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# Transition After Breast Cancer Treatment: Implementing Survivorship Care Plans

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Hahn School of Nursing and Health Science

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by

Susan Hope Klein

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## Transition After Breast Cancer Treatment: Implementing Survivorship Care Plans

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## **Abstract**

The success of cancer treatments have resulted in a rapid growth of survivors, providing the impetus for the oncology community to examine models of care supporting smooth transition from active treatment to survivorship care. While initially a recommendation of the Institute of Medicine, treatment summaries and survivorship care plans are now an accreditation requirement for many organizations. This article describes the implementation of an evidence based practice project designed to meet these standards while improving the knowledge and satisfaction of a population of breast cancer patients at a community-based oncology practice.

## **Background**

Today, an estimated 14.5 million people are survivors of cancer, and the number is steadily rising due to dramatic and rapid advances in the screening, diagnosis, and treatment of cancer.<sup>1,2</sup> Breast cancer survivors are a prominent subset, accounting for 3.1 million survivors.<sup>3</sup> Projections are that 68% of adults with cancer are expected to be alive in 5 years, a remarkable upward trend from 1977 when the 5-year survival rate was a mere 49%.<sup>1</sup> Regarding breast cancer, a woman diagnosed today, has an 89% chance of being alive in 5-years, 83% in 10 years, and 78% at 15 years.<sup>2</sup>

These expanding categories of patients, those presumed cured, and those living with cancer as a chronic disease, present a new dilemma in the paradigm of cancer care. Oncology providers are taxed with evaluating the evidence of a rapid expansion of fast-tracked chemotherapeutics, biologic agents, and immunotherapies and how to best sequence therapy. The demand to keep pace in the area of acute oncology has overshadowed the growing concerns on both ends of the spectrum of oncology care:

those who survive their disease and those who will succumb. The evaluation and implementation of care models to transfer these responsibilities to other qualified providers is a vexing challenge.

In the 2006 Institute of Medicine (IOM) Report, *From Cancer Patient to Cancer Survivors: Lost in Transition*, survivorship care was described as falling short of the ideal being plagued with poor communication, fragmentation, and lack of coordination of services. Inappropriate use of services, lack of attention to late- and long-term effects, and the absence of preventive care were also cited.<sup>4</sup> A major limitation of their survivorship care reported by patients was insufficient communication between their oncologist and primary care provider (PCP), leading to feelings of anxiety and abandonment.<sup>5,6</sup> A significant proportion of PCPs, 84%, report being uncertain of the frequency and type of surveillance tests they should be ordering.<sup>7</sup> Critical to monitoring survivors of cancer, is understanding the long-term side effects of the drugs and treatment modalities employed.<sup>8</sup> In the 2009 *Survey of Physician Attitudes Regarding the Care of Cancer Survivors*, of the 1072 PCPs who responded, only 6% were able to identify the four most common late adverse effects of the four most commonly used chemotherapeutics.<sup>9</sup>

Of the 10 recommendations for improving the care of survivors cited by the IOM, only recommendation two: “Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan...”<sup>4</sup> was concrete, and clearly directed to providers of oncology care.

Current cancer treatment modalities save many more lives than in the past but have considerable consequences and are far from benign.<sup>10,11</sup> The cancer experience does not culminate upon the completion of treatment and most survivors are left with physical and psychosocial lasting and latent effects.<sup>10,12</sup> Survivorship is a distinct phase in the trajectory of the cancer experience.<sup>4</sup> Studies of survivors report more than 25 problems and needs following treatment including fatigue, sleep deprivation, pain, depression, anxiety, and fear of recurrence.<sup>4,6,10,13</sup> Survivors of breast cancer also express concerns of weight gain, skin changes, pain, lymphedema, cognitive impairment, and for those with hereditary breast cancer syndromes, risk to family members.<sup>4,10,13,14</sup> Side effects of estrogen deprivation: hot flashes, vaginal dryness, premature menopause, infertility, and risk of osteoporosis also affect quality of life.<sup>4,13</sup> For breast cancer survivors, high levels of stress and feeling uninformed on the persistent side effects of cancer treatment give rise to feelings of isolation, anxiety, and depression.<sup>6,15</sup>

Cancer survivors have more co-morbidities and chronic health problems than the general population, and are at risk for receiving inadequate health care.<sup>6,12</sup> At the conclusion of active treatment, survivors report wanting more information about their diagnosis, treatment, long-term side effects, risk of recurrence, and health maintenance.<sup>6</sup> As the immediate crisis of diagnosis and treatments wanes, insurance issues, occupational concerns, medical bills, and relational issues become paramount as the survivors begin the process of finding their “new normal”.<sup>6,16</sup>

Treatment summaries and survivorship care plans (TS/SCP) were designed to synopsise the modalities used in treating a patient’s cancer, and as a guideline for follow-

up care.<sup>4</sup> The provision of a TS/SCPs and survivorship care is now a core measure of the American College of Surgeons Commission on Cancer (CoC), American Society of Clinical Oncology Quality Oncology Practice Initiative (ASCO QOPI®), and the National Accreditation Program for Breast Centers (NAPBC).<sup>17-19</sup> Presently, only 43% of the National Cancer Institute (NCI) designated cancer centers provide TS/SCPs for breast and/or colorectal cancer survivors.<sup>7</sup> A national survey of 1130 medical oncologists reported always/almost always discussing some aspect of survivorship care 64% of the time; however, less than 10% report consistently providing a written TS/SCP.<sup>20</sup>

## **Practice Innovation**

### **Aim**

The purpose of this evidence-based practice project (EBP) was to incorporate a TS/SCP for women completing adjuvant treatment for breast cancer that would enhance their knowledge and satisfaction with care. The TS/SCP and survivorship visit were designed to provide clarity to the breast cancer survivor on the frequency and purpose of the follow-up visits, and to educate on the possible long- and late effects of treatment, assess risk factors, and teach healthy behaviors to minimize recurrence and secondary cancers. An additional goal was to disseminate this information to the providers involved in the patient's ongoing care.

### **Local Problem and Setting**

California Cancer Associates for Research and Excellence (cCARE) is a community-based, multi-location, large oncology hematology practice located in Southern and Central California. This practice innovation was incorporated in a single

office setting with two full time oncologists, along with one full time, and one part time Nurse Practitioner (NP).

At the start of treatment, significant time and resources are allocated in preparing the patient for chemotherapy through a formal, standardized chemotherapy-teaching protocol. At the completion of adjuvant chemotherapy, no formal visits or written materials addressing survivorship, or TS/SCP were provided. The oncologists and NPs jointly shared post treatment follow-up visits aligned with ASCO's evidence based guidelines. No written protocol outlining the oncology follow-up care existed to formally communicate with the patient or their providers.

### **Benchmark and Evaluation**

Participants' confidence in their knowledge of survivorship care was measured pre- and post visit using the Confidence In Survivorship Information (CSI) tool. It was anticipated improvement would occur for at least 80% of the women. The CSI tool is a validated, 13-item, 3-point Likert-type scale developed for this population. Three items measure survivors' confidence in knowledge of diagnosis and treatment details; the reliability was established with a Cronbach's alpha= 0.77. The remaining 10 items, Cronbach's alpha=0.95, measure confidence in prevention, late- and long-term effects of treatment and the cancer, prevention of future disease, familiar risk for cancer, and access to resources. Respondents rate each item as "not at all confident", "somewhat confident," or "very confident".<sup>21</sup>

The benchmark for satisfaction, set at 80%, was measured using the Patient Satisfaction with Cancer-related Care (PSCC) tool. The PSCC is a validated tool of 18 item with a 5-point Likert scale where "5=Strongly Agree and 1=Strongly Disagree". It



demonstrates high construct validity, internal consistency, and reliability with diverse socioeconomic and cultural populations.<sup>22</sup>

The provider satisfaction tool was investigator developed, designed to be answered in less than three minutes, and consisted of three questions using a 5-point Likert scale. The goal was for 80% of the providers to agree/strongly agree the TS/SCP was easy to understand, useful in promoting effective patient care, and provided pertinent information.

### **Implementation**

After obtaining IRB approval, the project was guided using the John Hopkins Nursing Evidence-Based Practice Model. The model has a practice process with three areas of focus: practice question, evidence, and translation (*Figure 1*). The practice question was initiated by the NPs at the site and supported by the oncologist and staff who actively participated in the design and execution of the program. A comprehensive review of the literature provided the evidence base and examples of numerous written and computerized templates in which TS/SCPs had been implemented in various oncology settings, both academic and community-based.

Translation of the evidence into a working model began at the start of care. The *Journey Forward Care Plan Builder*® was downloaded onto the medical assistant (MA) and NP computers. A standard breast cancer survivorship template reflecting resources and practice patterns of the office was loaded onto a shared drive. At the time of the chemotherapy-teaching visit, the MA solicited the information to complete the demographic and care team portion of the TS/SCP. Using the pathology report, chemotherapy orders, and oncology consultation, the NP completed the background

information and treatment plan. An estimation of the date of completion of treatment was made and noted in a file. Each month the NP reviewed the progress of patients and a 50-minute survivorship visit was scheduled for those completing treatment. Prior to the visit, the NP completed the remaining sections of the TS/SCP.

On the day of the survivorship visit, participants received an explanation of the EBP project and were invited to participate in the pre/post evaluation process. Participants were given the opportunity to opt out of completing any or all parts of the evaluation. Participants electing to opt out still received the survivorship visit and personalized TS/SCP.

During the visit, the NP reviewed the TS/SCP and the NCI booklet, *Facing Forward: Life After Cancer Treatment*. Input was solicited on lingering effects of treatment, questions answered, and referrals generated. Modifications were made based on participant's input, and a revised hard copy was printed. The TS/SCP was scanned into the EMR and a personalized survivorship visit note was generated using a standard template. The PCP and care team were mailed a brief letter of explanation, the TS/SCP, provider survey, a self-addressed stamped envelope, and a \$5.00 coffee gift card. Each provider was surveyed only once.

## **Results**

During the evaluation period, 21 women participated in the practice innovation. Of the 26 providers who were mailed a TS/SCP, 19 (73%) returned the survey. Mean confidence in knowledge of cancer diagnosis/treatment details improved from 1.57 to 2.0. Similarly, mean confidence scores improved from .82 to 1.85 ( $t=8.66$ ) in knowledge of prevention, late/long-term effects, resources, and familiar risk for cancer (*Figure 2*).

Improvement occurred for 100% of the participants. Satisfaction was rated at 4 or better for 95% of the women and 84% of providers' agreed/strongly agreed with the elements of the survey (*Figure 3*).

### **Economics**

An analysis of cost per visit was estimated. Average reimbursement by payer mix for a level five follow-up visit was obtained. Estimates of NP and the MA resources based on hourly rate to complete all parts of the project were subtracted from the average reimbursement. An additional \$5.00 in cost was added to cover the printing of the NCI booklet. It was estimated that each visit generated approximately \$25-\$30 revenue.

### **Discussion**

Arguably, there are far worse diseases than cancer, but few in which people associate so dramatically with suffering, pain, and premature death. While feeling relatively well, the newly diagnosed cancer patient is thrust into a treatment plan that is difficult, lengthy, and potentially debilitating. Throughout the diagnosis and treatment, patients have numerous contacts with multiple healthcare providers. At the completion of treatment, this frequent contact suddenly, and abruptly, ceases. As previously stated, the literature on the residual physical, emotional, and psychosocial effects of cancer and its treatment is extensive. Therefore, it is paramount for the medical community to recognize the inherent anxiety emerging at the completion of primary cancer treatment and to embrace survivorship as a significant transition point.<sup>4</sup>

At the conclusion of adjuvant cancer treatment, the questions and concerns of the cancer patient are different. As early apprehensions around treatment side effects and impact on lifestyle fade, new issues emerge. As this EBP project demonstrated, TS/SCP

and survivorship visits provide a similar impact at the end of treatment as chemotherapy teaching provides at the start. Reduction in anxiety, fear, and confusion, increase in knowledge, and improvement in self-care recommendations are all outcomes of survivorship care supported in the literature.<sup>6,8,10-12</sup>

It is important to recognize aspects of this practice setting allowing the TS/SCP to be constructed at a reduced time and cost, than reported in the literature.<sup>7,23</sup> By creating a standard template and populating more than 40% at the chemotherapy teaching session, the NP was able to save considerable time then might have been appreciated in practices where the TS/SCP is generated at the conclusion of treatment when the medical chart is more extensive. The NPs at this practice were familiar with the patients, their treatment, and problems they had encountered in the course of care. This proved advantageous, as the NP was able to complete the TS/SCP in an efficient manner that might not be possible in large practice or where the TS/SCP is produced in a dedicated survivorship clinic or by a different set of providers. A meaningful reduction in the high labor costs reported by other institutions was achieved by training the MAs to complete the data entry and incorporating a significant portion of the process into the existing workflow.

While much of the literature on methods of delivering TS/SCP and survivorship care has originated from academic and large oncology centers, the vast majority of cancer patients receive the bulk of their treatment in community practices. For a large portion of patients who receive treatment with curative intent, their life as a survivor will be far longer than as an active cancer patient. It only makes sense, given this longevity, attention be given to the needs of this population. As this project demonstrated, it is

possible to not only to meet the requirements of the standards, but to provide value added, cost-effective care, that is meaningful to both patients and other providers.

While the CSI tool measured the confidence the patient had in their knowledge, it did not measure the accuracy of this knowledge. While not measured in a scientific manner, during the review of the TS/SCP a number of participants discovered they had an incorrect understanding of their diagnosis and/or treatment. This was most frequently observed when reviewing the stage of cancer; patients often “up or down” staged their disease. This was further validated, as the pre/post improvement in this domain was not as robust as in the follow-up care domain. Kessels<sup>24</sup> makes a salient point when stating that during an encounter, patients immediately forget 40-80% of medical information and 50% of what is retained is erroneous. The more complex and/or distressing the information, the more likely the patient will remember it inaccurately.<sup>24</sup>

Patient education reduces anxiety and depression, promotes self-care and engagement, and has a positive effect on satisfaction, clinical outcomes, compliance, and quality of life in the adult patients with cancer.<sup>25-27</sup> Furthermore, the use of written information improves the accuracy of recall of knowledge as well as demonstrating improvement in adherence to recommendations.<sup>24-27</sup> It is also cost-effective.<sup>28</sup> Given the length and complexity of cancer treatment the value of the TS/SCP and survivorship visit becomes even more vital as it represents an opportunity to correct inaccurate and erroneous information while educating on the next steps in care.

As demonstrated in this project, the advanced practice registered nurse (APRN) is uniquely trained and positioned to provide survivorship care. Their role in symptom management and support during the acute phase of cancer treatment results in frequent

contact, allowing for understanding of the individual dynamics by which each patient and their family experience cancer. The holistic lens by which APRNs view the care of patients' with serious illness, partnered with an education geared towards restoration of health and wellness, provides an ideal skill set for the provision of survivorship care.

### **Conclusions**

TS/SCPs only fulfill one of the ten recommendations in the area of survivorship care outlined by the 2006 IOM report. As new drugs and treatments, whose long-term side effects are still unknown, continue to expand the survivorship pool, the need to implement comprehensive survivorship care within community-based settings is crucial. The ability to provide curative cancer therapy is a noteworthy accomplishment worth celebrating. However, it is not enough if patients are left debilitated, vulnerable to other diseases, and with a poor quality of life. While transferring care to a dedicated survivorship clinic or a PCP is a viable and proven model, the value of the IOM's direction "...This 'Survivorship Care Plan' should be written by the principle provider(s) who coordinated oncology treatment..."<sup>4</sup> cannot be understated. It is these providers who possess the knowledge to accurately set the course necessary to insure appropriate and comprehensive follow-up.

The value of a TS/SCP is more pertinent then ever as our medical system remains one of ever evolving and expanding complexity. Compliance with accreditation standards and the IOM are the impetus for many organizations moving towards the provision of TS/SCPs. Yet, empowering patients with knowledge to participate in their own surveillance, risk reduction, and wellness, and improving the continuum of care, should be the driving force for oncology providers in expanding the scope and practice of

survivorship care. As the survivorship pool continues to grow, more research is needed to comprehensively address the unique and changing needs of the 21<sup>st</sup> century cancer patient.

**Disclosures:** The authors report no conflicts of interest in this work.

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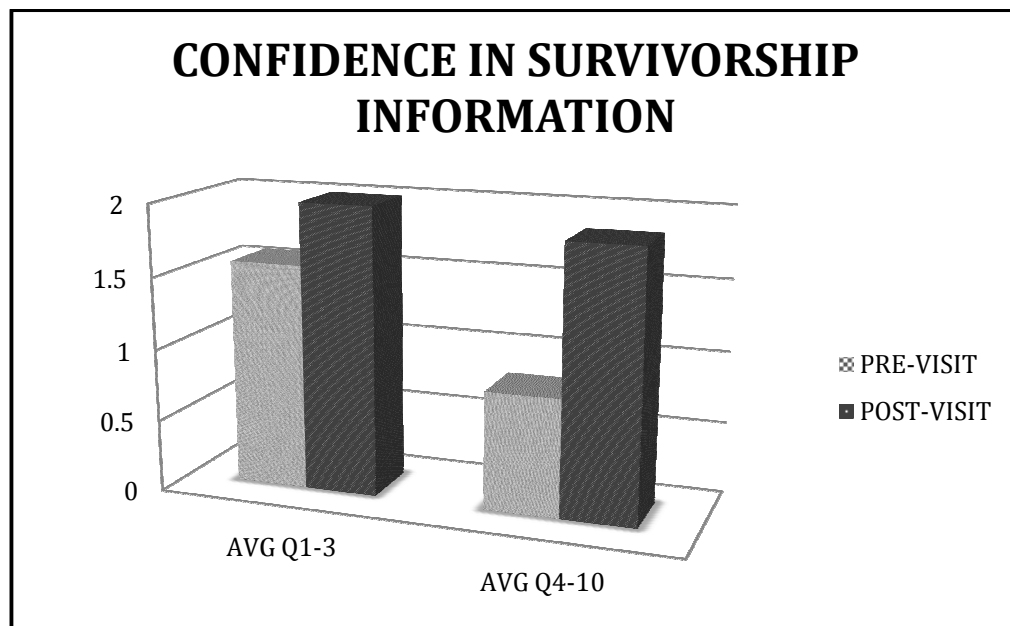
*Figure 1: Practice Model*

**Johns Hopkins Nursing Evidence-Based Practice  
Practice Question, Evidence, and Translation (PET)**



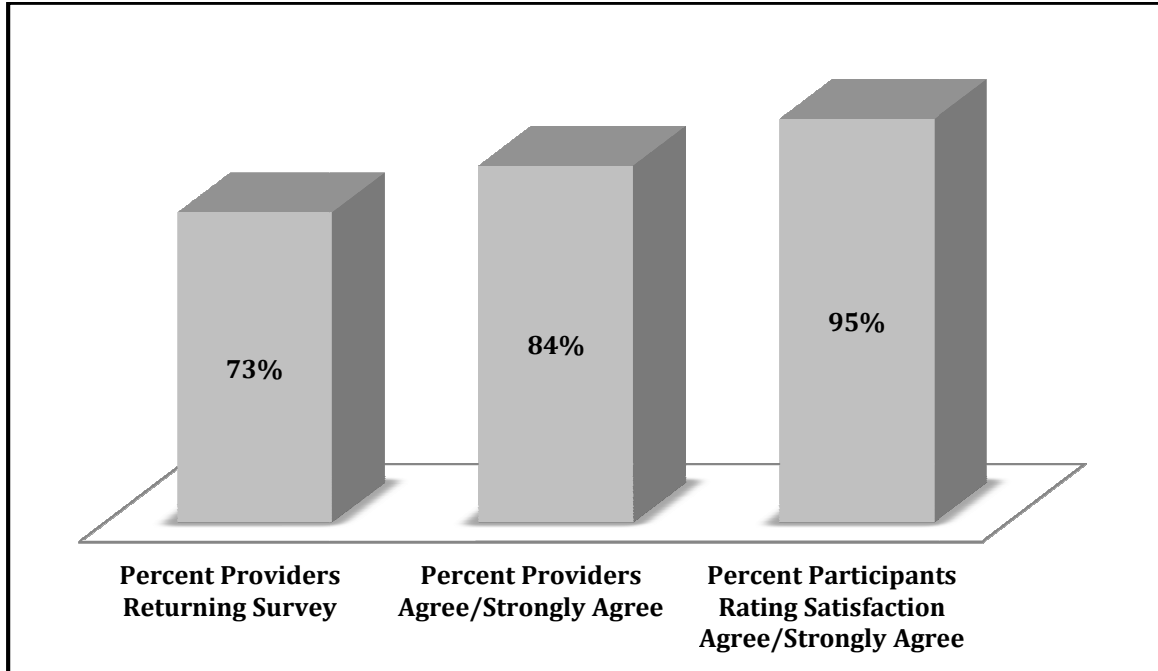
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*Figure 2: Confidence In Survivorship Information*



Question 1-3: Confidence in knowledge of past cancer diagnostics and treatment details  
Question 4-10: Confidence in knowledge of prevention/treatment of late/long-term effects, prevention of future disease, access to resources, familial risk of cancer

*Figure 3: Participant and Provider Satisfaction*



## Transition After Breast Cancer Treatment: Implementing Survivorship Care Plans

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**Purpose:** The purpose of this evidence-based practice (EBP) project was to incorporate a treatment summary and survivorship care plan (TS/SCP) for women completing adjuvant treatment for breast cancer in a community-based oncology practice.

**Background:** Over the last three decades, advances in screening, diagnosis, and treatment have created an evolution in cancer care. In the United States it is estimated 12 to 14 million people are survivors of cancer. Breast cancer survivors are a prominent subset, accounting for nearly 3.1 million survivors. The 2006 Institute of Medicine report; *From Cancer Patient to Cancer Survivors: Lost In Transition* identified survivorship as a distinct phase in the trajectory of cancer care and called attention to the significant gaps in the provision and coordination of care to this population. TS/SCP's are a tool designed to improve outcomes, bridge the knowledge gap, decrease fragmentation of care, and increase satisfaction in the post treatment phase of cancer care. TS/SCP's are incorporated into 43% of all National Cancer Institute (NCI) designated cancer centers. In the project facility, dedicated survivorship care was absent and there was no TS/SCP in use.

**Practice Innovation Process:** The John Hopkins Nursing Evidence-Based Practice Model was used to guide this project. At the chemotherapy teaching visit, the Medical Assistant documented the demographic information of the TS/SCP into the *Journey Forward Care Plan Builder*. Using the pathology report, chemotherapy orders, and oncology consultation, the NP developed the TS/SCP in preparation for a 50-minute NP/patient survivorship visit. A copy of the NCI publication: *Facing Forward: Life After Cancer Treatment* was reviewed and questions were addressed. Knowledge was measured pre and post visit using the Confidence in Survivorship Information tool (CSI) while satisfaction was measured using the Patient Satisfaction with Cancer Care (PSCC) tool. A copy of the TS/SCP was provided to the patient and mailed to the treatment team and PCP, whose satisfaction was surveyed. The project benchmark was for 80% of the participants to increase their knowledge and satisfaction with breast cancer survivorship care.

**Outcomes:** All of the 21 participants, or 100%, who participated in the practice innovation had improvement in confidence in knowledge. Specifically, knowledge of cancer diagnosis/treatment details improved from a mean average of 1.57 to 2.0 while knowledge of prevention, late/long-term effects, resources, and family risk for cancer increased from a mean average of 0.82 to 1.85. Similarly, satisfaction increased for 95% of participants. Of the 73% of providers who completed the survey, 84% agreed/strongly

agreed with the elements of the survey.

**Conclusions:** TS/SCP delivered in the context of a dedicated survivorship visit with an NP consistently increases knowledge of all domains measured in the CSI tool. Satisfaction with the intervention was positive. As with many education and wellness interventions, the NP is uniquely qualified to support patients completing chemotherapy with curative intent as they transition to survivorship care. Furthermore, depending on payer mix, post treatment survivorship visits represent a potential revenue stream for a community-based oncology practice.



# Transition After Breast Cancer Treatment: Implementing Survivorship Care Plans



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## Background

- Of the 14.5M survivors, 3.1M are Breast Cancer Survivors<sup>1,2</sup>
- Significant gaps identified in knowledge, provision & coordination of care<sup>3</sup>
- Survivors:
  - experience residual physical/psychosocial effects<sup>1,3,4</sup>
  - have more chronic health problems/co-morbidities than general population<sup>5,6</sup>
  - report more than 25 problems/concerns/needs after tx<sup>5,6,7</sup>
  - are at risk for receiving inadequate healthcare<sup>8</sup>
  - feel unprepared for end of tx<sup>4,9</sup>
  - report high levels of stress/anxiety
  - report wanting more information at the end of tx<sup>4</sup>
- Only 43% of NCI designated centers incorporate TS/SCPs for breast/colorectal cancer survivors<sup>10,11</sup>
- Dedicated survivorship care was absent in project facility

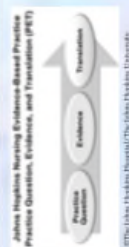
## Evidence

- TX summaries & care planning are fundamental to nursing & medical care
- Research shows significant impact with interactive interventions, written information & psychoeducation<sup>10,11</sup>
- Qualitative research support the use of TS/SCPs<sup>12,13,14,15</sup>
  - increase PT/provider knowledge
  - promote continuity/coordination of care
  - decrease cancer related stress/anxiety
- In *From Cancer Patient to Cancer Survivor: Lost in Transition*, the IOM recommended TS/SCP to bridge gaps in survivorship care<sup>16</sup>
- In *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, the IOM reiterated the need<sup>17</sup>
- The Commission on Cancer, ASCO Quality Oncology Practice Initiative & National Accreditation Program for Breast Centers all have standards requiring TS/SCPs<sup>18,19</sup>

## Aim

The purpose of this evidence-based practice project (EBP) was to incorporate treatment summaries and survivorship care plans (TS/SCP) for women completing adjuvant treatment for breast cancer in a community-based oncology practice that will enhance their knowledge and satisfaction with care.

## Practice Model

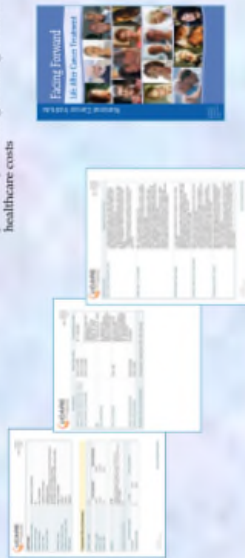


## Benchmark & Evaluation

- 80% of participants confidence in knowledge of survivorship information will improve as measured by pre/post scores on CSQ
- 80% of participants overall satisfaction will be rated at 4 or better on the PSQC
- 80% of providers would agree/strongly agree the TS/SCP was concise, pertinent, & useful

## Practice Innovation Process

- TS/SCPs were created using the *Journey Forward* Care Plan Builder
- Women attended an NP led survivorship visit
- Pre-visit participants completed the *Confidence in Survivorship Information* (CSI) tool
- Participants were assessed: lingering side-effects of tx & concerns
- The TS/SCP & NCI publication, *Facing Forward: Life After Cancer Treatment* was reviewed
- Post-visit, participants completed the CSI Tool & the *Patient Satisfaction with Cancer Care* (PSQC)
- TS/SCP was scanned into the EMR, survivorship visit note was created & referrals made

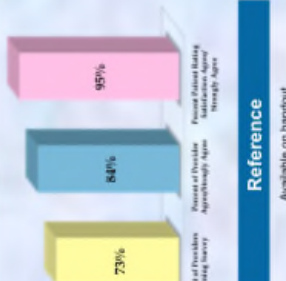


## Conclusions & Implications for Nursing Practice

- TS/SCP & NP led survivorship visits:
  - improve knowledge & ease transition
  - opportunity to educate: healthy behaviors, risk reduction, clarify information
  - assess impact of treatment
- engage PT in surveillance, wellness activities
- TS/SCP serve as a road map clearly defining EBP guidelines for follow-up care to entire team
- TS/SCP provide similar impact at end of TX as chemo teaching does at the beginning of TX
- Depending on payer mix, survivorship care is potentially revenue generating & can decrease healthcare costs

## Results

- 21 women participated in the practice innovation
- 100% experienced improvement in confidence
- Mean confidence in knowledge of Dx/Tx details ↑ 1.57 to 2.0
- Mean confidence in knowledge: prevention, late/long-term effects, resources, familiar risk ↑ 82 to 145
- 26 providers were mailed surveys, 19 returned
- 84% of providers agreed/strongly agreed with all elements of the survey
- 95% of women rated satisfaction at 4 or better



## Reference

Available on handout

# **TRANSITION AFTER BREAST CANCER TREATMENT: Implementing Survivorship Care Plans**



**Susan Hope Klein  
MSN, FNP-C, OCN**

## **Background**

- Of the 14.5M Survivors, 3.1M are Breast Cancer Survivors<sup>1,2</sup>
- Significant gaps identified in knowledge, provision, and coordination of care<sup>3</sup>
- Survivors report wanting more information at the end of Tx<sup>4</sup>
- Survivors experience residual physical/ psychosocial effects<sup>3,4,5</sup>



## Background



### SURVIVORS-

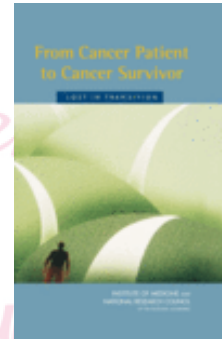
- experience more chronic health problems/ co-morbidities than general population<sup>3,4</sup>
- report more than 25 problems, concerns, and needs after Tx<sup>3,5,6,7</sup>
- are at risk for receiving inadequate healthcare<sup>4,8</sup>
- feel unprepared for end of treatment<sup>4,6,7</sup>
- report high levels of stress and anxiety<sup>3,4,6,9</sup>

## Evidence

- Treatment summaries/ care plans are fundamental to nursing and medical care
- Research shows significant impact with the use of interactive interventions, written information, and psychoeducation<sup>10,11</sup>
- Qualitative research supports the use of TS/ SCP<sup>4,5,6,7,8,12-20</sup>

## Evidence

In *From Cancer Patient to Cancer Survivor: Lost in Transition* the IOM recommended TS/ SCP to bridge gaps in survivorship care<sup>3</sup>



In *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, the IOM reiterated the need for TS/ SCP<sup>21</sup>

## Benchmarks

- Only 43% of NCI cancer centers incorporate TS/ SCPs for breast and/ or colorectal cancer survivors<sup>18,22</sup>
- The Commission on Cancer, ASCO Quality Oncology Practice Initiative and the National Accreditation Program for Breast Centers all have standards requiring TS/ SCP<sup>23,24,25</sup>
- Dedication survivorship care was absent at the practice

## Johns Hopkins Nursing Evidence-Based Practice Practice Question, Evidence, and Translation (PET)



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Hopkins University

### AIM:

"If you cure a woman with breast cancer, and she still suffers from the emotional aspects of the disease, that is not acceptable."

Dr. Timothy Pagana, FACS, Medical  
Director of the Breast Health Center.

- Enhance knowledge and increase satisfaction for women completing adjuvant treatment for breast cancer
  - ❖ Single NP directed survivorship visit
  - ❖ Provision of a personalized TS/ SCP
- Disseminate this information to other providers involved in the care



# Evaluation

80% of participants confidence in knowledge of survivorship information will improve as measured by pre/ post scores on *Confidence in Survivorship Information Tool (CSI)*

NUMBER \_\_\_\_\_ PRE/POST \_\_\_\_\_

How **confident** are you about your **knowledge** of each of the following aspects of your cancer and cancer related follow up care?

	NOT AT ALL CONFIDENT	SOMEWHAT CONFIDENT	VERY CONFIDENT
The type of cancer you had?			
The stage of cancer you have/had?			
The treatments you received/are receiving for cancer?			
Things you can do to help prevent your cancer from recurring?			
The long-term physical effects you may experience from cancer and its treatment?			
Strategies for preventing long-term physical effects of cancer treatment?			
Strategies for treating long-term physical effects of cancer treatment?			
The long-term emotional effects you may experience from cancer and its treatment?			
Strategies for preventing long-term emotional effects of cancer treatment?			
Strategies for treating long-term emotional effects of cancer treatment?			
Community resources available to help you deal with long-term effects of cancer and its treatment?			
Whether your family members are at increased risk for cancer?			
How your family members can get information on their risk for cancer?			

# Evaluation

80% of participants overall satisfaction will rate at 4 or better on the *Patient Satisfaction with Cancer Care (PSCC) Tool*

NUMBER \_\_\_\_\_

PLEASE RATE YOUR SATISFACTION WITH YOUR SURVIVORSHIP VISIT TODAY.

	STRONGLY DISLIKE	DISLIKE	CANNOT DECIDE	LIKE	STRONGLY LIKE
1. I felt my health concerns were understood					
2. I felt that I was treated with courtesy and respect					
3. I felt included in decisions about my health					
4. I was told how to take care of myself					
5. I felt encouraged to talk about my personal health concerns					
6. I felt I had enough time with my provider					
7. My questions were answered to my satisfaction					
8. Making an appointment was easy					
9. I knew what the next step in my care would be					
10. I felt confident in how I dealt with the health care system					
11. I was able to get advice I needed about my health issues					
12. I knew who to contact when I had a question					
13. I received all the services I needed					
14. I am satisfied with the care I received					
15. The providers seem to communicate well about my care					
16. I received high quality care from my regular provider					
17. I received high quality care from my specialist					
18. My regular provider was informed about the results of the tests I got.					

ADDITIONAL COMMENTS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Evaluation

80% of providers will agree/ strongly agree that the TS/ SCP was concise, pertinent, and useful

TREATMENT SUMMARY AND SURVIVORSHIP CARE PLAN (TS/SCP)

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE
1. The TS/SCP is easy to understand.					
2. The TS/SCP is concise and provides pertinent information.					
3. The TS/SCP will be a useful tool to promote effective patient care.					

ADDITIONAL COMMENTS

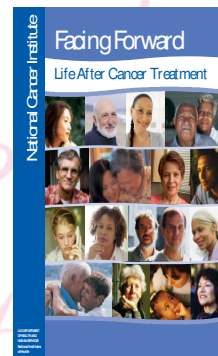
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## Practice Innovation

- TS/ SCPs were created using the *Journey Forward Care Plan Builder*
- Women attended an NP led survivorship visit
- Pre-visit participants completed the CSI tool
- The TS/ SCP and NCI publication *Facing Forward: Life After Cancer* are reviewed



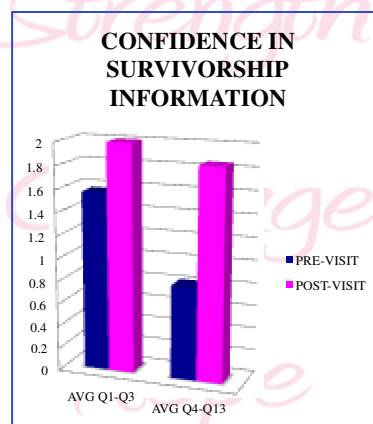
## Practice Innovation

- Post-visit, participants completed the *CS/Tool* and *PSCCTool*
- TS/ SCP was scanned into the EMR, survivorship visit note was created, and referrals completed
- TS/ SCP was mailed to the PCP, other providers.



## Results

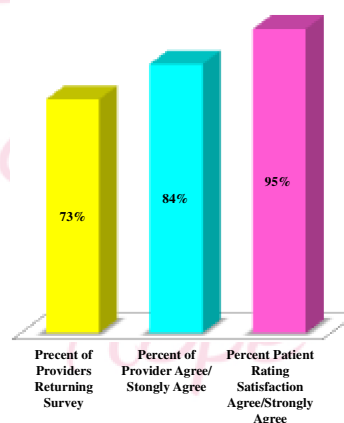
- 21 women participated, 100% experienced improvement
- Mean confidence in knowledge Dx/ Tx details ↑ 1.57 to 2.0
- Mean confidence in knowledge prevention, late/ long-term effects, resources, familiar risk ↑ .82 to 1.85





## Results


- 26 providers were mailed surveys, 19 were returned (73%)
- 84% of providers agreed/ strongly agreed with all elements of the survey
- 95% of the women rated satisfaction at 4 or better



## Economics



- Average reimbursement for payer mix level 5 follow-up visit
- Subtracted estimates of time/ cost for NP and MA based on hourly rates
- Additional \$5.00 to cover costs of NCI booklet
- Each visit generated \$25-\$30 of revenue



- CSI tool only captured what the PTs confidence was, not if the knowledge was accurate
- Unique aspects of the practice setting allowing for significant reduction in time/ costs
- Costs estimations were simplistic and actual revenue maybe more or less

## Practice Implications

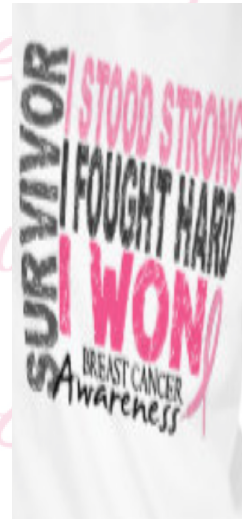
### TS/ SCP and Survivorship visits:

- Improve knowledge and ease transition
- Provide opportunity for NP to educate: healthy behaviors, risk reduction, assess impact of treatment
- Engages PT in surveillance, risk reduction, wellness
- Serves as a road map clearly defining EBP guidelines for follow-up care to entire team



## Conclusions

- TS/ SCP provide similar impact at the end of TX as chemo teaching does at the beginning
- Patients need/ benefit from assessment, education and goal setting at this juncture
- TS/ SCP should be completed by the principle providers
- Survivorship care is potentially revenue generating and can decrease healthcare costs



## Next Steps



- Addition of adjuvant Colon Cancer by Summer 2015
- Explore integrated EMR systems: OnQ, Varian Equicare CS
- Development of timeline for addition of all diagnoses in which adjuvant treatment is employed: Lymphoma, Lung, Prostate...

**I would like to express my most sincere gratitude to the following individuals whose help and support made this project possible.**

- Kathleen Haley, NP cCARE
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- Martha Jones, Lab Tech, cCARE
- Diane Hill-Nelms, MA, cCARE
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- Dr. Kathy James, USD
- Dr. Karen Macauley, USD
- Dr. Catie Madani
- Dr. Carrie Stricker, U of Penn, Founder, OnQ
- Kay Clark and The American Cancer Society
- Johanna Boucher, RN, MSN

***...And most notably, to all the brave women and men I have been privilege to meet over the last 27 years, who valiantly fight this disease and whose stories of the cancer experience and challenges of survivorship motivate me to do more and to do it better...***