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Facilitators of Survivorship Care Among Underserved Breast Cancer Survivors: A Qualitative Study

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Abstract

Purpose—Research investigating facilitators of survivorship care among underserved breast cancer survivors (BCS) is sparse. This study aimed to explore facilitators of survivorship care

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ETHICAL STANDARDS This research involved human participants. Informed consent was obtained from all individual participants prior to inclusion in the study. Institutional Review Boards at two universities approved this study prior to implementation. This study involving human participants was approved by the appropriate ethics committee and is therefore in accordance with the ethical standards set forth in the 1964 Declaration of Helsinki and its later amendments.

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among underserved BCS within the first five years following chemotherapy, radiation, or surgery for breast cancer.

Methods—In-depth interviews were conducted, using a semi-structured interview guide, with underserved BCS exploring survivorship care experiences. Content analysis of the verbatim transcripts was applied, and results were summarized according to themes related to facilitators of breast cancer survivorship care.

Results—Interviews were conducted with 25 BCS. Eight main themes were identified: Coordination of care; positive perceptions of health care providers; communication between patient and health care providers; financial and insurance facilitators; information, classes, and programs provided; assistance provided by organizations and health care professionals; transportation facilitators; and job flexibility.

Conclusions—This study provides a comprehensive look at facilitators of survivorship care among underserved BCS. BCS endorsed several facilitators of their survivorship care, mainly at the interpersonal, organizational, and societal level.

Implications for Cancer Survivors—This study adds to the research literature on catalysts of care among underserved BCS. Results from this study are currently being used to inform a patient navigation intervention to facilitate care among this population.

Keywords

breast cancer; cancer survivorship; survivorship care; underserved populations; facilitators; interviews

INTRODUCTION

More than 3 million breast cancer survivors (BCS) are living in the United States [1]. By 2024, it is predicted that this number will increase to nearly 4 million [1]. Approximately two-thirds of women diagnosed have hormone receptor-positive breast cancer [2]. This rapidly growing population possesses unique health care needs immediately following active treatment [3]. As such, the facilitation of optimal survivorship health care is essential to ensure both survival and quality of life.

Guidelines for survivorship care include prevention and surveillance of cancer recurrence; assessment and intervention to address late psychosocial and physical effects of cancer and its treatment; and coordination of care between oncologists and primary care providers [4]. Adherence to recommendations for breast cancer survivorship care is crucial for long-term survival [5]; however, adherence rates are often suboptimal [6]. Underserved women in particular, that is, ethnic and racial minorities, those lacking health insurance, and/or of low socioeconomic status (SES), are even less likely than their white, insured, and/or higher SES counterparts to receive optimal survivorship care following breast cancer treatment, and subsequently exhibit higher breast cancer mortality rates [1, 7–11].

Several barriers to obtaining optimal health care among BCS have been identified, including health care system fragmentation; language and communication barriers; unaffordable medical costs; and lack of health insurance, support, information regarding care, or a regular

health care provider [12, 13]. Less research, however, has explored facilitators of survivorship care; that is, aspects of the health system, social environment, or physical environment that assist BCS in obtaining health care, especially among underserved populations.

Some studies have explored BCS' experiences with survivorship care [12, 14–20], mainly describing BCS' preferences for, recommendations regarding, and endorsed positive aspects of survivorship care [14–20]. Survivors have expressed preferences for coordinated care as well as knowledgeable, trustworthy, and supportive doctors, with whom they have an emotional connection, good communication, and a good relationship [12, 14–18, 20]. Survivors have also expressed preferences regarding schedule, format, topics emphasized in care, and type of provider [14, 18, 19], as well as interest in survivorship care plans and clinics [14, 16, 19]. One study described factors that motivate African-American and African-Caribbean BCS to obtain care, including desire to maintain good health, fear of cancer recurrence, support from medical providers, coordination of care, relationships with family and survivors, and faith [12]. These studies, however, do not focus on facilitators of care specifically, and only one study was conducted among a predominantly underserved sample [12]. Additionally, several of these studies were conducted outside of the United States. The Institute of Medicine (IOM) and National Research Council (NRC) further describe barriers and facilitators of survivorship care of BCS. The IOM and NRC additionally recognize the need for continued survivorship care research to be conducted among diverse populations across both socio-demographic and health care characteristics [21]. The current study conducts such research among a diverse medically-underserved sample. It additionally provides the opportunity to assess whether or not medically-underserved BCS endorse the same facilitators of survivorship care that were proposed for the general population of cancer survivors by the IOM [21].

The objective of the present study was to comprehensively investigate facilitators of survivorship care within the first five years following chemotherapy, radiation, or surgery for breast cancer, among underserved BCS. This study was conducted using semi-structured in-depth interviews with BCS recruited from a comprehensive cancer center.

METHODS

Overview

Institutional Review Boards at two universities approved this study prior to implementation. A five member Community Advisory Board, consisting of health and psychosocial care providers and a breast cancer survivor, provided guidance on study implementation.

Participants

Participants were recruited from a National Cancer Institute-designated comprehensive cancer center located in the southeastern part of the United States. Hormone receptor-positive women were recruited, as the original purpose of the study was to improve adherence to endocrine therapy. BCS were eligible for inclusion if they were: (1) female; (2) 18 years of age or older; (3) fluent in English or Spanish; (4) residing in the region served by

the cancer center; (5) initially diagnosed with Stages IA (T1, N0, M0) to IIIC (Any T, N3, M0) hormone receptor-positive breast cancer within the past five years and had completed surgery, chemotherapy, and/or radiation; (6) able to provide informed consent; and (7) from a medically or historically underserved population. Individuals were considered to be medically or historically underserved if they met one or more of the following criteria: (1) member of an ethnic or racial group that is recognized as a minority in health care, such as African American, Hispanic American, Asian American, or Native American; (2) lacked private health insurance; (3) received public health insurance, such as Medicaid; (4) received Medicare without a supplemental insurance or prescription plan; or (5) participated in a hospital charity program.

Procedure

Between August 2012 and June 2013, researchers reviewed cancer center administrative and medical records to identify potential participants for study participation. A bilingual member of the research team recruited and contacted potential participants by telephone. Interested participants were informed of study procedures, completed an initial study screening, and were scheduled for study participation. On the day of the interview prior to participation, all participants verified that they met study inclusion criteria and provided written informed consent. The researcher reviewed informed consent procedures with each participant and answered any of the participants' questions. Participants completed a demographic survey and in-depth interview in a private room. Interviews were conducted by the research coordinator using a 20-question semi-structured interview guide developed in conjunction with the community advisory board, assessing experiences with breast cancer survivorship care. Table 3 lists questions from the interview guide. Interviews ranged from 30 minutes to 2 hours; were conducted in the participant's preferred language, English or Spanish; and were audio recorded. All participants received a \$25 incentive for participation. Research assistants and professional transcriptionists transcribed interviews verbatim, and translated Spanish interviews into English. The research team reviewed the transcripts, and once it was determined that saturation had been met the researchers stopped conducting interviews [22]. Saturation was defined as the point at which respondents are no longer providing new information during interviews.

Data Analysis

Study authors conducted a content analysis of the transcribed interviews. First we created a preliminary a priori code list based on knowledge of breast cancer survivorship care. Additional codes were created for emergent themes not included in the initial list. A final code list was drafted containing agreed-upon definitions and specific examples for each code. During the initial coding phase, three study authors coded transcripts independently and met as a group to discuss and resolve any discrepancies in coding. Discrepancies included authors disagreeing on whether or not content met criteria for a particular code; additionally discrepancies included instances when authors disagreed on the number of codes pertaining to particular content. Discrepancies were resolved through discussion and consensus. The authors repeated this process until it was determined that all three coders were coding interview content with 90% or more agreement. Atlas.ti was used to further analyze the data using the code mapping function [23]. The data were summarized

according to themes regarding facilitators of breast cancer survivorship care. Researchers defined facilitators of survivorship care as aspects of the health system, social environment, or physical environment that assist BCS in obtaining health care. Demographic data were entered into SPSS, and means, standard deviations, and frequencies of these data were calculated.

RESULTS

Medical records for 745 BCS were reviewed, of which 69 met inclusion criteria. Of these 69 individuals, 33 could not be reached, and 11 declined participation. The remaining 25 individuals participated in the study. Characteristics of study participants are presented in Tables 1 and 2. Participants' age ranged from 46 to 71 years ($M = 59.92$ years; $SD = 6.82$). Approximately one-half of participants were white, 40% were Hispanic, and 28% were Black. Most women were born in the United States (56%) and reported English (64%) as their primary language. The highest year of education completed by participants ranged from 3 to 18 years ($M = 13.6$ years; $SD = 2.99$). Ninety-two percent of participants reported currently taking a prescribed anti-hormone medication, mainly anastrozole (68%).

All 25 BCS identified facilitators of their survivorship care. Eight main themes emerged: Coordination of care; positive perceptions of health care providers; communication between patient and health care provider; financial and insurance facilitators; information, classes, and programs provided; assistance provided by organizations and health care professionals; transportation facilitators; and job flexibility.

Coordination of Care

Nearly all participants ($n = 24$) described that coordination of care facilitated their survivorship care. Survivors specifically identified two themes related to care coordination: appointment and scheduling facilitators and communication between providers. All 24 participants specifically described appointment and scheduling facilitators. BCS described that aspects of the process of scheduling and rescheduling appointments facilitated their survivorship care. For instance, survivors described that their appointments were automatically scheduled by their doctor's office during a previous appointment: *"each time I come for an appointment they schedule my next appointment so I don't have to... worry about calling and making appointments."* Additionally, many survivors described meeting with scheduling representatives to set up these future appointments. Participants also described that doctors' offices provided appointment reminders. For instance, doctors' offices called or sent a letter to remind patients of appointments. BCS also described receiving itineraries listing their doctors and appointment dates and times. Some survivors also mentioned that their doctors' offices provided phone calls for missed appointments: *"If you miss your appointments, they call and want to know why you missed it."* Twenty-one participants mentioned convenience of appointments as a facilitator of survivorship care. Survivors described that appointments were made that worked around their schedules. Participants also noted that multiple appointments were scheduled on the same day: *"And they always schedule appointments so that I can go in early enough to get my lab work done and see the doctors all in one day. And I loved that."* Further, some participants mentioned

that appointments were scheduled right away, started on time, and lasted a short amount of time. Survivors also noted that the convenient location of appointments, or the fact that all of their appointments were in one place, facilitated their survivorship care.

Eleven participants mentioned good communication between health care providers as a facilitator of survivorship care. Participants commonly emphasized that medical records, including test results and treatments, were sent between their oncologist, other specialists, and primary care provider.

Positive Perceptions of Health Care Providers

Twenty participants described that positive perceptions of health care providers facilitated their survivorship care. Participants described that they trust, feel comfortable and safe with, and confident in their health care providers: *"I have had everybody answer my questions and be totally honest with me. It seems like they've done their research...I trust the source."* Participants also described particular attributes of their health care providers, including being caring, honest, kind, thoughtful, considerate, helpful, willing to listen, concerned, and mindful, and treating patients well or like family. BCS also described good relationships and rapport between themselves and their health care provider, and mentioned that their health care providers "know them." *"It's like they're just unbelievable...everyone was considerate, kind and...understanding...they're just so different the way they treat you. Kindness, thoughtful, more concern, a deeper concern for you than I've ever seen at any other doctor's office."*

Communication Between Patient and Health Care Providers

Survivors ($n = 10$) also described good communication between themselves and their health care providers as a facilitator of survivorship care. BCS described their providers' willingness to listen and respond to their questions and concerns. They also mentioned that their providers review and explain aspects of survivorship care with them, such as test results. For instance, one participant noted: *"everyone was really, really helpful. I mean they were willing to listen...I didn't feel rushed with anyone...If I had any questions or any concerns...they took the time to sit...they reviewed things with me."* Participants additionally described that their providers were available to talk on the phone when they called them or that their providers called them personally to check in.

Additionally, five participants mentioned facilitators of care specific to Spanish speakers. Specifically, participants described the availability of translators, as well as the availability of Spanish speakers on the phone or in the health care facility: *"when I have an appointment with [doctors' names] there is always an interpreter... you get specialized interpreters that speak the same way the doctor does, specialized in those type of medical translations. That for me that has been a blessing because it has not been hard, and I understand everything perfectly."*

Financial and Insurance Facilitators

Twelve BCS mentioned financial facilitators of survivorship care specifically. For instance, some participants described that the hospital or their insurance paid for their care. Other

participants described that the hospital offered sliding scales or payment plans when charging for care.

Eleven BCS mentioned insurance as a facilitator to care. Eight participants specifically described that their Medicare or Medicaid coverage facilitated their care. Two participants mentioned county health plans. Five participants alluded to insurance generally as a facilitator of their survivorship care:

“my insurance apparently has a clinical oncologist that calls you and asks you how you’re doing...gives you some pointers...And then...she always called to see how I was doing...or what my treatment was, wanted to make sure that I had access to my doctor... that indeed...I’m doing my mammograms and doing whatever the heck I need to.”

Information, Classes, and Programs Provided

Eight participants mentioned information, classes, and programs provided as facilitators to survivorship care. BCS described the availability of classes, seminars, nutrition programs, websites, flyers, pamphlets, and emails that were helpful to them. Further, BCS indicated that receiving information from their health care team, such as handouts on what to expect after treatment, was helpful: *“they gave me like a little info sheet that let me know...these things will happen, and these things are normal...what to expect...it relieved me.”*

Assistance Provided by Organizations and Health Care Professionals

Seven participants alluded specifically to assistance provided by organizations as a facilitator of survivorship care. Survivors described that organizations provided help obtaining insurance, information, transportation, wigs, prostheses, scarves, and makeup, as well as financial assistance:

“Yes, there’s another one called [organization name] and...believe it or not, although I’m still in remission now, they’re still sending me applications advising me if I had to pay for out of pocket, they still have a grant...where I can turn in those receipts and I can get up to \$300 in reimbursement...the help is there, transportation wise, etc., gas cards, gift cards.”

Six BCS described assistance provided by health care professionals, including social workers, psychiatrists, and psychologists: *“My social worker, although I’m not seeing her that much since I’ve been in remission, every time I call her, she returns my calls and...I ask information and the information is there.”*

Transportation Facilitators

Three participants described transportation as a facilitator of care. One participant described a social worker offering to arrange transportation: *“the social worker told me that if for some reason I needed transportation, that I should tell her and she would make arrangements for someone to pick me up.”* A different participant mentioned Medicaid’s taxi service that transported her to and from appointments. Another mentioned charities providing transportation and gas gift cards.

Job Flexibility

Two participants described job flexibility as a facilitator of survivorship care: *“Even my job has been very flexible ... if I can’t schedule an appointment on one of my days off, the supervisor has been really great in letting me take time off and come back to work.”*

DISCUSSION

The period of breast cancer survivorship is characterized by uncertainty and several transitions [16, 24, 25]. Survivors shift from high medical supervision to having less contact with health care providers [26]. Survivors also frequently experience uncertainty regarding next steps in ongoing care, and some experience distress and fear of cancer recurrence [24, 25, 27]. Survivors also transition back into their “normal life,” some resuming previous roles and responsibilities, while others are unable to do so [26]. Notwithstanding, it is imperative for the survival of BCS that they adhere to survivorship care guidelines [5]; however, rates of adherence are often suboptimal among BCS [6], especially among those that are underserved [7, 8]. The research literature documents barriers to care contributing to these suboptimal rates of adherence [12, 13], but little attention has been paid to factors that facilitate survivorship care among underserved BCS and motivate these women to persist in obtaining health care despite the changes and uncertainty characterizing this time period.

In the current study, all BCS identified facilitators of their survivorship care, mainly at the interpersonal, organizational, and societal levels. Many participants described interpersonal facilitators, such as positive perceptions of health care providers, as well as good communication both between health care providers and between patient and provider. Survivors in the current study also endorsed organizational factors within the health care system that fostered their obtainment of care, including coordination of care, generally; financial assistance; transportation; information, classes, and programs provided; as well as appointment and scheduling facilitators. Survivors also described societal facilitators of care including insurance, job flexibility, and assistance provided by organizations. While previous studies have mentioned interpersonal factors related to breast cancer survivorship care [12, 14, 16, 17, 20], the current study elaborates upon survivors’ perceptions of interpersonal facilitators of care, and does so among a diverse sample. The current study’s findings surrounding coordination of care are also consistent with research conducted in Australia, as well as research conducted in the United States predominantly in non-ethnically diverse samples, which document BCS’ preference for well-coordinated care [12, 14–17]. The current study, however, adds to the literature in that it highlights specific aspects of care coordination necessary to achieve optimal receipt of survivorship care among diverse underserved populations.

In addition to the fact that little research has explored facilitators of survivorship care among underserved BCS, this research is also important as it provided the opportunity to address a recommendation set forth by the IOM and NRC regarding the need to conduct survivorship care research among diverse populations [21]. The IOM additionally provided a set of guidelines that survivorship care should embody for all cancer survivors (see Figure 1). In the current study, underserved BCS mentioned facilitators related to guideline #1 including that health care providers contacted them via telephone to communicate about care issues;

#2 in their description of language-specific resources as a facilitator for BCS; #4 in their description of positive communication and relationships between patient and provider as a facilitator of care; #7 through their mention of information, classes, and programs as a facilitator of care; #9 through their description of appointment scheduling facilitators; and #10 through their report of good communication between providers as a facilitator of care. This study adds to the literature base as it provides new information confirming that underserved BCS endorse many of the same facilitators as those suggested by the IOM for survivorship care for the general population of cancer survivors [21].

Findings from the current study also have broad implications for intervention research designed to improve adherence to care among underserved BCS. Current intervention research mainly focuses on change at the individual level, that is, increasing knowledge, motivations, and intentions related to obtaining health care among BCS [28]. The current study suggests that changes at the environmental level, both within health care systems and communities, as well as at the interpersonal level may facilitate breast cancer survivorship care among underserved populations. Findings from this study suggest several interpersonal, organizational, and societal strategies that could be incorporated into future interventions to facilitate survivorship care among underserved populations, such as automatic scheduling of future appointments; appointment reminders via phone or mail; schedules listing future appointment dates and times; phone calls for missed appointments; convenience of appointments including multiple appointments scheduled on the same day; facilitation of relationship between patient and provider; and financial/insurance assistance, including sliding scales and payment plans or assistance from organizations and charities.

While this study adds to the scant literature exploring facilitators of survivorship care among underserved BCS, it is not without limitations. Although the sample was comprised of diverse individuals with respect to age, ethnicity, race, marital status, and years of education, all 25 participants were recruited from one comprehensive cancer center in the southeastern part of the United States. Additionally, all participants continued to receive health care at this comprehensive cancer center up to five years post-surgery, chemotherapy, and/or radiation. Eleven of 36 participants contacted for the study declined participation; this presents a potential sampling bias and we do not know why participants declined. Further, this study explored facilitators of survivorship care among a particular group of individuals, underserved hormone receptor-positive BCS who had completed surgery, chemotherapy, and/or radiation. While it is a strength that this research was conducted among an underserved populations for whom little research exists, the degree to which these findings can be generalized to BCS residing in other parts of the United States or globally; those not receiving survivorship care at all; those obtaining care at institutions not designated as comprehensive cancer centers; or those with other diagnoses or in different stages of the cancer care continuum is unknown.

In conclusion, this study provides a comprehensive look at facilitators of survivorship care among underserved BCS. The study points to the main facilitators of survivorship care identified by underserved BCS including care coordination; positive perceptions of health care providers; good communication between patient and provider; financial, insurance, and transportation assistance; information, classes, and programs provided; assistance provided

by organizations and health care professionals; and job flexibility, and confirms that facilitators of care among underserved BCS are similar to those endorsed by the IOM for the general population of cancer survivors [21]. Results from this study are currently being used to develop a patient navigation intervention to facilitate care among underserved BCS.

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REFERENCES

1. DeSantis CE, Lin CC, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2014. *CA Cancer J Clin.* 2014; 64:252–271. [PubMed: 24890451]
2. Hammond ME, Hayes DF, Dowsett M, et al. American Society of Clinical Oncology/College Of American Pathologists guideline recommendations for immunohistochemical testing of estrogen and progesterone receptors in breast cancer. *J Clin Oncol.* 2010; 28:2784–2795. [PubMed: 20404251]
3. Kukar M, Watroba N, Miller A, Kumar S, Edge SB. Fostering coordinated survivorship care in breast cancer: Who is lost to follow-up? *J Cancer Surviv.* 2014; 8:199–204. [PubMed: 24317969]
4. National Comprehensive Cancer Network. NCCN Clinical Practice Guideline in Oncology: Survivorship. 2014 Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf.
5. Buist DSM, Bosco JLF, Silliman RA, et al. Long-term surveillance mammography and mortality in older women with a history of early stage invasive breast cancer. *Breast Cancer Res Treat.* 2013; 142:153–163. [PubMed: 24113745]
6. Wirtz HS, Boudreau DM, Gralow JR, et al. Factors associated with long-term adherence to annual surveillance mammography among breast cancer survivors. *Breast Cancer Res Treat.* 2014; 143:541–550. [PubMed: 24407530]
7. Freedman RA, Virgo KS, He YL, et al. The association of race/ethnicity, insurance status, and socioeconomic factors with breast cancer care. *Cancer.* 2011; 117:180–189. [PubMed: 20939011]
8. Nurgalieva ZZ, Franzini L, Morgan R, Vernon SW, Liu CC, Du XL. Surveillance mammography use after treatment of primary breast cancer and racial disparities in survival. *Med Oncol.* 2013; 30:1–8.
9. Siegel R, DeSantis C, Virgo K, et al. Cancer treatment and survivorship statistics, 2012. *CA Cancer J Clin.* 2012; 62:220–241. [PubMed: 22700443]
10. Sprague BL, Trentham-Dietz A, Gangnon RE, et al. Socioeconomic status and survival after an invasive breast cancer diagnosis. *Cancer.* 2011; 117:1542–1551. [PubMed: 21425155]
11. Wray CJ, Phatak UR, Robinson EK, et al. The effect of age on race-related breast cancer survival disparities. *Ann Surg Oncol.* 2013; 20:2541–2547. [PubMed: 23435633]
12. Thompson HS, Littles M, Jacob S, Coker C. Posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: An exploratory qualitative study. *Cancer Nurs.* 2006; 29:478–487. [PubMed: 17135822]

13. Virgo KS, Lerro CC, Klabunde CN, Earle C, Ganz PA. Barriers to breast and colorectal cancer survivorship care: Perceptions of primary care physicians and medical oncologists in the United States. *J Clin Oncol*. 2013; 31:2322–2336. [PubMed: 23690429]
14. Brennan ME, Butow P, Marven M, Spillane AJ, Boyle FM. Survivorship care after breast cancer treatment: Experiences and preferences of Australian women. *Breast*. 2011; 20:271–277. [PubMed: 21236671]
15. Brennan ME, Butow P, Spillane AJ, Boyle FM. Patient-reported quality of life, unmet needs and care coordination outcomes: Moving toward targeted breast cancer survivorship care planning. *Asia Pac J Clin Oncol*. 2014;1–9.
16. Kantsiper M, McDonald EL, Geller G, Shockney L, Snyder C, Wolff AC. Transitioning to breast cancer survivorship: Perspectives of patients, cancer specialists, and primary care providers. *J Gen Intern Med*. 2009; 24:459–466.
17. Mao JJ, Bowman MA, Stricker CT, et al. Delivery of survivorship care by primary care physicians: The perspective of breast cancer patients. *J Clin Oncol*. 2009; 27:933–938. [PubMed: 19139437]
18. Roorda C, de Bock GH, Scholing C, et al. Patients' preferences for post-treatment breast cancer follow-up in primary care vs. secondary care: A qualitative study. *Health Expect*. 2014; 18:1–10.
19. Thompson CA, Stan DL, Nes LS, Jenkins SM, Lackore KA, Pruthi S. Breast cancer survivors' self-reported needs and preferences of survivorship care. *Breast J*. 2013; 20:107–109. [PubMed: 24262015]
20. Wilson SE, Andersen MR, Meischke H. Meeting the needs of rural breast cancer survivors: What still needs to be done? *J Womens Health Gend Based Med*. 2000; 9:667–677. [PubMed: 10957755]
21. Hewitt, M.Greenfield, S., Stovall, E., editors. Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council. Washington, DC: The National Academies Press; 2006. From Cancer Patient to Cancer Survivor: Lost in Transition.
22. Patton, MQ. Qualitative Research and Evaluation Methods. Third. London: SAGE Publications; 2001.
23. Atlas.ti [computer program]. Berlin: Scientific Software Development GmbH; 2015.
24. Germino BB, Mishel MH, Crandell J, et al. Outcomes of an uncertainty management intervention in younger African American and Caucasian breast cancer survivors. *Oncol Nurs Forum*. 2013; 40:82–92. [PubMed: 23269773]
25. Miller LE. Sources of uncertainty in cancer survivorship. *J Cancer Surviv*. 2012; 6:431–440. [PubMed: 22815086]
26. Stanton AL. What happens now? Psychosocial care for cancer survivors after medical treatment completion. *J Clin Oncol*. 2012; 30:1215–1220. [PubMed: 22412133]
27. Costanzo ES, Lutgendorf SK, Mattes ML, et al. Adjusting to life after treatment: Distress and quality of life following treatment for breast cancer. *Br J Cancer*. 2007; 97:1625–1631. [PubMed: 18000503]
28. Halpern MT, Viswanathan M, Evans TS, Birken SA, Basch E, Mayer DK. Models of cancer survivorship care: Overview and summary of current evidence. *J Oncol Pract*. 2015; 11:e19–e27. [PubMed: 25205779]

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1. Care based on continuous healing relationships
 2. Customization based on patient needs and values
 3. The patient as the source of control
 4. Shared knowledge and the free flow of information
 5. Evidence-based decision making
 6. Safety as a system property
 7. The need for transparency
 8. Anticipation of needs
 9. Continuous decrease in waste
 10. Cooperation among clinicians
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Figure 1.
Institute of Medicine Guidelines for Survivorship Care

Table 1Demographic Characteristics of Study Participants ($N = 25$).

Characteristic		Number of Participants	%
Hispanic/ Latina	No	15	60.0
	Yes	10	40.0
Race	White	13	52.0
	African American or Black	7	28.0
	Asian	1	4.0
	Other	4	16.0
Primary Language	English	16	64.0
	Spanish	8	32.0
	Other	1	4.0
Marital Status	Separated	11	44.0
	Married	8	32.0
	Single	4	16.0
	Widowed	2	8.0
Employment	Not currently employed	11	44.0
	Part-time	8	32.0
	Full-time	6	24.0
Country of Birth	United States	14	56.0
	Puerto Rico	3	12.0
	Colombia	2	8.0
	Cuba	2	8.0
	Dominican Republic	1	4.0
	Germany	1	4.0
	Honduras	1	4.0
	Panama Canal Zone	1	4.0

Table 2Clinical Characteristics of Study Participants ($N=25$).

Characteristic		Number of Participants	%
Year of Breast Cancer Diagnosis	2005	2	8.0
	2006	1	4.0
	2007	3	12.0
	2008	4	16.0
	2009	5	20.0
	2010	4	16.0
	2011	6	24.0
Treated by Surgery	No	1	4.0
	Yes	24	96.0
Treated by Chemotherapy	No	13	52.0
	Yes	12	48.0
Treated by Radiation	No	7	28.0
	Yes	18	72.0
Currently Taking Hormone Medication	No	3	12.0
	Yes	22	88.0
Medication Name	Anastrozole	17	68.0
	Tamoxifen	6	24.0
	Missing	2	8.0

Table 3**Interview Guide**

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1. How do you like to get information about health? Who or what is the best source of information about your health? Why does this person/clinic/organization provide the best information? If the health information you were looking for was about cancer, would this still be the same source?
 2. Why are you comfortable with *(name of care provider)*? Is there anything about *(name of care provider)* that makes you uncomfortable?
 3. Tell me about the treatment that you received after you were diagnosed with breast cancer?
 4. Overall how do you feel on most days?
 5. What do you understand about when you should follow up with your oncologists/cancer doctor? Why do you need to see your oncologist regularly?
 6. Tell me about the last time you had a follow up appointment with an oncologist/cancer doctor.
 7. What makes it easier to get appointments that you need from your oncologists/cancer doctor? Does anything make it difficult?
 8. Do you have a doctor or clinic that you go to for your regular medical care? Does this clinic or doctor help you to get the health care you need? If so, what kinds of things do they do?
 9. Does anything make it easier to get the healthcare you need from your regular clinic or doctor? Does anything make it difficult?
 10. In general, what makes it easier to get mammograms that you need? What makes it more difficult?
 11. Are there people in your life who help you to get what you need? How do they help? Are there people who make it hard for you to get what you need? Tell me about that.
 12. Are there any organizations that help you obtain information or care? How do they help? Tell me about that.
 13. So you said that _____ (use participant's words) make(s) it easier/difficult to get the health care that you need. What could be changed to make it easier for a breast cancer survivor to get health care?
 14. How can we best help other breast cancer survivors to have a good quality of life?
 15. What other resources would you recommend to other women who have just finished (surgery, chemotherapy, radiation) for breast cancer?
 16. Do you take a hormonal medication? Which one? How often do you take this medicine?
 17. Please tell me some of the things that a woman needs to know to take this medicine correctly.
 18. Does anything make it hard for you to take your hormonal medicine as prescribed by your doctor? Does anything make it easier?
 19. So you said that _____ (use participant's words) make(s) it easier/difficult to take your hormonal medicine. Could anything be changed to make it easier for you to take your medication as directed?
 20. Is there anything else that you would like to tell me about your experience as a breast cancer survivor?
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