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Provider perceptions and expectations of breast cancer post-treatment care: A University of California Athena Breast Health Network project

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Abstract

Purpose—The Athena Breast Health Network collaboration is a University of California system-wide project initiated with the intent to drive innovation in breast cancer prevention, screening and treatment. This qualitative research examines provider perceptions and expectations of post-treatment breast cancer care across five Network sites with the goal of better understanding provider behavior during the post-treatment phase of the cancer care trajectory.

Methods—Investigators at each site conducted semi-structured interviews with oncology specialists and primary care providers (PCPs). Interviews used case study examples and open- and closed-ended questions on the delivery of post-treatment breast cancer care. Informant responses were manually recorded by the interviewer, compiled in a database, then coded and analyzed using NVivo 9 software.

Results—There were 39 key informants across the sites: 14 medical oncologists, 7 radiation oncologists, 11 surgeons, 3 oncology nurses, and 4 PCPs. Care coordination was a major unprompted theme identified in the interviews. There was a perceived need for greater care coordination across institutions in order to improve delivery of post-treatment health care services and a need for greater care coordination within oncology, particularly to help avoid duplication of follow-up care and services. Participants expect frequent follow-up visits and to use biomarker tests and advanced imaging services as part of routine surveillance care. Implementing survivorship care programs was perceived as a way to improve care delivery.

Conclusions—These results identify a need for increased focus on care coordination during the post-treatment phase of breast cancer care within the UC system, and the potential for system and provider level interventions that could help increase coordination of post-treatment care.

Implications for Cancer Survivors—Breast cancer survivors do not always receive evidence-based care. This research helps to better understand what motivates provider behavior during the

post-treatment phase and lays a foundation for targeted interventions to increase adherence to evidence-based recommendations.

Keywords

Breast cancer post-treatment care

Introduction

The number of individuals living with a personal history of cancer is increasing. In 1971 an estimated 3 million persons were living five years beyond a cancer diagnosis. As of 2012, it is estimated that there are almost 14 million survivors in the United States, with about one fourth of these breast cancer survivors. [1] With approximately 1.6 million individuals expected to be diagnosed with cancer in 2012, the provision of care for survivors already poses an important healthcare challenge, and there is increasing interest in improving the quality of post-treatment care of cancer survivors. [2] Survivorship care, especially with regard to coordination of post-treatment care, is now a national priority, well-described in the 2006 Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*. [3] There is concern that cancer survivors may not receive optimal post-treatment care within our fragmented health care system. The IOM report notes that "...the transition from active treatment to post-treatment care is critical to long-term health. If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks and a follow-up plan of action." [3] The University of California (UC) Athena Breast Health Network collaboration is a large scale, UC system-wide project initiated with the intent to drive innovation in breast cancer prevention, screening, treatment, and survivorship care. This paper describes research on provider perceptions and expectations of breast cancer post-treatment care within the UC system as part of the overarching Athena project. The purpose of this study was to determine real-world expectations and perceptions of providers involved in the delivery of post-treatment care to breast cancer patients, and to identify themes that may lead to a deeper understanding of provider behaviors and care delivery during this phase of the cancer care trajectory.

Background

It has been shown that there can be significant over- and underuse of both preventive services and surveillance care for post-treatment cancer patients. [4–9] There are evidence-based guidelines for post-treatment care of breast cancer from the American Society of Clinical Oncology (ASCO) [10] and the National Comprehensive Cancer Network (NCCN) [11] that are designed to help address this problem. These guidelines include recommendations for use of post-treatment surveillance care, such as mammograms for breast cancer survivors, as well as non-recommended surveillance care, such as use of most imaging services. In addition, ASCO recently released a "Top Five" list as part of the Choosing Wisely® campaign, an initiative of the American Board of Internal Medicine. [12] This campaign aims to promote clinical care that is well supported by evidence, has beneficial effects on patient health by improving treatment and/or reducing risks, and, where possible, reduces costs of care. [13] The ASCO Top Five list advises against routine recurrence surveillance testing in breast cancer survivors who have completed curative treatment, and discourages use of advanced imaging tests (positron emission tomography (PET), computerized tomography (CT) and radionuclide bone scans) and blood tests for biomarkers (CEA, CA 15-3, CA 27–29). [12]

Prudent use of these guidelines may help to reduce the use unnecessary services within oncology. However, the literature shows that adherence to guideline recommendations for

cancer survivors has been less than optimal. [7, 14] Additionally, it can be difficult for researchers examining the question of adherence to post-treatment guidelines to determine whether use of services is driven by symptoms and physical findings, or if these services are used in routine post-treatment surveillance. [4, 6, 9] Duplicative tests and services may be influenced by lack of care coordination for cancer survivors (e.g., lack of a common medical record among providers), as well as patient expectations and anxiety about cancer recurrence. Other important components that may drive patterns of post-treatment care are provider expectations and preferences, the focus of this research.

Given the increasing numbers of cancer survivors [2] and the research showing that high-intensity surveillance does not benefit early stage breast cancer survivors, [10, 15] it is important to understand what is driving the current post-treatment practice patterns that show overutilization of non-recommended services. We conducted a study using provider interviews and patient surveys at the five Cancer Centers participating in Athena (UC San Diego, UC Irvine, UC Los Angeles, UC San Francisco, and UC Davis) to examine how different tertiary cancer centers provide post-treatment survivorship care and how well the existing models of care at each site facilitate adherence to guideline recommendations for surveillance and management of common post-treatment symptoms. A qualitative method was chosen to allow providers to describe *in their own words* what their current practices, expectations, and perceptions are of post-treatment care delivery. This approach allowed us to identify and develop themes that arose from the data, an approach recommended for this type of health services research [16] and one that allows exploration of the perspectives of those involved in the delivery of breast cancer post-treatment care. This approach is more commonly called “generic qualitative research.” [17, 18] By examining these themes, we hoped to identify patterns of care delivery for this common cancer, as well as a deeper understanding of what is motivating provider behavior during the post-treatment phase of the cancer care trajectory. Our assumptions regarding post-treatment care delivery were based on the available literature, which shows that guideline adherence is poor but does not provide information on why this care is not guideline concordant. We viewed this qualitative information as being essential for the development of future interventions designed to motivate providers to increase adherence to evidence-based recommendations. Our generic approach was chosen to allow us to uncover and explore potential issues in quality of care and care delivery and to have our research process shape the collection of data. This paper reports the results of the provider study, which used qualitative methods to characterize provider expectations and experiences of post-treatment breast cancer care.

Methods

Setting and participants

The University of California has five NCI designated comprehensive cancer centers, each of a separate campus. As part of the Athena project, providers involved in caring for post-treatment breast cancer patients were identified at each of these centers. Provider identification was carried out by the site-affiliated Principal Investigator (PI). A broad sample of provider types was sought in line with maximum variation sampling theory, which attempts to capture main themes or ideas that appear across a small but varied sample. [19] Provider types targeted for the study included medical oncologists, radiation oncologists, surgeons, primary care physicians (internal medicine, family medicine, gynecology), and oncology nurses, who were viewed as opinion leaders and were directly involved in the care of many breast cancer patients at each institution. Providers were eligible to participate if they were employed and actively engaged in providing post-treatment care to breast cancer patients at the UC site at the time of the interview. Providers were invited to participate by the site PI via an electronic invitation with email follow-up. Each site had a target of 5 to 10 participants. All study activities were approved using a UC-

wide Institutional Review Board (IRB) Memorandum of Understanding (MOU) with UC Los Angeles as the lead IRB.

Data collection

In-depth semi-structured interviews were conducted in person or over the telephone using an interview guide developed by a committee of investigators from each site knowledgeable about the treatment and follow-up surveillance of breast cancer patients. The interview script focused on patterns of follow-up care, symptom management, and institutional challenges and included open-ended questions with ad-hoc probes as well case vignettes. The case vignettes were developed through a consensus process by the five site PIs: two medical oncologists, one breast surgeon, and two health services/cancer control researchers. The case vignettes described three different breast cancer patients with distinctive recurrence risk profiles that might influence follow-up patterns (Table 1). After presentation of each patient vignette, the key informant clinician was asked about the frequency of follow-up visits for the patient, the types of tests and/or procedures used for follow-up care, and the inclusion of other providers in follow-up care. Each interview took between 30–75 minutes to complete. Interviews were transcribed by the interviewers and oral informed consent was obtained from each participant at the start of the interview.

Data analysis

Qualitative data analysis followed the constant comparative method (CCM) as described by Glaser [20] and thematic analysis as described by Morse and Field. [21] CCM employs a data coding strategy that references new text coded in a particular category to previously coded text in that category, aiding in the recognition and development of the theoretical properties and themes in the data. While CCM arises out of Grounded Theory research, it is not used exclusively for Grounded Theory. [22] CCM has applications within other research frameworks, such as thematic analysis, and was chosen in order to allow for the development of meaningful themes within the interview data, a method that is appropriate given our stated goal of exploring the perspectives of those involved in the delivery of post-treatment breast cancer care. [23] All transcribed interview data was entered into NVivo 9 data management software (QSR International, Cambridge, MA) to assist with coding and theme development. Two independent coders, a nurse practitioner and a health services researcher, analyzed the transcribed data. The initial interview transcript was read several times prior to initiation of coding. The primary coder then developed a detailed categorization scheme of themes, sub-themes, and relationships based on the interview content. Subsequent interviews were read and coded with reference to the prior coding scheme. Frequent comparisons between the two coders ensured coding consistency and adherence to theme constructs. Discrepancies in coding were discussed at meetings between the two coders, with differences in theme identification resolved by consensus. We did not engage in respondent validation, but we did attempt to gather a wide range of perspectives. Twenty-seven distinct themes emerged from the data. Cohen's kappa was calculated to measure inter-coder reliability by individual theme and for the overall data. Overall, there was an 84% agreement rate between coders. This report highlights the most prevalent themes in the data.

Results

Characteristics

There were 39 key informants across the five participating sites: 14 medical oncologists, 7 radiation oncologists, 11 surgeons, 3 oncology nurses, and 4 primary care practitioners (PCPs). The mean number of years of employment within the UC health care system was 10.4 years (SD 6.8, minimum=1, maximum=30).

Themes and findings

Care coordination—Across all sites, care coordination was a major unprompted theme identified in the interviews. The concept of coordination had over 100 discrete mentions across the 39 interviews. The broad theme of coordination had relationships with the majority of other themes identified in the data as shown in the concept map (Figure 1). The concept map is a visual representation of the data that shows the relationships between themes and subthemes that were identified from the coded data. Three distinct coordination themes emerged from the data: shared care between oncology and primary care, care coordination across the institution, and care coordination within oncology.

Shared care between oncology and primary care was perceived as a positive method of post-treatment care for breast cancer survivors by most participants:

“Medical oncologist and PCP share care in the post-treatment phase--co-manage for first 5 years. After 5 years, PCP dominates.”

“PCP providers excellent to share care with; good model.”

“Oncologist and PCP co-manage, based on history of chemo; followed for several years by medical oncologist.”

A minority of participants expressed doubt that PCPs wanted to carry out shared-care responsibilities during the post-treatment phase.

“Most PCPs prefer not to be involved in oncology post-treatment care.”

“It can be difficult to communicate [with PCPs] during post-treatment...and sometimes patients are on inappropriate medications from PCP and I direct patients to stop or change meds.”

“PC [primary care] physicians don’t deal with breast issues.”

“Sometimes PCP doesn’t respond or provide any feedback.”

A perceived need for greater care coordination across the institution in order to improve delivery of post-treatment health care services was evident throughout the interviews.

“[We need] more integrated care and communication with PCPs, other specialists, and complementary medicine docs. Minimize repetitive visits between specialists.”

“[We need] an integrated EMR, need to have better communication and ability to flag records. Improved patient communication of symptoms to MDs--a patient portal...cancer care and support are decentralized.”

“I’d like to see coordinated effort with respect to psychosocial care, use of survivorship care plans...[and] more organized follow-up.”

“Improvements would be...streamlining after care issues; improved communication with medical oncology; access to care plans and other services.”

There was also a perceived need for greater care coordination within oncology, particularly to help avoid duplication of follow-up care and services. The responses demonstrate wide variability among provider types and participating sites.

“To improve care [we need] better communication among oncology specialists; burden is on patient—there is no coordination. Multidisciplinary care is desirable.”

“I would like to see coordinated scheduling of appointments; help to avoid duplication [of services].”

“Oncology follow-up is not systematic, intervals not regularized. [Follow-up can] depend on the medical oncologist and/or surgeon; if dismissed by surgeon or oncologist, radiation oncologist may follow more frequently.”

“[We need] better communication with oncology, role delineation. Survivorship plans of care could help with this.”

“Rad onc, med onc, and surg onc should alternate visits for follow-up.”

Use of imaging and tumor markers as expected part of routine post-treatment care—Participants were asked open-ended questions about types of routine follow-up services for post-treatment patients based on the three case vignettes. Almost all participants expected to use tumor markers as a routine part of post-treatment care. Few participants clearly articulated why they ordered specific tests and/or services, although some indicated that they generally repeated tests and services that had been ordered before. For example, discussion of PET scans used in routine follow-up care demonstrated that providers expect to order a PET scan if one has been done before, for any reason:

“PET CT as follow-up...[because] staging with scans at diagnosis often done.”

“I will do a PET CT, if done at baseline, will repeat; ad hoc patterns [for imaging].”

“PET CTs are done after treatment, it’s expected.”

The informants also perceived problems with coordination of imaging in post-treatment care:

“Imaging, mammography, I do whatever screening is necessary...need to make sure it is getting done.”

“Unclear who takes responsibility for ordering imaging.”

Ways to improve delivery of post-treatment care—These providers indicated that structured post-treatment clinical services would improve their ability to deliver care, such as survivorship clinics or a dedicated survivorship clinician (e.g., nurse practitioner, physician assistant). Use of survivorship care plans and/or treatment summaries was identified as a sub-theme of structured post-treatment care. These themes have a strong relationship to the theme of care coordination, with many responses cross-categorized into both themes.

“We need to offer post-treatment care to everyone in an organized way.”

“An improvement would be physician extenders to focus on survivorship population.”

“Increase support personnel; offer post-treatment care to everyone.”

“A goal—a multidisciplinary clinic for breast cancer survivors with hem/onc clinicians, pain management, psych...would have consultations.”

“[Patients] start redefining life after treatment, they aren't the same person. We have to help [them] redefine self and relationships and find a new normal.”

“We need survivorship clinic for post-treatment care.”

“Creation of survivorship plans [would improve ability to provide post-treatment care].”

Discussion

Findings from this qualitative study illustrate some of the ongoing issues in providing high-quality post-treatment care to breast cancer survivors. By gaining insight into the perceptions and expectations of providers involved in post-treatment care delivery, we sought to gain an understanding of some of the drivers of provider behavior. Based on these findings, care coordination is a critical missing element of post-treatment care delivery. This theme demonstrates both the strengths and weaknesses of post-treatment care delivery across the five centers. The theme of shared care between primary and oncology care demonstrates both an expectation and perception of coordinating care across specialties as an important aspect of post-treatment breast cancer care. Engaging in shared-care between oncology and primary care has been shown to result in improved general health care and cancer surveillance for breast cancer survivors. [24, 25] However, many participants identified a lack of coordination within oncology as a problem, specifically the inability to coordinate follow-up visits across oncology specialists. The lack of awareness and knowledge of how other members of the oncology team are following post-treatment patients is a serious hindrance to care coordination, and is described as sometimes leading to duplication of visits, tests, and other services. The providers in this study feel that care should be coordinated throughout the oncology team and with primary care, but have no simple mechanism for doing so within their institutions.

Our study participants reported use of blood work and imaging as part of routine post-treatment care. The literature shows that some ASCO and NCCN guideline-recommended services are being under-utilized, such as mammograms for detection of recurrence or new primary breast cancer in breast cancer survivors. [8, 9] Conversely, some non-recommended services have been shown to be over-utilized, such as tumor antigen testing and chest and/or abdominal imaging. [6, 14, 26] These non-recommended services have not been shown to be associated with significant differences in survival or quality of life, yet use of these services persists in breast cancer post-treatment care. [10] A recent study found that 40% of women treated for early stage (I–II) breast cancer had at least one non-recommended imaging test (computerized tomography scan, bone scan, breast MRI, PET) during the surveillance care interval. [14] Use of advanced imaging services such as breast MRI and PET scans are also not recommended according to the ASCO guidelines and “Top Five” list. [10, 12]

It remains somewhat unclear why oncology providers in our study reported routinely using non-recommended imaging tests as part of breast cancer surveillance care. Few reasons are given for use of these services other than indicating that if a service had been used once it would most likely be used again, as with the PET scans. Coordination was again an important element in use of imaging and other services. The participants perceived that gaps in their knowledge of what other providers were ordering could lead to confusion and potentially duplication of services.

The majority of participants identified structured post-treatment clinical services as a way to improve care delivery. Based on the interview data, post-treatment survivorship care is largely unorganized within the five institutions. Providers perceive this as a barrier to coordinating care delivery for this population. The reported need for an organized system of post-treatment care underlines the major themes found in the data. Care coordination, frequency of follow-up, and use of non-recommended surveillance services could all be potentially improved with a structured system of post-treatment care that appropriately utilizes health information technology. For example, if providers were able to easily coordinate centralized appointment scheduling within the oncology treatment team (medical oncology, radiation oncology, surgery), it could help providers to organize post-treatment visits and potential decrease repetitive visits and services. Or, a post-treatment care program

or provider could take the lead in organizing this phase of care, communicating with the oncology team as needed. However, there are practical barriers to implementing such strategies. For example, providers currently have a strong incentive to continue frequent follow-up visits based on fee-for-service reimbursement and the use of relative value units (RVUs) in provider salaries.

These results indicate that there are substantial opportunities for system and provider level interventions that could help to improve coordination post-treatment care. Knowledge translation (KT) or T3 translational research, defined as the incorporation of evidence-based findings into clinical practice, is a complex process that requires organizational and provider buy-in. [27, 28] A combination of KT/T3 strategies could be effective in helping post-treatment care providers to deliver evidence based care. For example, systems processes such as evidence-based computerized reminders combined with provider-level education and incentives, including individual audit with timely, customized feedback, may be an effective combined strategy to increase appropriate post-treatment care for breast cancer survivors.

This study used qualitative research methods to generate insights into post-treatment care delivery within the UC system and to explore provider expectations of care delivery. This methodology has its limitations, in that it is the opinions of a modest number of individual providers. However, those interviewed were among the institutional opinion leaders involved in the delivery of breast cancer care, and thus they likely reflect the general approach to post-treatment care delivery at these academic medical centers. The results demonstrate that there is significant room for improvement across the participating sites, and that organized survivorship care is still being developed within these five academic centers. We found that providers are engaging in shared-care between oncology and primary care during the post-treatment phase, but that overall care coordination within institutions and within oncology specialties could be improved. The recurrent theme of care coordination emphasizes the need for organized survivorship services within each institution. By illustrating the current state of post-treatment breast cancer care delivery these results can help to drive innovation and adaptation in cancer care delivery across the UC system as part of the UC Athena Network Breast Health Project and beyond. As our health care system moves toward using coordinated electronic medical records systems, opportunities to improve the organization and delivery of post-treatment cancer care will become more apparent.

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Figure 1.

Concept map of themes, sub-themes, and relationships discovered and coded from the interview data. The size and shape of the text box is related to the number of mentions in the data. Ovals indicate the highest number of mentions, followed by rectangles, then squares; larger shapes indicate more mentions than a smaller size of the same shape. For example, care coordination was mentioned the most of any theme so it is the largest oval. The next most common mentions are follow-up care perceptions related to the case vignettes, followed by follow-up care perceptions.

Table 1

Case vignettes presented as part of participant interview

	Low risk case	Medium risk case	High risk case
Age	67 years old	60 years old	41 years old
Menopausal status	Post-menopausal	Post-menopausal	Pre-menopausal
Tumor characteristics	1.2 cm, grade 2 IDC ER+/PR+/HER2- 0/2 + sentinel nodes	2.5 cm, grade 2 IDC ER+/PR-/HER2- 1/15 + lymph nodes	Locally advanced, high grade ER-/PR-/HER 2/12 + lymph nodes
Surgery	Lumpectomy with sentinel lymph node dissection	Lumpectomy with axillary lymph node dissection	Bilateral mastectomies with immediate reconstruction
Chemotherapy	No	Taxotere and Cytosan	Neoadjuvant AC-Taxol
Radiation	Yes	Yes	No
Other therapies	Aromatase inhibitor	Aromatase inhibitor	No
Comorbid conditions	None	Hypertension; obesity; non-insulin dependent diabetes; moderate to severe DJD	None

Abbreviations:

IDC: Infiltrating ductal carcinoma

ER: Estrogen receptor

PR: Progesterone receptor

HER2: Human epidermal growth factor receptor 2

DJD: Degenerative joint disease

AC: Adriamycin and cyclophosphamide