0.05$ ). (Table 3). Acceptance of materials was most common among survivors who reported concerns related to nutrition (n = 669/677; 98.8%) and activity/pain (n = 842/854; 98.6%). Acceptance of referrals was much fewer in number, with most related to primary care (n = 8/13; 61.5%) and genetics (n = 6/15; 40.0%). Some predictors, namely race and stage, were associated with increased likelihood of accepting materials or referrals for reported concerns. Survivors of color were 4.2 times more likely to accept materials or referrals than Whites for concerns related to employment/insurance (95% CI, 1.1, 15.9). Survivors with Stage III breast cancer were 6.3 times more likely to accept materials or referrals for concerns related to memory/concentration than those with Stage 0 breast cancer (1.0, 38.1).

## DISCUSSION

Few studies have examined concerns and resource needs of breast cancer survivors at the end of active curative-intent treatment, particularly in the context of SCP visits [9, 11]. Our retrospective analysis uniquely captures the specific resource needs of a large cohort of routinely referred breast cancer survivors seen for SCP visits. Similar to the literature, our survivors reported a wide range of physical and psychosocial concerns, with most reporting activity (e.g. fatigue) and nutrition-related (e.g. weight loss) concerns [2, 10, 11]. Another survey-based study, which evaluated early stage breast cancer survivors seen for SCP visits, found hot flashes, night sweats, and numbness/tingling to be the most commonly reported concerns [23]. Survey differences may explain the discrepancy between our findings and those of this study. We also found that most survivors sought materials related to activity/pain and nutrition, a finding similar to existing literature [24]. Similar to other studies, we found that demographics and clinical contexts, such as age, race, stage, and treatment, impact whether survivors report certain concerns [19, 25]. These findings suggest the importance of taking into account sociocultural and economic factors in improving survivors' post-treatment quality of life, as was supported by a study on Spanish-speaking Latina breast cancer survivors [19].

Assessments of whether survivor-reported concerns lead to acceptance of materials or resources, as well as referrals are few in literature. With a growing emphasis on comprehensive and personalized cancer care, an understanding of survivor preferences is increasingly important in order to provide resources that effectively meet survivors' specific needs while taking into account their personal circumstances. Our research uniquely highlights that survivors of color were more likely to accept materials or referrals for reported concerns related to employment/insurance. This finding contrasts with several studies in a systematic review of breast cancer survivors of color, which reported that while access to resources were desired, survivors were uncertain about their post-treatment status and relied on their own care strategies instead of seeking resources from their providers [26]. However, it is important to note that for all other concerns, our analysis did not observe



a tight correlation between reporting concerns and accepting resources. It is tempting to assume that survivors reporting a concern need or desire additional support but our results suggest this assumption may not be valid. Far fewer survivors accepted referrals than materials, potentially because patient education booklets were offered specifically during SCP visits, while referrals may be possible to obtain at other times during treatment and follow-up. Referrals might have already existed (e.g. survivor was already seeing occupational therapy for lymphedema) or have been perceived by survivors as a resource that they could ask for later. Survivors may have declined referrals due to barriers to health care access, such as those related to transportation, child care, and costs, as was suggested in another study [13]. Furthermore, survivors might obtain cancer information outside of the healthcare system [27]. It is also possible that resources provided during SCP visits may not have been perceived by survivors as useful for promoting their health and quality of life.

Our limitations include a relatively homogenous cohort of non-Hispanic White urban survivors, which may not reflect the concerns of other demographics. Some data were unavailable due to limitations in the documentation template (e.g. staging information was entered as free-form text and optional), or only present as an aggregate due to the flowsheet data capture fields (e.g. pain/activity/swelling). Our next steps are to re-design our care planning process to identify the degree of concern (e.g. mild, moderate, severe) and desire for resources, and capture why survivors decline resources for a reported concern (e.g. cost, time, transportation). We intend to administer follow-up surveys to assess whether survivors have utilized the resources provided to them during the SCP visits, their level of satisfaction of the resources, as well as reasons for not utilizing the resources.

Our findings illustrate the need for further research to determine how to effectively address survivor concerns within the setting of SCP visits, including qualitative and quantitative assessments examining what post-treatment resources are desired and conversely, what resources are not desired and why. More research exploring potential ethnic, social, and cultural variations in survivors' experiences and needs following active curative-intent treatment is also needed [15]. Additionally, the high prevalence of activity- or nutrition-related concerns suggest the importance of lifestyle modification education and interventions, such as exercise, physical rehabilitation, and nutrition guidance programs [10, 23]. Collectively, such research would provide the opportunity to deliver both individualized and comprehensive survivorship care and improve quality of long-term cancer survival in this population.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Funding:

This work was supported by the NCI Cancer Center Support Grant P30 CA014520 and the SMPH Shapiro Summer Research Program.

## REFERENCES

1. Howlader N, Noone A, Krapcho M, et al. SEER Cancer Statistics Review, 1975–2017. In: Natl. Cancer Inst. [https://seer.cancer.gov/csr/1975\\_2017/](https://seer.cancer.gov/csr/1975_2017/). Accessed 30 May 2020.
2. Runowicz CD, Leach CR, Henry NL, et al. (2016) American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline. *CA Cancer J Clin* 66:43–73. 10.3322/caac.21319 [PubMed: 26641959]
3. Dumas A, Vaz Luis I, Bovagnet T, et al. (2020) Impact of Breast Cancer Treatment on Employment: Results of a Multicenter Prospective Cohort Study (CANTO). *J Clin Oncol Off J Am Soc Clin Oncol* 38:734–743. 10.1200/JCO.19.01726
4. Naughton MJ, Beverly Hery CM, Janse SA, et al. (2020) Prevalence and correlates of job and insurance problems among young breast cancer survivors within 18 months of diagnosis. *BMC Cancer* 20:432. 10.1186/s12885-020-06846-w [PubMed: 32423486]
5. Dean LT, Moss SL, Ransome Y, et al. (2019) “It still affects our economic situation”: long-term economic burden of breast cancer and lymphedema. *Support Care Cancer* 27:1697–1708. 10.1007/s00520-018-4418-4 [PubMed: 30121786]
6. Huenerberg KJ, Anderson BM, Tevaarwerk AJ, et al. (2018) Integrating survivorship care planning in radiation oncology workflow. *J Community Support Oncol* 16:e66–e71. 10.12788/jcso.0392 [PubMed: 30631797]
7. Dietrich L, Smith AL, Watral A, et al. (2016) Effectiveness of a Survivorship Program: An Assessment of Patients With Breast Cancer in a Community Setting. *J Oncol Pract* 12:e688–e696. 10.1200/JOP.2015.010413 [PubMed: 27221994]
8. Hill RE, Wakefield CE, Cohn RJ, et al. (2020) Survivorship Care Plans in Cancer: A Meta-Analysis and Systematic Review of Care Plan Outcomes. *The Oncologist* 25:e351–e372. 10.1634/theoncologist.2019-0184 [PubMed: 32043786]
9. Garcia S, Kircher S, Oden M, et al. (2016) Survivorship care planning in a comprehensive cancer center using an implementation framework. *J Community Support Oncol* 14:192–199. 10.12788/jcso.0255 [PubMed: 27258051]
10. Binkley JM, Harris SR, Levangie PK, et al. (2012) Patient perspectives on breast cancer treatment side effects and the prospective surveillance model for physical rehabilitation for women with breast cancer. *Cancer* 118:2207–2216. 10.1002/cncr.27469 [PubMed: 22488695]
11. Cappiello M, Cunningham RS, Tish Knobf M, Erdos D (2007) Breast Cancer Survivors: Information and Support After Treatment. *Clin Nurs Res* 16:278–293. 10.1177/1054773807306553 [PubMed: 17991908]
12. Davis C, Williams P, Parle M, et al. (2004) Assessing the Support Needs of Women With Early Breast Cancer in Australia. *Cancer Nurs* 27:169–174 [PubMed: 15253175]
13. Gorman JR, Julian AK, Roberts SA, et al. (2018) Developing a post-treatment survivorship care plan to help breast cancer survivors understand their fertility. *Support Care Cancer* 26:589–595. 10.1007/s00520-017-3871-9 [PubMed: 28913697]
14. Ganz PA, Kwan L, Stanton AL, et al. (2004) Quality of Life at the End of Primary Treatment of Breast Cancer: First Results From the Moving Beyond Cancer Randomized Trial. *JNCI J Natl Cancer Inst* 96:376–387. 10.1093/jnci/djh060 [PubMed: 14996859]
15. Tompkins C, Scanlon K, Scott E, et al. (2016) Survivorship care and support following treatment for breast cancer: a multi-ethnic comparative qualitative study of women’s experiences. *BMC Health Serv Res* 16:. 10.1186/s12913-016-1625-x [PubMed: 26772389]
16. Collins LG, Nash R, Round T, Newman B (2004) Perceptions of upper-body problems during recovery from breast cancer treatment. *Support Care Cancer* 12:106–113. 10.1007/s00520-003-0554-5 [PubMed: 14593521]
17. Landmark BT, Bøhler A, Loberg K, Wahl AK (2008) Women with newly diagnosed breast cancer and their perceptions of needs in a health-care context. *J Clin Nurs* 17:192–200. 10.1111/j.1365-2702.2008.02340.x [PubMed: 18578795]
18. Cimprich B, Janz NK, Northouse L, et al. (2005) Taking CHARGE: A self-management program for women following breast cancer treatment. *Psychooncology* 14:704–717. 10.1002/pon.891 [PubMed: 15651055]



19. Nápoles AM, Ortiz C, Santoyo-Olsson J, et al. (2017) Post-Treatment Survivorship Care Needs of Spanish-speaking Latinas with Breast Cancer. *J Community Support Oncol* 15:20–27. 10.12788/jcso.0325 [PubMed: 28944260]
20. Zwahlen D, Tondorf T, Rothschild S, et al. (2017) Understanding why cancer patients accept or turn down psycho-oncological support: a prospective observational study including patients' and clinicians' perspectives on communication about distress. *BMC Cancer* 17:385. 10.1186/s12885-017-3362-x [PubMed: 28558713]
21. Pennery E, Mallet J (2000) A preliminary study of patients' perceptions of routine follow-up after treatment for breast cancer. *Eur J Oncol Nurs Off J Eur Oncol Nurs Soc* 4:138–145; discussion 146–147. 10.1054/ejon.2000.0092
22. Rural-Urban Continuum Codes. In: U. S. Dep. Agric. USDA Econ. Res. Serv. <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes.aspx>. Accessed 12 Jun 2020.
23. Mustafa Ali M, Moeller M, Rybicki L, Moore HCF (2017) Prevalence and correlates of patient-reported symptoms and comorbidities in breast cancer survivors at a tertiary center. *J Cancer Surviv* 11:743–750. 10.1007/s11764-017-0612-5 [PubMed: 28283875]
24. Muss HB, Tell GS, Case LD, et al. (1991) Perceptions of follow-up care in women with breast cancer. *Am J Clin Oncol* 14:55–59. 10.1097/0000421-199102000-00013 [PubMed: 1987741]
25. Ashing-Giwa KT, Lim J-W (2011) Examining emotional outcomes among a multiethnic cohort of breast cancer survivors. *Oncol Nurs Forum* 38:279–288. 10.1188/11.ONF.279-288 [PubMed: 21531679]
26. Lewis-Thames MW, Strayhorn SM, Molina Y, Nolan TS (2020) The use of survivorship care plans by female racial and ethnic minority breast cancer survivors: a systematic review. *J Cancer Surviv Res Pract* 14:806–825. 10.1007/s11764-020-00894-8
27. Edgar L, Remmer J, Rosberger Z, Fournier MA (2000) Resource use in women completing treatment for breast cancer. *Psychooncology* 9:428–438. 10.1002/1099-1611(200009/10)9:5<428::aid-pon481>3.0.co;2-1 [PubMed: 11038481]

**Table 1.**Demographic and clinical characteristics (N = 1,016)<sup>a</sup>

Characteristic	Mean (range)
Age of diagnosis, years	58 (22–88)
	<b>No. (%)</b>
<b>Sex</b>	
Female	1,014 (99.8)
Male	2 (0.2)
<b>Ethnicity</b>	
Non-Hispanic or Latino	985 (96.9)
Hispanic or Latino	25 (2.5)
Declines to Answer	6 (0.6)
<b>Race</b>	
White	962 (94.7)
Black or African American	23 (2.3)
Asian	12 (1.2)
American Indian or Alaska Native	5 (0.5)
Multiracial	2 (0.2)
Declines to answer	12 (1.2)
<b>Type of insurance</b>	
Private	626 (61.6)
Medicare	331 (32.6)
Medicaid	48 (4.7)
Self-pay	9 (0.9)
Other	2 (0.2)
<b>Has a primary care provider (PCP)</b>	1,015 (99.9)
<b>Survivorship care plan (SCP) generated at visit</b> <sup>b</sup>	1,014 (99.8)
<b>Place of residence</b> <sup>c</sup>	
Urban	826 (81.3)
Rural	159 (15.6)
Unknown	31 (3.1)
<b>Stage</b>	
0	56 (5.5)
I	339 (33.4)
II	118 (11.6)
III	33 (3.2)
Not captured as structured data within EHR	470 (46.3)
<b>Received endocrine therapy</b> <sup>d</sup>	718 (70.7)

Characteristic	Mean (range)
Aromatase Inhibitor	449 (44.2)
Tamoxifen	266 (26.2)
Both	3 (0.3)
Unknown	298 (29.3)
<b>Received chemotherapy</b>	<b>354 (34.8)</b>

<sup>a</sup>Demographic and clinical characteristics describe survivors at the time of their initial survivorship care planning visit.

<sup>b</sup>Two patients had survivorship care planning visits, but generation of an SCP was deferred until they completed adjuvant capecitabine.

<sup>c</sup>Urban represents RUCC 1–3 and rural represents RUCC 4–9.

<sup>d</sup>Represents patients on endocrine therapy at diagnosis (for chemoprevention or prior cancer)

**Table 2.**

Survivor-reported concerns captured discretely in the EHR

Concern Category <sup>a</sup>	No. (%)		
	Reported concern	Did not report concern	Missing
<b>Activity</b>	<b>739 (72.7)</b>	<b>276 (27.2)</b>	<b>1 (0.1)</b>
Fatigue	519 (51.1)		
Would like to increase physical activity	473 (46.6)		
Weakness	140 (13.8)		
Short of breath with activity	84 (8.3)		
<b>Employment/insurance</b>	<b>133 (13.1)</b>	<b>881 (86.7)</b>	<b>2 (0.2)</b>
Cancer-related financial issues	69 (6.8)		
Difficulty working due to cancer	49 (4.8)		
Cancer-related insurance issues	39 (3.8)		
Unable to work due to cancer	21 (2.1)		
<b>Endocrine therapy</b>	<b>231 (22.7)</b>	<b>785 (77.3)</b>	<b>0 (0.0)</b>
Hot flashes/night sweats	218 (21.5)		
Arthralgias	34 (3.3)		
<b>Genetics</b>	<b>15 (1.5)</b>	<b>1,001 (98.5)</b>	<b>0 (0.0)</b>
Would like to know about personal and family risk of future cancers	15 (1.5)		
<b>Memory/concentration</b>	<b>269 (26.5)</b>	<b>745 (73.3)</b>	<b>2 (0.2)</b>
Memory is poor	173 (17.0)		
Trouble concentrating	139 (13.7)		
Thinking is slow	135 (13.3)		
Trouble multi-tasking	110 (10.8)		
<b>Mood</b>	<b>324 (31.9)</b>	<b>690 (67.9)</b>	<b>2 (0.2)</b>
Nervous or worried	226 (22.2)		
Sad or depressed	134 (13.2)		
Noticed changes in social relationships	74 (7.3)		
Lost interest in things I used to enjoy	68 (6.7)		
<b>Nutrition</b>	<b>677 (66.6)</b>	<b>338 (33.3)</b>	<b>1 (0.1)</b>
Would like to lose weight	601 (59.2)		
Would like to improve diet	216 (21.3)		
Would like to gain weight	10 (1.0)		
<b>Pain/swelling</b>	<b>630 (62.0)</b>	<b>384 (37.8)</b>	<b>2 (0.2)</b>
Pain	492 (48.4)		
Numbness and tingling	222 (21.9)		
Swelling	84 (8.3)		
Trouble moving	22 (2.2)		
<b>Pregnancy</b>	<b>31 (3.1)</b>	<b>315 (31.0)</b>	<b>670 (65.9)</b>
Would like to avoid pregnancy	29 (2.9)		

Concern Category <sup>a</sup>	No. (%)		
	Reported concern	Did not report concern	Missing
Would like to get pregnant	2 (0.2)		
<b>Primary care</b>	<b>13 (1.3)</b>	<b>1,003 (98.7)</b>	<b>0 (0.0)</b>
Would like to find a PCP	13 (1.3)		
<b>Sexual health</b>	<b>366 (36.0)</b>	<b>643 (63.3)</b>	<b>7 (0.7)</b>
Hot flashes/night sweats	162 (15.9)		
Low interest in sexual activity	154 (15.2)		
Vaginal dryness	129 (12.7)		
Body image concerns	78 (7.7)		
Pain with sexual activity	27 (2.7)		
<b>Sleep</b>	<b>426 (41.9)</b>	<b>590 (58.1)</b>	<b>0 (0.0)</b>
Trouble staying asleep	314 (30.9)		
Trouble falling asleep	173 (17.0)		
Feels sleepy during the day	69 (6.8)		
Legs are restless when trying to sleep	56 (5.5)		
<b>Substance use</b>	<b>54 (4.3)</b>	<b>962 (94.7)</b>	<b>0 (0.0)</b>
Would like to quit smoking	49 (4.8)		
Would like to cut down on alcohol/drug use	6 (0.6)		

<sup>a</sup>Bolded values indicate the number/percentage of survivors who reported at least one concern per category. Non-bolded values indicate the number/percentage of survivors who reported the concern per category. Survivors were able to select more than one concern per category, so non-bolded values do not equal 100%.

**Table 3:**

Acceptance of materials or referrals among survivors who reported a concern

Concern Category (n) <sup>a</sup>		No. (%)				
		Accepted materials	Accepted referral	Accepted 1 <sup>c</sup>	Declined 1 <sup>c</sup>	Missing
Activity/pain <sup>d</sup>	(n = 854)	842 (98.6)	30 (3.5)	842 (98.6) <sup>e</sup>	11 (1.3)	1 (0.1)
Employment/ insurance	(n = 133)	<i>b</i>	15 (11.3)	15 (11.3)	118 (88.7)	0 (0.0)
Endocrine therapy	(n = 231)	<i>b</i>	10 (4.3)	10 (4.3)	221 (95.7)	0 (0.0)
Genetics	(n = 15)	<i>b</i>	6 (40.0)	6 (40.0)	9 (60.0)	0 (0.0)
Memory/ concentration	(n = 269)	146 (54.3)	<i>b</i>	146 (54.3)	123 (45.7)	0 (0.0)
Mood	(n = 324)	198 (61.1)	27 (8.3)	211 (65.1) <sup>e</sup>	113 (34.9)	0 (0.0)
Nutrition	(n = 677)	669 (98.8)	46 (6.8)	669 (98.8) <sup>e</sup>	3 (0.4)	5 (0.7)
Pregnancy	(n = 31)	<i>b</i>	5 (16.1)	5 (16.1)	26 (83.9)	0 (0.0)
Primary care	(n = 13)	<i>b</i>	8 (61.5)	8 (61.5)	5 (38.5)	0 (0.0)
Sexual health	(n = 366)	248 (67.8)	17 (4.6)	255 (69.7) <sup>e</sup>	109 (29.8)	2 (0.5)
Sleep	(n = 426)	240 (56.3)	<i>b</i>	240 (56.3) <sup>e</sup>	156 (36.6)	30 (7.0)
Substance use	(n = 54)	50 (92.6)	<i>b</i>	50 (92.6) <sup>e</sup>	3 (5.6)	1 (1.9)

<sup>a</sup>“n” denotes the count of survivors who reported at least one concern per category. This number was used to calculate the percentages.

<sup>b</sup>No field to support discrete EHR data capture regarding acceptance of materials or referral existed for this concern, as other pathways were deemed standard-of-care at the UWCCC.

<sup>c</sup>“1” refers to at least one resource (materials only, referrals only, or both). Survivors had the option to accept materials, referrals, or both; therefore, the percentages for “accepted materials” and “accepted referral” do not equal 100%.

<sup>d</sup>Activity/pain was aggregated into a single variable from the activity and pain/swelling variables for acceptance of materials or referrals, as the discretely collected data on acceptance of resources or referrals were not available for activity and pain as distinct categories.

<sup>e</sup>More than half of survivors who reported a concern for the given category accepted at least one resource (materials only, referrals only, or both) (p<sub>adj</sub>-value < 0.05).